Understanding health-seeking behaviours of people in Indonesia; and developing, piloting, and evaluating a culturally appropriate intervention for people with diabetes

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Abstract

Indonesia is facing a dual burden of communicable and non-communicable diseases. Childhood-immunisation coverage is lower than most countries in Southeast Asia, with vaccine-preventable disease outbreaks frequently reported. Prevalences of non-communicable diseases are also rising, including type 2 diabetes. Diabetes is further linked to tuberculosis and stunting - health problems which remain common in Indonesia. Understanding people’s health behaviour is an important step to establishing effective interventions. In Indonesia, a multicultural country with multiple health providers, health-related behaviour is more complex as. I aimed to improve outcomes related to child immunisation or diabetes through implementing an intervention based on understanding people’s health behaviour. Two stages of studies were conducted.

A qualitative study explored the perceptions, beliefs and behaviour of diverse communities in relation to child immunisation and diabetes. Six focus groups involving 53 mothers and six focus groups involving 45 people with diabetes were performed in West Sumatera and East Nusa Tenggara. Recorded discussions were transcribed, translated, and analysed for common themes.

For child immunisation, themes underlined the role of fathers and community-based health workers in influencing mothers’ behaviour. Issues related to Posyandu (an outreach programme for mother and child health) including lack of financial support, and potential missed opportunities were highlighted.

Diabetes patients’ behaviour in managing the disease was prompted by the individual lay evaluation of the disease and its treatment, a process influenced by family and peers with diabetes. This process changed the appeal and acceptability of specific health services. Further, cultural beliefs, family and community support challenged people with diabetes in practising self-management behaviours.

This qualitative work on diabetes revealed a complex situation contributing to late diagnosis, uncontrolled blood glucose, and prevalent diabetes-related
complications. Therefore, while acknowledging the importance of child immunisation, I subsequently focused on diabetes.

Informed by the literature review and qualitative work, a quasi-experimental pilot study was developed and conducted in Kupang, East Nusa Tenggara. Usual care was compared to an intervention consisting of ten sessions of weekly group activities including education, exercise, and healthy snacking, conducted in collaboration with primary health centres (PHCs). Sixty-seven participants were recruited from four PHCs, and were allocated into groups (intervention: 36; control: 31) based on the PHCs they were registered in.

Participants were 60% female, mean age 57, and had diabetes for an average of 4.5 years. Groups did not differ at baseline. Counter to prediction, no effects of the group-based intervention over usual care were observed. However, both groups made statistically significant improvement in HbA1c (intervention improved from 8.26%±1.89 to 7.84%±1.82; control from 8.35%±2.60 to 7.95%±2.53). Exploratory analyses found more intervention than control participants achieved an HbA1c reduction of 0.5% (43% compared to 31%). The intervention appears to have provided a positive impact through stimulating local healthcare providers to more intensively manage their diabetes patients, including the control group.

These findings are important for government and related stakeholders in managing health problems related to child immunisation and diabetes. Tailored interventions – based in socio-cultural context – to influence behaviour should be established, to improve child immunisation uptake and diabetes patients’ outcomes.
Acknowledgements

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<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>2-h PG</td>
<td>Plasma Glucose measured 2 hours after a 75 grams of anhydrous glucose intake</td>
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<tr>
<td>ANCOVA</td>
<td>analysis of covariance</td>
</tr>
<tr>
<td>ANOVA</td>
<td>analysis of variance</td>
</tr>
<tr>
<td>BCG</td>
<td>Bacillus Calmette-Guerin</td>
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<tr>
<td>BMI</td>
<td>Body Mass Index</td>
</tr>
<tr>
<td>BPJS</td>
<td><em>Badan Penyelenggara Jaminan Sosial</em> (see glossary)</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
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<tr>
<td>DFU</td>
<td>Diabetic Foot Ulcer</td>
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<tr>
<td>DHS</td>
<td>Demographic and Health Survey</td>
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<tr>
<td>DM</td>
<td>Diabetes Mellitus</td>
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<tr>
<td>DSME</td>
<td>Diabetes Self-Management Education</td>
</tr>
<tr>
<td>DTP</td>
<td>Diphtheria, Tetanus, Pertussis</td>
</tr>
<tr>
<td>EDTA</td>
<td>Ethylenediaminetetraacetic acid</td>
</tr>
<tr>
<td>EPI</td>
<td>Expanded Programme on Immunisation (EPI)</td>
</tr>
<tr>
<td>ES</td>
<td>Elementary School</td>
</tr>
<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
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<tr>
<td>FPG</td>
<td>Fasting Plasma Glucose</td>
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<td>GDP</td>
<td>Gross Domestic Product</td>
</tr>
<tr>
<td>HbA1c</td>
<td>Glycosylated Haemoglobin</td>
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<tr>
<td>HBM</td>
<td>Health Belief Model</td>
</tr>
<tr>
<td>HBsAg</td>
<td>Hepatitis B virus surface antigen</td>
</tr>
<tr>
<td>Hep B</td>
<td>Hepatitis B</td>
</tr>
<tr>
<td>HiB</td>
<td>Haemophilus influenza type b</td>
</tr>
<tr>
<td>HPLC</td>
<td>High Pressure Liquid Chromatography</td>
</tr>
<tr>
<td>IDR</td>
<td>Indonesian Rupiah</td>
</tr>
<tr>
<td>IFCC</td>
<td>International Federation of Clinical Chemistry</td>
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<tr>
<td>IFG</td>
<td>Impaired Fasting Glucose</td>
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<tr>
<td>IGT</td>
<td>Impaired Glucose Tolerance</td>
</tr>
<tr>
<td>IPV</td>
<td>Inactivated Polio Vaccine</td>
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<tr>
<td>JHS</td>
<td>Junior High School</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>LKC</td>
<td>Layanan Kesehatan Cuma-Cuma (see glossary)</td>
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<tr>
<td>MCV</td>
<td>Measles Containing Vaccine</td>
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<tr>
<td>MMR</td>
<td>Mumps, Measles, and Rubella</td>
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<tr>
<td>MoH</td>
<td>Ministry of Health</td>
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<tr>
<td>MoU</td>
<td>Memorandum of Understanding</td>
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<td>NGSP</td>
<td>National Glycohaemoglobin Standardization Programme</td>
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<tr>
<td>OGGT</td>
<td>Oral Glucose Tolerance Test</td>
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<tr>
<td>OPV</td>
<td>Oral Poliovirus Vaccine</td>
</tr>
<tr>
<td>PHC</td>
<td>Primary Health Centre</td>
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<tr>
<td>ProMAS</td>
<td>Probabilistic Medication Adherence Scale</td>
</tr>
<tr>
<td>SCT</td>
<td>Social Cognitive Theory</td>
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<tr>
<td>SD</td>
<td>Standard Deviation</td>
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<tr>
<td>SDG</td>
<td>Sustainable Development Goals</td>
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<tr>
<td>SHS</td>
<td>Senior High School</td>
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<tr>
<td>TBA</td>
<td>Traditional Birth Attendant</td>
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<tr>
<td>UHC</td>
<td>Universal health coverage</td>
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<tr>
<td>UNICEF</td>
<td>The United Nations International Children’s Fund</td>
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<tr>
<td>USD</td>
<td>The United States Dollar</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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Glossary

Adherence to medication
The process by which patients take their medications as prescribed.

Ajinomoto
Flavour enhancer, containing monosodium glutamate.

Akar kuning
Yellow root, (the root of Arcangelisia flava Merr.).

Angin duduk
Local term used by Javanese for symptoms related to heart disease.

Askes
Asuransi Kesehatan: health insurance for civil servants.

Askeskin
Asuransi kesehatan untuk rakyat miskin: a government-financed health insurance for the poor introduced in 2005.

Badan Kependudukan dan Keluarga Berencana Nasional
The National Population and Family Planning board, the government agency at the central level.

Badan Pengawasan Obat dan Makanan
Food and drug administration and control agency.

Badan Penyelenggara Jaminan Sosial (BPJS) Kesehatan
The Social Security Agency, the government agency which manages the universal health coverage programme (Jaminan Kesehatan Nasional).

Bahasa Indonesia
Indonesian National Language, the official language of Indonesia.

Basic immunisation
Imunisasi dasar (Indonesian): immunisation programme for children before the age of one.

Bemo
Local name for public transport in East Nusa Tenggara.
<table>
<thead>
<tr>
<th><strong>Bhinneka Tunggal Ika</strong></th>
<th>Indonesian national motto which is translated as ‘Unity in Diversity’.</th>
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<tbody>
<tr>
<td><strong>Bidan desa</strong></td>
<td>Village midwife, a midwife who lives in a village and provides health services for the people in the village.</td>
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<tr>
<td><strong>Binahong</strong></td>
<td><em>Anredera cordifolia</em> Steenis (Latin), its leaves are used as traditional medicines for diabetes.</td>
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<tr>
<td><strong>Booster child immunisation</strong></td>
<td><em>Imunisasi lanjutan</em>: booster doses of immunisation for children over the age of one.</td>
</tr>
<tr>
<td><strong>Bosan</strong></td>
<td>A word in Indonesian language that means not wanting to do it again because it has been done for too long, which is similar to ‘fed up’ or ‘bored’ in English.</td>
</tr>
<tr>
<td><strong>Buah pinang</strong></td>
<td><em>Betel</em> (<em>Areca catechu</em>) fruit.</td>
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<tr>
<td><strong>Community-based health workers</strong></td>
<td>Voluntary health workers (<em>kader</em>), and village midwives.</td>
</tr>
<tr>
<td><strong>Corn rice</strong></td>
<td>Corn that has been ground into smaller size.</td>
</tr>
<tr>
<td><strong>Cure</strong></td>
<td><em>Sembuh</em> (Indonesian), means being free from the disease and its treatment.</td>
</tr>
<tr>
<td><strong>Decentralisation</strong></td>
<td><em>Otonomi daerah</em> (Indonesian) or ‘regional autonomy’, which means that the regional government including provinces, districts and municipalities has power to regulate themselves.</td>
</tr>
<tr>
<td><strong>District/municipality</strong></td>
<td>Administrative division of the province. The number of districts/municipalities in each province of Indonesia varies.</td>
</tr>
<tr>
<td><strong>Duwe</strong></td>
<td><em>Syzygium cumini</em> (Latin). Other local names: <em>Jamblang hitam, duwet</em>.</td>
</tr>
</tbody>
</table>
Elementary school  *Sekolah Dasar* (Indonesian); a primary level of education comprises six years of education starting at 7 years old.

Ethnic language  Language spoken by people in certain ethnic groups. Ethnic languages are commonly used for everyday conversation with people within their group.

Family  *Keluarga* (Indonesian), in the Indonesian context, this word may include immediate family and extended family.

Formal health providers  Health facilities which provide medical services.

*Garam*  Salt.

*Gondongan*  ‘Swollen cheek’ literal translation in English, a sign of mumps.

*Gracia*  A brand name of herbal medicines in Indonesia, containing powdered and encapsulated mangosteen fruit peel.

*Gula lempeng*  Coin-shaped brown sugar made from *neera* (*lontar* palm nectar).

*Gula*  Sugar. Indonesian people commonly use the word *gula* for referring to white cane sugar.

*Gulai*  Yellow curry.

*Gulai padeh*  Red curry.

*Haram*  Forbidden by God, a word expressed mainly by Muslims.

*HbA1c*  Glycated haemoglobin. The HbA1c level reflects the average plasma glucose level over the previous 8–12 weeks.
<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Herbal medicines</td>
<td>Traditional medicines which are mostly from plants or part of plants. People often use term herbal medicines and traditional medicines interchangeably.</td>
</tr>
<tr>
<td>Immunisation coverage</td>
<td>Percentage of children who have received one or more vaccines in relation to the population for their age.</td>
</tr>
<tr>
<td>Incidence</td>
<td>The number of new cases for specific period of time.</td>
</tr>
<tr>
<td>Jamblang hitam</td>
<td>Other local plant name for <em>duwe</em> (Latin: <em>Syzygium cumini</em>).</td>
</tr>
<tr>
<td>Jaminan Kesehatan Nasional</td>
<td>The national health insurance programme, a universal health coverage programme in Indonesia managed by a single agency Badan Penyelenggara Jaminan Sosial Kesehatan-BPJ/Kesehatan.</td>
</tr>
<tr>
<td>Jamkesmas</td>
<td><em>Jaminan kesehatan masyarakat</em>: government-financed health insurance for the poor and near poor.</td>
</tr>
<tr>
<td>Jampersal</td>
<td><em>Jaminan persalinan</em>: government-financed health insurance of <em>Jamkesmas</em>, which aimed specifically to cover birth delivery services.</td>
</tr>
<tr>
<td>Jamsostek</td>
<td><em>Jaminan sosial tenaga kerja</em>: health insurance for industrial workers.</td>
</tr>
<tr>
<td>Jamu</td>
<td>Traditional medicines mainly from plants or part of plants. In some cases, mineral and animal sources might also be used. The word <em>Jamu</em> originally comes from the Javanese ethnic language, so the use of word <em>Jamu</em> is common among Javanese.</td>
</tr>
<tr>
<td>Junior high school</td>
<td><em>Sekolah Menengah Pertama</em> (Indonesian) comprising three years of education after the elementary or primary level of education.</td>
</tr>
</tbody>
</table>
Kader Posyandu: Voluntary health workers for Posyandu: lay people who were chosen by the community to manage the Posyandu. Their work is commonly not paid, or low paid based on financial support from the communities.


Katisen: Term for malaria in some parts of Indonesia (Central Java).

Kebal: Immune (English): resistant to or not susceptible to getting diseases.


Kupang: The capital city of East Nusa Tenggara Province.

Lauk: Side dishes mainly containing protein.

Layanan Kesehatan Cuma-Cuma – LKC: Charity health centre privately owned by Dompet Dhuafa, a faith-based non-government organisation.

Lemak: Fat (English).

Licenced drug stores: Stores that have a licence to sell non-prescription medicines.

Lontong: Rice cake wrapped inside banana leaves.

Maneira: A brand name of herbal medicines containing a mixed of some powdered ingredients including red ginger, mangosteen fruit peel, cinnamon bark, black cumin, etc.

Marungga: *Moringa oleifera* Lamk (Latin), another local name: kelor.

Masuk angin: Local term for describing a mild sickness caused by indigestion or over exposure to wind.
<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicines</td>
<td>Conventional, allopathic medicines. Indonesian people commonly refer to medicines as 'obat', the medicines they received from formal health providers.</td>
</tr>
<tr>
<td>Minangkabau</td>
<td>A large ethnic group in West Sumatera Province. The people of Minangkabau are called 'orang Minang' and look more like Malay people, and the language of Minangkabau is named 'Bahasa Minang'.</td>
</tr>
<tr>
<td>Missed opportunities</td>
<td>A missed opportunity for vaccination defined as contact with health services by individuals who are eligible for vaccination, which does not result in the person receiving one or more doses of vaccination.</td>
</tr>
<tr>
<td>Mungkin</td>
<td>A word in Indonesian for describing uncertainty, similar to perhaps, or maybe in English.</td>
</tr>
<tr>
<td>Nasi</td>
<td>Rice.</td>
</tr>
<tr>
<td>Non-formal health providers</td>
<td>Health providers, including clinics or individuals, which provide traditional or alternative therapies. For example, traditional healers, herbal medicines practitioners, and spiritual healers.</td>
</tr>
<tr>
<td>Non-state health centres</td>
<td>Health facilities own by non-government organisations or individuals. These health centres includes both not-for profit health centres (for example faith-based hospitals) and for-profit health centres.</td>
</tr>
<tr>
<td>Nusa Tenggara Timur</td>
<td>East Nusa Tenggara. A province located at the eastern part of Indonesia, next to West Nusa Tenggara.</td>
</tr>
<tr>
<td>Obat</td>
<td>Medicines or drugs (English). In Indonesian context, people refer to medicines received from formal health providers as 'obat'.</td>
</tr>
</tbody>
</table>
Olahraga

A word in Indonesian which is more related to ‘sport’ in English, and often to related to a subject of physical education at schools. However, this word is also used to convey the concept of exercise, as there is no other word in Indonesian similar to ‘exercise’.

Over-the-counter medicines

Medicines that can be obtained without prescription. In Indonesia, this include *Obat Bebas* (medicines with green circled label), and *Obat bebas terbatas* (medicines with blue circled label).

Pancasila

The official philosophical and national symbol of Indonesia which embodies the five principles of the Indonesian state: Belief in absoluteness of God, Justice and civilised humanity, The Unity of Indonesia, democracy guided by inner wisdom in the unanimity arising out of deliberations amongst representatives, and social justice for all Indonesian people.

Penyakit (sakit) kuning

Literally translated as ‘yellow disease’ (jaundice in medical term). A local term for liver-related disease.

Penyakit (sakit) lever

Liver disease.

Penyakit gula

Literally translated as ‘sugar disease’, a term used by lay people in Indonesia for diabetes.

Penyakit gula basah


Penyakit gula kering

Literally translated as ‘dry sugar disease’. Another lay classification of diabetes, for when people with diabetes are getting thinner, and not experiencing diabetes wounds.
Penyakit kencing manis  Literally translated as ‘sweet pee disease’, another lay term for diabetes.

Pharmacy  Apotik (Indonesia). Licenced places for obtaining medicines, including prescription and non-prescription medicines.

Pical  Indonesian vegetable salad with peanut sauce. The main ingredients for the peanut sauce are ground fried-peanut, brown sugar, and spices. Pical is from Minang dialect, the same as pecel in Javanese dialect.

Posbindu PTM  Pos pembinaan terpadu penyakit tidak menular, an integrated health post for non-communicable diseases. This programme addresses people aged 15 years and older for early detecting and managing risk factors of non-communicable diseases.

Posyandu lansia  Pos pelayanan terpadu lanjut usia, community-based health post for the elderly. This programme focus on early detection of risk factors of non-communicable diseases and improving general health of the elderly.

Posyandu  Community-based integrated health post for mother and child care. A government outreach programme managed by voluntary community members (kader), and monitored by Puskesmas. A Posyandu covers a quite small area within a village. The health services are commonly provided once a month, and include child growth monitoring, child immunisation, child-health education, and child supplemental nutrition.

Prescription only medicines  Medicines that can be obtained only with prescription. In the Indonesian context, this
includes *Obat Keras* (medicines with red circle label with letter K).

**Prevalence**
Proportion of people in a population who have a particular disease in some period of time.

**Prolanis club**
A club of people with diabetes and/or hypertension managed by the *Prolanis* programme at the health centres.

**Prolanis**
*Program pengelolaan penyakit kronis.* The health programme for managing chronic diseases, including hypertension and diabetes, which is currently under the management of universal health coverage (*BPJS Kesehatan*).

**Province**
Administrative division of the country. Indonesia is divided into 34 Provinces.

**Puskesmas**
Community health centres. Government-owned health centres located in sub-districts administrative level.

**Pustu**
Community health centres in village level. In a large sub-district, the *Puskesmas* might have subordinate *Puskesmas* named *Puskesmas Pembantu* or *Pustu* located in a village.

**Ramuan**
A mixture of traditional medicines mainly containing dried leaves, barks, or roots. Each *ramuan* has specific mix of ingredients prepared by a traditional healer for a specific disease.

**Rendang**
Spicy meat dish originally from *Minangkabau* ethnic group in West Sumatera. It is like a dry curry made from beef which is cooked slowly with spices and coconut milk (*santan*).
**Riset Kesehatan Dasar**

Basic health research. Nationally conducted health survey that has been done in 2007, 2010 and 2013.

**Rujuk balik**

'Refer back' policy, meaning referring back patients from secondary or tertiary healthcare facilities to primary care facilities after their condition improves.

**Salam**

Bay leaves, *Syzygium polyanthum* (Latin).

**Santan**

White coloured liquid obtained from the process of shredding coconut flesh and soaking it in water. Manually and freshly prepared coconut milk.

**Sei**

Smoked meat, a dish popular in East Nusa Tenggara.

**Self-efficacy**

Perceived capability to perform an action.

**Self-regulation**

A concrete skill that people should have to manage themselves.

**Senam**

A form of exercise done in a group where people move their bodies together with specific instruction, and often with music. The most popular form of physical activity in Indonesia.

**Senior high school**

*Sekolah Menengah Atas* (Indonesian). Comprises three years of education after junior high school.

**Sepat**

A taste like eating unripened banana, or unripened snake fruit. In this thesis this word is used to describe the taste of herbal or traditional medicines.

**Sinshe**

Chinese traditional medicines.

**Sirih merah**

*Piper crocatum* (Latin).

**Sirsak**

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stall or kiosk</td>
<td><em>Warung or toko</em> (Indonesian): small shops which sell everyday needs. Some kiosks also sell over the counter medicines. In some places, illegal prescription medicines might also be found.</td>
</tr>
<tr>
<td>State-owned health centres</td>
<td>Health centres own by the Indonesian government. This can be either the government at central, provincial or district levels.</td>
</tr>
<tr>
<td>Sub-district</td>
<td>Administrative division of districts/municipalities.</td>
</tr>
<tr>
<td><em>Sumatera Barat</em></td>
<td>West Sumatera. A province located in the Western-central part of Sumatera Island.</td>
</tr>
<tr>
<td><em>Terapi tertawa</em></td>
<td>Literally translated as ‘laugh therapy’, a form of exercise involving moving the body while laughing.</td>
</tr>
<tr>
<td>Traditional medicines</td>
<td>Any medicines other than conventional medicines. Indonesians commonly use specific terms for specific types of traditional medicines, the most common terms: <em>jamu, obat herbal, obat tradisional</em>, and <em>sinshe</em>.</td>
</tr>
<tr>
<td>Universal Health Coverage</td>
<td>Defined by WHO as ensuring that all people have access to needed health promotion, preventive, curative and rehabilitative health services, of sufficient quality to be effective, while also ensuring that people do not suffer financial hardship for those services. In the Indonesian context this concept was implemented on 1st January 2014 in form of <em>Jaminan Kesehatan Nasional</em>, national health insurance programme, which managed by single agency of BPJS.</td>
</tr>
<tr>
<td>Usual care</td>
<td>Regular care provided by health centres.</td>
</tr>
</tbody>
</table>
Village midwife  

Bidan Desa. A government outreach programme of deploying a midwife to live in villages and provide health services particularly related to mother and child health, including immunisation. However, it often broadened into general health services for people in the entire village.

Village  

The lowest administrative areas of Indonesia. Most villages are inhabited by about 2500 or fewer people. However, the size of a village varies depending on the provincial areas and local population density.
1 Chapter 1: Introduction

1.1 Background

Indonesia is a developing country whose health system has been facing epidemiological transition from communicable diseases to non-communicable diseases for the last three decades [1]. Although the number of deaths from communicable diseases dropped from 70% in 1980 to 30% in 2001, such diseases remain a significant health problem [2, 3]. Indonesia has low immunisation coverage compared to most other countries in the Southeast Asia region. In 2015, the percentage of MCV1 (first dose of a measles containing vaccine) coverage in Indonesia was approximately 68%, far below the average within the Southeast Asia region which was 85%, while the percentage of DTP3 (third dose of diphtheria, tetanus, and pertussis) coverage in Indonesia was 81%, also below the regional average of 87% [4-6]. Moreover, the Indonesia Demographic and Health Survey 2012 revealed that only 37% of children aged 12–24 months had received full basic immunisation. The percentage was lower in some provinces, such as West Sumatera where only 34.9% of children were fully immunised [7]. Aligned with low immunisation coverage, the incidence of vaccine-preventable diseases was high. In 2012, it was reported that measles was the cause of approximately 5% of children’s deaths under the age of five. Diphtheria outbreaks were declared in some provinces during the period of 2011 – 2016 [8, 9].

On the other hand, the prevalence of non-communicable diseases including cardiovascular diseases and diabetes is also rising, becoming major causes of deaths by 2012 [3, 9, 10]. In 2016, the prevalence of type 2 diabetes was 7%, an increase from 5.8% in 2014 [11, 12]. Although the diabetes prevalence in Indonesia was slightly lower than the average of other countries in the Southeast Asia region (7% compared to 8.6%, respectively), diabetes could be a serious health threat as it is strongly associated with tuberculosis [13, 14], undernutrition and stunting [15], the old health problems which remain prevalent in Indonesia. Recent studies including systematic review and meta-analysis confirmed that...
people with diabetes have a two to three-fold higher risk for developing tuberculosis [16, 17]. About 10% of global tuberculosis patients live in Indonesia, with 399 incidences per 100,000 population in 2016. This tuberculosis incidence rate is far higher than the average incidence either in the Southeast Asia region or globally, which was 211 and 133 respectively [18, 19]. Research has also found that diabetes and its risk factors are associated with undernutrition and stunting in childhood [15]. Studies in Indonesia also suggest that childhood undernutrition and stunting increase the risk of obesity in later life [20, 21], further increasing the risk of diabetes. It was reported that in 2013 that the national prevalence of undernutrition and stunting in children under five was high, 19.6% and 37.2% respectively [22]. The existing problems of tuberculosis and stunting in Indonesia, therefore, may increase the number of people with diabetes.

The problem of low immunisation coverage persists despite extensive governmental programmes providing greater access to health services. Since two decades ago, the Indonesian Ministry of Health has implemented the community-based health post for mother and child care (Pos Pelayanan Terpadu - Posyandu) at the sub-village level. Posyandu is an outreach programme aimed at improving mother and child health by providing health services including immunisation [23, 24]. Research showed, however, that the Posyandu was not well utilised [25, 26].

Similarly, to promote chronic diseases management, including diabetes, the Ministry of Health also introduced community-based health care for the elderly (Posyandu lansia) in the early 21st century. This programme is aimed at early detection of risk factors and better management of non-communicable diseases. The programme is designed to involve active participation of community volunteers in managing the programme in collaboration with community health centres [27]. The implementation of the Posyandu Lansia, however, varied among regions depending on the level of support from the community [28, 29]. Following the implementation of Universal Health Coverage (UHC) on 1 January 2014, the government implemented the Prolanis Programme, a programme for managing chronic diseases, particularly hypertension and diabetes, under insurance management. The effectiveness of the programme has not yet been evaluated. If
there is no revitalisation or new initiative in the implementation of this programme, however, it could potentially have the same problems as other government programmes. Lack of availability of resources and facilities, and lack of people’s interest in the programmes were the common obstacles that may hinder the success of the programmes [29, 30].

Increasing access to healthcare services is a key component of improving the nation’s health status. At an individual and community level, however, understanding people’s health-related behaviours is crucial in improving community health [31]. Greater understanding of people’s health-related behaviours might shed light on the problems that still exist in the community despite greatly increased access to health services. Gaining an understanding of people’s health behaviour is also an important step in establishing effective interventions aiming at improving people’s health [31, 32].

In the Indonesian context, people’s health-related behaviour is more complex due to it being a multicultural, ethnically diverse country with a variety of health providers. These providers range from the formal, including public and private healthcare services, to non-formal, among which are traditional healers, herbal medicine practitioners, spiritual healers, and homeopaths. As a multicultural community, Indonesians often practise what they call ‘local wisdom’ related to health, such as taking traditional medicines, and conducting traditional ceremonies to chase away the bad spirits that are perceived to cause illnesses. Some people believe that some diseases are caused by supernatural powers [33, 34]. Furthermore, this local wisdom ranges widely among different ethnic groups. Religious beliefs also play an important role in shaping people’s health-related behaviour. People would perform behaviour related to health, such as getting immunisation, if it is supported by their religious leaders or it is in line with their religious rules [35, 36].

Health seeking behaviours of people in Indonesia are also influenced by people’s perception of illness’ symptoms. People often delay treatment as they perceive their symptoms to be minor, so they choose to self-medicate or go to informal health providers as the first action. In contrast, when they perceive their
symptoms to be those of a more serious illness, they are likely to seek out formal health providers [37-40]. Self-medication is also supported by the fact that people can obtain most medicines including antibiotics without prescription from most pharmacies in Indonesia [41, 42]. People’s perception of diseases also influences their health-related action [39, 43, 44]. It is believed, for example, that diabetes is a disease of the wealthy, so the poor consider it impossible that they might get it [43]. Understanding people’s point of view in the Indonesian community, therefore, is an important step in establishing acceptable and effective health intervention.

This thesis identifies underlying behavioural factors focusing on two health issues – child immunisation, and type 2 diabetes. Focusing on these two health issues may differentiate people’s behaviour related to different types of health problems: preventive behaviour and long-term disease related behaviour. This understanding is then applied to develop and implement a community-based intervention for diabetes patients, and the effectiveness of the intervention is also evaluated.

1.2 Aims of the thesis

This thesis focused on the problems of child immunisation and type 2 diabetes in Indonesia. The goal was to improve indicators or outcomes related to child immunisation or diabetes through implementing interventions that are based on understanding of health behaviour. In order to achieve that goal, the research was conducted in two stages: a qualitative study, followed by a quasi-experimental pilot study. The qualitative study focused on both child immunisation and diabetes, and the intervention pilot study focused only on diabetes.

The qualitative study aimed to explore the perceptions, beliefs and behaviour of people in Indonesian communities related to child immunisation and diabetes. This understanding will have a significant impact on establishing more acceptable health programmes and increasing community participation in these programmes. Three research questions were addressed: 1) what are people’s perceptions, beliefs, and experiences relating to child immunisation and diabetes; 2) what are
the individual and social factors that may influence people's behaviour related to child immunisation and diabetes; and 3) what are the health provider factors that may determine people's behaviour in seeking care?

Based on knowledge gained from the qualitative study, an intensive community-based diabetes intervention was designed, and implemented. A quasi-experimental study design was used to evaluate the effectiveness of the intervention compared to usual care that patients would receive. The intervention aimed to increase self-management knowledge and practices among diabetes patients, increase medication adherence, and improve patients' outcomes. Three research questions that were also addressed for the intervention study were: are there any differences in: 1) knowledge and practices of self-management of diabetes; 2) medication adherence; and 3) clinical outcomes, between diabetic patients who receive a community-based intervention and those who receive usual care?

1.3 The researcher's personal motivation for the topic

My personal interest on the topic of child immunisation and diabetes came from an unforgettable memory of my childhood. When I was a child, I remember that I got mumps, which is locally known as 'gondongan' or swollen cheek. At that time, a lot of my friends also got mumps. My mother and almost all my friends' mothers applied blue-coloured bleaching powder to the swelling cheek. Thus, with that blue cheek you were easily recognised as having that disease. As I grew older, I noticed that some children still got that disease and their mothers still applied that blue-coloured bleaching powder. This led me to question why that blue-coloured bleaching powder was used for treating mumps, and from where they had acquired the idea that this was an appropriate treatment.

The other unforgettable memory of my childhood is when one of my extended family members – the younger sister of my grandmother – died from a frightening disease, described by local people as an unhealed and disgusting wound that led her to have her limb amputated. Even after receiving an amputation, however, the disease did not go away. At that time, many people had no idea of what kind of
diseases existed: some believed that the disease was caused by supernatural power.

Those memories had almost been forgotten until I began my Bachelor’s degree in Pharmacy and learnt about immunisation and diabetes. It was then that I understood that that blue-coloured bleaching powder had nothing to do with mumps, and that the unhealed wound was a complication of diabetes.

After that, I felt that diabetes was really close to my life: my aunt died of diabetes, and my father also suffers from diabetes. These experiences have led me to consider the impact of behaviour on health. I recall one thing from visiting my aunt before she died: even after her condition had deteriorated greatly, she was angry when we told her to restrict certain kinds of food in her diet. Instead, she said something like: “We live to eat, so how come the disease comes from the food we eat. We all will die, whether or not we eat or do not eat that food, so it’s better to eat rather than restrict some kind of food and then still die”. In the case of my father, for some time my mother and I knew nothing about his symptoms; finally, my mother told me that my father had a sexual problem. He tried traditional medicines for improving this problem, but none were effective. Soon I remembered that diabetes can cause these types of symptoms. I asked my mother to take my father to the health centre to get his blood checked, which revealed that my father did indeed have diabetes.

These experiences are the starting point of my interest in child immunisation and diabetes, particularly in relation to people’s behaviour around these two health issues.

After graduating with a bachelor’s degree, I worked as a member of the academic staff at the university I graduated from. At that time, there was a transition of ideas within the pharmacy department, from a ‘product oriented’ to more ‘patient oriented’ way of thinking. Discussions with experts have led to the conclusion that new expertise has to be created: the pharmacist who has more skills in dealing with patients. To facilitate this, I was asked to learn more about public health as it relates to pharmacy. I took the opportunity to learn more about behavioural
aspects of health, completing a Master’s degree in Public Health. Being a lecturer, I also did research with my undergraduate students, mainly focusing on how people really take their medicines. The studies found that people’s behaviour in medication taking is an essential factor that affects the effectiveness of the medicines.

My personal motivation with this PhD research was to do something that might change people’s health-related behaviour in diabetes and immunisation. I hope that the intervention can be applied widely so that there will not be a single person like my aunt who did not believe that the disease was caused by her eating behaviour; that there is nobody like my father who delayed in getting diagnosis with diabetes; and there is no child like me that is given a blue-coloured bleaching powder to treat an immunisation preventable disease.

1.4 Indonesia

1.4.1 Indonesia

Indonesia, or officially the Republic of Indonesia, is a Southeast Asian nation situated between the continents of Asia and Australia, and between the Pacific and Indian Oceans. It is an archipelagic state consisting of more than 13,000 large and small islands, with a total land area of 1,913,578.68 square kilometres [45]. The five biggest islands are Sumatera, Java, Kalimantan, Sulawesi, and Papua. Kalimantan, Papua, and Timor islands share a land border with Malaysia, Papua New Guinea and Timor Leste, respectively (Figure 1.1). The most world famous island of Indonesia is Bali, which attracts foreigners to enjoy its white sandy beaches. Borobudur temple, Prambanan temple, Sangiran early man site, and Komodo National park are among properties of Indonesia listed as World Heritage Sites [46].

Lying along the equator, stretching from 6°08’ N latitude to 11°15’ S latitude, and from 94°45’ E to 141°05’ E longitude, Indonesia is a tropical country with two seasons: dry and rainy [47]. The dry season usually occurs between May and September, and the rainy season occupies the rest of the year [48]. Other characteristics of a tropical country are that it is hot and humid. The temperature
commonly ranges between 23°C, particularly in mountainous areas, and 33°C in low land areas, while the humidity ranges from 60 – 90% [49]. Due to its geographical location, Indonesia is divided into three time-zones: Western Indonesia Time, which is seven hours ahead of Universal Time Coordinated (UTC +7), Central Indonesia Time, which is eight hours ahead of Universal Time Coordinated (UTC +8), and Eastern Indonesia Time, which is nine hours ahead of Universal Time Coordinated (UTC +9). Western Indonesia Time includes areas of Sumatera, Java, and western part of Kalimantan. Central Indonesia Time includes areas of eastern part of Kalimantan, Sulawesi, Bali, West Nusa Tenggara, and East Nusa Tenggara. Finally, Eastern Indonesia Time includes areas of Maluku and Papua [50].

Administratively, the country is divided into 34 provinces. Each province is further divided into districts or municipalities, then sub-districts, and the lowest administrative areas, the villages [45]. Most villages in Indonesia are inhabited by about 2,500 or fewer people. The size of a village, however, varies depending on the provincial areas and local population density. On Java island, with population density of more than 1,000 person/km², a village might incorporate only about 2.5 km², while outside Java island, a village might have a total area of more than 30 km² [45]. In 1999, the Indonesian government began to decentralise its political, administrative and fiscal functions from its formerly strongly centralised structure. This decentralisation programme is known in local term as ‘otonomi daerah’ or regional autonomy, which means that the regional government including provinces, districts and municipalities have their own power to regulate themselves [51, 52]. Since 2004, the Indonesian people have also elected the President and the regional government leaders with direct voting [53].
Figure 1.1: Map of Indonesia

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Indonesia is home to more than 255 million people, and with an annual population growth of 1.38%, is recorded as the fourth most populous country in the world [54, 55]. The population is spread unevenly across the country, with more than half of the people inhabiting Java Island which occupies only about 6.5% of total land area of Indonesia [45, 56]. Indonesia is a culturally diverse nation with more than 1,300 ethnic groups. Some ethnic groups which share similar characteristics are further categorised as a single ethnic group, making just 31 groups of distinct ethnic populations. Javanese is the biggest ethnic group, accounting for 40% of the total Indonesian population. This is followed by Sundanese (15%), and the Batak ethnic group (3.5%) [57]. Each ethnic group has a different ethnic language, and almost 80% of Indonesian people use their local or ethnic language for daily communication [57]. The Indonesian Language or Bahasa Indonesia is the official and national language, therefore the majority of people also speak Bahasa Indonesia.

In terms of religions, the Indonesian government recognises six official religions: Islam; Catholicism; Protestantism; Hinduism; Buddhism; and Confucianism. Islam is the predominant religion and accounts for about 87% of country’s population. In Bali, Papua, and East Nusa Tenggara, the predominant religions of the people are Hinduism, Protestantism and Catholicism, respectively [57]. Given this immense diversity, Indonesia has a strong national motto: Bhinneka Tunggal Ika, which is translated as ‘Unity in Diversity’. Moreover, the official philosophical and national symbol Indonesia is ‘Pancasila’ which describes five principles of the Indonesian state: belief in absoluteness of God; justice and civilised humanity; the Unity of Indonesia; democracy guided by inner wisdom in the unanimity arising out of deliberations amongst representatives; and social justice for all Indonesian people [58].

In the 21st century, Indonesia has developed significantly in its economy, education, and health indicators. The acceleration in economic growth is shown in an increase in gross domestic product per capita from IDR 6,569,760 (USD 780) in 2000 to IDR 44,807,496 (USD 3,346) in 2015 [59]. This economic growth is fuelled mainly by increasing household consumption due to a rising number of people
classed as middle income [60, 61]. Some of the factors driving the rise of the middle-income group are rapid urbanisation, increased new job opportunities in the services and industrial sectors, and improving educational status [60]. In line with this economic growth, Indonesia has also experienced an enormous reduction in poverty. The percentage of people who live below the national poverty line, which is described as consumption outlays of IDR 372,114 (USD 28) per month per person in urban areas and IDR 350,420 (USD 26.3) per month per person in rural areas, almost halved from about 20% in 2000 to 10.7% in 2016 [62, 63]. The percentage of poor is higher in the eastern part of Indonesia, including East Nusa Tenggara (22.01%), Papua Barat (25%) and Papua (28%) [64].

The progress in the people’s education level has been similar. In 2010, about half of Indonesian people above 15 years of age had completed nine years of basic education, which was an increase from 39.08% in 2000. Coupled with this, the number of Indonesian people who had completed some form of tertiary education doubled from 3.77% in 2000 to 6.64% in 2010 [65].

Indonesia has also made improvements in some health indicators mentioned in the Sustainable Development Goals (SDGs) related to health [6], as shown by decreasing infant mortality rates, and increasing life expectancy. The infant mortality per 1,000 live births dropped from 47 in 2000 to 13.5 in 2015, while life expectancy rose from 65.4 in 2000 to 69.1 in 2015 [6, 66]. These achievements were slightly higher than the average of other Southeast Asian countries, which saw an infant mortality rate of 24.3 and a life expectancy of 68.9 in 2015 [19]. Despite this progress, Indonesia still faces many challenges in other SDG health indicators, including low immunisation coverage, high incidence of tuberculosis, and increasing prevalence of and mortality rate due to non-communicable diseases [6].

1.4.2 Health system in Indonesia

The Indonesian health system consists of three levels: a central level Ministry of Health; the Provincial Health Departments; and the District or Municipality Health Department. The Ministry of Health (MoH) has overall responsibility for setting
regulations and healthcare policy, and ensuring availability of healthcare professionals. The MoH manages health programmes addressing public health issues, such as immunisation, tuberculosis, malaria, and HIV/AIDS programmes. At the central level, there are also other government agencies that are closely related to health including the National Population and Family Planning board (Badan Kependudukan dan Keluarga Berencana Nasional), the Social Security Agency (Badan Penyelenggara Jaminan Kesehatan – BPJS Kesehatan), and the Food and Drug Administration and Control Agency (Badan Pengawasan Obat dan Makanan) [67].

The Provincial Health Department has responsibility for managing provincial health services, monitoring and coordinating districts health services and addressing relevant health issues. Meanwhile, the District or Municipality Health Department is responsible for managing district or municipality hospitals and community health centres, and monitoring and coordinating sub-district health facilities. In 2001, however, following the implementation of administrative, fiscal and political decentralisation, the Indonesian health system, including responsibility for health services delivery was transferred from the central government to the district level. This means that the relationship between those three levels is no longer hierarchical, so that the provincial level of health care is now not subordinate to the MoH [67].

It was expected that with this decentralisation, each district would have better management of their budget and resources. Within the decentralisation era, the government health-related budget comes not only from direct funding from the MoH, but also from the provincial or district/municipality government budget, and from the health insurance fund. The national budget allocated for health, although quite low, increased from 2.0% in 2005 to 2.5% in 2014 [68]. More than a decade after its implementation, however, decentralisation has led to a wide variation in local health budgets, and the standard of health services across the country. The local provincial and districts or municipalities health budgets range widely from 15.79% to 1.95% [10]. These variations have resulted in increasing inequities of access to, and quality of health care throughout the country, increasing utilisation
of private health centres, while the performance of the health systems has not changed greatly [68-70]. These inequities of access and quality of health care can be seen in the wide range of health services indicators at the provincial level. In 2014, the ratio of hospital beds per 1,000 population ranged from 2.9 to 0.6 (Indonesia average 1.1), the ratio of general practitioner per 100,000 population ranged from 155.5 to 8.8 (Indonesia average 38.1), and the ratio of community health centres per 30,000 population ranged from 5.07 to 0.6 (Indonesian average 1.17) [10].

Meanwhile, health care in Indonesia is delivered by a mixed system in which government-owned health centres coexist with privately-owned health centres. The government-owned health centres consist of community health centres (Puskesmas-Pusat Kesehatan Masyarakat) at the sub-district level across the country, which are complemented by state hospitals at district and province level. Some villages are also supported by sub-community health centres (Pustu-Puskesmas Pembantu) and maternity centres (Polindes-Poliklinik desa). These health centres not only deliver inpatient and outpatient services, but also perform promotive and preventive health activities [71]. While primary care is the main focus of services given at the Puskesmas, those needing secondary and tertiary care are usually referred to hospitals. Figure 1.2 illustrates the Puskesmas and Figure 1.3 illustrates typical health consultation at the Puskesmas. In 2015, the number of Puskesmas was 9,754, of which 3,396 had inpatient services. This number has grown to meet the expected ratio of one Puskesmas per 30,000 population. By 2015, the number of government-owned hospitals in 2015 was 888 [9].

Privately-owned healthcare services range widely from not-for-profit religious charitable group-owned healthcare facilities and for-profit non-state healthcare facilities including ambulatory and out-patient care health centres, and hospital chains. Many medical staff who work at the government-owned health centres also open private clinics or work at other non-state health providers in the evening [72]. In some villages where there are not many medical doctors, village midwives also operate private health services. The number of private hospitals
grew rapidly to about 1,600 hospitals, almost double the number of state hospitals [9]. These private health centres are regulated by local and central government through registration, licencing and accreditation [67]. The growth of the private-for-profit hospitals, however, may impact on commercialisation of health care [72].

Despite its complex health system, Indonesia has experienced an increase in health insurance coverage. In 2005, the Indonesian government introduced a health insurance for the poor named *Askeskin* (health insurance for the poor); in 2007, this scheme was renamed *Jamkesmas* to also cover the near-poor [73]. In 2011, the government also expanded *Jamkesmas* to cover births, in a scheme which named *Jampersal*. Then, in early 2014 the government also introduced a Universal Health Coverage (UHC) programme: all Indonesians are expected to come under its umbrella by 2019 [74]. This universal health coverage programme is managed by single agency of *BPJS Kesehatan*, so that all other previous health insurance schemes are to be merged into this UHC, including the long-established health insurance for civil servants (*Askes*), and health insurance for industrial workers (*Jamsostek*) [75]. A year after it was introduced, the number of subscribers to the insurance programme had reached more than 150 million people or about 60% of total population [76]. Some studies suggested that increasing health insurance coverage correlates with an increase in health care utilisation [37, 77, 78].

As in other developing countries, despite the wide availability of formal health providers, informal health providers or non-conventional health providers comprise a significant component of health services [79]. In Indonesia, these informal health providers range from traditional health providers to traditional birth attendants. The traditional health providers in Indonesia are divided into four categories: biologically based therapies – traditional therapies with substances from nature, for example herbal medicines; physical therapies with tools – for example acupuncture, acupressure, cupping therapy; physical therapies without tools – for example massage; and mind-body therapies – for example hypnotherapy and meditation [22].
Figure 1.2: A community health centre (*Puskesmas*) in Kupang, East Nusa Tenggara

Figure 1.3: Typical health professional – patient consultation at the *Puskesmas*
With the wide availability of these traditional providers, the use of complementary and alternative medicines is also prevalent. The Indonesian government has recognised the importance of traditional medication in the society, and attempted to regulate these traditional providers [80]. Recently, in 2017, the government introduced an integration of traditional health services into the formal health services [81].

Meanwhile, pharmaceutical products in Indonesia are regulated by the National Agency for Food and Drug Control (Badan Pengawasan Obat dan Makanan-BPOM). To ensure the quality of medicines, pharmaceutical companies must meet the Good Manufacturing Practice [82]. The medicines that are obtained legally from formal health providers, therefore, should meet the quality standards. However, evidence of substandard and counterfeit medicines has been found [83].

Medicines in Indonesia are classified into five categories, and each category can be identified by the colour of the label: over the counter medicines (green circle labelled known as Obat Bebas); limited-over the counter medicines (blue circle labelled – known as Obat bebas terbatas); prescription-only medicines (red circle labelled with letter K – known as Obat keras); psychotropic medicines (labelled the same as prescription-only medicines); and narcotic medicines (red labelled with a ‘plus’ sign) [84]. Both over the counter and limited over the counter medicines can be obtained from licenced places without prescription. Indonesia has separated the prescription and dispensing of medicines. Under regulation, medicines can only be obtained from licensed places, including pharmacies (apotik), and licensed drug sellers (toko obat berijin). Licenced drug sellers can only sell non-prescription medicines. Non-licensed drug sellers, however, including informal outlets (stalls, kiosks) are available widely across the country.

1.5 Overview of study locations

1.5.1 Justification of study locations

The research was conducted in West Sumatera and East Nusa Tenggara, two provinces of Indonesia. Both provinces were chosen based on differences in their population characteristics and health related indicators. The population size of
both provinces was almost the same: about 5.1 million people in 2015 [85]. The demographics of each province are markedly different, however. The majority of people in West Sumatera are originally from a single, large ethnic group, *Minangkabau*, who look more like Malay people (Figure 1.4). Islam is the predominant religion in West Sumatera [57]. In contrast, the people in East Nusa Tenggara have heritage from many different small ethnic groups, and most of their origin ethnically and culturally lay in a transition border from Asia to Australia and Micronesia (Figure 1.5). The predominant religion in this province is Catholic [57]. Therefore, gathering data in those provinces is likely to contribute rich information and insight about sociocultural influences on health related behaviour.

**Table 1.1: Characteristics and health-related indicators in West Sumatera and East Nusa Tenggara**

<table>
<thead>
<tr>
<th>Characteristics / health related indicators</th>
<th>West Sumatera</th>
<th>East Nusa Tenggara</th>
<th>National average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>5,196,300 a</td>
<td>5,120,100 a</td>
<td>255,461,700 a</td>
</tr>
<tr>
<td>Total area</td>
<td>42,012.89 km² (b)</td>
<td>48,718.10 km² (b)</td>
<td>1,913,578.68 km² (b)</td>
</tr>
<tr>
<td>Number of islands</td>
<td>391 c</td>
<td>1,192 d</td>
<td>About 13,000 b</td>
</tr>
<tr>
<td>Bed ratio per 1,000 population</td>
<td>1.34 e</td>
<td>0.88 e</td>
<td>1.21 e</td>
</tr>
<tr>
<td>Community health centre ratio per 30,000 population</td>
<td>1.52 e</td>
<td>2.17 e</td>
<td>1.15 e</td>
</tr>
<tr>
<td>General Practitioner per 100,000 population</td>
<td>19.53 e</td>
<td>13.2 e</td>
<td>16.06 e</td>
</tr>
<tr>
<td>GDP per capita</td>
<td>USD 2,569 f</td>
<td>USD 1,114 f</td>
<td>USD 3,346 f</td>
</tr>
<tr>
<td>Immunisation coverage</td>
<td>34.9% g</td>
<td>46.5% g</td>
<td>37.0% g</td>
</tr>
<tr>
<td>Type 2 diabetes prevalence</td>
<td>1.8% h</td>
<td>3.3% h</td>
<td>6.9% h</td>
</tr>
</tbody>
</table>

Notes:  
* Statistics Indonesia [85]  
* Ministry of Home Affairs [45]  
* Statistics of West Sumatera Province [86]  
* Statistics of East Nusa Tenggara Province [87]  
* Indonesia Ministry of Health [9]  
* Statistics Indonesia [88]  
* Statistics Indonesia, et al. [7]  
* Department of Health Research and Development Ministry of Health of Indonesia [22]

In terms of health services indicators, as presented in Table 1.1, people in West Sumatera generally have higher access to hospitals and general practitioners than those in East Nusa Tenggara, but people in East Nusa Tenggara have higher access to community health services. East Nusa Tenggara province consists of more islands than West Sumatera, so that people in East Nusa Tenggara may experience
more obstacles in getting to health facilities than their counterparts. In terms of their economy, people in West Sumatera are generally wealthier than those in East Nusa Tenggara, as shown by their GDP per capita.

Given these conditions, it is interesting to note the fact that immunisation coverage in East Nusa Tenggara was higher than that of in West Sumatera. However, the prevalence of type 2 diabetes was higher in East Nusa Tenggara than in West Sumatera. These data of diabetes prevalence at provincial level were estimated based on a national survey of people with diagnosed diabetes or people who experienced diabetes symptoms in the last month [22]. This figure is likely to be even higher, given that most people with diabetes in Indonesia are undiagnosed, and people with diabetes often do not experience any symptoms [89].

1.5.1.1 West Sumatera Province

West Sumatera Province is located in the central eastern part of Sumatera Island (Figure 1.6). The Province is divided administratively into 12 districts and seven municipalities. In 2015, the population of West Sumatera was 5.1 million people, and it is estimated that 7.1% of these were living under poverty line [64]. The population consists of 31.9% children less than 15 years old, 62.4% adults and 5.6% elderly people (more than 64 years old) [86]. The majority of people over the age of 15 work in the agricultural sector (39.3%), while 21.3% work in the business sector, and the remainder work mainly in industrial setting or in professional service areas such as teaching and health [86].

West Sumatera Province has 64 hospitals, 260 Puskesmas and 896 Pustu [86, 90]. However, healthcare services utilisation was very low. The 2013 Basic Health Research survey estimated that about 6.9% of the total population utilised outpatient services in the last month preceding the survey, lower than the national percentage (10.4%). It was also lower than the West Sumatera population that self-medicated, which was 14.1% [22]. Of those who used outpatient healthcare facilities, the most common type used was Puskesmas (33.9%) followed by midwifery services (29.5%) and private-doctor services (11.9%) [22].
Figure 1.4: People of West Sumatera

Figure 1.5: People of East Nusa Tenggara
Figure 1.6: Map of West Sumatera Province (Provinsi Sumatera Barat) [91]

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Figure 1.7: Map of East Nusa Tenggara Province (Provinsi Nusa Tenggara Timur) [92]

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In terms of immunisation coverage, based on 2012 Demographic Health Research, the percentage of 12 – 23 months old children that received completed immunisation was only 34.9%, while 6.3% had not been immunised at all. This figure was lower than the average national immunisation coverage of 37% [7]. The immunisation with the highest uptake was BCG immunisation, which is given at no more than a month old, and the lowest rate was DTP-HB 3, the third dose of DTP-HB [22]. This shows a high immunisation dropout rate. This low rate of immunisation coverage has led to a high incidence of vaccine-preventable diseases. In 2015, there was a diphtheria outbreak in West Sumatera with a total of 110 cases [9].

Another disease that has become a major problem in Indonesia including in West Sumatera is type-2 diabetes. Despite the low prevalence of only 1.8% in 2013, the figure represents an increase from 1.2% in 2007 [22].

1.5.1.2 East Nusa Tenggara Province

East Nusa Tenggara Province is located in the eastern part of Indonesia, on the border of Timor Leste (Figure 1.7). It has 1,192 islands, of which only 43 are inhabited by about 5.1 million people [87]. The Province is divided into 21 districts and one municipality, which is Kupang municipality, the capital city of the province [87].

In 2015, East Nusa Tenggara Province was recognised as the poorest province in the country as shown by the lowest regional GDP per capita, which was only IDR 14,927,930 (USD 1114) compared to the national GDP per capita of IDR 44,807,496 (USD 3,346) [88]. Furthermore, about a million or 22% of its population live below the poverty line [64].

More than a half of people in East Nusa Tenggara are adults, and more than a third are children, while the remaining 5% of the population are the elderly. The majority of adults work in the agricultural sector (about 61%), services sector (13%), trades (7%), and industrial sector (7%). In terms of education, about 36.47% of people over 10 years of age have not completed primary school;
another 31.07% have completed elementary school; and only a minority of this population (4.4%) have completed tertiary education [87].

In terms of healthcare services, the province has 43 hospitals, 368 *Puskesmas* and 1,045 *Pustu* [87]. In general, health care utilisation is also low in East Nusa Tenggara. The 2013 Basic Health Research survey estimated that approximately 20% of the population self-medicating in the previous month preceding the survey, and only 11% of the population utilised outpatient services [22]. Among those who self-medicated, 80.17% used modern/western medicines, another 30.04% used traditional medicines, and the remaining 2.96% used another method of medicine/medication [22].

The biggest health problem in East Nusa Tenggara is related to mother and child health. In 2010, the infant mortality rate was 39 per 1,000 live births and the maternal mortality rate was 387 per 100,000 live births. These rates were far higher than the national rates [93]. Prevalence of undernutrition and stunting were also reported to be the highest in the country. In 2013, more than 30% of children under five experienced undernutrition, and more than 50% of children under five were stunted [22].

Besides that, the percentage of children 12 – 23 months old who had completed the basic immunisation programme was only 46.5%, while 6.7% had not been immunised at all [7]. This low immunisation coverage leads to a high number of immunisation preventable disease cases. In 2012, 114 measles cases occurred, which was a decrease from 967 cases in 2011 [93].

In terms of non-communicable diseases, hypertension had the highest prevalence in East Nusa Tenggara followed by type 2 diabetes. In 2013, the prevalence of diabetes in adults more than 18 years old was 3.3%, 1.3% of which was diagnosed and the remaining 2% was undiagnosed [22]. Furthermore, diabetes is not only prevalent among people in urban areas, but also those in rural areas. One study showed that diabetes prevalence in Ende, a rural area of East Nusa Tenggara, was 2% measured with fasting and post glucose load value and 2.83% with HbA1c criteria [94].
1.6 Scope of the thesis

The qualitative study explores the perceptions, beliefs, and behaviours of people in Indonesian communities in relation to child immunisation and diabetes. These perceptions, beliefs, and behaviours are investigated based on the actors of the health-related actions: the mothers of the children, and the diabetes patients. Although the perception, belief and behaviour related to child immunisation and diabetes in the community might also be investigated from wider community members other than the actors, their views are outside the scope of this study. The child immunisations referred to in this thesis are the basic childhood immunisations included in the National Immunisation Programme, which is intended for infants. Although the current child immunisation programme also includes booster doses for children older than one year, and booster doses for school-aged children, these are not included in the scope of this study.

The intervention project aims to evaluate the effectiveness of community intervention compared to usual care. Evaluating intervention may be performed using two different types of study: an efficacy study; or an effectiveness study. An efficacy study evaluates performance of an intervention under ideal and controlled circumstances, while the effectiveness study evaluates performance of an intervention under real world or usual clinical practice setting [95, 96]. The evaluation of intervention in this thesis is an effectiveness study, which examines the intervention with less controlled conditions: a more heterogeneous patient population; and a less-standardised protocol, delivered by available health professionals in community settings. Moreover, an effectiveness study might also answer a wide range of questions including the impact of the intervention on clinical outcomes, and medical costs [96]. This thesis, however, only focuses on effectiveness in terms of participants’ clinical outcomes, so that a cost-effectiveness analysis of the intervention is not included in the study. Furthermore, usual care is used as a comparison in evaluating the effectiveness of the intervention; however, this study does not evaluate the effectiveness of usual care. The intervention was also designed based on the results of the qualitative study done in the same community. Given the fact that the population of Indonesia possesses diverse community characteristics, applicability of intervention in other
communities should also involve careful assessment of the community’s characteristics.

In developing the study, some theories on health behaviours are reviewed and implemented. This thesis, however, was not aimed to test the theory. Descriptions about theories are made based on their applicability in Indonesian context. This thesis also focused on type 2 diabetes, therefore the term ‘diabetes’ used in this study refers to type 2 diabetes.

1.7 Structure of the thesis

This thesis is organised into four sections. Section A is an introductory section. It includes Chapter 1 and Chapter 2. Chapter 1 presents the background of the thesis and healthcare delivery system in Indonesia. An overview of the study locations is also described in this chapter. Chapter 2 provides an overview of the literature related to the topic and key concepts related to the study. This chapter includes the topics of child immunisation and diabetes mellitus. The key concepts described in Chapter 2 are health behaviours and their social components including health beliefs and cultural characteristics that might influence health behaviour. The literature review on health seeking behaviour of people in Indonesia is also presented in this chapter. Lastly, Chapter 2 highlights the key findings from the literature review, the gaps observed, and how the thesis might contribute to the filling these gaps.

Section B describes the process of understanding people’s health behaviours through a qualitative study exploring perceptions and experiences of Indonesian people related to child immunisation and diabetes mellitus. It is presented in Chapter 3. This chapter describes the methodology and methods of the study, and explains and discusses the result of the study. In the last part of this chapter, discussion and the introduction to the main study are also presented.

Section C presents the development, implementation, and evaluation of an intervention pilot study for people with diabetes. The section consists of three chapters: Chapter 4, Chapter 5 and Chapter 6. Chapter 4 presents literature review
related to diabetes interventions. This chapter describes the goals and the methods of diabetes interventions, then outlining diabetes intervention studies that have been done globally, in developing countries, and in Indonesia. Finally, this chapter details key findings from the review of the literature, identifies gaps, and presents the study’s contribution in the field. Chapter 5 presents the methodology and method for the intervention study. This chapter includes the rationale of the research, the theoretical framework, and research process. This is followed by explanations of the study design, sampling methods, and the instrument of the study. Lastly, Chapter 5 describes the data gained from this study: how the data were collected, managed and analysed. Chapter 6 explains the result of the intervention study, which is detailed in relation to each study outcome. Comparisons between control and experiment groups are also made, and a discussion related to the results of each outcome is also presented.

Finally, Section D which is presented in Chapter 7 gives a summary of research findings, both of the qualitative and the intervention pilot study. These findings are then related to the literature. Based on this discussion, conclusions and recommendations are presented.
2 Chapter 2: Literature review

2.1 Introduction

Chapter 2 reviews topics covered in this thesis. I identify and evaluate studies related to child immunisation programmes, diabetes, and health behaviours, particularly in the Indonesian context. This chapter is divided further into five subchapters. The first subchapter describes how the literature was collected, including key words and databases used in the process.

The second subchapter looked at child immunisation. The review begins with the description of vaccination programmes in the global and developing countries’ scope, and then concentrates on Indonesia. This description is then followed by the epidemiology of vaccine preventable diseases in global and developing countries and followed by their epidemiology in Indonesia. This subchapter finishes with the challenges of the immunisation programme in Indonesia.

The third subchapter focuses on type 2 diabetes mellitus (hereafter, diabetes). It starts with a short description about diabetes, followed by its epidemiology on a global scale, in developing countries and in Indonesia. The subchapter finishes with the description of challenges in managing diabetes in Indonesia.

The fourth subchapter is about health behaviour: the importance of health behaviour studies; and health behaviour theories. This understanding of health behaviours is then used to review findings related to health behaviours in Indonesia. The fifth and final subchapter explains the key findings from this literature review, and highlights the identified gaps.

2.2 Literature review strategy

Different data sources and strategies were used to collect relevant literature. These included searching with specific keywords, the combination of those keywords with three Boolean operators OR, AND and NOT. Further, articles’ references lists were also searched for relevant literature. The keywords used in each topic reviewed are listed in Table 2.1.
Using the keywords in Table 2.1, results were gathered from various databases including Ovid, PubMed, Scopus, Web of Science, Science Direct, ProQuest Central, and Google Scholar. A University of Otago library search was also used to find relevant literature. In addition, literature from Indonesian journals was also searched with the same keywords translated into Indonesian language. Google Scholar database is the main way to find articles in Indonesian journals. In addition, the grey literature was also searched, particularly to find information produced by the Indonesian government, such as health reports.

The articles yielded from those literature-searching methods came from a wide range of peer-reviewed journals. Some relevant articles from Indonesian journals were also identified. These articles added further information which cannot be found from peer reviewed journals.

### 2.3 Child immunisation

#### 2.3.1 Child immunisation programme

##### 2.3.1.1 Global child immunisation programme

Following the success of the smallpox eradication programme in late 1960s, the World Health Organization (WHO) initiated the Expanded Programme on
Immunisation (EPI) in 1974, targeting six immunisation preventable diseases: diphtheria; pertussis; tetanus; measles; poliomyelitis; and tuberculosis [97, 98]. This EPI was the first coordinated action worldwide, and it was scheduled to be given to children before their first birthday [97]. The original EPI included one dose of BCG (Bacillus Calmette-Guerin) vaccine, three doses of OPV (Oral Poliovirus Vaccine), three doses of DTP (Diphtheria, Tetanus, Pertussis) vaccine, and one dose of measles containing vaccine (MCV). Since then, additional vaccines have been added. Currently, WHO recommends that all countries also provide six other vaccines in their immunisation programme: Hepatitis B virus; Haemophilus influenza type b; pneumococcus; rotavirus; rubella virus; and human papillomavirus [99]. Its implementation into national immunisation programmes, however, varies among regions and countries. Most countries, including low-middle income countries have added Hepatitis B, and Haemophilus influenza type b vaccines in their national immunisation programme. A minority of them, particularly developed countries, have also introduced the other four vaccines into their national immunisation programme as well [5].

To evaluate immunisation programme performance, the third dose of DTP (DTP3) is used globally as an indicator [98]. DTP3 coverage is also mentioned as one of the indicators of essential health services coverage in the Sustainable Development Goals for Health [19]. WHO/UNICEF estimate immunisation coverage based on official reports submitted by governments and supplemented by published and grey literature [100]. According to WHO and UNICEF estimation, global DTP3 coverage rose significantly from just 20% in 1980 to 74% in 1990, but then stagnated at about 80% until 2005 [101]. In 2015, the global DTP3 coverage was 86%, but this achievement was less than the target of 90% DTP3 coverage [4]. These figures varied widely among WHO regions and countries. During 2015, the lowest DTP3 coverage was recorded in the Africa region at only 74%, and the highest DTP3 coverage was recorded in the Western Pacific region, which was 94% [102].

The DTP3 coverage in the South-East Asia region was 87% in 2015, ranging from 75% in Myanmar, to 99% in Bhutan, Maldives, Sri Lanka, and Thailand [6]. In
Indonesia in 2015, the DTP3 coverage was 81%, lower than the global and regional South-East Asia level. Moreover, Indonesia was also listed among ten countries which contribute to 60% of children globally who did not receive three doses of DTP at the age of one [102].

Some studies also reported immunisation coverage based on demographic surveys. The immunisation coverage calculated based on demographic survey was commonly lower than that of reported data [103, 104]. Global DTP3 immunisation coverage calculated based on survey data showed gradual improvement, from 65% in 1990 to 74% in 2006 [105]. Moreover, in low middle income countries, DTP3 immunisation coverage was under 80% in 2009 [104].

2.3.1.2 Child immunisation programme in Indonesia

Vaccines included in Indonesia’s National Immunisation Programme

Indonesia adopted the Expanded Programme on Immunisation (EPI) in 1977. At that time the national immunisation programme was for children aged 3 – 14 months, changing from 2 - 12 months in 1987. The vaccines included one dose of BCG, three doses of Oral Poliovirus (OPV) and diphtheria, tetanus, pertussis (DTP) containing vaccine, and one dose of measles containing vaccine (MCV) [106].

Following the success of the Lombok Hepatitis B Model Immunisation Project in 1987 – 1991 [107], the Indonesian Ministry of Health added Hepatitis B (HepB) vaccine into the national immunisation programme in 1997. During that time, a DTP and HepB containing vaccines combination (DTP-HepB) was also introduced, so that if the children received the combination of DTP-HepB vaccine, they would have 4 doses of HepB in total: one dose of HepB at birth, and 3 doses of DTP-HepB. If they received separate DTP and HepB vaccines, however, the HepB vaccine is given as three doses: at birth, at one month old, and at two months old [108, 109].

In 2013, Haemophilus influenza type b (HiB) vaccine was also introduced into Indonesia’s national immunisation programme after a series of studies measuring incidence, disease burden, and the cost effectiveness of vaccination [110-112]. The HiB vaccine was given in the form of pentavalent vaccine containing DTP, Hep-B
and HiB. With this vaccine addition, the current basic immunisation in Indonesia includes one dose of Hepatitis B vaccine at birth; one dose of BCG vaccine; three doses of pentavalent vaccines containing DTP-Hepatitis B-Hib; four doses of polio vaccines; and one dose of MCV. All these vaccines are scheduled before the child’s first birthday (Table 2.2) [113]. In terms of the types of polio vaccine, the Inactivated Polio Vaccine (IPV) was introduced in one province in 2007, and it was then included in the routine national immunisation programme in July 2016 [114].

<table>
<thead>
<tr>
<th>Age (month)</th>
<th>Vaccine given</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 (at birth)</td>
<td>HepB 0</td>
</tr>
<tr>
<td>1</td>
<td>BCG, Polio 1</td>
</tr>
<tr>
<td>2</td>
<td>Pentavalent 1 (DTP-HepB-HiB) 1; Polio 2</td>
</tr>
<tr>
<td>3</td>
<td>Pentavalent 2 (DTP-HepB-HiB) 2; Polio 3</td>
</tr>
<tr>
<td>4</td>
<td>Pentavalent 3 (DTP-HepB-HiB) 3; Polio 4</td>
</tr>
<tr>
<td>9</td>
<td>Measles</td>
</tr>
</tbody>
</table>

In 2013, the fourth dose of DTP-HepB-and Hib vaccines and the second dose of measles containing virus were also added as booster doses for children aged 18 and 24 months respectively [113]. Further booster doses for measles, and diphtheria toxoid and tetanus toxoid containing vaccines in the form of DT and Td vaccines are also scheduled for older children in school-based immunisation programmes. Therefore, in addition to the basic immunisation programme for children before one year of age, these booster doses for older children are also part of routine immunisation programme [113].

Other types of vaccines recommended for children by WHO such as rotavirus, pneumococcus, and a combination vaccine of mumps, measles, and rubella (MMR) are also available throughout the country, but these have not been included in the government’s programme of immunisation.

The basic immunisation target and immunisation service delivery

The population target for Indonesia’s basic immunisation programme in 2015 was 4,749,791 children under one year old, and total population target for routine immunisation of children under 15 years old was 69,857,409 or about 27% of
Indonesia’s population [9]. This child population is also distributed unevenly, with the majority of them living in the western part of Indonesia.

In the Indonesian health system, the procurement of vaccines for the child immunisation programme remain centralised, so that the central government is responsible for procuring the vaccines through a national budget line. As with other health services, the sub-national and district government are responsible for operational cost and service delivery [115].

The basic immunisation programme in Indonesia is delivered through community-based health posts for mother and child care (Pos Pelayanan terpadu-Posyandu), village maternity clinics (Poliklinik desa), community health centres (Pusat kesehatan masyarakat- Puskesmas), state hospitals, and private healthcare providers. The basic immunisation service is free of charge, except when provided by private health centres.

The government established outreach programmes of Posyandu and ‘village midwife’ in an attempt to increase access to basic health services, particularly related to mother and child health. The Posyandu was introduced in 1983 [23]. In the first year of the Posyandu programme implementation, approximately 25,000 Posyandus were established across the country, rising to 266,827 in 2009 with a ratio of about 3-4 Posyandu in each village [116]. A Posyandu covers a quite small area within a village. It is a community-based effort managed by voluntary community members (kader), and monitored by Puskesmas [23]. The Posyandu programme is designed to cover five basic health services including mother and child health, immunisation, family planning, improvement of nutrition, and prevention of diarrhoea [116]. The population target of the Posyandu services, therefore, includes neonates and children under five, mothers who are expecting or breastfeeding a baby, and people at their reproductive age. These health services are commonly held once a month. Figure 2.1 and Figure 2.2 illustrate some activities in a Posyandu.
Figure 2.1: Activity in a *Posyandu*: a nurse is preparing vaccine for a child.

Figure 2.2: Activity in a *Posyandu*: a child is weighed with a traditional scale.
The 'village midwife' (bidan desa) programme was first implemented in 1989, and aimed to deploy midwives to work and live in villages across the country [117]. Health services provided by the midwife mainly relate to mother and child health, including immunisation. It has often broadened into general health services for people in the entire village, however [118]. There is no research on the impact of this programme on child immunisation status, but some studies suggest that the programme has succeeded in improving child nutrition and development, with reduction in infant mortality [117-119].

*Immunisation coverage in Indonesia*

Data on immunisation coverage in Indonesia can be found from WHO databases, the Indonesia health profile report from the Ministry of Health, results from demographic and health surveys, and results of basic health research. Demographic and health surveys in Indonesia have been conducted in 1991, 1994, 1997, 2002, 2007, and 2012, whereas basic health research, which is a nationally-conducted survey, has been done in 2007, 2010 and 2013. In terms of immunisation coverage, those four data sources present different rates of immunisation coverage: the survey-based data show a lower rate than that of reported data. These findings are consistent with other studies comparing reported data to survey-based data [103, 104].

During the 2012 – 2013 period, DTP3 immunisation coverage recorded by Ministry of Health data was approximately 99%, higher than the WHO estimation of DTP3 coverage of 85%. The survey-based result produced much lower estimates. The 2013 basic health research calculated 75.6% DTP3 coverage, while the 2012 demographic and health survey reported 70.6% of DTP3 immunisation coverage [22, 101, 120, 121].

Based on government reported data, the full basic immunisation coverage also recorded reaching 89.9% in 2013, a decrease from 93.6 in 2010 [120]. In contrast, a nationally-conducted basic health survey done in 2013 calculated that 59.2% of children aged 12 – 23 months received full basic immunisation at any time before the survey, which was an increase of 5.4% coverage from the previous survey.
conducted in 2010 [22]. The demographic and health survey in 2012 showed that only 40.3% of children aged 12 – 23 months received full basic immunisation, with a percentage decrease to 36.8% of coverage of full basic immunisation given in accordance with schedule recommended, which is before 12 months [121].

Explanations of differences between these data sources have been presented in comparison studies [100, 103, 105]. All the data sources have their own potential biases in collection of data. The reported data relied mostly on the health services report, and health services may have varying quality in their health information systems. In contrast, the survey-based data may have recall bias as some respondents could not show an immunisation record card, so the data then relied on mothers’ or caregivers’ recollection. In Indonesia’s case, however, the reported data showed far higher estimates compared to that of both surveys’ data (nationally-conducted health survey, and demographic and health survey). The accuracy of the higher estimate is questionable as there were diphtheria outbreak cases in some provinces during 2011 – 2016, and also a polio outbreak during 2005 – 2006 [8, 9, 122, 123]. In 2012, the incidence of diphtheria and measles reported was also high, with 1,192 and 15,498 cases respectively, and also recorded as the second highest incidence of diphtheria and measles worldwide [124]. These outbreaks and high incidence rates suggest much lower coverage.

Immunisation coverage varies widely among provinces in Indonesia. Based on both demographic and health survey and basic health survey data, Papua and Yogyakarta Provinces consistently showed the lowest and the highest rate for all type of immunisation coverage, respectively. Only about 20% children aged 12 – 23 months in Papua Province received full basic immunisation, while more than 80% of children in Yogyakarta Province received full basic immunisation [22, 121]. The striking differences in these two provinces may be explained by geographical location, which influences access to and availability of health services [24]. Papua Province is situated at the most eastern part of Indonesia and shares a land border with Papua New Guinea. Topographical issues - it is mostly mountainous with vast forest areas - have limited both access to and the availability of immunisation services. The highest mountains in Indonesia, the
Jayawijaya Mountains, with their peaks at approximately 4,700 metres above sea level, are located in the centre of Papua province. Yogyakarta Province, a relatively small province compared to others in Indonesia, is located at the centre of Java Island, consisting most of lowlands. Yogyakarta is also a special region as it is led by a king, so that it is a kingdom within a country. It is also famous as an education centre, with a lot of accredited universities and schools located there. Thus, Yogyakarta Province has many recently graduated health professionals, enabling excellent access to and availability of health services, including immunisation.

As described earlier, trends over time for individual vaccines and full basic immunisation coverage showed that immunisation coverage in West Sumatera Province was lower than national totals, while in East Nusa Tenggara Province, it was higher [108, 121, 125, 126].

2.3.2 Epidemiology of immunisation preventable diseases

2.3.2.1 Global burden of immunisation preventable diseases

Immunisation has successfully improved public health through decreasing infant and child mortality from preventable communicable diseases. The higher the immunisation coverage, the lower the incidence of disease [127]. The number of reported cases of immunisation-preventable diseases dropped significantly within first decade of EPI implementation, and continued to decrease with increasing immunisation coverage. The number of reported measles cases, for example, dropped from 4.2 million in 1980 to 1.3 million in 1990, and in 2016 it was about 110,000 cases [128].

Polio is almost eradicated – some WHO regions have been freed from all type of poliovirus, leaving only one type of poliovirus to be eliminated [129, 130]. Currently, the world is also working toward measles elimination [131, 132]. This programme, however, is challenged by immunisation coverage gaps between developed and developing countries, and sub-national coverage gaps between rural and urban areas [133].

Vaccination preventable diseases, therefore, remain the major cause of child deaths worldwide. The World Health Organization estimates that in 2008 more
than 8.7 million global deaths of children under five were caused by immunisation preventable diseases, with more than half of those deaths in Africa and South-East Asia [134]. Although measles, pertussis and tetanus were among the first vaccines included in the Expanded Programme on Immunisation in the mid-1970s, those immunisation preventable diseases are still causes of neonate and child deaths in 2015 [135].

In South-East Asia, despite a significant increase in immunisation coverage, immunisation preventable diseases including measles, diphtheria, pertussis, and tetanus remain major public health problems. Reported cases of these diseases are prevalent. In 2015, with the average level of DTP3 immunisation coverage at 87%, there were more than 37,000 diphtheria, pertussis, and tetanus cases, and with 85% of MCV1 coverage, 29,000 measles cases were reported [136]. Introduction of new vaccines within this region also lags behind its developed counterparts, so that disease burden from new vaccines-related diseases such as Hepatitis B, pneumonia, and rotavirus diarrhoea are still high [137-140].

2.3.2.2 National burden of immunisation preventable diseases

The incidence of diphtheria and measles in Indonesia remains high despite extensive government outreach programmes to improve immunisation coverage. Indonesia’s Ministry of Health declared diphtheria outbreaks during 2011 – 2016 in some provinces, including East Java, West Sumatera, and West Java [8, 9]. Moreover, in 2012, 15,498 measles cases were reported, responsible for 5% of mortality in children under five [3, 124].

In 1995, Indonesia was declared free from polio. The polio eradication programme suffered a setback ten years later, however, when a wild poliovirus originally from West Africa was found in West Java. More polio cases occurred in that period particularly in Sumatera and Java, and there was also a massive vaccine-derived poliovirus outbreak on Madura Island [122, 141]. To address these problems, national mass immunisation programmes were implemented, and the last poliovirus cases occurred in 2016. In 2014, the entire South-East Asia region was certified polio free [142].
Prevalence of Hepatitis B infection in the population is indicated with Hepatitis B virus surface antigen (HBsAg). Studies have shown the prevalence of HBsAg between 4.0% – 7.1% in the general population [143]. This prevalence increases in high risk groups such as patients on haemodialysis, commercial sex workers, and health professionals [144]. A pilot mass Hepatitis B (HepB) immunisation for children in Lombok showed that three doses of Hepatitis B vaccine has successfully decreased HBsAg prevalence from 6.2% to 1.4% [107]. Recent studies, however, suggested that Indonesia still has low to moderately endemic areas of Hepatitis B virus, although a HepB vaccination has been included in the basic immunisation programme nationally since 1997. This may be an indication of low HepB immunisation coverage at birth [143, 145]. There is also a higher rate in young adults, as shown with HBsAg prevalence of 15.7% in Ternate, and 4.6% in Banjarmasin [146, 147]. This population group might have been born before the Hepatitis B immunisation programme was implemented or missed the Hepatitis B vaccination schedule.

Pneumonia, an infectious disease that is caused by some types of bacteria including *Streptococcus pneumoniae* (pneumococcus), and *Haemophilus influenza type b*, is a leading cause of mortality in children under five worldwide [138]. About 60% of those deaths occurred in only ten countries, one of which is Indonesia [148]. The Indonesia 2013 basic health survey revealed that the prevalence of pneumonia in the general population was 4.5% [22]. In a *Haemophilus influenza type b* vaccine-probe study conducted in Lombok, Indonesia during 1998 – 2002, more than half of children under two included in the study developed clinical pneumonia [112]. This high burden of pneumonia, particularly in children, has led the government to include *Haemophilus influenza type b* vaccine in the national immunisation programme from 2013. This vaccine may also prevent children from contracting meningitis [111]. Since 2007, WHO has also recommended pneumococcal vaccines to be added into national immunisation programmes, but it has not been incorporated into Indonesia's immunisation programme [149].
Another leading cause of child mortality in Indonesia is diarrhoea. In 2013, diarrhoea was responsible for 6% deaths in children under five, and more than half of acute diarrhoeal hospitalisation among children under five was caused by rotavirus [3, 150, 151]. Rotavirus vaccination is cost-effective and could potentially reduce the high burden of this diarrhoeal disease [152, 153], but it has not been introduced yet into the national immunisation programme.

2.3.3 Challenge for immunisation programmes in Indonesia

Challenges related to immunisation programme implementation in low and middle-income countries include health-system related factors on the supply side, and family and parental characteristics on the demand side [154, 155].

2.3.3.1 Supply side

Health system related factors in Indonesia are made more complex due to its many islands, making physical access – geography and topography – the first barrier to delivering healthcare services, including immunisation. There are still remote and inaccessible areas with limited transportation. This has resulted in inequity of access and availability of immunisation services between rural and urban areas, and inequality of health services across the country [156, 157]. Implementation of governmental outreach programmes in the late 1980s has increased access to immunisation services. More than three decades after implementation of Posyandu, however, the achievement of immunisation coverage has not met the national target of 91% coverage, and there are wide geographical disparities across the country [7, 9]. Acknowledging this, in 2001, the government introduced a programme named ‘Posyandu revitalisation’ aimed at improving Posyandu performance, particularly for Posyandu which were inactive or located in low-income communities [116].

The decentralisation implemented in early 21st century, moreover, worsened the geographical disparities. Central government was responsible for vaccine procurement and distribution, whereas local government was responsible for cold chain maintenance and immunisation delivery services. With this decentralisation, however, the local government does not report to central government, so that the
central government also cannot control the immunisation delivery services. Health performance among districts, therefore, relies on the capacity and capability of local government in managing their budget and health related programmes. This decentralisation has led to a wide variation in funding availability for health among districts. During the first decade of decentralisation, immunisation coverage stagnated, and more disease outbreaks occurred [67, 158-160].

Another practical obstacle in Indonesia is vaccine management, including distribution, handling and storage. Inappropriate vaccine management has been found in both government-owned health facilities and private facilities [161, 162]. Vaccines were properly stored and managed only at provincial level, and a wide variation of vaccine management occurred at district and primary health facility level. In Indonesia, vaccines are commonly stored in refrigerators and distributed with vaccine carriers. This storage relies on uninterrupted electricity supply. Most primary health centres do not have backup electricity generators even though total blackouts are still common. Some refrigerators are also not fitted with temperature monitoring [161]. A study conducted in Semarang, the capital city of Central Java Province, showed that more than half of private facilities managed vaccines inappropriately. It was found that there were no temperature monitors, and the refrigerators were not used solely for vaccine storage [162].

2.3.3.2 Demand side

On the demand side, child immunisation uptake is influenced by the community and the characteristics of their people, which are complex, and are country and region specific [154, 155]. Indonesian people comprise a number of distinct ethnic groups with different characteristics, cultures, and religions [116]. To improve immunisation coverage, therefore, more detailed information about people and community characteristics that influence vaccination behaviour is needed.

Establishing outreach programmes to improve access to and availability of immunisation services is crucial. However, the communities’ acceptance of and participation in the programmes determine their success. Studies showed that mothers’ participation in Posyandu was influenced by the mothers’ activities [26].
Most Posyandu provide health services once a month during the morning of work days – a major barrier for working mothers. Other factors associated with Posyandu participation were mothers’ satisfaction and economic status. Mothers dissatisfied with Posyandu services less frequently attend the Posyandu, and higher income families also participated less frequently in Posyandu as they are able to take their children to other health facilities, including private clinics [25]. Taking the child to other health facilities was also found to be one of the reasons of not attending Posyandu [163].

Further, the local community context needs to be acknowledged in delivering immunisation services. Administering the birth dose of the Hepatitis B vaccine (which has to be injected no more than 24 hours after birth), for example, is challenging particularly in rural areas where most mothers give birth at home. Although some of these home deliveries are attended by health professionals, unavailability of vaccine in the community, and people’s reluctance to inject babies less than seven days old has increased the number of missed opportunities, where there is contact with health professionals but the contact did not result in vaccination [164].

Immunisation acceptance was also related to cultural values. People in the eastern part of Indonesia, Southeast Sulawesi and Maluku provinces, believe that babies must not be taken out from the house for 40 days after birth, so mothers would not take their babies to health facilities for immunisation [164]. Past studies on Java Island found that the dominant Muslim beliefs played an important role in vaccine acceptance [36, 165]. Some people refused immunisation as they believed that that vaccines were haram (prohibited according to Muslim ideology) as they are made with pig products [35, 165].

Perceptions about disease also influence immunisation behaviour – mothers who perceive that the diseases the vaccines prevent are not dangerous tended not to immunise the children [36]. In one polio outbreak area, the communities’ perception that vaccine could make children sick was found to be the most frequent reason for non-vaccination [122].
Some demographic characteristics including the mothers’ education level, her occupation, and maternal age have been also shown to influence immunisation acceptance [36, 156, 163]. The higher the mothers’ education level, the more likely they are to have their children fully immunised [121]. The mothers’ education status was also positively correlated to higher knowledge about vaccines and their associated diseases, which in turn influences their attitude toward immunisation [166]. Maternal education level also influenced whether or not mothers utilise antenatal and postnatal care [167, 168]. Studies have shown that maternal age influenced mothers’ behaviour in immunising their children, as the highest prevalence of having fully immunised children was for mothers in their thirties, and a lower maternal age was associated with not immunising their children [156, 163].

2.3.4 Summary of literature study on child immunisation

Despite variations in the immunisation coverage reported by different data sources, the high prevalence of vaccine-preventable diseases and frequent occurrence of outbreaks demonstrates that immunisation uptake needs to be improved. The challenges reviewed showed that achieving target immunisation coverage in Indonesia requires a comprehensive strategy addressing both supply and demand sides. Merely improving access to and availability of immunisation services may not suffice in changing people’s behaviour. Community characteristics and their perceptions toward the services also influenced people’s acceptance of and participation in the programmes. It is thus important to understand community behaviour in child immunisation in order to maximise efforts by the health systems to improve the nation’s health. Acknowledging community behaviour and local context, therefore, enables interventions to be tailored to address specific factors influencing community behaviour related to immunisation.

However, studies on social determinants of immunisation uptake in Indonesia are limited. Most available studies are conducted on Java Island, with fewer studies conducted outside Java, and no studies on social factors influencing immunisation behaviour were found for either East Nusa Tenggara or West Sumatera. As
previously described in Chapter 1, people in these two provinces are culturally different. Despite the better access to health facilities in West Sumatera compared to those in East Nusa Tenggara, the immunisation coverage was lower than that in East Nusa Tenggara. Gathering information in these two communities would therefore likely provide rich information regarding factors determining immunisation uptake in less developed areas.

2.4 Diabetes mellitus

2.4.1 Definition, diagnosis and treatment of Diabetes Mellitus
Diabetes Mellitus (DM) is a metabolic disorder characterised by chronic hyperglycaemia as a result of impairment in insulin secretion, function, or both. Based on its underlying cause, diabetes is classified into four types: type 1 diabetes, caused by β-cells destruction that resulted in absolute insulin deficiency; type 2 diabetes, characterised mainly by inadequate insulin secretion or when the body becomes resistant to insulin; gestational diabetes, high blood sugar occurring during pregnancy; and other specific types of diabetes, such as caused by genetic defects of β-cells, or drug-induced diabetes [169]. Type 2 diabetes accounts for approximately 90% of the total diabetes patients in the world [169]. This thesis focuses on type 2 diabetes; therefore the term ‘diabetes’ used throughout the thesis refers to type 2 diabetes mellitus.

Symptoms of hyperglycaemia may include excessive urination, thirst, and hunger, weight loss, and blurred vision. Occurrence of these symptoms may vary, therefore diagnosis should be performed with diagnostic tests. According to the WHO, two main tests are recommended for diagnosing diabetes - fasting plasma glucose, and 2-h plasma glucose. Fasting plasma glucose (FPG) is plasma glucose level measured after at least eight hours of no food or drink other than water, and the 2-h PG is plasma glucose level measured two hours after a 75 grams of anhydrous glucose intake in oral glucose tolerance test (OGTT). Based on these two diagnostic tests, WHO also define two additional conditions where plasma glucose level is below the criteria for diabetes diagnosis, but the patient is at higher risk for developing diabetes. These are known as pre-diabetes: impaired glucose tolerance (IGT); and impaired fasting glucose (IFG). Table 2.3 describes
the level of FPG and 2-h PG for diabetes, IGT, and IFG diagnosis. The term ‘normoglycemia’ is used to describe people with a plasma level below these criteria.

In addition, random plasma glucose levels might also be used for diabetes diagnosis in people experiencing acute symptoms of hyperglycaemia [170]. Random plasma glucose is a blood glucose measurement from a blood sample drawn at any time, regardless of whether fasting or not. A diagnosis of diabetes is confirmed for people with acute hyperglycaemia symptoms with the level of random plasma glucose of ≥ 200mg/dL (11.1mmol/L) [170]. A study has also found that the random plasma glucose level also has potential for detecting undiagnosed diabetes. A random plasma glucose level of ≥100mg/dL indicates the need for further diabetes screening [171].

<table>
<thead>
<tr>
<th>Diagnoses</th>
<th>Fasting Plasma Glucose (FPG)</th>
<th>2-h PG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>≥ 126 mg/dL (≥7.0 mmol/L)</td>
<td>≥ 200 mg/dL (11.1mmol/L)</td>
</tr>
<tr>
<td>Pre-diabetes Impaired Glucose Tolerance (IGT)</td>
<td>&lt;126 mg/dL (&lt;7.0 mmol/L)</td>
<td>≥ 140mg/dl – &lt;200mg/dl (≥ 7.8 mmol/L – 11.1 mmol/L)</td>
</tr>
<tr>
<td>Impaired Fasting Glucose (IFG)</td>
<td>110mg/dL to 125mg/dL</td>
<td>&lt;140mg/dL (7.8mmol/L)</td>
</tr>
</tbody>
</table>

In 2011, WHO suggested that the HbA1c test can be used for diagnosing diabetes, provided the international standardised test is assured. The HbA1c (glycated haemoglobin) is formed through the non-enzymatic attachment of glucose to haemoglobin-a protein in red blood cells, so that the concentration of HbA1c depends on the concentration of glucose in blood and the life span of red blood cells (erythrocyte) [172]. The life span of red blood cells is approximately 120 days, consequently the HbA1c level reflects the average plasma glucose level over the previous 120 days. Research has showed that the HbA1c concentration most accurately reflects the glycaemic control over the previous 8 – 12 weeks [173, 174]. The measurement of HbA1c, therefore, provides long term assessment of glucose control which are free from daily fluctuation of blood glucose levels as shown with FPG or OGTT measurements [175]. Additionally, the HbA1c
measurement is easier to perform as the subject does not need to be fasting, and
the blood sample can be drawn at any time [175]. HbA1c levels are commonly
reported in two different values, the National Glycohemoglobin Standardization
Programme (NGSP) unit of percentage, and the International Federation of Clinical
Chemistry (IFCC) unit of mmol/mol [172]. The HbA1c level of 6.5%, equivalent to
48 mmol/mol, is recommended as the cut off point for a diabetes diagnosis [176].

Although diabetes is a chronic and progressive disease, people with diabetes can
have a healthy life if the condition is detected early and is well managed. Key
components to facilitate diabetes patients having a long and healthy life are access
to early screening, comprehensive management including lifestyle modification,
pharmaceutical intervention, patient education for self-care and monitoring, and
regular screening for early detection of complications [177]. Diabetes
management aims to improve clinical outcomes, including blood glucose, blood
pressure and lipids control to reduce risk factors for diabetes-related
complications [13].

The high level of sugar in the blood of people with diabetes affects the vascular
system. This increases the risk of microvascular (small blood vessel) damage and
macrovascular (large blood vessel) complications [178]. The small blood vessel
damage may lead to kidney disease, vision problems, diabetic foot ulcers, erectile
dysfunction and periodontal disease. The large blood vessel complications may
lead to stroke, coronary heart disease and other cardiovascular diseases [178].
Half of diabetic patients develop complications, mostly macrovascular. Individuals
with diabetes have two-fold risk of developing fatal cardiovascular diseases,
including coronary health diseases, and major stroke subtypes [179, 180].

Diabetes interventions include three layers of disease prevention - primary,
secondary, and tertiary. Primary prevention focuses on decreasing the prevalence
of modifiable risk factors, such as unhealthy diet and physical inactivity [181,
182]. In addition to diet and physical activity, many also include smoking cessation
programmes as a preventive strategy in diabetes, as there is evidence that most
smokers are insulin resistant [183]. Secondary prevention of diabetes focuses on
halting diabetes progression, and preventing complications; while tertiary prevention focuses on treating specific complications [182].

### 2.4.2 Epidemiology and cost implication of diabetes

The rapidly growing prevalence of diabetes worldwide, from 2.8% in 2000 to 8.3% in 2013, has made diabetes into a global epidemic [184, 185]. Approximately 382 million people were estimated to be living with diabetes in 2013, and more than half of them live in developing countries [184]. Moreover, almost half of all diabetes cases in adults were likely to be undiagnosed diabetes, mainly found in low and middle-income countries [186]. This diabetes epidemic, particularly type 2 diabetes, is caused by a complex combination of genetic predisposition interacting with societal and environmental factors [187]. Risk factors for developing type 2 diabetes are classified into modifiable and non-modifiable. The modifiable risk factors describe any factor as a result of people’s lifestyle, included being overweight or obese, physical inactivity, sedentary behaviour, poor eating habits, smoking, high cholesterol, hypertension, and low birth weight due to malnutrition during pregnancy. Non-modifiable risk factors include age, sex, ethnicity, family history and polycystic ovary syndrome [187].

About 60% of total deaths globally and 71% of total deaths in Indonesia were caused by chronic diseases including diabetes [188, 189]. Diabetes itself is responsible for 2% of total deaths worldwide, and 6% of total deaths in Indonesia [12, 189]. However, the real figure is likely to be much higher, as the deaths of people with diabetes are usually recorded as being caused by cardiovascular or kidney diseases, which are complications of diabetes, rather than being recorded as diabetes itself [189].

Diabetes has a large economic impact in addition to its impact on health. The direct impact is the cost of treatment [189]. Managing diabetes related complications is expensive, as most of the cases need hospitalisation. Research has shown that treatment costs for diabetic patients with macrovascular complications and microvascular complications is 2.7 and 1.5 times higher, respectively, than for those without complications [190]. This finding is similar to that found in a study in Indonesia. The cost of managing diabetes with
complications in Indonesia increased more than twofold compared to diabetes without complications (USD 774 compared to USD 336) [191]. The percentage of total health expenditure spent on diabetes was estimated at about 12% globally, and 7% in Indonesia [192].

The indirect economic impact of diabetes is on lost productivity through premature death, illness and disability. It was found that in the United States the loss of productivity due to diabetes was USD 7.3 billion per year [193]. These direct and indirect economic burdens impact not only on family and community income, but also on national loss of Gross Domestic Product (GDP). It is estimated that in 2015, for example, the loss of national income caused by chronic conditions including heart diseases, stroke and diabetes in China and India is USD 131.8 and USD 54 billion respectively [189]. If there is no effective intervention, the financial impact of diabetes will continue to rise. An effective action that reduces the burden of diabetes will therefore bring enormous economic benefit.

2.4.3 Diabetes in Indonesia

2.4.3.1 Increasing prevalence and risk factors

The increasing prevalence of diabetes, particularly in Asia and including Indonesia, has been attributed to lifestyle change as a result of rising income, in combination with a strong genetic predisposition [194]. Obesity has been suggested as the largest risk factor attributed to diabetes in Asia. Diabetes affects Asian people at a lower degree of obesity, and at younger age than in other parts of the world [195]. The WHO therefore recommended lower cut off points of weight classification by Body Mass Index (BMI) for Asia-Pacific people, with ‘obese’ set at BMI ≥25 [196].

These trends are also happening in Indonesia. Indonesia has the seventh largest diabetic population in the world, with a total of 10 million cases of diagnosed diabetes and an estimated 5.2 million cases of undiagnosed diabetes [197]. In 2016, the prevalence of type 2 diabetes was 7%, which increased from 5.8% in 2014 [11, 12]. This increasing prevalence of diabetes was a result of increasing modifiable risk factors including hypertension, abdominal obesity (waist...
circumference > 90 cm in men and > 80 cm in women), obesity, pre-diabetes, and smoking [20, 21, 198-205]. Diabetes in Indonesia affects more women than men (7.7% compared to 5.6%) as obesity is more prevalent among women than men (19.64% compared to 8.9%) [20, 206]. Metabolic defects were also detected earlier in the first-degree relatives of people with diabetes, implying a clear genetic component [207].

Diabetes in Indonesia affects not only people in urban areas, but also those in rural areas, as the increasing obesity rate also affects people who live in rural areas with low-economic status [20]. A national survey conducted in 2013 showed that the diabetes prevalence in rural areas was slightly higher than that in urban areas (7% compared to 6.6%) [206]. One study showed that diabetes prevalence in Ende, a rural area of East Nusa Tenggara, was 2.83% based on HbA1c criteria [94]. A recent study has also found that the prevalence of diabetes in people aged 30 – 65 years old living in rural areas of Yogyakarta, and of lower socioeconomic status was 9.5%, and more than half of the participants were obese [208]. A study in North Sumatera found that 68.5% of women aged ≥20 years were obese, and 11.5% of them suffered from diabetes [199]. The highest prevalence (19.6%) was found in suburban areas of Ternate, eastern Indonesia [209]. Low socio-economic status is associated with high prevalence of diabetes [210], and this might be caused by increasing risk factors, such as a higher prevalence of smoking, lower fruit and vegetable intake, and lower physical activity in people with low and middle income [211]. With this condition, interventions in Indonesia should not only cover people in urban and wealthier areas, but also rural areas with lower economic status.

While diabetes may be associated with an increasingly westernised lifestyle, this may be not the case in Indonesia. From the beginning of 21st century, Indonesia has had a remarkable increase in economic development [59], but for most Indonesian people, this increasing income has enabled them to practise culture-specific behaviours that have been considered as prestigious in the traditional context [212]. For example, Fanany and Fanany [212] described that the ability to eat meat, and drink sweet tea were long associated with high status, but now more
Increasing diabetes prevalence in Indonesia is therefore also associated with cultural beliefs.

### 2.4.3.2 Poor glycaemic control and prevalent diabetes-related complications

A national study in 2008 found that 97.5% of diabetes patients in Indonesia were categorised as having type 2 diabetes, with an average age of diagnosis 49.68 ± 6.8 years old. The majority of diabetes patients experienced poor glycaemic control with HbA1c of 8.1 ± 2.0% [213]. Type 2 diabetes is characterised by slow onset of symptoms. Many people in Indonesia, therefore, do not realise they have diabetes until they get complications. One study suggested approximately 70% of diabetes patients were undiagnosed [198].

Uncontrolled blood glucose has led many people with diabetes to experience diabetes-related complications [213-218]. A study in Yogyakarta showed that 55% of people with diabetes suffered from macrovascular complications, and 5% experienced microvascular complications [191]. Approximately 80% of diabetes patients experienced abnormal urinary excretion of albumin – a protein in the blood- which is a predictor of diabetic kidney disease, and approximately 36% had renal impairment [218]. Diabetic kidney disease caused approximately 18% of end stage renal disease in haemodialysis patients [219]. The prevalence of diabetic retinopathy, and vision threatening diabetic retinopathy found from a community based study in Yogyakarta was 43.1%, and 26.3%, respectively [220]. Diabetic foot ulcer (DFU) is the other most common complication found, with approximately 55.4% of diabetes patients having DFU risk factors, and 12% of them experiencing DFU [216, 217]. Further, diabetes was also an important risk factor preceding stroke [221], and both stroke and diabetes caused premature mortality in Central Java [222].

### 2.4.3.3 People’s perception and behaviour related to diabetes

Another problem related to diabetes in Indonesia is people’s perception of the disease and its treatment. A study conducted by Pujilestari, et al. [43] found that people perceived diabetes to be a disease of the wealthy, and so it would not affect the poor. People also believed that diabetes was inherited, and would only affect
people with a family history of diabetes. They also thought that they were free from diabetes if they lived in a traditional way, and they did not perceive that their eating and smoking habits might lead them to have diabetes [43]. Some diabetes patients also consider that diabetes is not a serious illness because they can still perform everyday activities. Regardless of their religion, people with diabetes also believed that the disease is part of God’s will [223]. Yuniarti [224] explained that diabetes was believed to be something bad and inherited. Many diabetes patients were also unable to accept their illness, and the illness was the source of stress as they got tired easily [224]. It was also found that beliefs about treatments were associated with seeking care [225]. These perspectives, views, and beliefs all together may affect people’s behaviour in seeking care and treating the disease. However, research on diabetes patients’ behaviours and experiences in managing diabetes is limited [226].

Many people with diabetes have low adherence to medications, and also take alternative and complementary medicines [227, 228]. Traditional medicines are favoured because of people’s confidence in traditional healers, fear of the side effects of modern medicines, and the perception that they may not have been cured after taking modern medicines [229]. Although some of herbal-derived traditional medicines for diabetes have been extensively studied [230], their doses in the community are not standardised, resulting in unpredictable clinical outcomes [231].

2.4.3.4 Diabetes is associated with tuberculosis, undernutrition, and stunting

Diabetes is a risk factor for tuberculosis, and this evidence is confirmed by studies conducted both internationally [16, 232, 233], and in Indonesia [14]. People with diabetes, particularly with poor glycaemic control, have a two to three times higher risk of contracting tuberculosis than people without diabetes [16]. A recent study in Semarang showed that about one third of tuberculosis patients experienced uncontrolled blood glucose, and the majority of these patients with uncontrolled blood glucose had a history of diabetes [234]. This diabetes and tuberculosis comorbidity will result in further problems in managing those two diseases. The main outcome of co-epidemic is an increase in tuberculosis
recurrence and fatality [233]. Tuberculosis drug treatments reduce the effectiveness of diabetes drug treatment and vice versa, which then requires dose adjustment and/or longer therapy [235, 236].

Diabetes, therefore, could be a serious health threat in Indonesia as approximately 10% of global tuberculosis patients live in Indonesia. Tuberculosis incidence in Indonesia recorded in 2016 was 399 per 100,000 population. This rate was far higher than the average of tuberculosis incidence in the South-East Asia region and globally, which were 211 and 133 respectively [18, 19].

Furthermore, diabetes and its risk factors are associated with undernutrition and stunting in childhood [15], other health problems that remain in Indonesia. Children who are undernourished in the first two years of life and have rapid weight gain later in childhood, are at high risk of developing chronic diseases including diabetes [15]. Stunted children also have a higher risk of being overweight in adolescence and adulthood [237-239]. Moreover, low birth weight and nutritional deprivation during pregnancy correlate with increasing risk of diabetes in later life [187].

In the case of Indonesia, the 2013 Basic Health Research survey reported that national prevalence of undernutrition and stunting in children under five were 19.6% and 37.2%, respectively [22]. The highest prevalence of undernutrition (>30%), and stunting (>50%) was found in East Nusa Tenggara Province [22]. Usfar, et al. [21] and Roemling and Qaim [20] therefore suggested that increasing prevalence of obesity in Indonesia is related to other nutritional problems of undernutrition and stunting.

2.4.3.5 National programmes and health delivery services for diabetes

Diabetes management in Indonesia is also challenged by the capability of health providers in delivering services. Guidelines for diabetes management have been developed in Indonesia, but health professionals often do not follow them [240, 241]. Studies also demonstrated that there is insufficient capacity of health professionals in early detection, treatment, and management of diabetes [241, 242].
In terms of national programmes related to non-communicable diseases, the government has introduced three different programmes: community-based health posts for the elderly (Posyandu lansia-Pos pelayanan terpadu lanjut usia); integrated posts for managing non-communicable diseases (Posbindu PTM-Pos Pembinaan terpadu penyakit tidak menular); and a programme for managing chronic diseases (Prolanis-Program pengelolaan penyakit kronis). The Posyandu lansia and Posbindu PTM programmes focus mainly on early detection of risk factors of non-communicable diseases and improving general health, while the Prolanis programme focuses on improving outcomes of people with diabetes and hypertension.

The Posyandu lansia was first introduced in the early 21st century. This programme targeted the elderly, and aimed to detect early risk factors of non-communicable diseases, and improve general health. As in the Posyandu for children programme, this programme invites voluntary participation of community members to manage the programme in collaboration with Puskesmas [27]. In 2010, the Indonesian Ministry of Health through its directorate of non-communicable diseases control introduced a programme named Posbindu PTM. This programme targets people aged 15 years and older to detect early and manage risk factors of non-communicable diseases. Activities within this programme may include counselling for a healthy lifestyle, along with measurement of body mass index, blood pressure, blood glucose, and blood cholesterol levels [243]. Following the implementation of Universal Health Coverage (UHC) on 1st January 2014, the government also expanded Prolanis, a programme for managing chronic diseases, including hypertension and diabetes to also cover the patients under the universal health coverage scheme [244]. Before the implementation of UHC, the programme was managed by health insurance for civil servants (Askes), and would only cover patients under the Askes insurance (i.e. civil servants).

Implementation of these programmes, however, particularly in the era of decentralisation, relies on local government capacity and commitment to improving health. This leads to a wide variation of programme implementation
across the country. The implementation of Posyandu lansia, for example, depended on support from voluntary community health workers within the community [28, 29]. Lack of resources and facilities, and lack of people’s interest in the programme are the most common obstacles that may hinder the success of the government programmes [29, 30]. Therefore, revitalisation or new initiative in the implementation of these national programmes for non-communicable diseases is needed to improve the performance of the programmes.

In terms of healthcare services for diabetes patients in Indonesia, before the implementation of Universal Health Coverage (UHC), people could choose for themselves which health services they wanted to go to: either public or private facilities; and either primary health centres or directly to hospital. Diabetes speciality clinics are commonly located in hospitals, as they have more sophisticated laboratory facilities, specialist doctors, and a more complete range of medications. Following the implementation of UHC, everyone (including diabetes patients) is required to go to primary healthcare facilities first, either Puskesmas, or other private primary health centres that collaborate with the insurance management agency (BPJS). If the primary care facilities cannot provide services, patients are referred to the higher level of health services, which are hospitals - either public hospitals or private hospitals that have collaborated with the insurance management agency. This means that the patients cannot go directly to secondary or tertiary care facilities, except in case of emergency. In the UHC era, moreover, there is also a ‘refer back’ (rujuk balik) policy, where patients from secondary or tertiary healthcare facilities are referred back to primary care facilities after their condition improves. Continuing treatment is then provided by the primary healthcare facilities. In the case of chronic diseases including diabetes, the ‘refer back’ programme means that primary healthcare facilities are responsible for patients’ regular treatments. They are allowed into the secondary or tertiary health care once every three months or in case of emergency [67, 245].

This new process of obtaining treatment is challenging. In terms of health systems, this new policy may be well implemented provided that primary care facilities have sufficient resources including health professionals, equipment, and
medications. In some areas of Indonesia, however, the resources available in Puskesmas are lacking [246]. In terms of patients’ opinions of UHC, some find that UHC limits their ability to access the secondary and tertiary health facilities they could before [247]. They also showed a higher trust in physicians or specialists in hospitals compared to primary care doctors. Moreover, they also argued that the Puskesmas provided lower quality of services as shown by long waiting times, and short opening hours [247].

2.4.4 Summary on literature study about diabetes
The diabetes problem in Indonesia is alarming. Diabetes not only affects people in urban areas, but also in rural areas. Effective intervention is needed not only to improve patient outcomes, but also to reduce the national burden of costly medical treatment, particularly in the era of UHC. Addressing these problems, the government has implemented three different health programmes for non-communicable diseases including diabetes. Variation in the resources of local government, and lack of community interest and participation in the programmes, however, has hindered the success of the programmes.

On the other hand, diabetes patients’ behaviours in managing disease that impacted their outcomes have not been well explored yet. Understanding people’s behaviour and views are important in designing effective interventions that are well accepted by the targeted community. However, studies focusing on this in Indonesia almost do not exist.

2.5 Health behaviour

2.5.1 The importance of health behaviour study
Health education and health promotion are essential in determining the success of public health programmes and medical interventions [32]. Health education is defined as “any attempts to close the gap between what is known about optimum health practice and that which is actually practiced” [248]. Moreover, Green, et al. [249] define health education as “any combination of learning experiences designed to facilitate voluntary adaptations of behaviour conducive to health”. Both definitions clearly state that health education includes not only providing
information to people who lack it, but also facilitating behaviour change for those who have enough knowledge but have not been able to put it into practice. Health promotion is sometimes used interchangeably with health education, but with a slightly broader concept involving not only the individual, but also groups or communities [32]. These definitions imply that the central concern of health education is on health behaviour, so that the aim of providing health education is behaviour change.

Health behaviour is a broad concept defined as "personal attributes such as beliefs, expectations, motives, values, and other cognitive elements; personality characteristics; including affective and emotional states and traits; and overt behaviour patterns, actions, and habits that relate to health maintenance and wellness, to health restoration, and to health improvement" [250]. This definition includes all three health-related behaviour terms described by Kasl and Cobb [251]: health behaviour; illness behaviour; and sick role behaviour. Health behaviour is any effort undertaken by people who consider themselves healthy for preventing or early detecting any diseases. Illness behaviour is any effort undertaken by a person who feels ill to find what illness he/she experienced. Sick role behaviour is any effort undertaken by a person who believes themself ill [251]. Health-seeking behaviour is another commonly used term which is "steps taken by an individual who perceives a need for help as she or she attempts to solve a health problem"[252]. This definition is also included in the broad concept of health behaviour defined by Gochman [250]. This thesis will apply the broader concept of health behaviour as it includes issues of disease prevention, such as immunisation, as well as action related to specific diseases, such as diabetes.

After the implementation of the Expanded Programme on Immunisation (EPI) in 1976, immunisation coverage rocketed within a decade. This trend stagnated, however, particularly in developing countries, and the problem of vaccine preventable diseases still exists. Nichter [253] argued that immunisation programmes are passively accepted by the community rather than actively demanded by the community. Passive acceptance indicates compliance where the public only follow recommendations by health providers or government. Active
demand describes adherence to the programme as a perceived benefit and need for the programme [253]. In order for the health programme to be sustained, therefore, it is important to understand social determinants that might influence uptake of the programme. Moreover, Nichter [253] argued there are three factors influencing vaccination acceptance: supply-service factors; social factors; and cultural perception of vaccinations and its related diseases. The last factor was suggested as the main factor influencing active demand of vaccination. Cultural values, and parental perception about the diseases were also key drivers of unvaccinated children [254].

Decision making related to vaccine acceptance is complex and not only driven by scientific or economic evidence, but also by psychological, sociocultural, and political reasons [255]. Moreover, there are also specific local influences on vaccination programme acceptance including cultures, beliefs, perception about diseases, vaccines, and how vaccination programmes should be delivered [256-258]. The success of vaccine programmes therefore depends on understanding behavioural and cultural values of the targeted population [258]. Streefland [259] further gave examples of how local culture influenced uptake of immunisation services. In India, social inequality based on caste was found to influence people's access to immunisation services, so that people from a lower caste were reluctant to come to the services held in upper caste areas. In Bangladesh, the vaccinations were given by a male vaccinator to mothers through a curtain. As previously noted, religious beliefs are also associated with resistance to vaccination [256].

Many interventions on immunisation focus on increasing services by bringing immunisation activity closer to the people. There is little attention to increasing demand for vaccination [260]. Andersson, et al. [261] demonstrated the success of structured community discussions done separately with male and female groups in increasing vaccine uptake without improving supply services in a low SES district in Pakistan. This community-based discussion was established based on previous studies on local community determinants of immunisation that derived appropriate interventions [262].
Similarly, the success of diabetes management is closely related to people’s views related to the disease and its management, and their cultural beliefs and practices. This happens globally, not only in developing countries or where people lack knowledge about diabetes. Greenfield, et al. [263] reported that in Western Australia, despite having good knowledge about diabetes, diabetes patients experienced uncontrolled blood glucose levels as many of them did not put diabetes management as a high priority in their life. Other studies also explained different cultural beliefs and values related to diabetes that correlate with how people seek care and manage their illness [264-270]. Nguma [270], for example, described diabetes patients in Tanzania commonly delaying seeking care as many people tend to ‘wait and see’ if they perceive symptoms, and seek care only when they perceived their condition to be severe. They also commonly would go to traditional healers and herbalists first before going to healthcare services. The reverse condition has been observed in Uganda, however, where people would go to traditional healers when they perceived that the health care had failed [271].

In order for diabetes programmes to be effective, therefore, people’s behaviour related to diabetes and its treatment needs to be understood. Other studies also demonstrate the effectiveness of community-based diabetes programmes tailored to people’s sociocultural and environment factors [272, 273]. Yazdanpanah, et al. [272], for example, set up nutritional education and physical activity intervention for diabetes patients and people at risk for developing diabetes based on a community needs assessment. Tucker, et al. [273] also gained success in diabetes intervention programmes that were set up in accordance with participants’ cultural backgrounds. The key element for a successful diabetes programme therefore is a good understanding of the community, including their health beliefs and cultures [274].

2.5.2 Health behaviour theories

Health behaviour theories explain why people perform health behaviours, identify factors that predict behaviours, and suggest targets for behaviour change interventions [32, 275]. Some theories focus more on determinants of individuals’ behaviours, while others focus more on broad factors influencing behaviour
including community, and organisational context. These theories have guided this thesis. At the beginning, theories related to people’s behaviour in adopting health services and seeking care were used to understand factors influencing mothers’ immunisation behaviours, diabetes patients’ behaviours related to diabetes, and to develop questions for the qualitative research. Then, theories were also used to guide intervention development, based on determinants of health behaviours found in the qualitative research. Theories that were considered applicable in this thesis are discussed. However, this study does not, attempt to test these theories.

The Health Belief Model (HBM) [276] is among the most popular theories in the study of people’s behaviour and behavioural interventions. This theory focuses primarily on individual health behaviours, and explains that they are influenced mainly by individual beliefs. These individual health beliefs are shaped by the major construct of the HBM: perceived threat – which is a combination of perceived susceptibility and perceived severity; perceived benefit; perceived barriers; and self-efficacy. These beliefs can be modified by individual characteristics and cues to actions (Figure 2.3).

![Figure 2.3: The Health Belief Model components and linkages [276]](image)

Stages in health seeking [277] or the Pathway Model, describes the logical process that people normally follow in seeking care, involving some stages of decision
making. Unlike the Health Belief Model which only focuses on the individual, the Stages in the health seeking model stressed the importance of society – family, relatives, and the wider social network – in the process of health seeking. The model suggests that disease is a social concept, as any disruption caused by a disease affects individuals’ social life and relationships with others. Significant others therefore also affect individuals in choosing treatments.

![Diagram of stages in health seeking]

**Figure 2.4: Stages in health seeking [277]**

There are eleven sequential stages in the health seeking process that individuals might experience. The seeking process is started with symptom experience, followed by self-medication or self-treatment, communication to significant others, assessment of symptoms, assumption of sick role, expression of concern (by kin and close friends), assessment of probable efficacy or appropriateness of source of treatment, selection of treatment plan, treatment, assessment or the evaluation of the effects of treatment, and finally recovery and rehabilitation (Figure 2.4). All stages in this sequence may vary in duration and may sometimes be concurrent or combined with the next stage.
Other than the Stages in health seeking model, some theories focus on explanatory factors influencing people’s decisions in choosing certain healthcare resources. The Andersen Model [278] explains that health services utilisation is determined by three main factors: characteristics of health system delivery; changes in medical technology and social norms related to illness definition; and individual characteristics. The individual determinants are further categorised into three factors: predisposing; enabling; and illness level. This framework is designed mainly based on studies in developed countries.

Kroeger [279] also proposed a framework explaining interrelated determinants of choices of healthcare resources in a developing countries context (Figure 2.5). This framework, therefore, is different from the previous model of Andersen and Newman [278]. The Anderson model explains the people’s behaviour in seeking care from formal health services available in the community, while the Kroeger Model includes people’s behaviours in seeking care from non-formal health providers. The Kroeger model also incorporates other factors that are better suited to the context of developing countries. In addition to predisposing and enabling factors in individual determinants described by Andersen and Newman [278], for example, Kroeger added anthropological concepts of people’s perceptions related to the disease they are experiencing. This includes whether the disease is chronic or acute, severe or trivial, has natural or supernatural causes, the expected benefit of modern or traditional treatment, and whether it is psychosomatic or a somatic disorder. These perceptions influence their choices in seeking care from a wide variety of options available in developing countries: traditional healer; modern healer; drug seller; self-treatment; or no treatment.

Social Cognitive Theory (SCT) developed by Bandura (1986) is one behavioural model that describes broader factors influencing individual behaviour [280]. According to Bandura (1986) “human functioning is explained in terms of a model of triadic reciprocity in which behaviour, cognitive and other personal factors, and environmental events all operate as interacting determinants of each other”. With this model (Figure 2.6), the SCT not only attempts to understand factors that influence behaviours, but also the processes through which learning occurs.
Figure 2.5: Determinants of choices healthcare services: the Kroeger's model [279]
Social Cognitive Theory concepts include psychological determinants, observational learning, environmental determinants, self-regulation, and moral disengagement. Psychological determinants of behaviour includes individual outcome expectation (perceived benefit of performing such behaviour), and individual belief in their own self-efficacy (perceived capability to perform an action). Self-efficacy has then been adopted into other behavioural models (such as the health belief model). Social Cognitive Theory emphasises that individual behaviour is also influenced through observational learning, such as learning from others, and learning through mass media. Peer modelling, therefore, is an important intervention that might be useful in altering people’s behaviour. Environment also shapes people’s behaviour, and vice versa, so that changing the environment has a powerful effect on behaviour. The environment can be changed through incentive motivation (rewards and punishment to modify behaviour) and facilitation (providing tools and resources to make new behaviours easier to perform). Social Cognitive Theory also includes self-regulation, a concrete skill that people should have to manage themselves. Increasing self-regulatory processes in SCT through self-monitoring, goal setting, feedback, self-reward, self-instruction, and enlistment of social support have also been applied widely for behavioural change interventions [280].
2.5.3 Reflection on health behaviour theories

The health behaviour theories presented above explain a variety of processes and determinants that may influence the way people behave, related to their health. These range from individual determinants including individual socio-demographic characteristics, and individual beliefs to the influence of other people, environment, and the wider health system factors. Although each model has a different focus, there are also overlapping factors that play a role in shaping people’s behaviour related to health. The Health Belief Model focuses on individual beliefs, and that the individual action depends on their perceived threat as compared to their perceived outcome and self-efficacy. This theory, however, does not incorporate the social aspects of individuals, or social aspects of the disease. That is, individual beliefs might not be enough to trigger action unless it is supported by their family, or society. In addition, that individuals’ illness may also influence their social role, therefore society also influences individuals’ decisions through social expectation norms. This social aspect of individuals and illnesses is important, particularly in context of people living in developing countries, in which most people are highly integrated in their family or community life.

The other theories and models explain that people’s actions are influenced beyond the individual decision. Their behaviours are affected by significant others, their family, and social network. Igun [277] describes that the process of seeking treatment is also influenced by family, kin, close friends and other social networks. This theory focuses on the process of decision making, and does not include determining factors that influence the process of thinking about which behaviour people are choosing. Andersen and Newman [278] and Kroeger [279] then provide explanatory and interrelated factors that might influence people in their decision-making process about which health provider to seek help. These two theories go beyond individual determinants. They also include individual interaction with family, the influence of society, and health system factors as determinants of health behaviours. Given their use of studies carried out in the ‘western cultural’ context, however, the Andersen and Newman [278] model emphasises the role of health professionals in the conventional health services. The model therefore does not incorporate the more complex system of cultural
and contextual perception of diseases and disorders, and healthcare providers beyond western medical services. Kroeger [279] on the other hand, reviewed studies carried out in developing countries, so that the model also incorporates non-western cultural context, including non-biomedical concept of disease and disorders, and traditional health providers.

This review of behavioural theories provided some direction around which my research was designed. I do not dwell much on the HBM as the HBM does not account for the role of the community, which is important in the Indonesian context. Although the pathway model proposed by Igun [277] emphasises the role of significant others in influencing behaviour, the theory does not provide an explanation of factors determining the choices of health providers. In the Indonesian context, with a wide variety of health providers - including formal and non-formal - the applicability of the Anderson model might be limited. The Kroeger model, therefore, is more relevant to be applied.

While Kroeger [279] looked specifically at factors influencing people's choices in seeking care, Social Cognitive Theory focuses on health related behaviour in general. The core concept of the Social Cognitive Theory is its interaction between cognitive, behavioural and environmental factors. Human behaviour is learnt from the environment through the process of observational learning. This theory, therefore, is widely used in behaviour change intervention that aims to modify people's behaviour through peer modelling, facilitation, and other methods that enable them to learn a new desired behaviour from their environment. This model is applied in developing the intervention study explained in Chapter 4.

All these theories led me to the summary that determinants of people's behaviours should be understood based on people's contexts, individually and socio-culturally. Furthermore, in order to change the people's behaviours, the behavioural intervention methods should be designed based on an understanding of those specific determinants.
2.5.4 *Indonesian people’s health behaviour, beliefs, and culture*

This section aims to document existing literature on health-seeking behaviour in Indonesia, identify areas and medical conditions that are under-studied, and highlight the major findings related to people’s behaviour in seeking care. To do this, a specific literature search was performed as outlined in subchapter 2.2, using the ‘Health behaviour’ keywords from Table 2.1.

2.5.4.1 *Description of relevant literature*

Fifty-six peer reviewed international articles were found from 1987 to 2017 [33, 39-41, 44, 223, 281-330], and 19 articles from Indonesian journals from 2001 to 2016 [331-349]. Looking at the publication dates, health-seeking behaviour in Indonesia drew little attention before 2000, with only six articles before that time. A complete list of literature included in the review of health-seeking behaviour of people in Indonesia can be seen in Appendix 1.

2.5.4.2 *Methodologies*

Quantitative cross-sectional designs (39 articles) were more frequent than qualitative designs (26 articles), with the same pattern for the Indonesian journals. Quantitative studies usually used an interviewer-administered questionnaire, possibly to reduce misunderstandings with self-administered questionnaires, due to literacy and language issues.

Quantitative studies provide evidence of factors determining people’s behaviour, but are limited in their ability to explore the wider narrative of reasons for choosing specific care, which can be better explored in qualitative studies. There were also 10 studies applying mixed methods design [33, 285, 300, 312, 315, 323, 324, 345, 346, 348]. Brooks et al., for example, explored secondary data from the Indonesian Demographic and Health Survey to quantify the effect of the insurance programme on maternity services, and explored barriers to the services utilisation qualitatively [285].

Most studies were community-based. Of those conducted in healthcare facilities, Indonesian journals were more likely to carry out studies based in traditional
clinics. Clinic-based studies exclude people who never seek care [279]. Recruiting participants with a specific condition from the community means a large number of people need to be screened to find respondents. Some researchers, however, have conducted household surveys to study health-seeking behaviour related to acute respiratory illness, tuberculosis, and malaria [39, 289, 294, 303]. Some studies used secondary data from national surveys, revealing patterns of health care utilisation, and socio-demographic determinants [285, 307, 318, 337, 342, 347, 349].

One study asked about a hypothetical scenario [293], but hypothetical behaviour can differ from actual behaviour. Most of the other studies gathered retrospective information, from people who have a certain illness and asked them to recall what they have done to manage it [350]. This can lead to recall bias. To minimise this, some researchers set up inclusion criteria, for example, newly diagnosed, or having symptoms during the last month. In contrast, Utarini, et al. [315] used a longitudinal prospective design to explore people’s behaviour in seeking care for malaria over a one year period. They detected malaria cases in six endemic malarial villages and what people did during that period. Thus, prospective studies collect more accurate data health-seeking behaviour from the beginning of symptom experiences to the final stage of recovery.

2.5.4.3 Medical conditions covered

Many studies focused on infectious diseases such as malaria, tuberculosis, and leprosy. Maternity-related health was also common. Tuberculosis, malaria, and mothers’ and infants’ health are an important focus of the Sustainable Development Goals (SDGs) [6]. Despite low immunisation coverage, however, with wide gaps in the coverage at sub national level [121], and prevalent immunisation-preventable diseases cases in Indonesia [3, 124], studies on people’s immunisation behaviour were scarce. One study was found on the social aspects of the immunisation programme, published in 1988 [351].

Non-communicable diseases studied included mental illnesses and cancer, but there were fewer studies on stroke, hypertension, and diabetes. The prevalence of
non-communicable diseases in Indonesia is rising and they became major causes of death in 2012 [3, 9]. The real figure is likely much higher, as most people in Indonesia with chronic diseases do not seek care until their health deteriorates [352]. Thus, more studies of health-seeking behaviour should focus on chronic diseases. Other diverse studies included health-seeking behaviour of infertility patients and transgender people related to HIV risk [299, 304].

2.5.4.4 Study location

Figure 2.7: Coverage of geographical areas in the studies reviewed

Most reviewed studies were on Java, the most populated island of Indonesia, which also includes the capital Jakarta (Figure 2.7). Java is the most developed region of the country. Within Java, most studies were in Yogyakarta and Jakarta. Beyond Java, some studies were performed in Aceh and Bali Provinces. Aceh is located on the far north of Sumatera, whereas Bali is an island to the east of Java. Socio-culturally, these provinces are different, as most people in Aceh are Muslim, and in Bali, Hindu.
2.5.4.5 Lay concepts of health and illness

Concepts of health and illness are influenced by people's socio-cultural background [353]. Indonesian people consider themselves healthy if they can perform their everyday activities without disruption. Thus, people generally sought help when symptoms hindered these [40, 44, 223, 281, 284, 294, 295, 297, 301, 303, 319, 320, 324, 330]. Eeuwijk [324], for example, described that most older people sought care from health professionals for rheumatism, because it hindered their activities. In contrast, they did not seek professional help for problems with eyes, ears or teeth, because there was less impact on their daily lives. People thus delayed seeking care, until their diseases were severe.

There is also a strong concept of 'balance and harmony', particularly among Javanese. Health is a physical status that cannot be achieved without an individuals' spiritual wellbeing. Life in general should be balanced physically and spiritually, between individual and social life, so that a status of 'harmony' can be reached [223, 311]. Most Indonesians are also religious. Regardless of specific religion, people believe that health is God's gift, and illness is their fate, and is sometimes viewed as God's punishment [223, 284, 302].

2.5.4.6 Determinants of health provider choices

Indonesian people's choice of health providers is determined by complex and interrelated factors: socio-demographic characteristics; influence of significant others; socio-cultural beliefs; perception about diseases and their causality; and perception of medical services including accessibility and availability particularly in rural and areas, and its related cost [44, 223, 284-286, 290-292, 296, 298, 299, 301, 302, 304, 305, 307, 309-311, 313, 314, 317, 318, 320, 325].

Socio-demographic characteristics

Age, household size, education, and economic status determine people's choices of health providers [318, 327, 347]. Poorer households were more likely to use traditional medicines for treating malaria [281]; older people and those in rural areas were also more likely to seek traditional and alternative treatment [337, 342, 349]. Women were more likely to seek health care for tuberculosis-related
symptoms [303]. Other studies, however, did not find a link between seeking care and socio-demographic characteristics [303, 308, 328, 331, 334], suggesting other factors may have greater impact in influencing people's choices in health providers.

**Influence of significant others**

In most Indonesian communities, seeking care involves not only patients but also family, friends, and other community members [284, 286, 287, 290, 291, 296, 301, 303, 310, 313, 317, 320, 325]. Recommendations from significant others were associated with visiting alternative healthcare providers for treating tuberculosis [303], and cancer [284, 301]. Religious leaders influenced tuberculosis patients' choices [286]. The husband and older family members made decisions related to birth attendant choices [290].

**Socio-cultural beliefs**

Most women chose to give birth at home, helped by a traditional birth attendant, despite the proximity of health facilities or health professionals, mainly because the birth attendant also performs prayers, and other traditional practices and ceremonies. People believe that birth is sacred and should occur in a way consistent with traditional beliefs [285, 290, 310].

Cultural beliefs also favoured traditional remedies or alternative treatments. These practices have been passed down for generations, and this embedded culture cannot be ignored. They are commonly used for treating most diseases, including malaria [33, 281, 315, 322], tuberculosis [40, 297, 303, 313, 320, 325], leprosy [302], rheumatoid arthritis [329], cancer [284, 296, 301], hypertension [346], stroke [44], and diabetes [348]. Traditional remedies are also used for promoting health and preventing disease. As an example, women took traditional herbal drinks in order to stay healthy during pregnancy and breastfeeding [282, 306], and some people took bitter-tasting plants to prevent malaria [33, 39, 322, 338, 343].
People perceived that conventional medicine was failing to cure illness. Fear of side effects, dependence on medication, and fear of medical procedures were other common reasons cited for using traditional or alternative treatments [284, 288, 296, 345, 346, 348]. People view full cure as successful treatment. Conventional medicine was not believed to cure diabetes and hypertension, leading to the choice of traditional treatment [346, 348].

Indonesians regard traditional remedies as safe, because they are made from natural resources [340, 345]. People also perceived that traditional healers provided comprehensive services as they were also dealing with patients’ feelings [301], and in some cases, payment can be made in kind, for example with food [325].

Many forms of traditional remedies and alternative treatments are available in Indonesia. Jamu, a traditional herbal drink, is the most popular [230]. Other popular alternative treatments include traditional Chinese medicines, known as sinshe [340], treatment with animal media such as leeches [332], traditional bone setters [335], cupping therapy [339], and coin scratching [336].

Perception of causality

Health-seeking behaviour was also influenced by perceptions related to diseases and causality. There were strong beliefs that mental illnesses have supernatural causes, so people first sought care from traditional, spiritual, or religious healers [291, 292, 317]. In some areas, tuberculosis and leprosy were also believed to be caused by black magic or bad spirits and so people sought help from traditional healers [302, 320, 325].

Communities commonly have their own local term, description, and interpretation of illnesses or symptoms. Tuberculosis, for example, was believed to be caused by smoking, stress, sleeping on the floor, or other physical causes [313, 320, 325]. Thus, early symptoms of tuberculosis were not perceived as serious. People in Central Java did not recognise malaria, but the local term katisen has similar symptoms to malaria. Again, katisen is seen as a minor illness, leading to self-medication [322]. Javanese often misidentified heart diseases with masuk angin.
(wind sickness), using the term *angin duduk* (sitting wind sickness) for heart disease. *Masuk angin* is a mild illness caused by over exposure to wind, and people treated it with coin scratching, so heart disease is treated in the same way [311].

*Perception about healthcare systems*

Perceptions about medical services also influence health-seeking behaviour. Many people were reluctant to go to public health facilities as they experienced complex administrative procedures, one-sided communication style of health professional, and long waiting times [284, 285, 291, 298, 299, 320]. Thus, many people choose to go to private health providers [40, 289, 293, 294, 313, 318, 320]. Further reasons driving the choice of private providers include perceived quality of provider, availability of brand name medicines, and short waiting times [293, 313, 319, 320].

*Health cost and people perception of health insurance*

Expanding health insurance alone was not enough to increase health care utilisation for people residing in rural areas [307]. Indirect costs of treatment, such as transportation are barriers to medical treatment [284, 290, 291, 301, 309]. In many cases requiring hospitalisation, family members accompanied the patient during their stay. Extended families were often a source of finance for extra costs, providing further burden [284, 290, 291, 301].

People experienced the insurance scheme as complicated and time consuming, and it was poorly socialised and understood [284, 285, 310, 312]. People therefore only applied once they perceived the need for help. People also perceived that health providers offered a low quality of service for the poor under the scheme [284, 285, 310, 312]. From the providers’ perspective, there has been incomplete reimbursement, and low payment [312].

2.5.4.7 *Care pathways*

After experiencing symptoms, people generally used self-care: taking rest; self-medicating with medicines bought from drug stores or pharmacies; or taking traditional medicines. If they perceived that the symptoms persisted, they would
seek help from formal health care. If that failed, they then would try other traditional or alternative treatments (Figure 2.8) [39, 284, 286, 296, 300, 301, 313, 322, 325, 326, 341, 349]. Most then went to either formal or informal health providers, often combining or alternating medicines from different providers [40, 320, 330, 331]. If the sick person is a child, however, going direct to formal health care is common [298, 321, 326, 341, 344, 349]. A strong belief exists that the effectiveness of treatment is a matter of being ‘suited to you’, so they would try alternatives to find one that suits [300, 322].

Figure 2.8: The pathway of seeking care

1. General process of seeking care
2. If the sick person is a child
3. If the disease is strongly attributed to supernatural caused such as mental illness, or if they perceive that their symptoms have a supernatural cause
4. Both providers, medical services providers and alternative providers, or type of medications, traditional and biomedicines are used as an alternate or in combination in order to find “fit” treatment to them.

Another pathway, as mentioned before, was when people first went to any alternative treatments for illness attributed to supernatural causes, switching to formal health care when they perceived alternative treatments as ineffective [291, 292, 302, 316, 317, 320, 325].
**Self-medication**

Self-medication with biomedicines was common practice [349]. As with many developing countries, most prescription medicines are available illegally over the counter. People self-medicated with antibiotics for treating a common cold, headache and other minor symptoms [41, 283, 298]. People also self-medicated for malaria and tuberculosis [39, 40, 286, 297, 313, 315, 320, 322, 326, 333], and musculoskeletal pain [329]. Many observed self-medication practices are inappropriate [326].

### 2.5.5 Summary of health-seeking behaviour of people in Indonesia

We found that studies were concentrated on Java. Moreover, most studies focussed on tuberculosis, malaria and maternity-related health. Without minimising the importance of these problems, it must be noted that the prevalence of non-communicable diseases is growing, which will increase costs and could hinder the newly implemented universal health insurance.

Choices of care in Indonesia were influenced mainly by socio-cultural beliefs, and perceptions related to the disease and its causality, similar to other developing countries [354-359]. Traditional treatments were chosen when people perceived supernatural causes of the disease, and when they perceived that the biomedical system failed to cure their chronic diseases [356, 359]. The characteristics of the medical care provider, including availability and cost, were also relevant [360, 361]. These factors influencing peoples’ choices align with the Kroeger’s framework [279].

Traditional medicine systems are important in developing countries. People value their efficacy, and they are widely accepted. Thus, integrating these into formal health care may be more effective than discouraging them. Mothers’ preference for a traditional birth attendant, for example, has resulted in collaboration between village midwives and birth attendants in some areas of Indonesia [290]. The Indonesian government has also initiated efforts to ensure the safety and effectiveness of traditional herbal medicines [230]. In many cases, however, the safety and efficacy of techniques used in traditional medication systems are
questionable and not scientifically proven. Their existence, therefore, should not replace formal health care.

Serious efforts should be made to address misconceptions related to diseases and perceived causality, which hinder people from seeking care. One study attempted to do this through implementing tuberculosis leadership groups within the community, who held meetings discussing peoples' perceptions about tuberculosis and addressing any misunderstanding found, leading to greater engagement with formal health care [297]. This effort should be expanded to other communities and diseases.

Negative past experiences with the public healthcare system have made people reluctant to engage. Improving availability and accessibility, therefore, might have to be balanced with improving quality of care. Another health system issue is the availability of prescription medicines over the counter, driving increased self-medication.

In summary, understanding people's behaviour in seeking care is an important step for health intervention planning. This understanding would allow more evidence-based healthcare policy.

2.5.6 Health behaviour of people in Indonesian communities: evidence of relevance of the Kroeger theoretical framework

The Kroeger [279] model incorporates many factors that determine health seeking behaviour of people in Indonesia identified in the literature review. It models people’s choice within the wide range of health providers available being influenced by three major characteristics: characteristics of the person (predisposing factors); characteristics of disorders and their perceptions; and characteristics of the health services system.

2.5.6.1 Characteristics of subject

The characteristics of the person (predisposing factors) include age, sex, marital status, status in the household, household size, ethnic group, degree of cultural adaptation, education, occupation, assets, and interaction with family, neighbours
and community. Suswardany, et al. [281], for example, found that poorer households are more likely to take traditional medicines for treating malaria. Ahmad, et al. [303] also found that female patients are more likely to seek care for tuberculosis related symptoms. Older people, and those who are living in rural areas are also more likely to use traditional or alternative treatments [337, 342, 362]. Many studies also suggested that individual interaction with significant others influence which providers they choose. Ahmad, et al. [303], for example, also found that recommendations from significant others were significantly associated with visiting alternative healthcare providers for treating tuberculosis. Fles, et al. [284], [301] also stated that people with a specific cancer of the nose started seeking care with traditional and alternative treatments with support from their family and friends. The use of traditional herbal remedies for tuberculosis was also generally recommended by family members or neighbours.

2.5.6.2 Characteristics of the disorder and their perception

Among factors determining the choices of health providers, characteristics of disorder and their perception seemed to be cited in most of studies of health seeking behaviour in Indonesia. People would seek help if they perceived that the symptoms were severe enough and resulted in impairment of their daily activities [40, 44, 223, 281, 284, 294, 297, 301, 303, 320, 324, 330]. Most people with tuberculosis, cancer, malaria, and other diseases delayed seeking treatment as they perceived that the symptoms to be harmless. Perceived causes of the diseases also clearly influence health seeking behaviour in the example of mental illnesses. Most people in Indonesia believe that mental illnesses are caused by supernatural power, so they will seek care from traditional or religious healers [291, 292, 317].

2.5.6.3 Characteristics of health providers and their perception

The characteristics of health providers include accessibility, appeal, acceptability, quality, communication, and cost. Women’s choices to give birth at home using a traditional birth attendant (TBA), for example, were also influenced by the accessibility, appeal and acceptability of the TBA [285, 290, 310]. The TBA mainly lived in their neighbourhood, so that they were available at any time. Although many women recognised the skills of the professional birth attendant, which were
more sophisticated than the TBA, the appeal of the TBA was higher as the TBA conveyed not only birth related matters but also the mothers’ feelings and emotions. They therefore also provided comprehensive services including massage and performed prayer before the delivery process. Unless the delivery was complicated, many mothers preferred to choose the TBA over the formally trained birth attendant. Many people also complained about the methods of communication with professional health providers [284]. With the alternative healers, they often have much time to talk in a convenient home setting. Cost, particularly indirect cost, was also found to influence people’s choice of health care [284, 285, 290, 291, 301]. Although the government has implemented universal health insurance, the indirect cost of health care may therefore still be a key consideration, particularly for the rural poor living further from healthcare facilities.

Apart from that, the Igun [277] model seems to also align with the Indonesian care seeking process. This process is started with the recognition of symptoms, including self-assessment of symptoms and whether or not they affect their daily activities. Then they first treated with self-medication, with traditional or over the counter drugs. If they then perceived that the self-medication failed, they then will seek care from other health providers after consulting with their significant others. Their significant others also recommend some other treatment perceived as a better way for the illness. If they felt that that choice also failed, they will find other possible alternatives until the final state of ‘fit’ or health providers that suit them.
2.6 Key findings and gaps observed from the literature review

The reviewed literature in this chapter examined an array of studies focused on the problems of child immunisation and diabetes, particularly in the Indonesian context. The key findings observed from the literature underlined that effective interventions should be developed to improve child immunisation uptake, and diabetes patients’ outcomes. It has been widely recognised that in designing an effective intervention, targeted people’s behaviours related to the health problem need to be understood. Numerous theories and models have attempted to explain the determinants of people’s health behaviours. The theories highlighted that people’s health behaviours are determined by individual characteristics, and their relationship within the socio-environmental context.

Many studies on health-related behaviour have been conducted in the Indonesian context. Many of them, however, focused on a restricted range of health problems in Indonesia. Research on health behaviour on child immunisation has not been updated for a long time, and no studies on diabetes patients were found. Moreover, in terms of geographical areas, most studies in Indonesia were conducted within Java Island. Some studies outside Java were focused only in particular areas including Aceh and Bali Provinces. Limited studies were conducted in the eastern part of Indonesia.

These key findings showed there are significant gaps in the literature. Although the gaps observed might include a wide range of health topics and locations given the wide variation of community characteristics in Indonesia, limited studies were observed from some areas of Indonesia, including East Nusa Tenggara and West Sumatera Provinces. This study, therefore, intends to fill some of those gaps. This current study was carried out in East Nusa Tenggara and West Sumatera Provinces, and aims to understand people’s health behaviour in relation to child immunisation and diabetes (Chapter 3). This understanding was then applied to establish, and implement an intervention to improve diabetes patients’ outcomes in East Nusa Tenggara (Chapter 4, Chapter 5, and Chapter 6).
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Section B – Understanding health-seeking behaviours of people in Indonesia in child immunisation and diabetes

3 Chapter 3: Indonesian people’s perceptions and experiences related to child immunisation and diabetes: A qualitative study

3.1 Introduction

Chapter 3 presents the methodology, methods and findings of the qualitative study. The study was an attempt to understand health problems from the communities’ perspectives. Based on the literature study on health seeking behaviour in Indonesia detailed in Chapter 2, it was found that there are few studies on the topics of child immunisation and diabetes. It was, therefore, important to conduct a preliminary study to explore people’s beliefs and behaviours on these topics. Results from this study were then used to inform the design of the major study.

Chapter 3 is divided into three major subchapters. The first subchapter describes the methodology and methods. It begins with the rationale for qualitative research, followed by the research process and description about recruitment of participants. The first subchapter ends with an explanation about instruments used, data collection and data handling processes. The second subchapter details the results of the study, including those related to child immunisation, and results related to diabetes. Discussions about the results are also presented. A short final subchapter concludes the findings and suggests future study directions.

3.2 Methodology and methods

3.2.1 Study design

This qualitative study aimed to explore perceptions, beliefs and behaviours of people in Indonesian communities related to child immunisation and diabetes. It was therefore designed qualitatively to get a deeper understanding from the community [363]. Qualitative study enables a researcher to understand the reality from the actors’ perspective and explore any contextual constraints that shape the
Deeply rooted in social sciences, the qualitative design has been used widely in health research. Topics studied have ranged from healthcare organisation to social inequalities in healthcare [365].

In health behaviour studies, qualitative design enables researchers to reveal social aspects of health behaviours including people’s socio-cultural beliefs related to the condition, perceptions about the disease, and decision-making process preceding the action of seeking care. The qualitative enquiry has been applied to understand immunisation programme acceptance in Southeast Asia, and ethnic minorities in the United Kingdom [36, 257], and care-seeking behaviour of people with diabetes in Uganda, rural Australia, and ethnic minorities in the United States [263, 264, 267, 366, 367].

Within the qualitative design, this study applied a phenomenological perspective. The fundamental question in phenomenological study is “what is the meaning, structure, and essence of this phenomenon for this person or group of people” [363]. In health research, the phenomena studied might be related to people’s health or illness, health care, or health delivery services that are subjectively understood, practised or experienced [365]. In this research, the phenomena studied are mothers’ behaviour in child immunisation programmes, and people’s experiences in managing diabetes.

The data were gathered using Focus Group Discussions (FGDs). A series of FGDs are an ideal method for obtaining people’s perspectives and their behaviour in a community. The FGD enables the researcher to explore the social context that influences people’s perspective and decision-making process in a community [363]. This discussion method is recommended particularly when the study involves people who are hard to reach or have a negative view towards medical services [365]. With the group discussion, those people might feel less threatened than when they are individually interviewed. In this qualitative study, potential participants may be people who are not willing to take part in child immunisation programmes, or may be diabetes patients who have negative views towards medical services. The FGD, therefore, was the best choice for collecting data.
3.2.2 **Theoretical framework**

The literature review of health seeking behaviour of people in Indonesia described in Chapter 2 revealed that the framework that aligns best with the Indonesian socio-cultural context is Kroeger’s framework [279]. Indonesian people’s behaviour is influenced by a number of complex interrelated factors including individual characteristics that interact within their society, perceptions about disease, and also perceptions about health services. The Kroeger framework, therefore, was applied in this qualitative study to develop the questions and interview guideline.

3.2.3 **The study location and justification**

The qualitative study was conducted in East Nusa Tenggara and West Sumatera Provinces. In each province, some regions were further purposively selected as study locations. The selection of these regions was done in order to represent rural and urban populations. Gathering data from urban and rural population groups provided rich information based on their socio-cultural context, and access to health care. The urban areas were characterised by high population density, whereas the rural areas are characterised by low population density. In term of health care access, the urban areas are also often characterised by higher availability and accessibility of healthcare facilities compared to their rural counterparts.

In East Nusa Tenggara, the study was carried out in Kupang city, Kupang district, Manggarai district, and Manggarai Timur district (Figure 3.1). Both Kupang city and Kupang district are located on Timor Island, and Manggarai and Manggarai Timur district are located on Flores Island. Kupang city is the capital city of East Nusa Tenggara Provinces, and it represents the urban areas, whereas the other locations represent rural areas. Table 3.1 compares the population density and the number of healthcare facilities in study locations in East Nusa Tenggara Province.

In West Sumatera, the study was firstly designed to collect data in Padang city, Pariaman city, and Solok district (Figure 3.2), as these three locations represent urban and rural areas in West Sumatera. Table 3.2 compares study locations’
characteristics, i.e. population density and number of health facilities. Based on population density, both Padang and Pariaman city are categorised as urban areas. Padang is the capital city of the Province, and has a more sophisticated transportation system compared to other cities. Therefore, people in Padang city have greater access to healthcare facilities, compared to people in Pariaman city.

Table 3.1: Population and healthcare facilities available in study locations in East Nusa Tenggara Province

<table>
<thead>
<tr>
<th>District/city</th>
<th>Number of population (Population density per km$^2$)</th>
<th>Number of hospitals</th>
<th>Number of community health centres (Puskesmas)</th>
<th>Number of pharmacies</th>
<th>Number of licenced drug stores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kupang city</td>
<td>358,382 (2,296)</td>
<td>9</td>
<td>10</td>
<td>58</td>
<td>26</td>
</tr>
<tr>
<td>Kupang</td>
<td>328,688 (60)</td>
<td>1</td>
<td>25</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Manggarai</td>
<td>309,614 (183)</td>
<td>2</td>
<td>21</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Manggarai Timur</td>
<td>264,979 (106)</td>
<td>0</td>
<td>20</td>
<td>3</td>
<td>0</td>
</tr>
</tbody>
</table>

Notes:  
\(a\) Statistics of East Nusa Tenggara Province [87]  
\(b\) Indonesia Ministry of Health [368]  
\(c\) Indonesia Ministry of Health [369]

Table 3.2: Population and healthcare facilities available in study locations in West Sumatera Province

<table>
<thead>
<tr>
<th>Districts/ municipalities</th>
<th>Number of population (Population density per km$^2$)</th>
<th>Number of hospitals</th>
<th>Number of community health centres (Puskesmas)</th>
<th>Number of pharmacies</th>
<th>Number of drug stores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Solok</td>
<td>355,077 (95)</td>
<td>2</td>
<td>18</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Padang city</td>
<td>854,336 (1,229)</td>
<td>30</td>
<td>22</td>
<td>160</td>
<td>83</td>
</tr>
<tr>
<td>Pariaman</td>
<td>80,870 (1,102)</td>
<td>1</td>
<td>7</td>
<td>25</td>
<td>5</td>
</tr>
</tbody>
</table>

Notes:  
\(a\) Statistics of West Sumatera Province [86]  
\(b\) Indonesia Ministry of Health [370]  
\(c\) Indonesia Ministry of Health [369]

During the time of data collection process, however, there was a severe haze problem which affected West Sumatera Province. In some areas, the haze was so thick that the local government recommended people not to go outside. With this situation, the data could only be collected in Pariaman city, and Solok district. Pariaman city represents urban areas, while Solok district represents rural areas.
Figure 3.1: Map of study locations in East Nusa Tenggara Province
https://commons.wikimedia.org/wiki/File%3ALokasi_Nusa_Tenggara_Timur_Kota_Kupang.svg
Ewesewes at id.wikipedia [CC BY-SA 3.0 (http://creativecommons.org/licenses/by-sa/3.0)], from Wikimedia Commons, modified

Figure 3.2: Map of study locations in West Sumatera Province
https://commons.wikimedia.org/wiki/File%3ALokasi_Sumatera_Barat_Kota_Padang.svg
Ewesewes at Indonesian Wikipedia [CC BY-SA 3.0 (http://creativecommons.org/licenses/by-sa/3.0)], via Wikimedia Commons, modified
3.2.4 Ethics approval and local government research approval

Ethics approval for the qualitative study was sought through and granted by the University of Otago Ethics Committee New Zealand (Appendix 2.1). In study locations, local government approval was sought from the provincial government. The research approval letters were issued by Kantor Pelayanan Terpadu Satu Pintu (The Integrated Office of Community Service) (Appendix 2.2 – Appendix 2.6). The documents required for obtaining approvals were a reference letter, which was the official letter requesting permission to conduct research from the head of the researcher's institution, and a research proposal. The reference letter must be in the Indonesian language, so I requested the reference letter from the Dean of the Faculty of Pharmacy, Gadjah Mada University, the institution in Indonesia in which I work. As a result, research approval letters from local government offices included the Faculty of Pharmacy, Gadjah Mada University as the researcher's institution.

3.2.5 Study methods

3.2.5.1 Sample, sample size, and sampling process

Sampling strategy

As appropriate for a qualitative study, the sample was recruited with non-probability sampling techniques. A purposive sampling strategy, which is defined as selecting participants intentionally with predefined conditions [371] was applied. The selection criteria were set up in order to find people who have rich information about the topic studied.

Sample description and eligibility criteria

Because two different topics were covered, this study involved two groups of participants. The first group of participants were mothers aged at least 17 years who had a child or children under 3 years old. The second subject group involved participants who had been diagnosed with diabetes by formal healthcare providers; and were able to communicate clearly. The exclusion criteria for both groups were: having any health educational background; or working for a formal healthcare provider.
Sampling process

Discussions were held with healthcare workers at the selected community health centres, and local community members to gather information on suitable methods for recruiting participants in the study locations. Most mother participants were recruited through the Pos Pelayanan Terpadu – Posyandu (community-based health post for mother and child care) programme. In some study locations, the invitation was announced to mothers who attended the Posyandu services. In some other study locations, the voluntary health workers in the Posyandu invited eligible participants by visiting their house, or calling them on the phone. Most diabetes participants were recruited from a list of patients at community health centres or the Prolanis programme (a programme for managing chronic illnesses) at the community health centre (Puskesmas). In study locations with limited patient data, the participants were sought by snowball sampling (asking people with diabetes, health professionals, or community health centres staff about their diabetic relatives, neighbours, or friends), and announcing the study after a Sunday service at a church.

Sample size

In the mothers group, a total of 53 mothers participated in six FGDs, with 3 – 12 participants attending each FGD. Some mothers participating in the FGDs were also voluntary health workers (kader) in the Posyandu. There was one FGD which was attended by only three participants, as the other invited participants did not come. A discussion with a village midwife was also held after this FGD.

In the diabetes group, 45 diabetes patients participated in six FGDs. Each FDG was attended by 6 – 10 participants. Some participants who were older or had problems in reaching the discussion sites (for example, could not ride a motorbike) came to the FGDs with one other family member – her/his daughter or his wife. The family members sometimes also helped the participants answer the questions and were involved in the discussions.
3.2.5.2 Data collection

The process of collecting data

Participants who had been contacted and agreed to participate were invited to attend the FGDs. The FGD were conducted in the most convenient place for the participants. Among six FGDs with mother participants, three of them were in Posyandu, and the other three were conducted in one of participant’s or village midwife’s house. Among the six FGDs with diabetes participants, four of them were conducted in Puskesmas, and the other two were carried out at one of the participant’s house. Table 3.3 describes all the FGDs and the number of participants involved. Figure 3.3 and Figure 3.4 illustrate the data collection process involving diabetes and mother participants.

Table 3.3: The focus group discussions conducted in the study

<table>
<thead>
<tr>
<th>Location</th>
<th>Date</th>
<th>Time</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FGD with mother participants</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kupang municipality</td>
<td>10 September 2015</td>
<td>04.30PM</td>
<td>7</td>
</tr>
<tr>
<td>Kupang district</td>
<td>12 September 2015</td>
<td>10.30AM</td>
<td>11</td>
</tr>
<tr>
<td>Manggarai Timur district</td>
<td>16 September 2015</td>
<td>10.00AM</td>
<td>10</td>
</tr>
<tr>
<td>Solok district</td>
<td>4 October 2015</td>
<td>01.00PM</td>
<td>12</td>
</tr>
<tr>
<td>Pariaman municipality</td>
<td>8 October 2015</td>
<td>10.00AM</td>
<td>10</td>
</tr>
<tr>
<td>Pariaman municipality</td>
<td>8 October 2015</td>
<td>01.00PM</td>
<td>3</td>
</tr>
<tr>
<td><strong>FGD with diabetes participants</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kupang municipality</td>
<td>9 September 2015</td>
<td>04.30PM</td>
<td>6</td>
</tr>
<tr>
<td>Manggarai district</td>
<td>19 September 2015</td>
<td>09.00AM</td>
<td>8</td>
</tr>
<tr>
<td>Manggarai Timur district</td>
<td>20 September 2015</td>
<td>10.00 AM</td>
<td>7</td>
</tr>
<tr>
<td>Solok district</td>
<td>4 October 2015</td>
<td>03.00PM</td>
<td>10</td>
</tr>
<tr>
<td>Pariaman municipality</td>
<td>3 October 2015</td>
<td>09.00AM</td>
<td>7</td>
</tr>
<tr>
<td>Pariaman municipality</td>
<td>8 October 2015</td>
<td>08.00AM</td>
<td>7</td>
</tr>
</tbody>
</table>

During the FGDs, I was helped by local research assistants. I was the moderator for most of the FGDs, and the research assistants took notes. Before the FGDs started, I provided information about the study (Appendix 3.1 – Appendix 3.4), and invited them to ask any questions. After that, I provided them opportunities to consider whether or not they would continue to participate. Some of them asked further questions about the study, and all individuals who came gave consent to take part in the study, and signed the informed consent form (Appendix 3.5 – Appendix 3.8). All participants agreed to be tape recorded.
Figure 3.3: Focus group discussion with diabetes participants in Manggarai Timur district

Figure 3.4: Focus group discussion with mother participants in Kupang city
The FGDs with mother participants lasted for about an hour, while the FGDs with diabetes participants lasted for about two hours. Personal conversation with participants was also held before and after the discussions. During the discussion, a lot of participants asked questions related to their personal conditions, and I answered the questions personally after the discussions.

As an appreciation to participants for their time spent for the FGDs, souvenirs were provided after the discussion with mother participants. For the FGDs with diabetes participants, before the FGDs were performed, rapid blood glucose, cholesterol, and uric acid measurements were provided. In the study locations, people with diabetes have their blood measured when they visit health facilities and are advised by the health professionals. These measurements are commonly available at health centres. Some local pharmacies also provide blood glucose measurement services, but the people had to pay to get it. Based on observations in study locations, and participants expressions such as: “So, thank God, that I had my sugar level checked today and it’s 109 [mg/dL]”. They were pleased and wanted to have their condition checked.

**Language used**

Most people in Indonesia speak ethnic languages for everyday conversation. The majority of the population, however, understand and speak *Bahasa Indonesia*, the Indonesian national language. The Indonesian language is the formal language used in schools, and in healthcare settings. I originally come from Javanese ethnic group, which is different from the participants involved, so I do not speak the participants’ ethnic language. *Bahasa Indonesia* was therefore used as the main language in the FGDs. Before each FGD commenced, I explained to the participants that I would ask questions in *Bahasa Indonesia*, but they could answer in any language. In many cases, the participants answered in a combination of *Bahasa Indonesia* and their local language. I was helped by local research assistants who were native speakers of the participants’ language. During the research, I also learned about local languages.
In one FGD involving mother participants in Manggarai Timur district, East Nusa Tenggara, many participants answered in their local language, so the research assistant helped me moderate this FGD. People in this area rarely speak *Bahasa Indonesia* for everyday conversation. All FGDs in West Sumatera were conducted in combination of *Bahasa Indonesia* and the *Minang* language. The *Minang* language is similar to Malay language, and it is almost the same as *Bahasa Indonesia*. The differences are in the word choices, pronunciation and dialect. I therefore understood the language even though I cannot speak in their dialect.

The use of multiple languages poses a risk of losing meaning, and respondent validation is an important strategy to minimise this risk. During the process of discussion, when they answered with local language where I was not sure about the meaning, I repeated what they said in *Bahasa Indonesia* to check the meaning. After the discussion, I summarised the result of the discussion, and asked the participants to indicate whether or not the summary was consistent with what had been discussed. After each FGD, I also had a discussion with the research assistants, to make sure that I understood the conversation as a whole, and understood local words that were used.

**Study instrument**

The FGDs questions guides were developed in English, and translated into *Bahasa Indonesia* (Table 3.4 and Table 3.5).

**Table 3.4: Focus group discussions guide for child immunisation topic in English**

<table>
<thead>
<tr>
<th>Number</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>What do you think makes your children healthy?</td>
</tr>
<tr>
<td>2</td>
<td>What do you do to keep your children healthy?</td>
</tr>
<tr>
<td>3</td>
<td>What are your views about immunisation?</td>
</tr>
<tr>
<td>4</td>
<td>Do you have any experience, or have you heard about the experience of your family or friends, about immunising children?</td>
</tr>
<tr>
<td>5</td>
<td>How do you make the decision about whether or not to immunise your children?</td>
</tr>
<tr>
<td>6</td>
<td>Do you face any challenge in immunising your children? If so, what are they?</td>
</tr>
<tr>
<td>7</td>
<td>What do you think about the immunisation services given by Posyandu in your areas?</td>
</tr>
</tbody>
</table>
Table 3.5: Focus group discussion guide for diabetes topic in English

<table>
<thead>
<tr>
<th>Number</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>How were you first diagnosed with diabetes?</td>
</tr>
<tr>
<td>2</td>
<td>What do you think about diabetes?</td>
</tr>
<tr>
<td>3</td>
<td>What do you think is the cause of diabetes?</td>
</tr>
<tr>
<td>4</td>
<td>Could you please tell us your experiences in managing your diabetes after being diagnosed?</td>
</tr>
<tr>
<td>5</td>
<td>In terms of medicines, what type of medicines are you taking?</td>
</tr>
<tr>
<td>6</td>
<td>Is there any medicine that you are taking other than medicines from your doctors?</td>
</tr>
</tbody>
</table>

3.2.5.3 Data management and analysis

All the Focus Group Discussions were recorded, and transcribed verbatim in Bahasa Indonesia. Words or sentences in local languages were also translated into Bahasa Indonesia with the help of research assistants. Some words or phrases that do not have the same meaning were recorded in the local language without any translation. Due to time constraints, the process of transcription could not be completed in the study locations. Contact with the research assistants, however, continued until all the transcription process was finished.

These transcripts were then translated into English. In doing this, I was assisted by a person who was fluent in both languages. After the translation process, discussions were made to indicate sentences, phrases, and words that might have different meaning in each language. Some words that were specific to Indonesian or the local languages were left without any translation.

These translated transcripts were analysed using inductive qualitative content analysis as there was no previous research that had been published describing this phenomenon [372]. The analysis involved three stages: a preparation stage, including selecting of a unit of analysis and understanding the data as a whole; followed by an organisation stage, including coding, grouping and categorising data; and finally, a reporting phase in which the results are reported in the form of a model and conceptual system [372]. Nvivo software (Nvivo Pro edition version 11) was used in this process.
To increase the trustworthiness of the findings, the content of categories was checked by supervisors. Discussions involving all supervisors and myself were also made to finalise the coding process. The results of data analysis are presented from the themes that emerged, and detailed with some quotes.

3.2.5.4 Ethical issues

Several ethical issues were considered while undertaking the study. First, the research was conducted in accordance with the Ethical Guidelines of the University of Otago. The information sheet for the study was read and explained to the participants. Written informed consent was sought before the process of collecting data. The participants were also informed that their participation was voluntary, and that they might withdraw from participating at any time without any consequences.

Secondly, during the Focus Group Discussions, I tried to uphold the participants’ cultural practices. As an example, I showed respect towards all participants by acknowledging them in accordance to their cultural practices. Instead of addressing them with their formal title from Bahasa Indonesia, I addressed them with titles in their local language. I also prepared drinks and snacks in all the FGDs. This is part of the culture of inviting others. Before asking questions related to the study, I also made personal conversation, for example, by asking them anything related to everyday life. Personal conversation in Indonesia increases personal relationship among people.

Lastly, participants’ names were not mentioned anywhere in the research report, including the thesis and publications. The respondents’ names were coded. Some photographs were also taken after the FGDs, and verbal consent was sought for including some of the photographs in the thesis. The participants’ names, however, are not mentioned alongside the photographs.
3.3 Results

3.3.1 Results related to the topic of child immunisation

3.3.1.1 Socio-demographic characteristics of the participants.

In total, 53 mothers participated in six Focus Group Discussions related to the topic of immunisation. Table 3.6 shows demographic characteristics of the participants.

<table>
<thead>
<tr>
<th>Socio-demographic characteristics</th>
<th>Categories</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>20 – 29</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>30 – 39</td>
<td>24</td>
</tr>
<tr>
<td></td>
<td>40 – 50</td>
<td>9</td>
</tr>
<tr>
<td>Education</td>
<td>Elementary school</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Junior high school</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Senior high school</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>Tertiary education</td>
<td>4</td>
</tr>
<tr>
<td>Occupation</td>
<td>Housewives/ no formal occupation</td>
<td>52</td>
</tr>
<tr>
<td></td>
<td>Civil servant</td>
<td>1</td>
</tr>
</tbody>
</table>

As seen in the table, the majority of participants were in their twenties and thirties. In terms of education, the majority of them graduated from senior high school, and only four of them had tertiary education. Almost all participants were housewives. Because participants were recruited through Posyandu services, which are held in the morning of work days, they are attended mostly by mothers who have no current paid occupation.

3.3.1.2 Knowledge and perception related to child health and immunisation

The discussions were started by asking participants about general child health, and common childhood illnesses. Discussion on this topic revealed participants’ knowledge and perceptions related to child health and immunisation (Figure 3.5). Participants mentioned that good food and a clean environment were essential in keeping the children healthy. Most respondents breastfed their children exclusively until 6 months of age, and started solid food afterwards. Cleaning the
children, including regular showering twice a day, and cleaning their hands before eating, were also regarded important to maintain child health.

Keep their clothes clean. Have our kids to take shower (FGD Kupang district, East Nusa Tenggara).

To keep them healthy, the key is eating regularly, and paying attention to our kids’ activity (FGD Pariaman 1, West Sumatera).

[take them] go to Posyandu regularly, manage their diet, and monitor their weight (FGD Kupang city, East Nusa Tenggara).

Figure 3.5: Participants’ knowledge and perception related to child health and immunisation
Discussions about this topic also revealed mother’s care-seeking behaviour for childhood illnesses. The most common childhood illnesses were fever, cold, and cough. In dealing with these, most mothers took the child to medical services, either to village midwives, the village level community health centres (Pustu), or to the community health centres (Puskesmas). Self-medication, either with medicines bought from a drug kiosk or traditional medicines, was rarely used. In villages with a village midwife living there, most people first sought care from the midwife for child illnesses. The midwives would refer to Puskesmas if they could not handle it.

Hardly do kids suffer from diarrhoea, cough and cold are the most common they get (FGD Kupang district, East Nusa Tenggara).

If it’s fever, we give a warm compress [to our kid] [by putting warm wet napkin on baby’s forehead], [and give them] medicines from the midwife (FGD Manggarai Timur, East Nusa Tenggara).

I’m just afraid [to buy from the stall, kiosk], not like when we were kids. At that time, we bought the medicine from the stall, but now we don’t (FGD Pariaman 1, West Sumatera).

Moreover, some participants believed that taking their children regularly to Posyandu, and having their children immunised was also an action for keeping the children healthy. Most participants related immunisation to the immune system, so that the injection was believed to increase immunity and keep them healthy. Lay people refer to ‘immune’ in Indonesian as ‘kebal’ which means resistance from or insusceptibility of contracting diseases. Only a few participants, however, said that immunisation was for preventing specific diseases. Some participants also thought that immunisation was related to child growth. Some participants explicitly said that they did not really understand immunisation – what it is and what it is for – but they kept immunising their children anyway.

To improve our kids’ immune system, to keep our kids healthy, to preserve the immune system of our baby (FGD Manggarai Timur, East Nusa Tenggara).

It will, if we don’t give our kid the immunisation, it will affect our kid’s growth (FGD Kupang city, East Nusa Tenggara).

Although I don’t really understand what immunisation is, I just do what the midwife told me to do … (FGD Pariaman 1, West Sumatera).
Further discussions also revealed that participants did not understand the diseases related to the vaccines. This came up when the discussion went to the topic of the diphtheria outbreak that happened in West Sumatera in 2014. They also did not understand why an outbreak happened to their areas.

Is it [diphtheria] the same as typhoid? Diphtheria is like itchy [on skin] (FGD Pariaman 1, West Sumatera).

No, we don't know, it was an outbreak, but thank God there's no [cases] anymore (FGD Solok, West Sumatera).

3.3.1.3 Mothers’ experiences in immunising their children

This second topic discussed related to mothers’ experiences in immunising their children. This topic generated two themes: Posyandu and the important roles of community-based health workers – including voluntary health workers and village midwives –; and factors influencing mothers’ acceptance of immunisation. In this thesis, the term ‘community-based health workers’ is referred to voluntary health workers (kader) and village midwives.

Posyandu: the important roles of community-based health workers

As the participants were recruited by community-based health workers involved in the Posyandu programme, most of them went to Posyandu for child immunisation. Gathering data from these participants, however, enabled us to get information about the Posyandu programme implementation (Figure 3.6). The Posyandu is a community-based initiative, and self-managed by the community. In most places, the Posyandu health services are organised by community-based health workers, in collaboration with and monitored by Puskesmas.

In all study locations, the Posyandu health services were held once a month, either in the village administrative office, or in the community-based health worker’s house. The main activities included weight measurement, vitamin A supplementation, and immunisation. Sometimes, there were education sessions related to mother and child health. In some places, contraception services for the mothers were also provided.
Injection [immunisation], body weight, family planning [contraception] (FGD Manggarai Timur, East Nusa Tenggara).

We have Posyandu service every month...to check their health, give them vitamin A, polio injection or BCG all are provided here (FGD Pariaman 1, West Sumatera).

Figure 3.6: Posyandu activities, problems and implementation

The main problem with Posyandu was targeting community attendance to the designated time and place of Posyandu services. Some participants reported that mothers lacked motivation to attend Posyandu services.

There are 47 infants here, [but] only 20 of them coming here. (*How about the rest 20?*) They rarely come here. Perhaps, this month they come, and the month after probably not (FGD Kupang district, East Nusa Tenggara).

I asked them to take their children to the Posyandu, but they said that they are lazy [to take them] (FGD Kupang city, East Nusa Tenggara).

Solutions depended on the capacity of community-based health workers. Some of them invited mothers a day before the Posyandu services door to door. However, this approach might not work everywhere.
Yes, they are. We don’t even have to go to the Posyandu [before the day], they are the one who come to our place asking us to come. (*So, each of you are being informed before the day, like that!*). Yes (FGD Manggarai Timur, East Nusa Tenggara).

The Posyandu is held on the 4th of every month. On the 3rd, the day before we [the cadres] come to all houses in the neighbourhood that have kids. But, they don’t come. They are lazy to come though we’ve already informed them (FGD Kupang district, East Nusa Tenggara).

In some other locations, the community-based health workers implemented food supplementation for children, and this increased mothers’ attendance at the Posyandu. Lack of funding, however, hindered the sustainability of this food programme. Overcoming this, some community-based health workers implemented a ‘donation for Posyandu’ programme. The community-based health workers asked each community member, each household, or each Posyandu member to donate a certain amount of money for the Posyandu Programme.

Yes, we also have additional food for kids programme in the Posyandu, in order to attract people. So, every month we come to every house to ask them [to donate] money for the programme. (FGD Solok, West Sumatera).

But, because I’m really busy with working, then, that programme, the additional food programme, is now ended... we [should] collect IDR 1000 (USD 0.07) each people again, to provide additional food for kids, hence they could come here vigorously (FGD Kupang district, East Nusa Tenggara).

During discussions in Kupang district and Kupang city, participants also mentioned aid they received from non-government organisations. The aid helped them to provide better services. However, the aid was given only for a specific period.

In 2007, there was also aid from UFP, an NGO for 6 years. During that time, health services in this Posyandu were great. (*I see, the problem is the fund, right?*). Yes, something like that. There has been no other NGO since then, we have been managing it by our self (FGD Kupang district, East Nusa Tenggara).

In the past, the aid from overseas, was delivered directly to the community, and didn’t go through the Puskesmas. They held an educational program, then everyone only had to come, and everything and everyone were ready, it was great to be like that (FGD Kupang city, East Nusa Tenggara).
Posyandu is a community-based programme, so although the vaccines are supplied by the government for free, other financial support to facilitate the programme implementation comes mainly from the community. Therefore, health services included in the programme differed in each location, depending on community participation and financial support.

(Don't you get any help [funding] from the Puskesmas?) None. (How about from the district government?) Nothing (FGD Kupang district, East Nusa Tenggara).

I [kader] have already asked the government to give such aid, they said they would try to help, but nothing has happened until today. We also need a proper scale to weigh kids... (FGD Kupang city, East Nusa Tenggara).

Basic immunisation services for children are available in Posyandu. The vaccines are stored in Puskesmas, and they are distributed to the Posyandu on the day of Posyandu services by village midwives or health professionals in the Puskesmas. However, because the Posyandu health services are only once a month and cover quite small areas, participants reported often encountering practical problems. These included the child’s immunisation schedule not matching with the day of Posyandu service, children who were sick at the time of Posyandu service, and concerns about vaccine wastage. Many mothers reported delayed immunisation or having to go to other immunisation services because their children were sick on the day of Posyandu services. The vaccine wastage concern was particularly for multi-dose vial vaccines that will only be opened provided a minimum number of children were gathered together. The concern about vaccine wastage was reported by participants in East Nusa Tenggara. When these problems were encountered, the children then were referred to other immunisation providers. This would potentially increase missed opportunities.

If the immunisation date in the Posyandu don’t fixed with our kids’ immunisation schedule, we take them to the Puskesmas to have the immunisation (FGD Kupang city, East Nusa Tenggara).

The immunisation programme is scheduled, if the children suffer from fever at that time, they are referred to have the immunisation in the Puskesmas, (FGD Pariaman 2, West Sumatera).
[I think] the BCG vaccine is hard to get, isn't it? Yes, it is, it's because it needs 3 kids gathered beforehand, otherwise the immunisation will be postponed, and we have to get it from the Puskesmas. But then, the problem is sometimes the mothers forget about it, then they become lazy [to come back] to get the immunisation (FGD Kupang city, East Nusa Tenggara).

Some participants mentioned that they then took their children to village level community health centre (Pustu), community health centres (Puskesmas), village midwife, or private doctors for immunisation. However, private immunisation services are not free. Some participants also mentioned that health services provided by Pustu outside working hours were not free. These may further increase the number of children missing out on immunisation.

Yes, I have had, for measles. Because my kid suffered from cough and cold when he was supposed to get the measles immunisation [in Posyandu] that time... So, my kid had measles immunisation in the private clinic. (Did you have to pay for it?) Yes, I did, it was 150 thousand [IDR] (USD 11) (FGD Kupang city, East Nusa Tenggara).

We take them to the Pustu if it's cough and cold. (Do you need to pay for the medical treatment there?) It's free of charge. We don't have to pay the treatment during 7 am to 12 pm. From 12 pm to 5 pm, it's not free of charge anymore is it?yes, it's the off hours. (FGD Kupang district, East Nusa Tenggara).

The success of immunisation programme in Posyandu also depended on the active and collaborative work of community-based health workers. Community-based health workers spread the information about the importance of immunisation to the community. Moreover, community-based health workers often visited mothers with children who did not come to the immunisation services, and gave the vaccines at home.

Yes. We come to their house, give them the immunisation at their house. If they don't show up, the midwife come to their house eventually. (Such great cadre you are) (FGD Kupang district, East Nusa Tenggara).

If we couldn't make to the Posyandu, we called village midwife to come to our house, she would come eventually and brought the vaccine with her (FGD Pariaman 2, West Sumatera).
Factors influencing mothers’ behaviour related to child immunisation

Most participants in the study stated that they had their children immunised completely, and only a few of them had not immunised their children. Some participants also mentioned that they had their youngest children immunised completely, while their older children were partially immunised or did not have the immunisation at all. Information about reasons for refusing immunisation, therefore, was gathered by asking participants about their relatives or neighbours who refused immunisation, or asking participants why they did not immunise their older children.

In the past, there weren’t any information about immunisations, were there? Yes, I have 4 [children]. To be honest, 3 of them didn’t get any immunisations, only one got complete immunisation (FGD Pariaman 1, West Sumatera).

My second child had all the immunisations, but the eldest one didn’t get complete immunisation, this kid [the third one] had complete immunisation as well (FGD Pariaman 1, West Sumatera).

Factors influencing mothers’ behaviour of child immunisation found in this study are described in Figure 3.7. The main factors are shown in bold: fathers as a decision maker; and interaction with community-based health workers. These two factors were frequently mentioned and observed in almost all study locations. The other factor was related to individual characteristics including religious beliefs and knowledge about immunisation. These factors were less frequently mentioned or found only in some study locations. They may therefore be specific to certain locations or they may not strongly influence behaviour.

The father as a decision maker
The most important factor influencing mothers’ behaviour in child immunisation found in this study was the role of the father as the decision maker within the family. This emerged in discussions in almost all study locations. Participants mentioned that the main reason mothers refused to take their children to the immunisation programme was that they were not allowed to do so by the father. In some cases, they did not know the father’s reason. In other cases, participants mentioned that the fathers believed that the immunisation would make the child
sick instead of being healthy. This belief might come from their children’s previous experiences of adverse reactions after immunisation.

I asked her to come, but [she couldn't do it since] her husband wouldn’t allow her, he thought that the immunisation made their kids got sick instead of being healthy (FGD Kupang city, East Nusa Tenggara).

My husband said that if [our kids] got immunisation, they would get sick, become this and that, so he told me not to give it. But, for my youngest child, I took him here once a month [to have immunisation], I always had it here from the beginning till the last one (FGD Pariaman 1, West Sumatera).

Yes, there are some. They are not allowed to do that by their husband, but we don’t know the reason why (FGD Pariaman 2, West Sumatera).

Yes, there are husbands do that. The mothers just can’t do if their husband doesn’t allow them to do so. (why is it like that?) [their reason is] after having immunisation, their kids get fever (FGD Solok, West Sumatera).

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**Figure 3.7: Factors influencing mothers’ behaviour in relation to child immunisation**

Therefore, although in some cases, the mothers were willing to take the children to the immunisation programme, they often could not do that as the fathers did not agree. Interestingly, some mothers kept taking the children to the *Posyandu* and had their children immunised even though their husband did not allow them to do so. They lied to their husband, although consequently they argued when the husband noticed that the children got fever after having immunisation.
Another case, there is also wife and husband arguing at their house. [I asked] why did you have an argument yesterday? [she said] My kid got fever, he [the husband] didn’t allow me to go to the Posyandu but I went there, and our kid got fever (FGD Kupang district, East Nusa Tenggara).

Sometimes we lied to our husband...I said no though our kid did get injection, [we did that] just so we didn't have to argue... But he would know if our kid got sick, eventually (FGD Pariaman 1, West Sumatera).

Relationships with community-based health workers

Relationships with community-based health workers also influenced mothers' decisions on child immunisation. Some participants mentioned that they had a good relationship with village midwives. The mothers trusted them, therefore they regularly immunised their children despite limited understanding about immunisation. They describe this relationship as not one of authority but of trust. With this trust, a belief that immunisation is good for their children’s health was enough to encourage them to do so.

It's good if the midwife can help us to recover [from any sickness]. If the midwife tells us something, we do so. Yes, we just trust her [the midwife] and let her treat us. Yes, true, true... (FGD Pariaman 1, West Sumatera).

The key role is the midwife, if she's not active, doesn't approach the cadres, it [the Posyandu] doesn't work. If there is a rumour that she [the midwife] is going to move out [from the village], we protest immediately (FGD Solok, West Sumatera).

Participants in this study also demonstrated positive attitudes toward health services, as shown with their engagement with health services, including immunisation and other medical services for childhood illnesses. Some participants also mentioned that they went to midwives for birth delivery, and maternal health services. The relationship with village midwives also showed their availability at any time to help the community. Participants therefore acknowledged the importance of village midwives’ role in the community health.

(Is there any traditional birth attendant here mam?) Yes, there is, a traditional birth attendant. She does massages. [but] people come to see her not to give birth anymore, but only to have the massages (FGD Pariaman 2, West Sumatera).
If your kids suddenly get sick in the night time, how do you get the medicine? Yes, we immediately visit the midwife. [once] It was at 2 or 3 am since our kids were babies (FGD Solok, West Sumatera).

This finding showed that interaction between health professionals and community influenced people’s attitude to, and acceptance of, health programmes. Establishing a good relationship between health professionals and the community increased people’s trust, and this led to the community accepting health intervention. Moreover, the capacity of village midwives in solving the problems might also increase people’s acceptance of immunisation. In Pariaman, for example, the village midwife shared her experience when she gave the mothers paracetamol to be taken to the children, not after the children had the injection, but before they received the vaccines. She did this to prevent fever from happening, and reduce parents’ anxiety of having adverse events after the injections.

For preventing [fever], I give them medicine before giving the immunisation, so the mothers don’t worry afterwards, they were given the medicine first, then they have the immunisation after that. So, we give them medicine first before having that immunisation (personal communication with a village midwife in Pariaman, West Sumatera).

Individual characteristics

Personal characteristics including religious belief and limited understanding about immunisation and prevention concepts were also found to influence immunisation acceptance. Religious beliefs were only found as a reason to refuse vaccines in West Sumatera, in which the dominant religion is Islam.

They think the immunisation is *haram* [forbidden by the God]. We give more explanations about it, that [the vaccines] are produced in Indonesia now, they still can’t buy the idea (personal communication with a village midwife in Pariaman, West Sumatera).

They say that immunisation is *haram* [forbidden by God], [so] it is forbidden to be injected into our body. So many reasons, like, the immunisation is made from pork (FGD Solok, West Sumatera).

A lack of understanding about the concept of prevention was mentioned as the effect of immunisation is not obvious, and some mothers prefer to treat illness with medicines rather than try to prevent it with immunisation.
My younger sister has 4 children, ever since the first kid was born, she never gives them immunisation. I asked her once to come to the Posyandu, and she said “no, there is no difference [whether or not taking the children for immunisation], I would take them to the doctor if they get sick” (FGD Kupang city, East Nusa Tenggara).

They said that there are still many other medicine than the immunisation (FGD Pariaman 2, West Sumatera).

3.3.1.4 Discussion.

Themes generated in the current study suggest that mothers’ immunising behaviour for their children is influenced mainly by external factors: their interaction with community-based health workers; and their husband as a decision maker within the family. Therefore, although they commonly had limited knowledge related to vaccines and the diseases vaccination prevents, their behaviour was strongly driven by those external factors. Studies about immunisation in other Indonesian communities also showed that mothers had limited knowledge about immunisation [36, 166, 351, 373]. Poor understanding of what vaccinations do and what diseases they protect against, however, did not always mean that mothers had negative attitudes towards it. Participants accepted the immunisation programme as they trusted the community-based health workers. Mothers trusted the community-based health workers as the health workers were able to integrate with and became an important part of the community. It has been widely acknowledged that the patients’ and health professionals’ relationship influence patients’ acceptance and adherence to health intervention, which further improves patient outcomes [374]. Trust in health professionals in particular, has been shown to encourage people to utilise medical services, and further indirectly improve patient outcomes through increased adherence, and continuation [375, 376]. Further, LaFond, et al. [377] also found that integration of health workers in the community has been able to increase people’s trust and participation in immunisation programmes in some districts in African countries.

Interaction of mothers with community-based health workers found in this study, therefore, resulted in more positive attitudes to health services. Compliance with
health instructions shown in this study is, however, somewhat different from compliance as a result of social pressure or from a higher authority. Previous studies found that external factors, such as interaction with health professionals and authority created social pressure that forced people to comply with the instruction [253, 351].

This study also showed that the presence of a village midwife increased health services utilisation. The village midwife programme is a programme to deploy midwives to serve and live in villages. This strategy has succeeded in decreasing socioeconomic inequalities in accessing skilled birth attendants dramatically, and improving child nutrition status [118, 378]. There is, however, inequity in the distribution of midwives between remote and urban areas, with low retention rates of midwives in remote areas [117, 379].

Mothers’ action whether to immunise their children or not is also strongly influenced by the fathers’ decision. In all study locations, participants mentioned that the fathers’ refusal stopped children being immunised. Indonesia has a strong patriarchal culture, so that the father is the leader and the main decision maker for the entire family. A study also showed that the husband was a decision maker for family planning use [380]. This inequitable distribution of power within the family, particularly in decision making of health services utilisation, however, may shift according to the women’s ownership of household assets, women’s education, and social status. Beegle, et al. [381] argued that the more the women have shared assets, the more educated, and from higher social status, the more power they had in influencing family decisions. More educated women also tended to have fewer children, and utilised reproductive health services [382]. Most participants in this study were housewives. This may suggest that they have less power in decision making in the family, as they have less shared assets. In the community where women have less power in decision making, the fathers should be involved to increase immunisation uptake.

Further, the rationale behind the fathers’ decision of immunisation refusal showed that they also had limited understanding about immunisation. It was widely believed that the injection made the children sick instead of healthy. Concerns that
vaccines made the child sick were also found as the major reason for vaccine refusal in one polio outbreak area of Madura [122]. This perception was commonly based on past experiences of adverse effects after immunisation. The experience of adverse effects challenged what people commonly believed - that the vaccine would make the children healthy. Perception that the immunisation would make the children healthy might also be interpreted as a curative action – an action intended for sick children – so that they would not take the children to be immunised if they are healthy [36]. Reasons related to parental attitude and knowledge including the perception that vaccines could cause harm, questioning the impact of vaccines, and other family member refusal of vaccines were also commonly found in studies of immunisation acceptance in other developing countries [254, 262].

Therefore, although limited knowledge may not always lead to vaccine refusal, education programmes to improve people’s understanding about immunisation and the disease they protect against are also important in shaping people’s understanding of immunisation as preventive action. While in some cases, it might be difficult to deliver complex messages about immunisation, relevant information should be given appropriately. Misunderstandings about immunisation may lead to misperceptions, and unrealistic expectations, that may then further develop negative attitudes to vaccination [253]. It was found also that having correct knowledge about vaccination affected immunisation uptake by people in Pakistan [383].

This study also highlights issues related to the implementation of *Posyandu*. The backbone of the programme was the work of community-based health workers including community volunteers (*kader*) and village midwives, and their partnership with the whole community. Lack of community participation and lack of funding were found in this study to hinder implementation of the *Posyandu* programme. Previous studies also found irregular participation of mothers in *Posyandu* [25, 26]. The active and collaborative work of community-based health workers with the whole community is important in solving these problems. Implementing additional nutritional programmes for children increased mothers’
participation. However, this programme was challenged by lack of funding, which was overcome by some *Posyandu* that could build collaboration with the whole community by creating a ‘donation for *Posyandu*’ system, for example.

Consequently, there is inequality of services given by each *Posyandu* depending on the community-based health workers’ capability and the level of community support for the programme. These findings align with the result of a study by LaFond, et al. [377], who investigated why some districts performed better in immunisation coverage than the others despite similarities in basic health system resources. They found that direct drivers of immunisation coverage improvement were the work of community-centred health workers in partnership with community volunteers that were capable of tailoring strategies to specific setting and community needs.

Another key finding is that there were noticeable cases of missed opportunities in *Posyandu*. There was a concern about vaccine wastage, particularly in East Nusa Tenggara, and delayed vaccination services because the children were considered ill. In order to minimise these missed opportunities, a clearer procedure related to vaccines with multi-dose vials, and to assess and monitor sick children has to be implemented.

Although interventions to increase immunisation coverage from the demand side have been poorly investigated, some have shown their effectiveness in empowering the community and increasing immunisation acceptance [260, 384]. The findings from this study suggest some interventions that should be implemented. Firstly, for improving skills of community-based health workers, regular training is needed. A study conducted in Maluku has shown that peer-training of immunisation nurses improved immunisation coverage [385]. Secondly, increasing people’s contact with community-based health workers may increase people acceptance of immunisation. Ethnographic studies found that people’s relationship with health professionals and their personal contact largely determine their willingness to immunise their children [386]. This type of intervention has been done, for example, in Ghana. Community health workers
systematically visit mothers at home, and encourage them to attend immunisation services, and this is effective in increasing immunisation uptake [387].

Lastly, in order to increase knowledge and understanding of immunisation for not only mothers, but also fathers and the wider community, discussion involving community members could be an effective intervention. This type of intervention has been done, for example, in Pakistan [261]. This community discussion is not only effective in increasing people’s understanding about immunisation and willingness to immunise the children, but also created community initiatives to overcome barriers to getting the services without improving the services [261]. This type of intervention could improve community involvement with the Posyandu programme, and increase community initiatives to improve the sustainability of the programme.
3.3.2 Results related to diabetes mellitus

3.3.2.1 Socio-demographic characteristics of respondents

In total, 45 diabetes patients participated in six FGDs. Each FDG was attended by 6 – 10 participants. Characteristics of participants are described in Table 3.7

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>Categories</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (year)</td>
<td>20 – 39</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>40 – 59</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>60 – 79</td>
<td>9</td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
<td>31</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>14</td>
</tr>
<tr>
<td>Education</td>
<td>Elementary school</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Junior high school</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Senior high school</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Tertiary education</td>
<td>18</td>
</tr>
<tr>
<td>Occupation</td>
<td>Housewives</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td>Entrepreneurs</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Civil servants</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Retired</td>
<td>5</td>
</tr>
</tbody>
</table>

As seen in Table 3.7, the majority of participants were aged between 40 and 59 years old, nine participants aged more than 60, and only two participants aged less than 40 years old. The youngest participant was aged 26, and she experienced gestational diabetes. Participants were predominantly female, and housewives. Participants’ socio demographic characteristics were similar to other studies of diabetes patients in Indonesia, and in Asia. The prevalence of diabetes is higher in females than males, and starts rising sharply from 40 years of age [89]. The highest prevalence of diabetes in Asia is in the 40 – 59 age group [388]. A previous study also demonstrated that housewives had the highest prevalence of diabetes of any occupational category [89]. In terms of education, more people had completed tertiary education, and the majority of participants who completed tertiary education worked as civil servants in the formal sector. The table also shows that participants came from a wide range of socio demographic backgrounds. Education level often represents economic capacity. People who completed higher levels of education commonly had higher economic status.
3.3.2.2 Lay perception about diabetes

During the discussions, participants shared their view about diabetes, which included local terms for diabetes, beliefs about its causality, and common local knowledge related to diabetes.

Local terms and lay knowledge of diabetes

Although the term diabetes was often used in clinical settings, lay people referred to diabetes as ‘penyakit gula’ literally translated as ‘sugar disease’, or ‘penyakit kencing manis’ literally translated as ‘sweet pee disease’. These terms are an easy way to describe diabetes. Sugar disease referred to diabetes causality: the disease is caused by too much sugar in the body. Participants therefore also used the term ‘blood sugar level’ instead of ‘blood glucose level’. ‘Sweet pee disease’ is an easy description of diabetes symptoms: having sweet pee is the symptom of diabetes. Some participants observed having sweet pee as indicated by ants gathered around it.

When I saw my urine attracted ants, and it was brown, I checked. It [blood sugar level] was 318 [mg/dL] (17.7 mmol/L) at that time (FGD Pariaman, West Sumatera).

During the discussions, participants often mentioned their blood glucose level, although they often did not remember whether it referred to fasting or random blood glucose measurements. The healthcare facilities in Indonesia commonly provided fasting and random blood glucose measurements for diabetes patients. All units of blood glucose level mentioned by participants were in mg/dL.

Other than local terms, participants in all study locations classified diabetes into: ‘penyakit gula basah’, literally translated as ‘wet sugar disease’, and ‘penyakit gula kering’, literally translated as ‘dry sugar disease’. People differentiated these two types based on patients’ characteristics. People suffered from wet sugar disease if they were getting fatter after contracting the disease, and experienced unhealed wounds. In contrast, people suffered from dry sugar disease if they were getting thinner after having the disease, and commonly did not experience wounds.
I have a family member in Jakarta, he experienced extreme weight loss. He is getting thinner and thinner. Is that true that he suffered from dry sugar disease? (FGD Kupang city, East Nusa Tenggara).

Yes, somebody in my neighbour also have sugar disease, but she could not come here, her feet got wounded... Yes, that's wet sugar disease. It's really difficult condition if you got wet sugar disease (FGD Solok, West Sumatera).

Moreover, participants in West Sumatera were confused between diabetes and liver-related disease. The local term for liver-related disease is ‘sakit kuning’, literally translated as ‘yellow disease’ (jaundice in medical term), or ‘sakit lever’, literally translated as liver disease. Participants in Pariaman considered that diabetes was the same as sakit kuning. The other participants explained that diabetes was different from sakit kuning, and that sakit kuning was related to haemoglobin level. Meanwhile, participants in Solok assumed that sakit kuning was caused by sugar deficiency. One other participant explained that people with sakit kuning had to eat sugar to ease their liver in digesting.

So, is it [sakit kuning] different from sugar disease? Sakit kuning is different from sugar disease. Sakit kuning is caused by the haemoglobin level. Sakit kuning is a symptom of liver disease. So, sakit kuning is different from sugar disease, isn't it? Yes, it's different (FGD Pariaman 2, West Sumatera).

Is it true that sakit kuning is caused by sugar deficiency? No, sakit kuning is liver disease, so that in order for easing the liver in digesting sugar, (the patient) should eat sugar. It doesn't mean that sakit kuning is caused by sugar deficiency (FGD Solok, West Sumatera).

**Beliefs about diabetes causality**

Participants attributed diabetes to genetic factors, eating habits, and lifestyle changes. They however elaborated these causal beliefs further with their own personal explanation, based on their illness and treatment experiences. In some cases, where they could not find personally relevant explanations, they started questioning why they got the disease, and in the end, they made their own unsure conclusions about that. As can be seen in quotes below, they often use word ‘mungkin’ in the Indonesian language, or perhaps, probably, which shows uncertainty.
But sometimes I think why I got the disease, what’s the symptoms of diabetes, that’s my questions… I work in training department, and my job is to prepare food for the training programmes, so perhaps [because] I always taste the food (FGD Kupang city, East Nusa Tenggara).

I’ve suffered from sugar disease for about 15 years. [my sugar level] was 387 [mg/dL] (21.5 mmol/L), and it increased to 400 [mg/dL] (22.2 mmol/L). Yes, even though I have taken medicines … I didn’t eat meat anymore, I [also] do exercise. I still teach. Perhaps, it’s inherited, have run in our family blood (FGD Manggarai Timur, East Nusa Tenggara).

Participants who mentioned heredity as a cause also had other family members with diabetes. In the Indonesian context, term ‘family’ or ‘keluarga’ include extended families and other relatives. Some participants who experienced failure of treatment despite their behavioural change efforts eventually believed heredity was a cause. As described by participants:

But, we got these diseases, sugar disease and high blood pressure, from our ancestors, it is inherited, all of my family, my grandmother, my aunt, all of them died of this disease. So, I have got the disease for more than 4 years, but in the last 3 years I take medicines. Then, just recently, about 2 months, I have given injection … insulin. but everything just the same, my sugar never goes down. Ya, perhaps that because my eating habit, but I have tried to control diet, my weight has decreased from 105 kg to 93... (FGD Kupang city, East Nusa Tenggara).

I am taking it [the medicines] till now, and I already have had 2 times insulin injection, but still, [the sugar level] has never dropped… [It has been] 21 years, it’s genetic, my mother as well (FGD Pariaman 1, West Sumatera).

Further, notions that diabetes is inherited also led people to feel vulnerable to the disease if they have a family history of it. They also questioned the risk of diabetes for future generations.

I don’t have sugar disease, but I also want to check it, because my mum has sugar disease. So that I don’t want to have dinner (FGD Solok, West Sumatera).

I have a question though, if our parents suffer from [sugar disease], do their children will definitely also suffer from it? All of their children? (FGD Manggarai, East Nusa Tenggara).

In terms of diet as a cause, participants explained their own experiences which they thought contributed to their dietary habits. As described in Table 3.8, some participants mentioned that their dietary habits were related to a life event in the
past which encouraged them to eat a lot. Further, participants also said that their dietary habits were part of their culture. Diet in the participants view, therefore, is not only an individual choice, but is also influenced by their community. This implied further, that their efforts to change their diet were also problematic, as it is not only depended on their own choices. Moreover, some participants also put the increasing number of people with diabetes into a historical perspective of community eating habits. They compared recent generations’ eating habits to those in the past. It is believed that there were no diabetes cases in the past as people ate a lot of different kinds of food, while today’s generation only depended on white rice as a staple food.

Table 3.8: Participants narrative concept of diet causality

<table>
<thead>
<tr>
<th>Past life events triggering unhealthy diet</th>
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<tbody>
<tr>
<td>[I had sugar disease] Since I stopped exercising. Then, I worked as a plastic seller, many customers come in the morning. In the afternoon, almost no one come, so what I’ve done was only eating and eating again… (FGD Solok, West Sumatera).</td>
</tr>
<tr>
<td>For me, I got sugar disease because in the past, I had suffered from another disease which made me eat a lot in the morning, and I bought [food] in a big box (FGD Manggarai Timur, East Nusa Tenggara).</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Eating habit as part of culture</th>
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</thead>
<tbody>
<tr>
<td>I have a cousin died of sugar disease, her toes were amputated, because of sugar. People in his village usually drink coffee or tea [with sugar] in the morning before going to farmland for working. Then, at 10am and 4pm they will drink it [coffee or tea] again… Afterwards, they will also eat cassava, if they also have corn or banana, they will eat again, then they will also eat rice (FGD Kupang city, East Nusa Tenggara).</td>
</tr>
<tr>
<td>Yes, we will have a lot of parties in wedding or school season. Sometimes, there are a lot of families in one neighbourhood who do the feast at the same time. Yeah…we will eat a lot, because we can have 10 or perhaps 100 invitations, so, we will eat 10 times or 100 times in a day. That’s why we have high sugar level (FGD Manggarai Timur, East Nusa Tenggara).</td>
</tr>
<tr>
<td>We rarely eat vegetables here. What could we do. We are the biggest producers of coconut; everyday coconuts fall down from the tree. If we don’t use it to make gulai [yellow curry], we think it’s a waste. We have no choice, it’s like something missing if we don’t make gulai (FGD Pariaman 1, West Sumatera).</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Dietary habits influenced by community changing</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the past, we are, people in Manggarai have a wide range of food diversity. But, all changed when our Governor, humiliated us, if you not eat rice, you… Actually, it means to encourage people to grow rice, but our people interpreted it literally. After eating rice become more usual, the other food products are left behind. It was in 1983 (FGD Manggarai Timur, East Nusa Tenggara).</td>
</tr>
</tbody>
</table>
Other than heredity factors and diet, participants also attributed the increase in diabetes to a modernised lifestyle. With the development of transportation systems, people were no longer walking as a form of transport. Interestingly, some participants also mentioned that diabetes was associated with a change from the traditional way of cooking rice to the modern one. They perceived that their sugar level in rice cooked with a rice cooker is higher than that in rice cooked traditionally. Before rice cookers were popular, people in Indonesia commonly cooked rice slowly in two steps. First, the rice grain was boiled until it was half-cooked. In this first step, people often took out the water used for boiling. In the second step, the half-cooked rice was then steamed for about 30 minutes. Participants argued that as the sugar is dissolved in the water, taking out the water used for boiling the rice grain, and steaming the rice reduced the amount of sugar in it. In contrast, they argued that the modern rice cooker eliminated those steps, and consequently, the sugar in rice was believed to be higher.

Long before now, people cooked using the fire woods, then they took the water out, the water was thick. Therefore, many people suffer from sugar disease because of the modern way of rice cooker (FGD Pariaman, West Sumatera).

The doctor told me that that it's better to cook the rice by steaming it than using rice cooker, since if we steam it, the water will fall down, it [the water] contains sugar. On the other hand, the rice cooker preserves the water, so the water will be absorbed [by the rice], thus more people suffer from diabetes nowadays (FGD Pariaman, West Sumatera).

3.3.2.3 Participants’ illness experiences

This theme was generated from participants’ experiences from the first time they were diagnosed until recently. Participants’ illness experiences are presented in Figure 3.8. Most participants in the study reported almost the same illness experiences. They were first diagnosed when their blood glucose reached a very high level that resulted in dramatic consequences such as stroke, eye surgery, and stillbirth. After being diagnosed, they experienced uncontrolled blood glucose, had comorbidities, and developed complications.
Figure 3.8: Participants’ illness experiences

Diabetes diagnosis

Participants shared their experiences of how they were first diagnosed with diabetes. Some of them found out that they had diabetes unexpectedly when they went to healthcare facilities for another health complaint, including blurred vision, gastritis, asthma, and stroke. These health problems could be signs and symptoms, or complications of having high blood glucose level. Because of limited knowledge prior to diagnosis, however, they had not realised this. Generally, participants’ blood glucose levels when they were first diagnosed were very high, more than 300 mg/dL (16.7 mmol/L). Some participants had blood glucose levels of 500 mg/dL (27.8 mmol/L) or more. Most of them remembered their blood glucose level at diagnosis, although they did not mention whether it referred to fasting or random blood glucose measurements.

Last year, 2014, I got blurred vision, cataract, so I visited a doctor, ...So, I checked my blood glucose level, and it was 200 [mg/dL], no, 374 [mg/dL] (20.8 mmol/L). I was confused, I was told to fast at night before the checking day, and my sugar level was 374 [mg/dL] (FGD Kupang city, East Nusa Tenggara).

Yes, indeed, in the past I suffered also from gastritis, yes, then I often vomited, and then I was hospitalised. [When I was hospitalised], I just knew that I suffered from sugar disease. It was told by the doctor that [my sugar level] was 300 [mg/dL] (16.7 mmol/L) (FGD Manggarai, East Nusa Tenggara).
I did medical check because of asthma. Ya, I had asthma and I didn’t get better for a quite long time. Ya, the asthma didn’t get better, and I checked, and (it was found that) I had sugar disease (FGD Manggarai, East Nusa Tenggara).

I just knew that I have sugar when I had stroke. It [sugar level] was 307 [mg/dL] (17.1 mmol/L). I’ve had it [stroke] twice...but thank God, [I got cured] because I took sinse (Chinese traditional medicines) (FGD Pariaman, West Sumatera).

Others experienced symptoms, and went to health providers to find out what disease they suffered from. The symptoms they mentioned including urinating frequently, tingling on tips of the fingers, often feeling hungry, dizziness, and always thirsty.

It was in 2008, and at that time, I didn’t know, I didn’t understand about sugar disease and the symptoms. I just felt exhausted, always feeling hungry and eating a lot. Not more than 1 hour [after eating], [I was] hungry again, thirsty even though I’ve drunk 2 big bottles of water...I went to have a complete medical check, including blood sugar, and it almost reached 500 minus 2, so 498 [mg/dL] (27.7 mmol/L). The doctor shook his head, and I asked, “is it not good?” (FGD Kupang city, East Nusa Tenggara).

Yes, I’ve, it was 300, almost 400 [mg/dL] (22.2 mmol/L), it was in 2014 when I was in Cancar. I just felt dizzy, and I felt tingling in tip of my fingers and toes, it was like pins and needles in my legs (FGD Manggarai Timur, East Nusa Tenggara).

I felt dizzy in my head, I felt that I had no energy, I kept eating yet I felt drowsy after that, I took pee so many times as well. Then, I went to village midwife, and my sugar level was above 500 [mg/dL] (27.8 mmol/L)... (FGD Pariaman, West Sumatera).

Only one participant was aware of the symptoms, and knew that it was diabetes.

I felt that my condition deteriorated, I lost weight from 63 to 56 in a week, and it was 7 kilos drop. Then, I felt something wrong happening, I was always thirsty at night, often urinating, and feeling so weak... So, I told my-self that I have to check my blood glucose, and it was 375 [mg/dL] (20.8 mmol/L), the blood glucose before meal. So, I know that I must have got sugar disease... (FGD Manggarai, East Nusa Tenggara).

Two participants experienced gestational diabetes. One participant found out about this when she was about to give birth, and the baby was stillborn. She also had diabetes during her second pregnancy, but because of her previous experience, she was prescribed insulin, and her second baby survived.
Three years ago, I got pregnant, and in the ninth month, I went to private clinic because I felt that there was no movement in my bump, and I was referred to a hospital. At that time, I was ok, only feeling so weak...and the doctor told me that the baby need to be delivered through surgery. That I had sugar disease was just known after that surgery, and it [sugar level] was 600 [mg/dL] (33.3 mmol/L). The baby was stillborn. After that, I did medical treatment... but after 40 days, my sugar level came back to normal. Yes, it happened also in my second pregnancy. but I went to the doctor and got early treatment... (FGD Manggarai, East Nusa Tenggara).

When I was pregnant my youngest kid, I felt the [sugar disease's] symptoms... I just let it [diabetes symptoms] happened, and I didn't take any medicines, but thanks God, now my sugar level is normal (FGD Solok, West Sumatera).

Most participants in the study were diagnosed late when they had experienced very high blood glucose levels. They commonly sought medical care when they perceived any symptoms. This behaviour has resulted in dramatic consequences such as stroke, eye surgery, and stillbirth. Prevention behaviour including regular medical check-up was uncommon. People were commonly, as expressed by one participant in this study, afraid of getting medical check-ups as they were afraid of knowing that they suffered from any disease.

Somebody told me to do medical check. He/she said that you were pale, getting thinner, but at that time I was afraid, afraid to go to the doctor because [I was] afraid to know that I suffered from any disease [that I haven't known before]... (FGD Kupang city, East Nusa Tenggara).

**Uncontrolled blood glucose level**

Most participants suffered from diabetes for between two and seven years, but two participants had it for fifteen and twenty-one years. During this time, they experienced uncontrolled blood glucose levels. Many participants also had high blood glucose levels when it was measured with a rapid test as part of the study. Some participants expressed frustration in controlling their blood glucose level.

My fasting blood glucose level can be as high as, now it, 270, 280 [mg/dL] (15.6 mmol/L) and sometime 300-ish, and it is, of course, higher after eating, I’m stress, [thinking of my blood glucose level after eating]. I have a rapid blood glucose check tool... So, after checking fasting blood glucose level and knowing the result, I don’t want to check again after eating, because I’m afraid, I’m stressed (FGD Kupang city, East Nusa Tenggara).
Diabetes complications and other comorbidities

Uncontrolled blood glucose level increases risk of diabetes related complications. One participant developed kidney complications, and needed haemodialysis. Foot problems also affected diabetes patients, as told by participants about their relative or neighbour who had diabetes but could not come to the discussion because they could not walk. Optical problems of blurred vision, cataract, or requiring eye surgery, were experienced by some participants before knowing that they had diabetes, and after being diagnosed with diabetes.

He suffered from kidney failure for about 3 to 4 months...Yesterday, the doctor told me that he had to be haemodialysed. I answered, “I don’t know what I have to do”, but the doctor said again, yes mum, he need haemodialysis... (FGD Manggarai, East Nusa Tenggara).

Yes, my neighbour also have sugar disease, but she could not come here as his feet got wounded. Her/his sugar level is high, and it is inherited (FGD Solok, West Sumatera).

Yes, I was worried, I had [eyes] surgery in Penang (a city in Malaysia), [a couple of months ago]... (FGD Pariaman 1, West Sumatera).

Hypertension and hypercholesterolemia were the most common comorbidities suffered by participants. These diseases may also increase risk of developing diabetes related complications.

However, I also suffered from stomach disease [gastritis], also hypertension, so it may be different from the others. So, I’ve suffered from sugar disease, hypertension, urinary tract infection. In a year, I was hospitalised several times, 3, 4, or even 5 times, and in the last year 6 times, and even in this year I have hospitalised 4 times... (FGD Kupang city, East Nusa Tenggara).

3.3.2.4 Participants’ medication experiences

Participants discussed their experiences of any medicine – including conventional and traditional medicines – they took for managing diabetes, why they chose those medicines, and how they found taking those medicines. In the Indonesian context,
people use the word ‘medicines’ or ‘drug’ which are translated in Indonesian as ‘obat’ to refer to conventional medicines. On the other hand, people will use term ‘obat tradisional’ (traditional medicines) or ‘obat herbal’ (herbal medicines) to refer to any medicines other than modern medicines. People also use specific terms such as ‘sinse’ (traditional Chinese medicines), for describing other specific types of medicines or medication. In this thesis, therefore, the term ‘medicines’ refers to conventional medicines, and specific terms such as ‘traditional medicines’, ‘herbal medicines’, or ‘traditional Chinese medicines’ are applied to distinguish the meaning.

Participants’ medication taking behaviours and their reasons for these

Generally, after being diagnosed at healthcare facilities, participants started taking the medicines prescribed by healthcare professionals for some period. Diabetes patients were commonly prescribed with medicines for a one-month course, and they were instructed to refill after it finished. From this point then, the participants’ medication taking behaviours varied based on their individual perception and the influence of significant others. These variations in medication taking behaviour can be grouped into three patterns: participants who discontinued taking medicines; participants who also tried other types of medicines; and participants who continued taking only medicines (Figure 3.9).

Discontinued taking medicines

Some participants stopped taking medicines and either did nothing, only exercising, and controlling diet, occasionally bought medicines from the drug store or pharmacy without prescription, or changed to traditional medicines.

After finishing the medicines for a month, I don't take medicines anymore. To be honest, I don't take medicines anymore, but I control my diet and drink more water (FGD Kupang city, East Nusa Tenggara).

(What medicine do you take?) Nothing, I just do exercise, I drink goat milk every day (FGD Pariaman 1, West Sumatera).

[I took] metformin. [I got it] from Java. (Are you still taking it until now?) Yes, sometimes I take, but sometimes I don’t take it. (If it all gone, where do you usually buy?) In drug store. It also available in pharmacies, it is sold without prescription (FGD Solok, West Sumatera).
The most common reason mentioned by participants who discontinued taking medicines was that they got fed up with taking the medicines. Participants expressed in the Indonesian language as ‘bosan’. The word ‘bosan’ in Indonesian means do not want to do it again because it has been done for too long. In English translation, it might refer to ‘fed up’ or ‘bored’. In the discussions, participants related the word bosan with some other explanatory notions. Some participants said that they got fed up with taking modern medicines, as they did not perceive them to be effective in curing the disease. Other participants referred bosan to hassles they experienced in taking medicines, such as taking a large number of medicines at the same time, and taking medicines that were big in size.

Me? What medicines? I’ve been fed up to take medicines, because more and more medicines, but I’ve never been cured, so now I gave up and did nothing (FGD Manggarai Timur, East Nusa Tenggara).
Given medicines for a month is really bored. Especially if the medicines are in big size. If it’s small, it’s easy (FGD Kupang city, East Nusa Tenggara).

Yes, me too. I took medicines only for three months, and I got fed up (FGD Kupang city, East Nusa Tenggara).

Other issues related to availability and accessibility of medicines also emerged. Two participants preferred taking the medicines they got from hospitals to the medicines from the *Puskesmas*, as they experienced or believed that the medicines from the hospitals were more effective. One participant mentioned that her blood glucose level decreased if she took Acarbose, which was not available at the *Puskesmas*. Acarbose was available at hospitals but it was expensive. One other participant believed that the quality of medicines available at the *Puskesmas* was not as good as those in hospitals. However, she also mentioned that the medicines at the hospitals were expensive. For these reasons, these two participants discontinued taking medicines.

I found Glucobay is good for me, it is acarbose, half of it, it’s good. It’s expensive, the *Puskesmas* doesn’t have it and glimepiride as well. [the *Puskesmas*] only have Gliben [glibenclamide]. (Where did you buy it?) [I got] from the doctor in the hospital. (Are you still taking it?) No, I am not, that’s why my sugar level becomes high (FGD Pariaman 2, West Sumatera).

It has been about 4 years. She only took medicine from the hospital, the medicines were expensive, 500 thousand rupiah (USD 36), it was taken a half of tablet. (Does she take any medicine now?) No, the medicines are expensive. She refused to be taken to *Puskesmas*, she said that the medicines there was not good (FGD Solok, West Sumatera).

Some participants stopped taking medicines after they were finished because they did not know that the medicines for diabetes should be taken continuously.

( Mum, your sugar level is high, 595 [mg/dL] (33.1 mmol/L), do you take any medicine?) Yes, I take, what the name… metformin. Should I take it continuously? (FGD Solok, West Sumatera).

Tried traditional medicines

After taking medicines for a period, some participants discontinued them and tried taking traditional medicines, or continued taking medicines alternatively or
in combination with traditional medicines. The use of traditional medicines was mostly based on a significant others’ recommendation.

My father also [take herbal medicines]. He had wound on his legs, lots of wound [like his legs were] burned, and somebody informed us to take bark ... *duwe* bark [*Java plum, Syzygium cumini* bark]. It is boiled and he drink the water. After that, all the wound dried and cured. Yes, and his sugar level also decreased. (*Does he still take it until now?*) Yes, he is still taking it, combined with medicines (FGD Manggarai, East Nusa Tenggara).

I take Betel fruit [*pinang, Areca catechu*], the dried one, [I take it] after having breakfast, I soak it and drink the water, every day. I also still take glicose [*metformin*] (FGD Manggarai Timur, East Nusa Tenggara).

Gliben [glibenclamide], and another one that taken 3 times a day, I forget the name of it. (*Metformin?*) yes, yes. [I take] some leaves, the bitter [leaves] twice a week. yes, those bitter leaves (FGD Pariaman 1, West Sumatera).

Participants tried traditional medicines or accepted other people’s recommendations to take traditional medicines for various reasons. Some of them experienced side effects or discomfort after taking medicines, and some others perceived that the medicines could not cure the disease. Some participants believed that the medicines were ineffective. On the other hand, they also believed that traditional medicines were more natural, have been used for generations, and gave other benefits such as an increase in their energy and strength.

Yes, I just do what people recommend because I want to be cured. But after taking herbals for a quite long time, I got gastritis, and then, urinary tract infection, then, I stopped again, but someone recommend this and this, I just want to try, only want to try (FGD Kupang city, East Nusa Tenggara).

Just imagine, [I’ve taken] metformin, but it doesn’t work (FGD Manggarai Timur, East Nusa Tenggara).

[My sugar level dropped] from 360 [mg/dL] (20 mmol/L) to 260 [mg/dL] (14.4 mmol/L). By taking *Gracia* [brand name of herbal medicines], it is mentioned on [*its box*] for preventing diabetes (FGD Pariaman 2, West Sumatera).

Herbal [medicines] don’t make the sugar level drops, it gives us more energy so we feel fresh. I had taken herbal for more than 2 years. I felt stronger (FGD Pariaman 2, West Sumatera).
After taking traditional medicines for some period, they self-evaluated its effectiveness, and made a decision afterwards. Some participants stopped taking medicines, and continued taking only the traditional medicines.

[I took] Maneira [brand name of herbal medicines] ... (So, now are you still taking prescribed medicine?) No, I don’t take it again (FGD Manggarai Timur, East Nusa Tenggara).

A month after checking the blood sugar level, every time I took medicines I always vomited, got a headache, so that then I [only] take traditional medicines. After taking traditional medicines, my condition is getting better (FGD Manggarai, East Nusa Tenggara).

I don't take [any other medicine] anymore, I only take mangosteen fruit peel for almost 1 year (FGD Pariaman 1, West Sumatera).

Some other participants did the reverse, and discontinued taking the traditional ones and went back to the medicines. The reasons for doing this include perceived ineffectiveness of traditional medicines, and side effects of the traditional medicines. One participant shared that she had another disease which emerged because of the traditional medicines.

What I’ve tried that made me almost die were cinnamon bark, and Java plum (Jamblang hitam Syzygium cumini) bark, I got severe gastritis until I got difficulty in breathing. Because, those are really sepat [the taste like eating unripened banana]. Then... Singapore cherry leaves, soursop leaves, java plum bark, cinnamon bark, I’ve tried all of those, yes, I want to be cured, but, instead of being cured, another disease emerged. I got another illness, so I’m back to medicines from the doctor (FGD Kupang city, East Nusa Tenggara).

Then I also took yellow roots [the root of Fibraurea chloroleuca], I took it at night and in the following morning my sugar level dropped, from 400 [mg/dL] to 48 [mg/dL] ... Yes, so I don’t take it anymore, so now, I only take medicines from hospital (FGD Kupang city, East Nusa Tenggara).

In this process of evaluation of both traditional and modern medicines, the participants mentioned that effectiveness of medicines is a matter of the medicines being suited to you. They therefore often argued about the types of traditional medicines they took, and came to a conclusion that it is a matter of the medicines being suited to the individual.

It’s because it works on her, but it doesn’t work on me. It varies. I took 2 sets [of traditional medicines], yet nothing happened to my sugar level, it didn’t drop (FGD Pariaman 2, West Sumatera).
Continued taking medicines

After initiating taking medicines, some participants continued taking it. There were also various reasons related to this. Some participants believed that traditional medicines have no specific doses, and did not take them because they were not recommended by the doctor. Meanwhile, some others were fearful of having side effects from traditional medicines.

Only medicines from the hospital, because if it is traditional medicines, I don’t understand its dosage (FGD Pariaman 1, West Sumatera).

[I] fear of [traditional medicines’ side effect] to kidney (FGD Kupang city, East Nusa Tenggara).

In taking medicines, however, some participants also modified doses based on their experiences without consultation with health professionals. One participant did not take the night time dose of medicines, and only took one of the two medicines she had been prescribed. This participant mentioned that she experienced low blood glucose level if she took the medicines as prescribed.

At first, I was [also] given Glibenclamide in combination with metformin to be taken before meal, and then I experienced weakness and sweating, the doctor instructed me to take it [metformin] 3 times a day. [But] I only take it twice a day, only in the mornings and afternoons. The doctor asked me, did you finish the medicines? [I answered], yes, even though I never took the evenings dose, because I’m afraid if the sugar level drops at night. So, I [also] never take the glibenclamide (FGD Kupang city, East Nusa Tenggara).

Types of medicines used

Medicines from formal health providers

Oral antidiabetics were the most common medicines prescribed. Metformin was mentioned often, followed by glibenclamide. Few participants mentioned other oral antidiabetics including glimepiride and acarbose. Four participants had also been prescribed insulin.

For me, I have suffered from diabetes for 4 years, but for about the last 3 years I take medicines, metformin and glibenclamide... Then, just recently, about 2 months, yes in the last 2 months I was given injection, what injection... insulin (FGD Kupang city, East Nusa Tenggara).
So, just in the last one month I was prescribed with insulin, the 300-unit insulin pen to be injected 10 unit once a day before bed. And, my sugar level decreased. After that, the doctor prescribed me insulin combined with metformin 3 times a day, and my blood glucose level dropped to 68 (FGD Manggarai, East Nusa Tenggara).

Traditional medicines
The most common traditional medicines mentioned were parts of plants, including leaves, bark, or root which were dried. These are also known as herbal medicines. The dried parts of plants were soaked in hot water, or boiled. By doing this, people believed that the medicinal ingredients dissolved in the water, so then they drank the water. The most common sources of leaves mentioned by participants were *kersen* (Singapore cherry, *Muntingia calabura* L), *sirsak* (soursop, *Annona muricata*), *salam* (bay leaves, *Syzygium polyanthum*), and *sirih merah* (*Piper ornatum*). Bay leaves were quite popular, and they were mentioned by participants both in East Nusa Tenggara and West Sumatera Provinces. The most common barks were cinnamon bark, Java plum bark, and *kersen* (Singapore cherry, *Muntingia calabura* L) bark. Other traditional medicines mentioned for diabetes were *buah pinang* (betel nut), and *akar kuning* (the root of *Fibraurea chloroleuca*).

Some participants also took readily available branded herbal medicines, including *Gracia* (encapsulated powdered mangosteen fruit peel), and *Maneira* (contains a mixture of some powdered ingredients including red ginger, mangosteen fruit peel, cinnamon bark, black cumin, etc.). These branded herbal medicines were available at local shops or pharmacies.

For me, I take bay leaves, so I boil 9 bay leaves, yes, only 9, with 2 glasses of water, and boil it until it become one glass. Then, I drink it, and my sugar level and blood pressure will definitely decrease (FGD Manggarai, East Nusa Tenggara).

One participant in Manggarai, East Nusa Tenggara got the traditional medicines from a traditional healer living in Manggarai Timur. The FGD in Manggarai Timur also mentioned the traditional healer, who had a lot of different kinds of *ramuan*, a mixture of traditional medicines. Each *ramuan* has a specific mix of ingredients prepared for specific diseases. The ingredients mainly contained dried leaves, barks, or roots.
Eh, I’m not sure [the name and ingredients], I got it from Manggarai Timur. Yes, it contains leaves and bark, I got it from Borong. *(How do you take it?)* Yes, it’s boiled. People said that the doctor [traditional healer] there is trusted by many people and the *ramuan* I bought can lower the sugar level... (FGD Manggarai, East Nusa Tenggara).

Ya, he has 76 kinds of *ramuan* he is head of our village. For all kind of diseases. Specific *ramuan* for specific disease. Each has specific dose instruction. He has a lot of patients, perhaps, thousands... (FGD Manggarai Timur, East Nusa Tenggara).

Two participants, one in East Nusa Tenggara and one in West Sumatera stated that they drank goat milk as a supplement that they believed maintained their health and their sugar level.

Another time in the past I couldn’t remember the year, it (the blood glucose level) was 165 [mg/dL] (9.2 mmol/L). But now, perhaps because I often drink goat milk and thanks God, now it slightly decreases with that milk. I drink the goat milk, yes, the goat milk. (FGD Kupang city, East Nusa Tenggara).

It was 265 [mg/dL] (14.7 mmol/L). *(what medicine do you take?)* Nothing, I just do exercise, I drink goat milk every day, and... yes, I feel good (FGD Pariaman 1, West Sumatera).

3.3.2.5 *Participants experiences of self-managing diabetes*

Other than taking medicines, participants also frequently discussed controlling diet as part of managing diabetes. Some participants reported doing exercise, and checking their blood glucose level regularly. The participants’ experiences of diabetes self-management are described in Figure 3.10.

*Controlling diet*

Methods of controlling diet

The view that eating behaviour contributed to diabetes led people to discuss controlling diet as part of managing diabetes. However, they reported diverse opinions about methods of controlling diet. Some participants demonstrated substantive knowledge about reducing rice portions, and eating more vegetables. Others believed that reducing meat and fatty food consumption, skipping main meals, and also reducing sweet food or using non-calorie sweetener were methods for controlling diet.
I eat only a small portion of rice, more portion of vegetables, without oily food. I don't eat meat, it has been several days... but I eat eggs two times in the time between 15 September until today (FGD Manggarai, East Nusa Tenggara).

Reduce eating food contains coconut milk (FGD Solok, West Sumatera).

Mummy often eat pical [Indonesian vegetable salad with peanut mixed with palm sugar sauce], its sauces contains peanut and sugar, it contains sugar. So, you should not eat pical Pical contain sugar, palm sugar (FGD Solok, West Sumatera).

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**Figure 3.10: Participants’ experiences of diabetes self-management**
Some participants also stated that they ate diverse carbohydrate sources, such as taro, sweet potato, corn or cassava, as they believed that it was good for their health. The others substituted rice with corn rice (corn that has been ground into smaller size), and brown rice.

We, who has got [this] illness, must eat a lot kind of food. The food should be diverse. [for example] we eat cassava or other tubers at noon... (FGD Manggarai Timur, East Nusa Tenggara).

People also regarded methods of cooking as being important in controlling diet. Fried food was considered as bad, and boiled food as good. Not using any food additives in cooking was also stated as a method of good eating behaviour. A few of them also argued that eating cold rice is better than the warm rice, as cold rice contains less sugar.

I boiled papaya leaves, potatoes, taro, cassava [for my uncle who suffered from diabetes], yes, he really persistent in controlling the diet. Yes, it’s better boiled food (FGD Kupang city, East Nusa Tenggara).

But, my brother has really controlled his diet, he never put ajinomoto [flavour enhancer containing monosodium glutamate] in his food, never, even in a little amount, but... [he still got this disease] (FGD Kupang city, East Nusa Tenggara).

The diversity of common knowledge and opinions related to proper diet for diabetes resulted in confusion. Some participants asked whether or not some dishes were good for diabetes.

Does it affect [the sugar level] if I eat lontong [rice cake wrapped inside banana leaf]? (FGD Pariaman, West Sumatera).

Do the snacks also have an impact? Does eating snacks, such as biscuits also have an impact? (FGD Kupang city, East Nusa Tenggara)

Moreover, the wide range of local food, and diverse methods of cooking in Indonesia has made controlling diet much more complicated. Some participants self-evaluated the impact of local food on their blood glucose, and came to their own conclusion whether or not the food was good for them.

I ate jackfruit, and no... I experienced weakness at night, so we, diabetic patients, cannot eat a lot of jackfruit, yes, the ripen jackfruit. [My blood sugar level increased] to 400 [mg/dL] (22.2 mmol/L), and [I experienced] difficulty in urinating ... (FGD Manggarai Timur, East Nusa Tenggara).
Barriers to controlling diet

Participants also identified barriers to controlling their diets. The main perceived barriers came from social supports, either from the community or family. Participants, particularly those living in East Nusa Tenggara expressed difficulties in controlling their diet because they had a lot of ethnic and religious feasts. Socially, they were not able to refuse to eat in those feasts. Eating food provided showed respect, and providing enough food for the guests showed honour. These ethnic or religious ceremonies were commonly held in a specific time period which was culturally regarded as a good time. Many people, therefore, held feasts at the same time.

Just like what I’ve said before, we have a lot of feasts, and in the feast all people eat, so it looks weird if we do not eat... Sometimes, if we do not eat, people will say that we are arrogant, ... So, even in small portion, we have to take a bite, but later on, we will have its effects (FGD Kupang city, East Nusa Tenggara).

Yes, we often have feasts, too often. For lay people, feast is like a chance for having good food, so they eat a lot. That’s also applied for calculating the need of rice. The lower the economic class of the guests, the higher amount of rice we need to prepare. This calculation is important, as it is shameful if we prepare less food for guests (FGD Manggarai Timur, East Nusa Tenggara).

On the other hand, participants in West Sumatera did not mention feasts as a barrier to controlling diet. However, they considered that their cultural cuisine might damage their health.

We rarely eat vegetables here. What could we do, we are the biggest producers of coconut, and every day coconuts fall down from the trees. If we don’t use it to make gulai [yellow curry], we think it’s a waste. We have no choice, it’s like something missing if we don’t make gulai. Besides, the vegetables are added with the coconut milk as well. But, because of that coconut milk, it tastes delicious (FGD Pariaman, West Sumatera).

What a coincidence, we are about to cook squid. My children love eating squid or cuttlefish [sotong]. Then we eat it along with jengkol [the beans of Archidendron pauciflorum], it is so delicious. That’s why we [Minang people] have a high cholesterol level, because of those food, our food contains too much fat. yes, rendang... gulai padeh [red curry], gulai [yellow curry], we add the coconut milk in it (FGD Pariaman, West Sumatera).

In Indonesia, cultural diversity within the country has made dietary control for diabetes much more challenging. In this study, we found that participants in West
Sumatera identified their cultural cuisine as a barrier for controlling diet, while people in East Nusa Tenggara identified frequently attending cultural or religious ceremonies as the main barrier to controlling diet. The traditional cuisine in West Sumatera is rich in coconut extract or coconut milk, or ‘santan’ in the Indonesian language. *Santan* is white coloured liquid obtained from the process of shredding coconut flesh and soaking it in water. It is widely used in cooking, including for cooking meat, fish, and vegetables. People commonly cook these dishes slowly until the *santan* become thick enough or sometimes until it becomes oily. The most popular dish in West Sumatera is *rendang*, which is slowly cooked meat combined with spices and *santan*. Their dishes, therefore, are generally high in fat.

In contrast, participants in East Nusa Tenggara did not identify a type of cultural dish as a barrier in adopting a healthy diet. People in East Nusa Tenggara do not use coconut milk a lot. The method of cooking in East Nusa Tenggara is also much simpler than that in West Sumatera. The most popular dish in East Nusa Tenggara is *sei*, which is smoked meat. The traditional cuisine in East Nusa Tenggara is therefore lower in fat. Frequent cultural and religious feasts, however, were mentioned as the main barrier in controlling diet. Culturally, people in East Nusa Tenggara are different from people in West Sumatera. The dominant religion in East Nusa Tenggara is Catholicism, while in West Sumatera it is Islam. People in East Nusa Tenggara mentioned that they often had sacrament ceremonies, which are specific to Christianity. People attending the feast are supposed to eat to show respect. In both places, however, as is also common in Indonesia in general, people eat a large portion of white rice in every meal.

Another barrier to controlling diet was support from family members. Participants expressed that they found it difficult to have a different type of food from other family members.

> Eating boiled food is not easy, because we cook the food for all family members. And they said it is tasteless. So, it’s difficult (FGD Kupang city, East Nusa Tenggara).

> Yes, mum yes, we say that we cook it but then we divided our food into two [one mostly boiled for the diabetic, and the other for other family members ... Yes, this one is delicious, but another one is tasteless (FGD Kupang city, East Nusa Tenggara).  

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The discussion about eating habits revealed that participants were aware of the impact of eating habits on diabetes. However, their opinion on proper diet for diabetes varied, and they also expressed barriers to implementing it.

**Exercise**

Some participants were aware of the importance of exercise in controlling blood sugar level, but only a few of them exercised regularly. Some barriers to doing exercise were also reported, including lack of time.

> For me, I have never had more than 200 [mg/dL], because I also join [specific type of exercise], three times in a week every 5.30 AM, so I leave home after Subuh prayer (FGD Kupang city, East Nusa Tenggara).

> Yes, me too, I always go up and down the hill every day (FGD Manggarai Timur, East Nusa Tenggara).

> Yes, it’s hard to do exercise, as we are mothers. Will we go out for walking or cooking for the whole family? Because we don’t only think about our self, but also the other family members, so it’s quite difficult (FGD Kupang city, East Nusa Tenggara).

**Regular blood glucose measurement**

The majority of participants measured their blood glucose level once a month at the primary health centres. A few of them had their own rapid blood glucose measurement tool.

> Usually the Puskesmas held regular sugar checking on date 15 every month… (FGD Pariaman 1, West Sumatera).

> Once a month, at minimum, but if I feel that sugar level is likely going up or down, it’s better to check it again (FGD Manggarai, East Nusa Tenggara).

> I have a rapid blood glucose check tool. Doctor recommended me to have it, because [I have] high sugar level (FGD Kupang city, East Nusa Tenggara).

The blood glucose measurement at the primary health centres was free of charge. At the hospitals, however, participants said that they had to pay for measuring blood glucose.
If we do medical check in hospital, we have to pay 325 thousand rupiah (USD 24), and 25 thousand rupiah (USD 1.8) for sugar level check (FGD Solok, West Sumatera).

3.3.2.6 Coping response and the meaning of diabetes

In coping with the disease at the early stage, some participants denied having diabetes, as they sought second opinions from various health professionals. Others questioned why they got the disease, as they did not experience any symptoms.

I went to village midwife, and [it was found that] my sugar level was above 500 [mg/dL] (27.8 mmol/L), I was told to take medicines. But I didn’t trust the result, so I went to another place, [but] it was the same, and I was asked to be hospitalised, but I refused it. Then, I went to the Puskesmas and had my sugar level checked. I had to fast before checking my sugar level (FGD Pariaman 2, West Sumatera).

But sometimes I think why I got the disease, what’s the symptoms of diabetes, that’s my questions. What are the symptoms, I really don’t know … I felt nothing (FGD Kupang city, East Nusa Tenggara).

Some of them also expressed frustration about having uncontrolled blood glucose levels despite the efforts they have made.

My fasting blood glucose level can be as high as, now it, 270, 280 [mg/dL] (15.6 mmol/L) and sometime 300-ish, and it is, of course, higher after eating, I’m stress, (thinking of my blood glucose level) … (FGD Kupang city, East Nusa Tenggara).

Last Saturday I checked my blood sugar, it [blood sugar] used to be normal. However, it increased to 320 [mg/dL] (17.8 mmol/L) after I had lontong. It (blood sugar) can’t be stable, it always fluctuates, we can’t make it balance… (FGD Pariaman 2, West Sumatera).

Participants commonly knew ways to manage the disease, including controlling diet, taking medicines regularly, and exercising, although to some extent this knowledge is misunderstood. However, they also reported barriers which were beyond their individual control. These included personal barriers such as lack of self-efficacy, and social environmental barriers, such as lack of social supports. Despite the knowledge they had, therefore, they found it difficult to apply this knowledge to their personal lifestyle.

Then, we had an event for the elders, they held activities like a light exercise to move our body. Having done that, my sugar level dropped to 121 [mg/dL] (6.7 mmol/L). But I still have to take medicines for the rest of my life, [but] how could I? … (FGD Pariaman 1, West Sumatera).
An attitude of fatalism was also found. This view was commonly expressed by participants with strong religious beliefs, shown by frequent references to God during the discussions. These participants, however, acknowledged that their diabetes was affected by their own unhealthy behaviours, and they also emphasised the importance of controlling diet, and exercising as ways to manage the disease. In this case, fatalism constructed in their narrative did not mean a passive acceptance to fate. Rather, it reflects their submission to God, after all efforts they have made.

I’m sorry, a pastor in a church said to me “the healthy will die, the sick will also die, the professors will die, the rich will also die, so don’t stress”. The pastor also said that we are, the 50 years people or older, have to avoid LGG (Lemak, Gula, Garam) fat, sugar and salt. Fat for preventing from cholesterol, sugar for diabetes, and salt for hypertension. That’s all… (FGD Kupang city, East Nusa Tenggara).

So, the summary is, don’t think too much about that, stay calm. God has arranged our life (FGD Manggarai Timur, East Nusa Tenggara).

Most participants acknowledged that being stressed might worsen their condition, so that they believed that controlling their mind is an important part of managing the disease. The words ‘jangan dipikir’, ‘jangan terlalu penat pikiran’, ‘jaga pikiran’, which can be translated as ‘don’t think too much’, or ‘controlling mind’, were often used as expressions for minimising stress. These expressions may imply both denial or acceptance of their condition. In this study, however, those words were often combined with other expressions, such as ‘God has arranged our life’, which might be interpreted as acceptance and resignation to a Higher Power. The expression is more relevant to the lay concept of health as a balance of physical condition and spiritual well-being. With this belief, although they experienced uncontrolled blood glucose level, their emotional burden was minimised. This shows a positive method of coping response.

Yes, so don’t stress, if we are sick and stress, it can deteriorate our condition… (FGD Kupang city, East Nusa Tenggara).

Calm mind is a medicine, just relax, don’t worry, it’s a medicine. If we think too much, the disease will relapse (FGD Manggarai Timur, East Nusa Tenggara).
3.3.2.7 Discussion

Lay perceptions of diabetes

Findings from this study emphasised that diabetes patients constructed illness concepts into their own narratives based on their experiences. The use of local terms and common lay knowledge about diabetes classifications were also found in other areas of Indonesia [43, 223]. The use of local terms, however, may also lead to misconceptions of the disease. The term penyakit gula (sugar disease) narrows people's perception to white cane sugar or any sweet food as being the cause of diabetes. The term 'sugar' was also often used by diabetes patients in many countries [389-392]. Association of diabetes and having 'sweet pee' was also found in people in Bangladesh and Thailand [390, 393]. This may also diminish the understanding of other symptoms of diabetes. On the other hand, medical terms are often too complex to understand. Given the impact on communities' vague conceptualisation, avoiding use of lay terms particularly by healthcare professionals may be beneficial to improving people's understanding.

This study also found that participants connected their beliefs about causality into their own narratives to make sense of why they got the disease. When they could not find a personal explanation, or failed to succeed after any efforts they have done, they began questioning and found another logical reason. This finding is similar to a study in Tanzania, where diabetes patients questioned and felt unsure about diabetes causality when they could not relate it to their personal experiences [270]. Although it seemed that participants in this study further related diabetes causality to something beyond their control, no participant stated that their disease is a matter of chance, luck, fate, or caused by a supernatural power. This finding, however, may be limited by the characteristics of people with diabetes involved in the study, and the methods of gathering data through group discussions. All participants in this study had received a diabetes diagnosis from health professionals, and this might imply that they have received information about diabetes from the health professionals. Further, with FGDs, some participants might feel ashamed to mention an individual opinion which differs from the group opinion. Studies in Sri Lanka, Thailand, and India found that diabetes patients believed that their diabetes was caused by supernatural powers.
or bad karma when they could not identify a personal reason for contracting diabetes [354, 392, 394-396].

Findings on lay concepts of disease and its causality showed that these narratives are important in conceptualising the disease into their own logical and accepted explanation. As described by Hunt, et al. [397], this personal concept of disease causality gave meaning to the individual about their own role in the disease process and its treatment. This further implied that having a personalised diabetes narrative is important to empower an individuals’ role in managing it. Further, Anderson, et al. [398] suggest that in order to empower diabetes patients, the first and second steps of the counselling model involve personalising the diabetes problem into the patients’ perspectives. A study comparing Arabic-speaking migrants and Caucasian English-speaking patients in Australia found a significant relationship between participants’ illness and treatment perception, and adherence to self-management practices [399].

Moreover, participants in this study also related diet causality into a broader concept of cultural practices. In this view, however, they did not seem to blame their culture for them getting the disease, but they recognised their disease in their cultural context and understood barriers to practising healthy diet in a broader perspective. Consequently, the wider community needs to be involved in any action for managing diabetes. In behavioural change theory, individuals would be more likely to adopt behaviour if they perceive that it is accepted by their community, and they have enough self-efficacy, or confidence to do so in a challenging environment [400, 401].

As part of developing a lay account of diabetes, participants also tried to explain why the number of people with diabetes is increasing. They believed that less walking, and changing eating habits such as moving towards dependence on white rice, contributed to diabetes. Improving economic conditions have meant that more people in Indonesia can afford a motorbike, and these have also changed eating habits. In the Indonesian context, changes in eating habits have not seen a move towards westernised food, but instead an increased ability to eat food which is traditionally seen as desirable but was not affordable in the past. This is similar
to findings from other studies in the Indonesian context [212]. Interestingly, some participants blamed the rising diabetes on modernised ways of cooking rice. This has not been found in other literature. Regardless of the anecdotal evidence, this shows that the participants tried to make sense of their communities’ experience of diabetes.

**Illness experiences**

Most participants in this study were diagnosed late, and similar situations were also observed in Iran, and India [402, 403]. Type 2 diabetes has a long asymptomatic preclinical stage, with metabolic abnormalities possibly occurring four to six years before symptoms of retinopathy appeared [404]. Moreover, the health seeking behaviour of people in Indonesia, where they would not go to health facilities unless they experience any symptoms – as described in Chapter 2 – further delays diabetes diagnosis. This situation is complicated by limited knowledge about diabetes prior to diagnosis. Intervention to increase community awareness about diabetes is urgently needed.

This shows the importance of screening for early detection of diabetes. In Indonesia, a guideline for diabetes screening and treatment has been developed, and was last revised in 2015 [405]. A study revealed that health professionals in Indonesia, however, showed low adherence to the guideline including for detecting risk factors and early screening. The doctors tended not to advise their patients to be screened for diabetes unless several cardiovascular risk factors had emerged [241].

Most participants in this study had suffered from diabetes for a long period of time, and most of them had poor glycaemic control, which eventually led to complications. These problems can be seen from two perspectives: the patients’; and the health providers’ perspective. From the patients’ perspective, the problem might be a result of limited skills in self-managing the disease. Meanwhile, from the health providers’ perspective, this problem might be caused by limited diabetes management by health professionals. These are discussed further in the medication experiences, and self-management experiences.
Medication experiences

Analysis of medication taking behaviour in this study highlights the concept of people’s resistance to medicine taking [406] and a therapeutic decision model [407]. Resistance to medicines taking is defined as “considerable reluctance to take medicine and a preference to take as little as possible” [406]. Both the concept of resisting medicines and a therapeutic decision model stressed the process of lay evaluation, which shows that people are concerned about taking medicines, particularly for a long period of time [406, 407]. Only a few participants in this study accepted taking medicines passively without question as they trusted in health professionals, and no participants rejected the regimen completely. The majority of them evaluated the impact after taking medicines for some period, both subjectively and objectively. The lay evaluation process included: evaluation of its effectiveness; adverse effects; cost; and acceptability of regimen. With the availability of alternative medicines, many participants compared modern medicines to other alternative medicines. They compared both medicine types by actually testing and evaluating objective and subjective impacts on their body, or by comparing both treatments’ characteristics.

This process was influenced by significant others, as people also observed and received information from others: other family members or friends with diabetes. This finding is similar to a study involving diabetes patients with an Arabic cultural background, demonstrating that their medication taking was heavily influenced by the diabetic patients’ peers and family members [408]. Participants also evaluated their acceptability of medicines including the psychosocial burden resulting from the daily routine of taking them. Cost was also another consideration. Medicine taking behaviours found in this study were described in Figure 3.11. Based on this lay evaluation, participants then divided into three groups: participants who remained committed to medical treatment; participants who also tried traditional treatment; and participants who were medically inactive, who discontinued taking any medicines. These findings are similar to a study involving diabetes patients in Ghana [265].
After initiation, the first group of participants discontinued taking medicines. A key factor in this behaviour was the psychosocial burden of the daily routine of drug taking. Participants reported being fed up with taking medicines regularly. Long-term medicine use is reported as creating psychosocial burden on the patients, and impacts on their quality of life [409]. The notion of being fed up was also commonly stated by patients taking long term medication [410]. Some participants experienced side effects or discomfort from the medicines, and a few others also stopped taking medicines as they could not afford them. The second group of participants were active modifiers, with most of them taking both prescription medicines and traditional medicines as an alternative or a combination. A few participants modified the dose of the prescribed medicines, or took them occasionally. Finally, the third group of participants were active acceptors, accepting the medicines after evaluating them. Some participants in this
The group decided to go back to medicines, after trying some other alternative treatments and experiencing perceived ineffectiveness or side effects from the traditional medicines. Other participants in this group believed that the traditional medicines have no specific doses, and may have adverse events so that they committed to only taking medicines prescribed by their doctor.

Many participants took traditional medicines as they believed that traditional medicines are more natural, and have been used since previous generations. The use of different sources of treatment, both from medical and traditional systems as an alternative or in combination, is prevalent in countries with pluralistic medical systems, and in communities with strong socio-cultural beliefs [265, 391, 392, 394, 395, 408, 411]. Other than cultural beliefs, some participants chose traditional treatment because they experienced adverse effects or discomfort after taking medicines, and some others perceived medicine to be ineffective. This needs to be explored further as these may relate to problems from the medicines themselves. Some participants shared that their blood glucose level has never decreased although they have taken medicines. One other participant also stated that her blood glucose level will decrease if she takes Acarbose, but it was not available at the Puskesmas. Further questions emerged: did the patients receive medication appropriate to their clinical needs; and did the patients receive medicines which meet the quality standard?

The main type of traditional medicines taken by most respondents in this study was plant-based or herbal medicines. Studies have been conducted to analyse chemical content and efficacy of frequently used plants for treating diabetes [412-416], and found that they had potential antidiabetic effect. The main problem related to the use of traditional medicines, however, is that they are commonly taken based on anecdotal evidence without any specific information about dose. Because of this, some participants experienced side effects including hypoglycaemia, and having other diseases emerge after overusing herbal medicines. Further research about traditional medicines for diabetes is needed.

Furthermore, it is important to note that the main aim of diabetes treatment is to maintain blood glucose levels within a target range in order to delay the progress
of the disease, prevent complications and improve patients' quality of life. This needs to be highlighted because some participants reported frustration with medicines because they did not provide a cure. They took traditional medicines in search of a cure for the disease. Another study also confirmed the reason frequently mentioned by participants who choose traditional therapy for diabetes was to search for a cure for the disease [229]. Perception of ineffectiveness of medicines, and searching for a cure with traditional therapies was also found in a study involving communities in Nepal [417]. The notion of ‘cure’ described is being free from the disease and its treatment. Another reason for trying other traditional medicines was to find those which they perceived to be suited to them.

Similar findings were also gathered from previous studies done in Indonesia as detailed in Chapter 2. Strong belief that the effectiveness of medicines is a matter of being ‘suited to you’ also encouraged people to try any available alternatives to find the best fit medicines for them.

**Self-management experiences**

The majority of participants believed that controlling their diet was essential in managing their blood glucose level. Although some respondents also mentioned exercise, for most of them, it remained a missing ingredient. Misconceptions about the proper diet for diabetes were prevalent, however, which was also complicated by wide variation in local food and methods of cooking. Moreover, cultural practices including social events and traditional cuisine were regarded by participants as the main barrier to controlling diet. These findings were also observed in other studies conducted mainly in developing countries [390-392, 394, 395, 402, 418-421]. A systematic literature review of research involving people in South Asian countries suggested that limited availability of culturally-specific tailored diets, traditional food habits, and misconceptions related to diabetic diet were barriers to adopting dietary changes for diabetics [418]. In places where people eat rice as main dishes, limiting portion size was regarded to be difficult [390, 394, 395, 420, 421]. These findings suggest that dietary guidelines for diabetes which are tailored to cultural practices and availability of local foodstuffs need to be developed and widely disseminated to the patients.
Participants had diverse opinions related to proper diet for diabetes, and showed confusion about which food is good or bad for diabetes. Rice was commonly believed as bad for diabetes, so reducing portions, or substituting brown rice or corn for white rice was regarded as good for managing diabetes. Discussion about the effect of local fruits on blood glucose level also emerged. Studies on the effect of certain food on blood glucose levels have been widely conducted. Tables of glycaemic index, defined as the ranking of carbohydrate in food in affecting blood glucose level, of numerous food types have been established [422]. It has been suggested also that eating food with low glycaemic index could be beneficial for diabetes patients [423, 424]. Glycaemic index of the same food, however, for example rice, varies widely depending on botanical differences in rice species across the globe. Moreover, lists of glycaemic index are developed based on food available in western countries. The types of food available, such as fruits, vary widely from country to country. Unfortunately, although the glycaemic index of some local food available in Indonesia has been studied a lot [425-432], the results have not been integrated yet. Moreover, the methods of determining the glycaemic index also differ among those studies, and publications of the results in many cases are also limited. It is therefore important to integrate research about local food in Indonesia and publish it widely.

Interestingly, some participants, as they said they were told by their health professionals, also argued that eating cold rice, or cooking rice traditionally might reduce the sugar level in rice compared to eating freshly cooked rice, or rice cooked in a rice cooker, respectively. Studies have also been conducted on modifying the rate of starch digestion to glucose through altering the processing conditions [433, 434]. Slowly digestible starch could be potentially useful in decreasing absorbable glucose rates in the small intestine [434]. Wang, et al. [433], Svihus and Hervik [434] suggested that one method that could potentially lower the rate of digestibility of starch-contained food is through modifying storage conditions after cooking. It is explained that storing freshly cooked starch-containing food for prolonged time in cooler temperatures may potentially lower its digestion rate [433, 434]. In practice, therefore, storing cooked rice in a cooler place for prolonged time could also have potential for reducing its digestibility.
rate. More research needs to be done in this particular area to understand its implications in the Indonesian context.

However, Evert, et al. [435] suggested that both glycaemic index and starch modification strategies showed moderate effects and variability of results between individuals. These strategies may potentially be used as guidelines, but where there is no specific data, the general principal of healthy eating should be recommended to diabetes patients. Further, it is stated that an eating plan for diabetes should be individualised based on the patient’s clinical needs and condition, and that eating pattern is not a ’one size fits all’. Further, it is evident that carbohydrate plays an important role in blood glucose level. Modifying intake of carbohydrate-containing food, therefore, both in quantity and type is recommended [435]. Healthy eating strategies for people with diabetes include nutrient-dense, and high-fibre carbohydrate-containing foods, high saturated fats, leaner protein, no sugar-sweetened drinks, and limiting alcohol consumption. In the Indonesian context, with wide variation of education level and socio-economic status of people with diabetes, a simple recommendation of eating pattern, such as reducing portions, and choosing types of food which are recommended or not could be the best strategies. It is also suggested that for people with lower literacy or older age, a simple healthy eating plan should be recommended [435].

In terms of exercise, some participants acknowledged its importance in managing diabetes. However, only a few of them practised regularly. Indonesian’s refer to olahraga to convey the concept of exercise. The term ‘olahraga’ is, however, more related to ‘sport’, and often relates to the subject of physical education at schools. The most popular form of physical activity in Indonesia is called ‘senam’ which is a form of exercise done in a group where they move their body together with specific instruction, and often with music. Individual exercise is uncommon in Indonesian culture. Moreover, in the Indonesian context, with the current, more modernised situation and the development of rapid transportation systems, more people can afford a motorbike. For people who do not have a motorbike, the motorbike taxi is available everywhere, even in remote areas. Even in rural areas, walking is unusual nowadays. Moreover, there are also limited public places which
are safe enough for people doing exercise. With this cultural context, encouraging people to do exercise regularly is quite challenging.

Limited access to blood glucose measurement is also found to complicate the practise of self-managing diabetes. A rapid blood glucose measurement tool is relatively expensive, so people cannot afford it. Under the universal health coverage programme, diabetes patients who register as members have access to blood glucose measurement at the primary health centre, and usually the health centres organises the measurement once a month.

*Coping response and meaning of diabetes*

Based on participants’ experiences during their illness, at the early stage after being diagnosed, a denial response was common, followed by frustration at not being able to decrease their blood glucose levels. Diabetes is a chronic disease that needs persistent effort to manage. Diabetes-related distress may come from its treatment, which includes changing diet pattern, and taking medicines regularly, often viewed as burdens that interrupt normal life [436]. As found in this study, the notion of being fed up with taking medicines can strongly affect willingness to adopt it into the patient’s regular routine. Moreover, changing diet can seem to be impossible, with the barriers from socio-cultural environment. Research has shown that diabetes patients are at risk of depression, and other emotional problems [437, 438]. Furthermore, diabetes-related distress has been found to affect the patients’ clinical outcomes, and quality of life [436, 439-441].

The ways diabetes patients deal with these life stressors, known as coping, also affects their clinical outcomes and quality of life [442, 443]. This study found that religious belief played an important role in the participants’ coping strategy. From this coping strategy, it seems that participants showed a fatalistic attitude, that they perceived themselves as not having much control over their health status [444]. Fatalistic beliefs among people with chronic diseases has been suggested as the major cause of patients’ non-compliance with healthy lifestyle change, as they viewed that their health and illness resulted from their destiny, fate, or luck [444]. Fatalism has been shown to have a detrimental effect in the management of
chronic diseases, for example it became a barrier for cancer screening [445], and it is also associated with poor management of diabetes [446].

In this study, however, fatalism was not always associated with a negative coping response. Spiritual belief does not always mean passive acceptance of fate, but was often a way of finding support in facing stressful life events. This finding is similar to research involving diabetes patients in Java, Indonesia. People with religious belief showed a more fatalistic view, but this did not mean a passive resignation, instead it is an attitude of submission to God [223]. Studies involving communities with different spiritual beliefs have shown that despite being more fatalistic, individuals with a strong religious belief appeared to have more positive coping responses, as seen by not being frustrated over difficulties as a result of having diabetes [447-450]. People perceived religion as a means of coping, and a support in the struggle with diabetes [448]. As described by Moos and Holahan [451], seeking guidance and support including religious support is one strategy of coping.

Spiritual belief is also an important element in shaping people’s lay concept of health and illness. Health is often viewed as a balanced condition of physical and spiritual wellbeing, and illnesses might emerge as a result of pursuing only physical health, and ignoring spiritual health, or vice versa. This concept might be rooted in eastern traditional medical philosophy, which emphasised balance, energy systems, and holistic integration of the body and mind [452], but it is also shown in people living in the Pacific Islands [453].

These findings further suggest that involving religious leaders may potentially support diabetes patients to better manage the disease. Religious practices may further encourage patients to implement a healthier lifestyle. In one discussion in Kupang city, one participant also mentioned that a pastor also gave advice on healthy lifestyle: “A pastor in a church said to me: we are, the 50 years people or older, have to avoid LGG (acronym for Lemak, Gula, Garam) fat, sugar and salt. That’s all. Fat for preventing from cholesterol, sugar for diabetes, and salt for hypertension. That’s all”. Furthermore, health professionals should also
acknowledge the concept of balance and harmony, so that a more holistic approach could be implemented in health practices.

*Diabetes patients’ behaviours in managing the disease and recommended intervention focus*

Diabetes patients’ behaviour in managing the disease is synthesised further from findings described previously (Figure 3.12). Individuals’ behaviour in managing the disease was mainly a result of a lay evaluation process of their disease and its treatment. With the nature of diabetes as long-term disease, lay evaluation is a continuing process over time. Diabetes patients perceived the disease in their own narrative explanation of an aetiological model and expected benefit of treatment. Participants started to question the dietary cause of diabetes, for example, after experiencing a negative result from controlling diet. Participants discontinued taking medicines, and chose the traditional medicines as they perceived ineffectiveness or side effects from medicines, in contrast to perceived effectiveness of traditional medicines. The process of lay evaluation, however, was limited by misconceptions and lack of knowledge about diabetes and its treatment.

![Diagram](image.png)

**Figure 3.12: Factors influencing diabetes patients' behaviour in managing the disease**
Moreover, input from significant others was crucial in determining behaviour. Significant others may influence behaviour through the process of lay evaluation or direct suggestion of behaviour. The significant others mentioned by participants were mainly the other diabetic family members or friends with diabetes. The participants commonly contacted and interacted with other diabetic peers for sharing their experiences. For example, people chose to take traditional medicines based on success stories of other family members or friends with diabetes.

Perceptions about health providers also influence diabetes patients in managing their disease. The lay evaluation process of the disease and its treatment effectiveness may further influence appeal and acceptability of specific health services. As an example, patients who perceived positive experiences after using the medicines from the hospital would prefer to get their medicines from the hospitals instead from *Puskesmas*.

Cultural beliefs and practices also influenced people’s behaviour in managing the disease. Diabetes participants in the study saw the disease in a broader cultural context. In practising dietary control, for example, they were challenged by types of local food available, as well as cultural practices. These conditions reduced people’s self-efficacy – a belief about individual capability in performing behaviour.

These findings suggest that the interventions for diabetes patients in Indonesia should focus on assisting participants in a lay evaluation process and providing social support from significant others and the community. In assisting a lay evaluation process, knowledge about diabetes and its recommended treatments, and skills in practising the recommended treatment need to be improved. Providing support would likely improve the patients’ self-efficacy in practising the recommended behaviour in a challenging environment.
3.4 Conclusion and further study direction

This qualitative study explored knowledge, perception, and experiences of mothers in relation to immunisation, and diabetes patients in managing the disease. This study adds substantial value to existing literature and fills gaps in previous research. The findings provide substantial understanding of health-related topics from the people’s perspectives. Understanding the problems from the participants’ perspective enables researchers to design more effective interventions in order to improve people’s health status.

On the topic of immunisation, it can be concluded that mothers’ behaviour in regard to child immunisation is mainly influenced by external factors: their relationship with community health workers; and the fathers as the decision makers. Without ignoring the importance of proper education programmes to improve understanding about immunisation, efforts should be made to acknowledge the important role of community-based health workers and involve fathers in the immunisation programme.

Further, the mothers’ immunisation behaviours were also affected by their attitude towards health services, which may be influenced by the quality of immunisation services in the Posyandu programme. Lack of support, both from the community and government were found to be the main barriers in Posyandu programme implementation. This further suggests that it is important to empower the community and involve them in the management of the programme. A simple community discussion about immunisation intervention has been shown to improve people’s interest in the immunisation programme. This could be potentially adopted into the Indonesian context, where community gatherings are common. This intervention may further increase community belonging in the programme. Barriers to implementation of the Posyandu programme may be different from place to place, and from community to community. Community discussions therefore have the potential to identify specific barriers in their community context. Because of inequality in the distribution of socioeconomic and health resources within the country, however, communities in remote areas
struggle more to better implement the programme. At this point, external influences, such as government authority, are needed to overcome the situation.

Aforementioned findings in the topic of diabetes revealed more complex situations which contributed to participants’ illness experiences including late diagnosis, uncontrolled blood glucose level, and prevalent diabetes related complications. Diabetes participants’ behaviour in managing the disease was influenced by interrelated factors of the individual and their interaction with significant others and their community, the continuing process of lay evaluation of the disease and its treatment, and cultural practices. Findings on participants’ medication and self-management experiences revealed that self-management practised by participants was not sufficient, as shown by misunderstanding, limited knowledge, self-efficacy, skills, and motivation for practising the recommended behaviour regularly. Participants’ medication taking behaviour varied based on their subjective and objective evaluation of the treatment on their disease state. In the Indonesian context, with availability of traditional medicines and other alternative therapies, the process of lay evaluation became much more complex. Participants compared medicines to the other types of traditional medicines available. In practising dietary behaviour, limited information on proper diet for diabetes led participants to evaluate for themselves the effect of particular food, and methods of cooking on their disease.

This implies that interventions for diabetes are urgently needed. Without proper management, diabetes severity and risk of complications increases over time. This impacts not only on people’s health status, but also increases the financial burden of diabetes. In the universal health coverage era, this burden from diabetes could affect the whole country. New initiatives, therefore, should be established to also reduce this financial burden from diabetes. The only way of doing this is making efforts to prevent, detect diabetes early, and improve patients’ outcomes. Without ignoring the importance of the child immunisation topic, therefore, the rest of this study focuses only on an intervention for diabetes. Furthermore, as the financial burden of diabetes may be higher in lower socioeconomic communities, the intervention was conducted only in East Nusa Tenggara Province.
Section C – Developing, piloting and evaluating a culturally appropriate intervention for people with diabetes

4 Chapter 4: Literature review of diabetes interventions

4.1 Introduction

The qualitative study findings presented in Chapter 3 underline the urgent need for an intervention study aimed at improving diabetes patients’ outcomes. The main study, therefore, focused on establishing, piloting, and evaluating an intervention for people with diabetes in Kupang, East Nusa Tenggara. The results of this study contribute not only to filling the literature gaps on diabetes interventions in Indonesia, but also to informing health professionals, the health system, and policy makers in designing an effective intervention. The results of the study also direct future research in this area.

Chapter 4 describes the process of developing an intervention study through a literature review covering diabetes interventions that have been successfully implemented worldwide and in developing countries. The main objective of this chapter is to identify relevant studies of type 2 diabetes interventions and evaluate these on their relevance and applicability in the Indonesian context. This information, together with the results of the qualitative study reported in Chapter 3, were used to design an intervention study aiming at improving outcomes for people with diabetes.

4.2 Approach

The review was limited to publications from peer-reviewed journals. Different data sources and strategies were applied to locate relevant literature. Key words, and a combination of key words with three Boolean operators OR, AND and NOT were applied. Further, relevant literature from the articles’ references was also hand-searched. The key words used are listed in Table 4.1.

Using the key words in Table 4.1, literature was gathered from various databases including Ovid, PubMed, Scopus, Web of Science, Science Direct, ProQuest Central,
and Google Scholar. Searches were also performed in the University of Otago library database. In addition to this, literature from Indonesian journals was also searched with the key words translated into the Indonesian language. Google Scholar database was the main source of articles in Indonesian journals. The articles yielded from those searching methods come from a wide range of peer reviewed journals. Some relevant articles were also found in Indonesian journals.

Table 4.1: Keywords applied for locating relevant literature

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<thead>
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<th>Keywords</th>
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<tr>
<td>“type 2 diabetes”</td>
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<tr>
<td>“self-management”</td>
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<tr>
<td>Intervention*</td>
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<td>community intervention*</td>
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4.3 Diabetes intervention

4.3.1 Goals of diabetes management

As described in Chapter 2, diabetes is a chronic and progressive disease, and much of its morbidity and mortality is associated with long term complications [179]. The main goal of diabetes management, therefore, is to reduce or delay microvascular and macrovascular complications by controlling blood glucose and blood pressure close to normal range [454, 455]. Intensive glucose control of HbA1c of less than 7%, and blood pressure less than 140/80 mmHg has been shown to be associated with reduced risk of diabetes complications [454, 456].

The key for managing type 2 diabetes and maintaining glycaemic control is patients’ adherence to a daily treatment regimen, which includes recommended lifestyle changes, and in many cases is combined with pharmacological treatment. Interventions for diabetes worldwide have therefore been focused on diabetes self-management education programmes (DSME) [457-459]. Diabetes self-management education programmes are defined as “ongoing process of facilitating knowledge, skill, and ability necessary for prediabetes and diabetes self-care” [460].
4.3.2 Diabetes interventions worldwide

Diabetes self-management education (DSME) interventions have been intensively studied in developed countries. The intervention approach differed in types, teaching methods, mode of delivery, educational providers involved, content, and contact time. Outcomes measured also varied, and have included biomedical, behavioural and psychological outcomes [457-459]. The types of interventions were categorised based on their objectives into educational, behavioural, psychological, and mixed. Educational interventions focus on providing information to improve patients’ knowledge; behavioural interventions aimed at improving patients’ self-management skills and implementation; and the psychological interventions focused on improving patients’ coping strategies and emotional status [457]. Teaching methods can be divided into didactic, which focus only on conveying messages, and interactive, which involves active participation of patients [457]. The mode of delivery varied from individual education, group education, a combination of individual and group sessions, and with technological help for delivery including online or telephone [457, 458]. A diverse range of health professionals, including physicians, registered dietitians, nurses, and pharmacists [461], and also lay educators [462-464] have been involved as educational providers in the intervention studies. Differences in outcomes and effect size of DSME interventions were also observed. With this heterogeneity, there is no specific formula for the intervention to be effective [459].

Larger effect sizes were found in interventions that applied a combination of group and individual one-on-one sessions, which focused on behavioural skills, had a higher number of interactions, and were delivered with more interactive teaching methods [457, 458]. There is also a strong suggestion that self-management programmes should be tailored to specific populations, taking into consideration population characteristics, including culture and socio-demographic characteristics. Culturally tailored interventions have been widely developed and shown to be accepted, and improve patients’ outcomes [462-467]. These culturally tailored interventions were commonly delivered by community health workers, or peer educators who were lay people from the community targeted. The
educational materials were also designed in the targeted people’s language [462-467]. Furthermore, it is also suggested that community-based interventions are the most ideal form for type 2 diabetes education programmes, compared to clinical or worksite based interventions [468, 469]. Community gathering places are often culturally relevant, and more convenient, especially for those living in more rural areas. Church-based interventions have also been conducted [470-472]. Most of those studies, however, were conducted in Western communities. The culturally tailored studies found were commonly performed for ethnic minorities living in developed countries.

4.3.3 Diabetes interventions studies in Asian countries

In Asian countries, diabetes self-management education interventions have been performed in China [473-475], Korea [476], India [477], Malaysia [478-480], and Thailand [481]. Studies conducted in Asian countries also varied in types, content, delivery methods, and intervention doses. Most studies showed positive outcomes for diabetes participants after the interventions. All but one study focused on knowledge and lifestyle modification. A study in Malaysia by Alvani, et al. [478] focused on a psychological intervention designed with cognitive behavioural therapy (CBT), conducted in eight group sessions spread over three months.

In terms of delivery methods, a combination of group sessions and individualised counselling were applied in some studies [473, 481-483]. Community-based [478, 481-483], clinic-based [473, 475, 476, 480, 484], and worksite-based [474] deliveries were also applied. The community-based studies in India utilised community health workers and trained trainers as the education providers, and they also involved a wider community - not only the diabetes patients - in a lifestyle intervention, [482, 483]. Clinic-based studies involved various health professionals, including pharmacists [479]. The workplace-based intervention was implemented in collaboration with the companies’ health clinics, and involved diabetes participants who worked in those companies [474].

In terms of study design, the intervention studies conducted in Asian countries implemented pre-and post-experimental design [473, 482, 483], quasi-
experimental [478], quasi experimental with wait-list design [475], and randomised controlled trial [474, 476, 479-481].

Lifestyle intervention studies aimed at preventing diabetes have also been developed in Asian countries, including three large randomised controlled trial diabetes prevention studies in India (Indian Diabetes Prevention Programme, IDPP) [485], China (The Da Qing IGT and diabetes study) [486], and Japan (A Japanese Trial in IGT males) [487]. A quasi-experimental study for diabetes prevention has also been performed in Malaysia (Community-based healthy lifestyle intervention programme, Co-HELP) [488].

These studies show that diabetes intervention programmes can be adapted to specific country contexts and cultural settings. People living in Asia and developing countries commonly have a great variation of cultures, religions, and customs which affect their lifestyle behaviours, including eating and physical activity behaviours. Intervention programmes aiming at modifying lifestyle behaviours should therefore be built based on a good understanding of the community and socio-cultural characteristics [489]. As an example, Balagopal, et al. [483] in India and Ibrahim, et al. [488] in Malaysia built a partnership with the community, and utilised community health workers or community volunteers as education providers. This method increased acceptability of the lifestyle change programme. Those two studies also focused on changing to more healthy eating habits based on local food available.

Specific diabetes care programmes have also been developed in three low and middle-income countries. Van Olmen, et al. [490] described Kin-réseau, MoPoTsyo and FiLDCare programmes for diabetes care and self-management support in the Democratic Republic of Congo, Cambodia, and the Philippines, respectively. Kin-réseau is a network of primary care centres which deliver diabetes care. The Kin-réseau has not been formalised into an organisation, but two religious organisations are responsible for most facilities, and health services. MoPoTsyo is a community-based peer educator network who worked actively in screening the community and providing health services including diabetes education. FiLDCare is a programme in which diabetes patients received care in health facilities, and
self-management support from a community health worker [490, 491]. After studying these three programmes, Van Olmen, et al. [490] further suggested that health outcomes depended not only on individuals and their behaviours, but were also influenced by the people around them including family, community and larger social context. Diabetes patients’ outcomes also depended on the support from the health systems through diabetes-specific programmes. This further suggests that it is possible to establish and maintain a diabetes care programme with self-management support in low resource settings.

4.3.4 Diabetes intervention studies in the Indonesian context

Studies about diabetes in Indonesia have been widely conducted, but mostly focus on establishing diabetes prevalence [89, 198, 209, 492-494], risk factors [201-204, 207, 494, 495], and diabetes related complications [213, 215-218, 220, 496-505]. Some studies focused on diabetes management from the health providers’ perspective [214, 240-242, 506]. Studies have also been conducted to investigate the role of pharmacist in managing diabetes patients [214, 506].

A few studies have investigated diabetes patients’ behaviours including medication adherence [227, 507], smoking behaviour [508], dietary habits [509], and factors predicting those self-management behaviours [510]. Diabetes patients’ coping strategy [511], and quality of life [507, 512, 513] have also been studied. Findings of the studies emphasised that patients’ medication adherence is correlated with their quality of life. Most diabetes patients, however, showed low adherence to diabetes medications, some of them combining medicines with traditional or alternative treatment [227, 228, 507]. Further, patients’ self-management behaviours needed to be improved, particularly by improving their knowledge, self-efficacy, and social support [509-511]. Smoking behaviour was prevalent in male diabetes patients, so that smoking cessation programmes should also be implemented in diabetes clinics [508].

However, studies focused on interventions for improving diabetes patients’ outcomes were limited. A study has attempted to analyse factors influencing glycaemic control by comparing poorly controlled diabetes patients to well-controlled counterparts, and it was found that glycaemic control was not related
to age and sex, but duration of illness and dietary habits [514]. Three intervention studies have been implemented. One study was a hospital-based study conducted in Banten Province. This study focused on improving patients’ adherence to medication by providing them with a medication booklet and a 30-minute counselling session focused on adherence [515]. This study was designed with a pre-and post-test single group, and analysed patients’ medications adherence and clinical outcomes of HbA1c after 10 weeks of the intervention. Diabetes participants experienced a huge reduction of HbA1c (3.19 ± 2.42%), and there was a significant correlation between medication adherence and HbA1c level [515].

Another study was a community-based study in Yogyakarta Province that aimed at improving diabetes patients’ quality of life through an interactive education programme [516]. This study was designed quasi-experimentally, comparing an intervention group to a diabetes club (an existing diabetes programme) and usual care. The intervention activities were done in one two-hour session, with the main activities of active facilitated self-learning in groups. The participants’ quality of life outcomes were measured repeatedly: at baseline; after one month; at three months; and six months following the intervention [516]. The result indicated that the patients’ quality of life in the intervention group increased significantly over time, however this increase was smaller compared to the diabetes club control group [516]. The diabetes club is a regularly-conducted programme for diabetes patients. This implied that, consistent with the findings above, health education should be repeated to maximise the positive outcomes.

One other intervention study for diabetes patients was found; however, the full text article could not be retrieved [517]. Wardhani, et al. [517] has investigated the effectiveness of community-based intervention with pre-and post-experimental design. Interventions included continuous education programmes for diabetes patients delivered by community health workers in the community health promotion posts. From the study, it was suggested that empowering the community in diabetes programmes can be applied in an Indonesian context, and had positive impact in diabetes patients’ outcomes [517].
Because so few studies of diabetes interventions in Indonesia were found, the literature search was expanded into the broader context of non-communicable diseases. By doing this, two studies focused on reducing non-communicable disease risk factors were found: one study was conducted in Depok, West Java Province [518]; and one other study was performed in Yogyakarta Province [519]. These two studies focused on building community-based programmes for healthier lifestyle change in order to decrease the risk of cardiovascular disease and non-communicable diseases. The studies emphasised that the success of a community-based programme depended on its sustainability, and the result might not be seen in a short period of time. The programme needed to be reiterated so that the expected outcome could be achieved [519].

### 4.4 Key findings and recommendations for diabetes intervention in the Indonesian context

The literature review provided valuable input into how to design a diabetes self-management intervention in the Indonesian context. A large body of literature suggested that intervention programmes should be specifically tailored to the population target, based on understanding of the specific culture and socio-environment characteristics. A community-based type of intervention is more relevant with this type of culturally tailored programme. Furthermore, it has also been found that interventions focused more on skills with interactive communication could have a more positive impact. In overcoming the challenges of limited health resources in a low and middle-income country setting, partnership with the community, and involving wider community members was beneficial. With limited studies on diabetes intervention in Indonesia, it is difficult to compare the effectiveness of different types of intervention programme. Findings from the available studies suggest that improving diabetes patients’ outcomes is feasible, and community-based intervention is strongly recommended to improve the acceptability of the intervention.
The qualitative study described in Chapter 3 was an attempt to understand the problem of diabetes from the patients’ perspectives, and to explore their experiences in managing the disease. Findings from the qualitative study underlined that diabetes patients’ behaviours in managing the disease are influenced by interrelated factors of individual lay evaluation of the disease and its treatment, significant others, and cultural practices. The findings suggest that an intervention for diabetes patients in Indonesia should focus on assisting participants in the lay evaluation process, and providing social support from significant others and the community. In assisting the lay evaluation process, knowledge about diabetes and its recommended treatments, and skills in practising the recommended treatment need to be improved. Although diabetes patients accepted a medical perspective of diabetes causation, their personal narratives were diverse based on their personal condition. There is also a wide variation of opinions, lay knowledge, and misconceptions about diabetes and its management. Although some studies showed that there is no consistent relationship between knowledge and diabetic control [520-522], proper knowledge about diabetes self-management is essential for people to be able to manage their disease [523, 524]. As a simple example, some participants believed that diabetes is caused by modern ways of cooking rice. With this knowledge, they considered that the traditional way of cooking rice is a way for preventing or managing the disease. Improving diabetes patients’ understanding about the disease by relating the explanation to their condition and experiences is therefore essential in diabetes interventions.

Findings from the qualitative study also underlined that cultural beliefs and practices, and family and community support challenged diabetes patients in managing the disease. This emphasised the role of social support, either from the family, or the community in diabetes management. Social support has been widely acknowledged as influencing diabetes management behaviour [525, 526]. Limited social support was often perceived as a barrier that further undermined self-efficacy, and the belief in the ability to perform the recommended behaviour. Limited support from other family members in controlling diet has made participants feel that controlling diet is impossible, for example. King, et al. [525],
Sarkar, et al. [527] emphasised that perceived barriers negatively affect self-efficacy, so these should be addressed in the intervention. Self-efficacy belief was associated with diabetes patients’ self-management behaviour, including in people with low health literacy, and across a wide range of ethnicities [523, 525, 527].

Other than social support, limited self-efficacy might also relate to perceived failure after doing the recommended behaviours. Negative experiences resulted in low self-efficacy which further reduces motivation, affecting behaviour in managing the disease [528, 529]. Some participants shared that they did not experience any difference in their disease state although they had tried to implement the recommended actions. These negative experiences in patients’ perspective might relate to their lack of skills in implementing the recommended behaviour. This should, however, be studied further as many factors may contribute to the success of managing diabetes.

The main components of diabetes intervention therefore included knowledge, social-support, self-efficacy, skills and motivation (Figure 4.1). These components for behavioural change aligned with the Social Cognitive Theory (SCT) described in Chapter 2. The SCT concept explains that behaviour change is not only mediated by knowledge, but it also requires self-efficacy, skills, and social support [280, 530]. In health promotion programmes, the theory can be translated into interventions addressing determinants of behaviours: psychological determinants of self-efficacy; observational learning; environment support; and self-regulatory processes [280, 528, 530]. Based on the principle of observational learning, peer modelling is an important intervention that might be useful in improving people’s self-efficacy, and facilitating behavioural change. Moreover, the other important concept of SCT is self-regulation, a concrete skill that people should have to manage themselves. Increasing self-regulatory processes in SCT through self-monitoring, and feedback can also potentially change behaviour [280]. Environmental support through facilitation, and incentive motivation can also potentially be applied to improve skills and motivation in performing behaviour [280].
Based on information gathered, we therefore developed an intervention with several elements (Figure 4.1):

1. The intervention was conducted with the patient group outside their usual interaction with health professionals. The patient group provided social support through frequent contact with friends with the same condition. The group also enabled people to learn from others through observational learning, and peer modelling.

2. Educational content focused on addressing misconceptions about the disease, and improving patients’ skills in self-management. Education sessions were delivered through interactive communication, with educational material that was designed to be simple and clear.

3. For improving self-regulatory processes, self-monitoring and feedback were implemented.

4. To increase motivation and support, facilitation through demonstration, and providing tools, and incentive motivation through providing rewards for performing behaviour were also applied. Demonstration improved skills in performing behaviour.
In terms of intervention programmes, the government has introduced three distinct programmes aimed at early detection and management of non-communicable diseases including diabetes. The programmes are *Pos pembinaan terpadu penyakit tidak menular - Posbindu PTM* (integrated health posts for non-communicable diseases), targeting people aged 15 or more for early detection for risk of developing chronic disease; *Pos pelayanan terpadu lanjut usia - Posyandu lansia* (integrated health posts for the elderly), aimed at managing illnesses in the elderly; and *Program pengelolaan penyakit kronis – Prolanis* (Programme for managing chronic diseases), a programme for managing hypertension and diabetes for people under the government health insurance scheme. The implementation of these programmes, however, differed across the country, depending on the capacity and capability of health professionals, and there is no such evaluation yet related to their effectiveness in achieving goals.

The intervention study in this project was therefore conducted in collaboration with these existing government programmes. With this collaboration, the intervention project made use of available resources in the study location. This collaboration and use of existing resources improved the sustainability of the intervention because it could easily be adopted, and continued after the research project was ended. Collaboration with the existing programme also emphasised empowerment, using the available resources for improving the performance of the programme. This collaboration also enabled the intervention to be implemented into other community settings using available resources.
Chapter 5: Methodology and methods

5.1 Introduction

Chapter 5 describes the methodology and method of the pilot intervention study. This chapter presents the design of the study, details the research process, describes the participants involved in the study, and explains the intervention sessions. Chapter 5 also explains the outcomes measured including HbA1c, and knowledge, medication adherence, and self-management behaviours. This explanation is then followed by description about data collection process. The chapter is finished with description about data management and analysis.

5.2 Study design

5.2.1 Rationale for quasi-experimental research

A quasi-experimental study design with a control, a pre-test and a post-test non-equivalent group was chosen for diabetes intervention in this study. Although randomised-controlled trial is the gold standard for determining the ‘true experiment’ effect, there are many contextual situations in practice-based and public health areas where individual randomisation is not possible [531]. As an example, randomisation might be considered impossible because the health providers or policy makers have decided that the interventions have to be conducted in the most needy areas or individuals, or when having control groups is considered as unethical as the practitioners believe that the intervention is generally beneficial and should not be restricted to certain individuals [531]. In behavioural interventions, individual randomisation might also increase cross-contamination bias, in which the participants in the experimental group share the experiment to participants in the control group [532]. A quasi-experimental design enables the researcher to undertake an experiment in these situations [531, 533, 534].

Given the social nature of the community and the contextual situation in the study location, randomisation of participants to intervention and control groups was neither practical nor feasible. Findings from the qualitative study highlighted that
people with diabetes interacted each other to find support and treatment recommendations. This interaction would likely increase for those who visit the same health providers, those who have familial relationship, or those who are living near each other. People in the study locations are highly sociable and are closely connected to their community. The researcher, therefore, was concerned about spreading the intervention through word of mouth from participants in the intervention group to those in the control group. This could potentially increase cross-contamination bias. Although cluster randomisation would be appropriate in a larger sample, to avoid contamination we opted to run the intervention in geographically distinct communities.

Figure 5.1: Main transportation methods in Kupang, motorbikes, and ‘bemo’ a public transport

The intervention study was designed to include a community-based patients group. Participants in the intervention group were invited to attend group activities regularly. The intervention was therefore performed in the most convenient and accessible place closest to the participants’ homes, to improve the participation rate. Selecting participants based on their home location could not be
performed if the participants were randomised. In the study location, the main transportation method is motorbike (Figure 5.1). *Bemo*, the public transport in Kupang, is only available for connecting people living near the main city roads. In suburban and rural areas, motorbike taxi is the main transportation method for those who do not have a motorbike. The costs for taking a motorbike taxi, however, are more expensive, which is often an issue for people of low socio-economic status.

### 5.2.2 Experimental design

In this quasi-experimental study, the effect of the intervention was evaluated and compared with usual care. The experimental group included people with diabetes who were involved in a group-based intervention, while the control group involved diabetes patients who received usual care provided by healthcare facilities. The intervention consisted of ten sessions conducted within three months. Baseline and follow-up data were collected in both groups (Figure 5.2).

![Figure 5.2: Experimental design of the study](image-url)
5.3 The research process

5.3.1 Ethics, and local approvals

Ethics approval for the intervention study was sought through and granted by the University of Otago Human Ethics Committee, New Zealand (Appendix 4.1). In the study locations, local government approval was sought from the provincial government. The research approval letters were issued by Kantor Pelayanan Terpadu Satu Pintu (The Integrated Office of Community Service) (Appendix 4.2). The documents required for getting the approvals were a reference letter, which was the official letter asking permission to conduct research from the head of the researcher’s institution, and a research proposal. The reference letter must be in the Indonesian language, so I requested the reference letter from the Dean of the Faculty of Pharmacy, Gadjah Mada University, the institution in Indonesia in which I work. As a result, research approval letters from local government offices included the Faculty of Pharmacy, Gadjah Mada University as the researcher’s institution.

The approval letters from the provincial government were then submitted to the Kupang municipality government (Appendix 4.3) and the health department office (Appendix 4.4). The letters of approval from the municipality government and health department office were then submitted to the primary health centres (PHCs).

5.3.2 Study locations and justification

The qualitative study exploring diabetes patients’ perceptions and experiences was performed in West Sumatera and East Nusa Tenggara. In this following intervention study, the study was conducted in Kupang, the capital city of East Nusa Tenggara Province. As detailed in Chapter 1, diabetes prevalence in East Nusa Tenggara was higher than in West Sumatera. Further, with lower socio-economic status, the financial burden of diabetes in East Nusa Tenggara is higher than the other regions in Indonesia. Kupang, the capital city and the most urban area of the province was chosen as the study location. The population density in Kupang is higher than in other areas of the province. The city also has more health resources including health centres and laboratory facilities. The intervention
study was conducted in collaboration with healthcare facilities, and the HbA1c outcome was measured in collaboration with the local clinical laboratory.

Kupang is situated on Timor Island. With a total land area of 180.27 km$^2$, Kupang has a population of 402,286 people in 2016 [535]. The city is divided into six sub-districts and 51 villages (Figure 5.3). The six sub-districts in Kupang include Alak, Kota Raja, Kota Lama, Kelapa Lima, Oebobo, and Maulafa sub-districts [535]. Kupang city has 11 state-owned and private hospitals, 11 community health centres (Puskesmas), 29 private clinics, and 39 village level community health centres (Pustu) [535]. Table 5.1 describes the number of healthcare facilities in each sub-district in comparison with the population.

![Figure 5.3: Sub-districts in Kupang municipality](https://commons.wikimedia.org/wiki/File:Peta_Timor_Barat_-Kabupaten_dan_Kecamatan.png)

By Maximilian Dörrbecker (Chumwa) [CC BY-SA 2.0 (https://creativecommons.org/licenses/by-sa/2.0) or ODbL (http://opendatacommons.org/licenses/odbl/1.0/)], from Wikimedia Commons, modified
Table 5.1: Population and healthcare facilities in sub-districts in Kupang city [535]

<table>
<thead>
<tr>
<th>Sub-districts</th>
<th>Population</th>
<th>Number of hospitals</th>
<th>Number of community health centres (Puskesmas)</th>
<th>Number of private health clinics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alak</td>
<td>62,090</td>
<td>1</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Maulafa</td>
<td>75,459</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Oebobo</td>
<td>97,696</td>
<td>4</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Kota Raja</td>
<td>53,953</td>
<td>2</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Kelapa Lima</td>
<td>78,850</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Kota Lama</td>
<td>34,238</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

5.3.2.1 Languages used in the study location

As the biggest urban city in East Nusa Tenggara Province, Kupang is the melting pot where people from rural areas of the province and other surrounding provinces come and live together. Culturally, therefore, the people of Kupang come from diverse ethnic groups, both from within the province and from outside the province. Because of this, ethnic languages are rarely used for everyday conversation, particularly in public places. The people mainly use the Indonesian national language (Bahasa Indonesia) as their everyday language.

Local cultures, however, have influenced the Bahasa Indonesia, so that local dialect and local word choices are commonly applied. People in Kupang commonly speak more loudly and faster than the people from the western part of Indonesia. Because of the speed of speech, they often only say the first syllable of words. They also often change the word order in their dialect from the common word order in the Indonesian language.

Culturally, I am Javanese, which is different from the study participants. Bahasa Indonesia was therefore used throughout the study process. Modification with local dialect and word choices were made. During the research process, I lived in the houses of local people in Kupang. Subsequently, I also learnt about the local dialect and word choices.
5.3.3 Establishing collaboration with health professionals and the community

The first stage in conducting the study was establishing collaboration with health professionals and communities in Kupang. During this stage, I invited health professionals in primary healthcare facilities – including community health centres (Puskesmas) and private health centres – and academic communities to collaborate in the study. I approached the head of eight primary health centres (PHCs), and discussed the possibility of implementing the project. Based on the discussions, we decided to implement the project in four PHCs:

1. Puskesmas Sikumana, located in Maulafa sub-district.
2. Puskesmas Oepoi located in Oebobo sub-district.
3. Puskesmas Oebobo, located in Oebobo sub-district.
4. Layanan Kesehatan Cuma Cuma – LKC - Charity health centre privately owned by Dompet Dhuafa, a faith-based non-government organisation, located in Alak sub-district.

The eight primary health centres approached welcomed and appreciated the project. Some of them, however, expressed lack of capacity and capability of health professionals who might be involved in the programme. Health professionals in Puskesmas are often overburdened with clinical and administrative tasks, so that they have limited time for additional tasks.

During this stage, I also approached academic staff at the Faculty of Public Health, Nusa Cendana University, and Kupang Health Polytechnic (Politeknik Kesehatan Kupang) to collaborate in the project. Eight research assistants were recruited from undergraduate students at the Faculty of Public Health, Nusa Cendana University. The research assistants were involved in data collection processes as interviewers. Some academic staff at Kupang Health Polytechnic agreed to take part as providers in some educational activities.

5.3.4 Existing diabetes related programmes at the healthcare facilities who collaborated in the study

Most Puskesmas in Kupang have implemented Posyandu lansia and Posbindu PTM, the national programmes focused on non-communicable diseases. These two
programmes are designed for early detection of risk factors for non-communicable diseases. The programmes, therefore, invite participation from the general population, and not specifically for those who have been diagnosed with non-communicable diseases.

In mid-2015, health centres in Kupang started implementing Prolanis, a programme focused on people with diabetes and hypertension, aimed at improving their outcomes. The Prolanis programme was managed by the Universal Health Coverage (UHC) scheme; therefore, the programme is implemented not only by government-owned healthcare facilities but also private healthcare facilities which collaborated with insurance management. Based on observation and communication with health professionals, however, implementation of the Prolanis in health centres depended on the availability of resources and capability of the health centres. In some Puskesmas, the Prolanis programme is integrated with the Posyandu Lansia. The main activity of the Prolanis programme is establishing a Prolanis club. The members of the Prolanis club are people with diabetes and/or hypertension registered in the healthcare facilities under the UHC scheme. Activities within the club are mainly light exercise and health status measurements. Education sessions were also sometimes provided. The four health centres involved in the study have implemented the Prolanis programme. The frequency of activities, and the number of people with diabetes registered to the clubs, however, differed.

Initial discussions were held with the head of the health centres involved in the study. As the intervention targeted diabetes patients, the head of the health centres agreed that the intervention would be conducted in collaboration with the Prolanis programme. They also agreed that the activities within the Prolanis would be modified according to the research project agenda.

Table 5.2 shows that there are considerable differences in the number of diabetes patients involved in the Prolanis club in the four health centres involved in the study. Based on Table 5.1 described previously, the population in Oebobo sub-district, in which Puskesmas Oebobo and Oepoi are located, is higher than that of in Maulafa sub-district, in which Puskesmas Sikumana is located. The Oebobo sub-
district has more health centres, however, including private clinics. Consequently, diabetes patients in Oebobo sub-district may also be distributed over those health facilities as people commonly registered to a health centre closest to their home. The number of the patients registered in Puskesmas Oebobo and Oepoi, therefore, was fewer than that in Puskesmas Sikumana. The LKC health centre is a non-government faith-based health centre. This health centre provides health services only for its members, and specific criteria are applied for people to become members. This health centre therefore has the fewest diabetes patients.

Table 5.2: *Prolanis* programme implementation in the healthcare facilities that collaborated in the study and the number of diabetes patients in the *Prolanis* club

<table>
<thead>
<tr>
<th>Health facilities involved in the study</th>
<th>Frequency of <em>Prolanis</em> club activities</th>
<th>Number of diabetes patients in the <em>Prolanis</em> club</th>
</tr>
</thead>
<tbody>
<tr>
<td>Puskesmas Oepoi</td>
<td>Once a week</td>
<td>16</td>
</tr>
<tr>
<td>Puskesmas Oebobo</td>
<td>Once in two weeks</td>
<td>16</td>
</tr>
<tr>
<td>LKC health centre</td>
<td>Once a month</td>
<td>8</td>
</tr>
<tr>
<td>Puskesmas Sikumana</td>
<td>Once a month</td>
<td>59</td>
</tr>
</tbody>
</table>

5.4 Participants

5.4.1 Eligibility criteria

Eligibility criteria were applied to ensure that the participants were capable of doing intervention activities. Inclusion criteria included: diagnosed with type 2 diabetes mellitus at a healthcare facility or by healthcare professionals; taking diabetes medication; and able to understand and comprehend information. The exclusion criteria of participants included having major organ complications of diabetes, or being pregnant.

5.4.2 Sample size calculation

Currently, there is no published literature on similar interventions conducted in the Indonesian context, so it was difficult to estimate an effect size for interventions conducted in similar settings. Therefore, we estimated the sample size for the study based on Lifestyle Over and Above Drugs in Diabetes (LOADD) study conducted in New Zealand [536]. The sample size calculation used a standard deviation of HbA1c of 1.4%, and a correlation between measures of 0.74. We needed to include at least 32 participants in each group to detect a change of
0.5% in HbA1c using the analysis of covariance (ANCOVA) method, with power of 80% and at 5% level of significance, allowing for a 10% dropout rate.

5.4.3 Participant recruitment

5.4.3.1 Finding potential participants

Data about potential participants were gathered from the list of diabetes patients registered in the four health centres involved in the study, and screened for eligibility by the researcher and health professionals at the health centres. Attempts were also made to increase the number of potential participants through a community screening programme. The community screening enabled us to find undiagnosed diabetes patients. Two community screening sessions in Oebobo sub-district were performed. The screening programmes were conducted in collaboration with *Puskesmas* Oepoi.

Invitations to attend a health check were announced to the community using a portable loudspeaker with an ambulance going around the areas (Figure 5.4). After conducting two screening programmes (Figure 5.5), we found that the screening activities were ineffective in finding potential participants. Only a few people were detected to have high blood glucose levels. The likely explanation for this might relate to the Indonesian people’s health seeking behaviours explained in Chapter 2. Most Indonesians would not seek care unless they experience symptoms which hinder their everyday activities. The people who were detected with high blood glucose level were invited to the *Puskesmas* for diagnosis confirmation, and were also invited to attend the *Prolanis* activities. Only one person detected from the community screening process came to *Puskesmas* and was confirmed to have diabetes. This person was also invited to participate in the study.
Figure 5.4: Announcement of the screening programme

Figure 5.5: Diabetes community screening activities
5.4.3.2 Participants recruitment

A total of 72 eligible potential participants were contacted through short messages, and phone calls to attend information sessions about the study. The information sessions were conducted at the same time as Prolanis club activities in the health centres. Sixty-eight diabetes patients came to the designated place at the time. The information sheet (Appendix 5.1 and Appendix 5.2) about the project was explained, and time to ask questions and think about whether or not to continue participating was provided. Those who agreed to participate were then provided consent forms to sign (Appendix 5.3 and Appendix 5.4). All 68 potential participants who came to the sessions agreed to participate and signed the consent forms. They were then invited to have their baseline data collected.

Figure 5.6: Prolanis teams (with the researcher) in the health centres that collaborated in the study
Notes: Left above: Puskesmas Sikumana, Left below: Puskesmas Oebo, Right above: Puskesmas Oepoi, Right below: LKC health centre

5.4.4 Intervention and control group allocation

Further discussions were conducted with Prolanis programme managers, and decisions were made about allocation of participants into the control and intervention groups. The decision about how participants in each health centre were allocated was mainly based on the availability of the health professionals at...
the health centres to be involved in managing the intervention activities. The Prolanis team at the health centres consist of one health professional, mainly a nurse, as the leader of the team, and other supporting health professionals, including physicians and nurses. Puskesmas Sikumana had the fewest health professionals involved in the Prolanis team, compared to other health centres (Figure 5.6). Participants registered in Puskesmas Sikumana were therefore allocated to the control group, and the participants registered in Puskesmas Oebobo, Puskesmas Oepoi, and LKC health centre were allocated into the intervention groups.

Initially, 68 participants were recruited: 32 participants in the control group; and 36 participants in the intervention group. After the baseline data collection process, however, one participant from the control group was excluded. This participant was not confirmed to suffer from diabetes based both on HbA1c
measurement and questionnaire responses. This participant was originally enlisted on the basis of being registered as a diabetes patient in the health centre. In total, therefore, 67 participants were involved in the study: 31 participants in Puskesmas Sikumana were assigned into the control group; and 36 participants in Puskesmas Oebobo, Puskesmas Oepoi, and LKC health centre were assigned into the first, second, and third intervention groups, respectively (Figure 5.7).

Participants in the intervention group received an intensive group-based intervention conducted in collaboration with the Prolanis club, and the participants in the control group received usual care provided by Puskesmas Sikumana. Apart from the intensified activities, participants in the intervention group also received usual care provided by their physician. The usual care provided in the Puskesmas Sikumana may include care by a physician at the Puskesmas, and may also include usual activities in the Prolanis club in the Puskesmas. The study did not prohibit self-management education recommended by usual care providers or sought by study participants.

5.5 The intensive group-based intervention

5.5.1 Initial meeting and discussion with providers of the intervention

Separate meetings were conducted with the health professionals in the Prolanis team in each health centre. During the meeting, details of the project were explained. Schedules, content, and education material were also discussed and explained. The educational materials were prepared by the researcher. The content of the educational material and method of delivery were also explained.

5.5.2 Content and new initiatives

The intervention designed in the study was an intensification of the usual Prolanis club activities with new initiatives added. Development of these new initiatives was guided by the results of the qualitative study described in Chapter 3, and the literature study about diabetes interventions described in Chapter 4. Table 5.3 describes the new initiative implemented.
Table 5.3: New initiatives in the Prolanis implementation

<table>
<thead>
<tr>
<th>Activities</th>
<th>New initiatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of activities</td>
<td>During the intervention study, the frequency of activities was intensified: ten sessions conducted within three months. To increase participation, a friendly short message was sent by health professionals reminding them a day before each session.</td>
</tr>
<tr>
<td>Educational session</td>
<td>Educational sessions focused on improving self-efficacy and skills. <strong>Interactive communication:</strong> The education activities were delivered interactively in a group. <strong>Literacy tailored education material:</strong> Leaflets were developed by the researcher in simple language. Pictures were used for illustrating the explanations. <strong>Peer modelling:</strong> Some participants were invited to tell their story in managing diabetes in the group. <strong>Incentive motivation:</strong> Focus on encouraging people to implement the intended behaviour: after some educational sessions, they were encouraged to implement an individual task during the next week. On the following session, they were invited to share their experiences in implementing the task. Small rewards were provided for those who implemented the task well.</td>
</tr>
<tr>
<td>Physical activity</td>
<td><strong>Culturally tailored:</strong> some physical activity sessions incorporated traditional dance with traditional music.</td>
</tr>
<tr>
<td>Health and medication check</td>
<td><strong>Self-regulation:</strong> Two health cards were provided along with a small bag for participants to keep the education material and the cards. The cards included:</td>
</tr>
<tr>
<td></td>
<td>• A health card, on which their blood pressure or blood glucose level were written. With this card, they were able to monitor their disease.</td>
</tr>
<tr>
<td></td>
<td>• A medication taking card: a card on which the participants put a mark after taking medicines. This card was designed as a tool to improve adherence to medicines taking, and minimise forgetfulness when taking the medicines.</td>
</tr>
<tr>
<td></td>
<td><strong>Feedback:</strong> Feedback was also provided in line with the results after health check.</td>
</tr>
<tr>
<td>Snack programme</td>
<td>Healthier snacks for diabetics were introduced in some sessions.</td>
</tr>
</tbody>
</table>

5.5.3 Intervention sessions

5.5.3.1 Timing

Intervention sessions in Puskesmas Oepoi and Oebobo were conducted every Saturday morning at 6.00 AM to 8.00 AM. In Puskesmas Oepoi, the intervention activities were performed in the Puskesmas, while in Puskesmas Oebobo, the activities were conducted in the sub-district government office. Meanwhile, in the LKC health centre, the agreed times for intervention activities were two different schedules: on Saturdays of the first week of the month; and on Fridays for the rest of the month. Timing was the same for both schedules, from 7.30 AM to 9.30 AM. The activities were conducted in the health centre.
5.5.3.2 Intervention schedule and participants’ attendance

The intervention sessions were conducted in collaboration with Prolanis club activities. The members of the Prolanis clubs were people with diabetes, people with hypertension, and people with both hypertension and diabetes. Based on discussions with health professionals in the Prolanis team, separating them into two groups was not practical as some participants suffered from both diabetes and hypertension. Furthermore, health professionals also argued that it was a good idea to involve patients with high blood pressure for activities focused on diabetes, as having high blood pressure is a risk factor for developing diabetes. The intervention sessions were therefore attended by not only diabetes patients, but also the club members with hypertension.

Ten sessions were conducted within three months starting from 15 October 2016 to 13 January 2017 (Table 5.4). Attendance rate of participants in each session varied from 43% to 100%.

Table 5.4: Intervention sessions in each group and percentage of participants attending each session

<table>
<thead>
<tr>
<th>Sessions</th>
<th>First intervention group (Puskesmas Oebobo)</th>
<th>Second intervention group (Puskesmas Oepoi)</th>
<th>Third intervention group (LKC health centre)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Date</td>
<td>Participant attendance</td>
<td>Date</td>
</tr>
<tr>
<td>1</td>
<td>22 Oct 2016</td>
<td>100%</td>
<td>15 Oct 2016</td>
</tr>
<tr>
<td>2</td>
<td>29 Oct 2016</td>
<td>100%</td>
<td>22 Oct 2016</td>
</tr>
<tr>
<td>3</td>
<td>5 Nov 2016</td>
<td>87.50%</td>
<td>29 Oct 2016</td>
</tr>
<tr>
<td>4</td>
<td>12 Nov 2016</td>
<td>75%</td>
<td>5 Nov 2016</td>
</tr>
<tr>
<td>5</td>
<td>19 Nov 2016</td>
<td>68.75%</td>
<td>12 Nov 2016</td>
</tr>
<tr>
<td>6</td>
<td>26 Nov 2016</td>
<td>75%</td>
<td>19 Nov 2016</td>
</tr>
<tr>
<td>7</td>
<td>10 Dec</td>
<td>62.50%</td>
<td>26 Nov 2016</td>
</tr>
<tr>
<td>8</td>
<td>17 Dec</td>
<td>81.25%</td>
<td>10 Dec 2016</td>
</tr>
<tr>
<td>9</td>
<td>7 Jan 2017</td>
<td>43.75%</td>
<td>17 Dec 2016</td>
</tr>
<tr>
<td>10</td>
<td>14 Jan 2017</td>
<td>75%</td>
<td>7 Jan 2017</td>
</tr>
</tbody>
</table>

Table 5.5 describes the percentage of sessions attended by each participant in the intervention groups. It shows that two participants in Puskesmas Oebobo group only attended two sessions and two participants in LKC health centre group attended only three sessions or less. The two participants in Puskesmas Oebobo mentioned that they worked in the morning on some Saturdays, so they could not
come regularly. The two participants in LKC health centre who attended only three sessions or less did not provide a reason for non-attendance.

Table 5.5: Percentage of sessions attended by each participant in the intervention groups

<table>
<thead>
<tr>
<th>Percentage of sessions attended by each participant</th>
<th>First intervention group (Puskesmas Oebobo)</th>
<th>Second intervention group (Puskesmas Oepoi)</th>
<th>Third intervention group (LKC health centre)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 1: 60%</td>
<td>Participant 1: 80%</td>
<td>Participant 1: 90%</td>
<td></td>
</tr>
<tr>
<td>Participant 2: 100%</td>
<td>Participant 2: 70%</td>
<td>Participant 2: 30%</td>
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<tr>
<td>Participant 3: 90%</td>
<td>Participant 3: 70%</td>
<td>Participant 3: 90%</td>
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<tr>
<td>Participant 4: 100%</td>
<td>Participant 4: 70%</td>
<td>Participant 4: 90%</td>
<td></td>
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<tr>
<td>Participant 5: 100%</td>
<td>Participant 5: 80%</td>
<td>Participant 5: 90%</td>
<td></td>
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<tr>
<td>Participant 6: 60%</td>
<td>Participant 6: 60%</td>
<td>Participant 6: 90%</td>
<td></td>
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<tr>
<td>Participant 7: 90%</td>
<td>Participant 7: 90%</td>
<td>Participant 7: 20%</td>
<td></td>
</tr>
<tr>
<td>Participant 8: 100%</td>
<td>Participant 8: 60%</td>
<td>Participant 8: 90%</td>
<td></td>
</tr>
<tr>
<td>Participant 9: 70%</td>
<td>Participant 9: 90%</td>
<td></td>
<td></td>
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<tr>
<td>Participant 10: 80%</td>
<td>Participant 10: 100%</td>
<td></td>
<td></td>
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<tr>
<td><strong>Participant 11: 20%</strong></td>
<td>Participant 11: 70%</td>
<td></td>
<td></td>
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<tr>
<td>Participant 12: 60%</td>
<td>Participant 12: 80%</td>
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<tr>
<td>Participant 13: 90%</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Participant 14: 90%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Participant 15: 20%</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant 16: 100%</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

5.5.3.3 Intervention activities

There were four main activities in each intervention session: physical activity; education; health check; and healthy snacking. Prayers led by a participant or health professional were also conducted, either for opening or closing the sessions. The order of these activities differed in each intervention group.

Physical activities

The physical activities were done mostly in the form of ‘senam’ - light aerobic dance exercise with music. Foot exercise, and ‘laugh therapy’ (terapi tertawa) were also conducted (Figure 5.8). The laugh therapy was introduced by academic staff at Politeknik Kesehatan Kupang. The therapy has never been practised before by these groups. During the laugh therapy, we moved our bodies while laughing.
Figure 5.8: Physical activities conducted in the intervention group

a. *Senam* – light aerobic dancing exercise  
b. Laugh therapy (*terapi tertawa*)  
c. Foot exercise  
d. *Senam* activity in LKC health centre
Figure 5.9: Education sessions in the intervention group

a. Education session in the first intervention group, participant answering the question asked by the education provider.
b. Education session in the second intervention group, participants asking questions.
c. Education session in the third intervention group.
d. Rewards were provided to the participants who completed an individual task from the previous week.
The types of dance in each health centre and each session were varied, based on the creativity of the facilitators. In some sessions, traditional dancing with music was also performed. People in Kupang love dancing, and they often have dancing sessions in cultural or traditional feasts. The exercise activities lasted for about half an hour.

**Educational activities**

As discussed previously, the new initiatives of educational activities focused on improving self-efficacy – confidence about the ability to perform recommended behaviours – and skills. The educational content was delivered with an interactive teaching style. Educational materials were developed by the researcher, considering people’s literacy and general understanding about diabetes explored in the qualitative study. The materials were leaflets with big font and many pictures and diagrams (Appendix 6). A small bag was also provided to each participant for them to keep the education materials in, so that the leaflets could be read again at home, or read by other family members.

The educational providers involved in the study were mainly the researcher, and the health professionals in the *Prolanis* team. In one session, the education was also provided by academic staff from *Politeknik Kesehatan Kupang*. Figure 5.9 illustrates some education sessions conducted in the intervention group.

Observational learning through peer modelling was also applied by inviting some participants to share their positive experiences in managing diabetes. Incentive motivation was also applied by providing an individual task to be completed during the following week. The participants recorded their achievement in the leaflets provided. On the following session, they were given opportunities to share their experiences in implementing the task. Small rewards were provided for participants who implemented the task well.

The educational sessions covered seven topics of diabetes including: understanding diabetes; the meaning of blood glucose level; diabetes medicines and medication adherence; diet for diabetes; physical activity; foot care; and diabetes complications. The topics about diabetes medicines and medication
adherence, and diet for diabetes were delivered in two sessions. One education session was storytelling, in which one participant in each intervention group was invited to share his or her experience in managing diabetes.

_Mengenal diabetes_ (understanding diabetes)

This topic presented basic knowledge related to diabetes including early symptoms and risk factors. During the explanation, participants were invited to share common understandings about diabetes. Misconceptions encountered were addressed. Misconceptions encountered were related to diabetes classification, and the lay terms for diabetes. Participants mentioned that diabetes was classified into two types: _penyakit gula basah_ (wet sugar disease), and _penyakit gula kering_ (dry sugar disease). Local terms describing diabetes were _penyakit gula_ (sugar disease), and _penyakit kencing manis_ (sweet pee disease). The use of term _penyakit gula_ often misunderstood that _gula_ or sugar is the main cause of diabetes. Participants associated _gula_ with white cane sugar. Many participants therefore questioned about a local type of sugar, known as _gula lempeng_. _Gula lempeng_ (coin-shaped brown sugar) is made from _neera_ (_lontar_ palm nectar). Some of them believed that _gula lempeng_ would not cause diabetes. Some participants also asked about honey from bees; they also believed that honey would not cause diabetes.

_Apa arti hasil kadar gula darah anda?_ (What is the meaning of your blood glucose level?)

This topic covered types of blood glucose measurements, including fasting blood glucose, random blood glucose, _HbA1c_, and their meanings. After the explanation, the copy of the _HbA1c_ test result at baseline was provided to the participants. They were then asked to write the result in the table provided on the leaflet, and evaluate the result by themselves. They were also encouraged to write down results of the last blood glucose measurements, and evaluate them. Many participants wanted to know more about the results, and individual consultations were provided afterwards.

The _HbA1c_ test was a new type of blood glucose measurement for the vast majority of participants involved in the study. The blood glucose measurements
provided by the health centres were commonly the fasting or random blood glucose, measured mainly with a point of care device. In this session, the topic of pre-diabetes was also introduced.

_Tahukah anda obat diabetes atau hipertensi yang anda minum?_ (Do you know about diabetes and/or hypertension medicines you are taking?)

This topic was delivered in two sessions. The first session was an explanation about the medicines for diabetes and hypertension: how they work; and why they need to be taken regularly. Medicines for hypertension were included in this session, as some diabetes patients experienced co-morbidity with hypertension. This medication session particularly stressed the problems encountered by participants in taking the medicines regularly. Participants mentioned that forgetfulness was the main problem in taking medicines. Some participants mentioned that they did not know the name of the medicines they were taking, and some of them described it based on the medicines’ characteristics, for example, ‘the small white tablets’.

After the first session of about diabetes medication, the participants were encouraged to practise some individual tasks including:

- **Recognising the name of the medicines they were taking.** The participants were encouraged to have a look at the medicines they had, and read or have their family members read for them the names of each medicine.
- **Filling in a ‘medication taking card’** (Figure 5.10). This medication taking card was developed to improve adherence to medication. After recognising the name of the medicines, the participants were encouraged to write the name of the medicine and its dosage instruction on the card. The rows of the table are for the date of the month, and the columns of the table are for the dosage, 1<sup>st</sup> dose, 2<sup>nd</sup> dose, and 3<sup>rd</sup> dose. After taking each dose of the medicine, the participants were encouraged to put a mark in the relevant row and column. Explanation of how to fill in the card was done in group, and in one-on-one sessions afterwards.
Figure 5.10: The medication-taking card

| Tgl |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| 1   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 2   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 3   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 4   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 5   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 6   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 7   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 8   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 9   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 10  |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 11  |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 12  |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 13  |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |

Figure 5.11: Medication-taking card made by one participant
The second session of the topic about medication was a sharing session about the participants’ experiences of practising the individual tasks. Participants found that the medication taking card was helpful for minimising forgetfulness in taking the medicines. Interestingly, one participant made his own medication taking card based on all the medicines he was taking. The medication taking card provided was intended for one medicine, so that if the participants received three medicines, they would have three cards. So, this one participant made his own card and combined the three medicines in one card (Figure 5.11).

*Diet sehat, bagaimana caranya?* (Healthy diet, how to do that?)

Diet for diabetes was also delivered in two sessions. The first one explained about the plate method, and the second one was a discussion about local foods available and their impact on diabetes. The participants shared that controlling diet, particularly in reducing the rice portion, was the most difficult part of managing diabetes. They said they did not feel full if they had not had enough rice in their meals. After the explanation session, participants were also encouraged to write about what they ate during the following week.

In the second session, participants were invited to share efforts they have made for managing diet. Discussion about diet revealed some misunderstanding about proper diet for diabetes. Participants questioned about whether the way of cooking rice impacted on the amount of sugar in it, and what food sources should be restricted for diabetes patients and why.

*Sudahkah anda berolahraga hari ini?* (Have you been exercising today?)

The education about exercise aimed at encouraging participants to practise individual physical activity. Walking, particularly, was encouraged as it is the cheapest and easiest form of exercise. Some participants asked about walking barefoot on gravelly surfaces. They believed that walking on gravel may improve blood circulation to their foot, like a foot massage. Some pedestrian paths in Kupang are designed with gravel on them. This may imply that participants were not aware of the risk of foot injury as a result of walking barefoot. After the explanation session, an individual exercise task was also provided. The participants were encouraged to record the exercise they practised during the
upcoming week in the table provided on the leaflets. Some participants did this well, as illustrated in Figure 5.12.

**Figure 5.12: Participants’ individual exercise activities**

*Perawatan kaki untuk diabetes* (Foot care for diabetes)

Education about foot care aimed to increase participants’ awareness about foot complications of diabetes, and encouraged the diabetes participants to practise daily inspection of their feet. This topic was presented along with a foot exercise programme.

**Storytelling**

One education session focused on providing role models for the diabetes participants (Figure 5.13). The role models were chosen from diabetes participants in each intervention group who experienced better control of diabetes than the others. These role models were invited to share their experiences in managing the diabetes. In the first intervention group (*Puskesmas Oepoi*), the role model was a participant who had suffered from diabetes for 21 years. He explained that he managed the diabetes with controlling diet, exercising regularly, and taking medicines. He mentioned that it was not easy at the beginning, and being persistent and patient was the key to successfully managing diabetes. In the second intervention group (*Puskesmas Oebobo*), one participant
aged 70 had experienced diabetes for around four years. She also had her diabetes well-controlled and had an active life. She shared that the key point was to always have a happy life. She actively participated in activities for diabetes patients.

In the LKC health centre, one participant had diabetes for 10 years, and her blood glucose level was also well-controlled. She shared that her success in controlling diabetes was mainly because of very supportive health professionals at the health centre. She mentioned that the health professionals sometimes home-visited the patients. One other participant also shared that he experienced a diabetes wound on his limb. Because of the wound, he could not come to the health centre, but the health professional home-visited him to take care of his feet regularly.

*Komplikasi, apa dan bagaimana mencegahnya?* (Diabetes complications, what and how to prevent them?)

This topic was provided in the last intervention session. This final session aimed to remind and encourage the participants to practise the recommended actions for managing diabetes explained at the previous sessions, and explain the diabetes-related complications. This topic was delivered interactively with a question and answer session. The majority of participants responded well to the questions asked. Some of them, however, commented: “it’s bit easy for answering questions, but actually it’s difficult to practise. Often after we got home, we still did what we usually did, although we knew that we should not do those things, not eat those things. But ... it’s hard, but ... at least we know”.

5.5.3.4 *Measurement of blood pressure and blood glucose*

During the intervention sessions, blood pressure was measured in each session, and fasting or random blood glucose measurements were provided twice (Figure 5.14 and Figure 5.15). The measurements were conducted as part of routine assessment for the members of *Prolanis* club, and these data were not included as part of the research. This was because different measurement tools were used in each group, therefore, the chance of having variability of result because the variability of measurement tools was high. Participants’ attendance at the sessions also varied, so that complete data could not be gathered.
Figure 5.13: Role models’ education sessions
Figure 5.14: Blood pressure measurement

Figure 5.15: Blood glucose measurement during the study period
5.5.3.5 *Healthy snacking*

In some sessions, a healthy snacking programme was also introduced. The researcher and *Prolanis* team prepared snacks suitable for diabetes participants. We ordered snacks with specific instructions. For example, low sugar bread, green bean porridge with low-calorie sweetener, and rissoles with vegetables inside. Although the participants enjoyed the snacks, some of them complained about the taste, that it was not the proper way of serving it, for example, the snacks were not as sweet as they should be.

5.5.4 *Participants’ and health professionals’ perspectives related to the implementation of the intervention programme*

After the intervention session finished, four individual interviews and a focus group with participants involved in the intervention group were conducted. Individual interviews with two *Prolanis* team leaders in the intervention groups were also conducted. The interviews and focus group aimed at gathering participants’ and health professionals’ opinions related to the implementation of the intervention.

5.5.5 *Safety consideration*

During the intervention sessions, participants’ conditions were closely monitored. Individual assessment was conducted before each group session to ensure that the participants were capable of doing exercise. No adverse events were encountered during the study.

5.6 *Outcomes measured*

Outcomes of this experimental study were collected at baseline, and at follow-up – approximately three months after baseline data collection. The outcomes measured were HbA1c, knowledge, medication adherence, and self-care behaviours. The clinical outcome of HbA1c was gathered in collaboration with a local clinical laboratory. The socio-demographic characteristics, knowledge, self-care behaviour, and medication adherence were collected using interviewer-administered questionnaires.
5.6.1 HbA1c

The clinical outcome measure HbA1c, and its measurement was conducted by the local clinical laboratory, PT. Prodia Widyahusada (Figure 5.16). After discussion with the marketing manager in the laboratory, a Memorandum of Understanding (MoU) was signed. The laboratory analysed HbA1c level from venous blood samples with an Ion Exchange High Pressure Liquid Chromatography (HPLC) method which has been standardised by the National Glyco-haemoglobin Standardization Programme. The blood samples were drawn by qualified laboratory staff. It was also agreed that the laboratory staff came to the health centres at the time of baseline and follow up data collection. Venous blood samples were taken and stored in a tube containing anticoagulant Ethylenediaminetetraacetic acid (EDTA). These blood samples were then brought to the laboratory for analysis.

5.6.2 Questionnaires

The questionnaire for collecting socio-demographic, knowledge, medication adherence and self-care behaviours was administered orally. According to academic staff in Nusa Cendana University, based on their experiences of conducting surveys, lay people in Kupang commonly have difficulty in filling questionnaires by themselves, particularly when the questions are in formal Indonesian language. The questionnaire was therefore administered orally to the participants by research assistants. The research assistants were native speakers of the participants’ language, so that they were able to modify questions to a more conversational style to improve participants’ understanding of the questions.

The questionnaire was originally developed to include 14 questions on socio-demographic and diabetes experiences, 10 questions on knowledge, 18 questions on medication adherence, and 14 questions on self-management behaviours. After testing the questionnaire, however, it was modified. The knowledge section was changed to include 38 questions. Explanation on this in detail is provided in the questionnaire testing section.
Figure 5.16: Collaboration with laboratory clinic of PT. Prodia Widyahusada for HbA1c measurement

Figure 5.17: Participants involved in the questionnaire testing along with the researcher
5.6.2.1 Questionnaire translation

The questionnaires were developed in English, and translated into the Indonesian national language (Bahasa Indonesia) with a forward and backward translation process. The English version was translated into Indonesian, and the Indonesian version was back translated into English by different translators. This process involved four translators who were fluent in both languages, two of them as forward translators, and the other two as backward translators.

After the forward and backward translation process, the backward translated version was compared to the original version by the researcher's supervisors. No major differences were found between versions. Different word choices found were synonyms, and can be used interchangeably without altering the meaning. Some issues related to words with specific meaning in the Indonesian language were encountered and resolved.

As an example, in the English version, there were technical terms in questions about dietary behaviour: carbohydrate; and protein. For lay people in Indonesia, these terms were not commonly used. Carbohydrate was therefore translated into nasi or rice, and protein was translated into lauk, which in English, literally translated as ‘side dish’. Nasi or rice is the staple food mostly eaten in every meal, and lauk is referred to a side dish mainly as a source of protein which is eaten with rice. People referred lauk to meat, chicken, fish, tempeh, or tofu.

Another example was related to the translation of the word ‘exercise’. In one back translated version, the translator used the term ‘sport’, which in English has a different meaning from exercise. In the Indonesian language, both words ‘exercise’ and ‘sport’ are translated into the same word in Indonesian: olahraga. In this case, more explanation was given in translating the word exercise by including examples of activities in the meaning of exercise.

There was also an issue related to the use of word ‘herbals’. One translator used ‘alternative medicines’ for herbals. In the Indonesian language, the word herbal is often used interchangeably with alternative medicines, or traditional medicines, which describes any medicine other than medicines from formal health providers.
The Indonesian people refer to medicines as ‘obat’, which means conventional medicines.

5.6.2.2 Questionnaire testing

The translated version of the questionnaire was tested before the data collection process. The participants involved in the questionnaire testing were people with diabetes who were registered in a health centre which was not included in the experimental study. They were recruited with snowball sampling, in which one diabetes participant who agreed to be involved in the trial invited his or her diabetic friends registered in the same health centre. The trial involved seven participants and was performed on 1st October 2016 at 09.00 AM to 12 PM (Figure 5.17). Two research assistants who had been previously trained were involved in the process of questionnaire testing as interviewers. After the interview process, discussions were held with respondents to get feedback about the questions. The discussions pointed out two important points of the questionnaire:

1. The multiple choice questions in the knowledge section were difficult to administer orally as the participants needed to remember the choices before choosing the best option. Remembering the choices took more time, and the interview process often went back and forward to the choices several times. Finding this problem, the participants answered one by one of each choice after it was read to them. At the end, however, we sometimes found no clear final answer to the questions, as they answered ‘true’ for more than one option. The multiple choices questions, therefore, were then changed into dichotomous – true and false – questions. Consequently, the 10 multiple choice questions about knowledge were changed into 38 true and false questions.

2. In the self-management behaviour section, questions about dietary habits were found to be the most difficult part, particularly in the questions about the ‘plate portions’ [537]. Some participants shared that the ways they put food on the plate was different, so that it was difficult to approximate the portion compared to the whole plate. As an example, they usually put the vegetables over the rice, or put the vegetables in separate bowl. Addressing
this problem, we then decided to elaborate more on the plate portion questions in an easier way. If, therefore, the participants were confused in answering the plate portion questions, they were asked which part of their meal was the largest. If they answered the largest portion was the rice, we assumed that the rice portion would be more than a quarter part of their plate, and the vegetable portion would be less than the recommended portion of half of the plate.

5.6.2.3 The final version of the questionnaire

The final version of the questionnaire included 14 questions about socio-demographic characteristic and disease experiences, followed by 38 questions about diabetes knowledge, 18 questions related to medication adherence, and 14 questions on self-management behaviours (Appendix 7).

Socio-demographic characteristics and diabetes experiences
Socio-demographic data included age, gender, income per month, marital status, and completed education level. These socio-demographic characteristics were asked at the beginning of the questionnaire followed by questions about diabetes experiences such as diabetes duration, medication taking, and other diabetes management experiences, including attending diabetes programme, and visiting a dietitian (Figure 5.18).

Knowledge
The questions on diabetes knowledge were developed based on the results of the qualitative study. Findings of the qualitative study indicated that peoples’ basic knowledge about diabetes symptoms, risk factors, causes, complications and management were limited. As previously mentioned, the knowledge outcome was first designed to be collected with 10 multiple choice questions. After the questionnaire testing, these 10 multiple choices knowledge questions were changed into 38 dichotomous questions (Table 5.6). The 38 questions consisted of nine positive questions, and 29 negative or reverse questions. The reverse questions were coded with (R) in the Table 5.6. The questions asked participants’ understanding of the causes of diabetes (question numbers 1-4; and 24-26),
diabetes risk factors (questions numbers 5-7; and 23), diabetes medication (questions numbers 8-11), diabetes-related complications (question numbers 12-15), diabetes symptoms (question numbers 16-19), diet for diabetes (question numbers 20, 21, and 27-34), and exercise and smoking (question numbers 22, and 35-38).

| Your name | : .......................................................... |
| What is your age? | ....................... Years |
| What is your gender? | □ Male □ Female |
| How long have you had diabetes? | .......... years or .......... months or .......... days |
| Do you take medicines from doctors for your diabetes? | □ Yes □ No |
| If yes, what type of your medicines from doctors? | □ Tablets and/or □ injection |
| If you use injection, how many injections per day? | □ 1 □ 2 □ 3 □ 4 □ other, please specify ................. |
| If you use tablets, how many different tablets? | □ 1 □ 2 □ 3 □ other, please specify ................. |
| Do you also take herbals for your diabetes? | □ Yes □ No |
| Have you ever attended specific diabetes programme? | □ Yes □ No |
| Have you ever seen a dietitian? | □ Yes □ No |
| Income per month (in IDR): | |
| □ < 500,000 |
| □ 500,000 – 1,499,999 |
| □ 1,500,000 – 2,499,999 |
| □ 2,500,000 – 4,999,999 |
| □ > 5,000,000 |
| Marital status | |
| □ Married |
| □ Not married |
| □ Widowed |
| Highest education level | |
| □ Elementary school |
| □ Junior high school |
| □ Senior high school |
| □ University |

**Figure 5.18: Questions on socio-demographic and disease experiences**

**Medication adherence**

Medication adherence was measured with a Probabilistic Medication Adherence Scale (ProMAS) developed by Kleppe, et al. [538]. It consists of 18 yes/no questions, of which 12 items were reverse questions (Table 5.7).
<table>
<thead>
<tr>
<th>Number</th>
<th>Statement</th>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Diabetes is a condition that can be cured by adopting a healthy lifestyle (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Diabetes is a condition that can be cured with medicines (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Diabetes is a condition that currently not curable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Diabetes is a disease that cannot be prevented (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Diabetes is only suffered by people who have family history with it. (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Diabetes is only suffered by obese people (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Diabetes is a disease only suffered by older people (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>If your blood sugar levels are normal or if you feel better, you can stop taking medicines from your doctor (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Long-time use of medicines from the doctors may cause kidney damage (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Regular medical check-ups are necessary to assess whether to adjust diabetes medicines</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>People taking diabetes medicines from doctors do not need to worry about healthy eating (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>If your diabetes is getting worse, you might get cancer (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>If your diabetes is getting worse, you might get rheumatoid arthritis (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>If your diabetes is getting worse, you might get lung problems (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>If your diabetes is getting worse, you might get heart disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Feeling weakness is early symptom of diabetes (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Headache is early symptom of diabetes (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Feeling pain at the back of your neck is early symptom of diabetes (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Always feeling sleepy is early symptom of diabetes (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Avoid carbohydrates food is part of managing diabetes (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>Taking food supplement is part of managing diabetes (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Stop smoking is part of managing diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Having high blood pressure makes you more likely to get diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Having contact with unhealed wound of diabetic patients makes you more likely to get diabetes (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>Sharing your food, eating equipment or clothing with diabetes patients makes you more likely to get diabetes (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>Unhealthy environment makes you more likely to get diabetes (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>People with diabetes must not eat anything sweet (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>Potato is a vegetable, so it is carbohydrate free (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>Taro, sweet potato, and corn cannot substitute white rice (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>Diet recommendations for people with diabetes are the same as healthy diet recommended for general people</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31</td>
<td>Skipping dinner is as part of healthy diet for people with diabetes (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>32</td>
<td>Eat specific food product designed for diabetes is as part of healthy diet for people with diabetes (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>33</td>
<td>Reduce the rice portion in every meal is as part of healthy diet for people with diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34</td>
<td>No meat diet is as part of healthy diet for people with diabetes (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35</td>
<td>Exercise for diabetes patients has to be done in a specific exercise class with an instructor (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36</td>
<td>Walking regularly is a form of exercise for diabetes patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>37</td>
<td>Exercise for diabetes patients should be avoided in people with high blood sugar and hypertension (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>38</td>
<td>It is OK to eat more after doing exercise to replace energy used (R)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 5.7: Questions on medication adherence

The following questions ask about how you usually take your medicines from your doctor for diabetes.

<table>
<thead>
<tr>
<th>Number</th>
<th>Statements</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>It has happened at least once that I forgot to take (one of) my medicines</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>It happens occasionally that I take (one of) my medicines later than usual</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>I have never (temporarily) stopped taking (one of my) medicines</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>It has happened at least once that I did not take (one of) my medicines for</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>a day (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>I am positive that I have taken all the medication that I should have</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>taken in the previous year</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>I take my medicines exactly at the same time every day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>I have never change my medicine use myself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>In the past month, I forgot to take my medicine at least once (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>I faithfully follow my doctor’s prescription concerning the time I take my</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>medicines</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>I sometimes take (one of) my medicines at a different time than prescribed</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(e.g., with breakfast or in the evening) (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>In the past, I once stopped taking (one of) my medicines completely (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>When I am away from home, I occasionally do not take (one of) my medicines</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>I sometimes take less medicines than prescribed by my doctor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>It has happened (at least once) that I changed the dose of (one of) my</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>medicines without discussing this with my doctor (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>It has happened (at least) once that I was too late with filling a</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>prescription at the pharmacy (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>I take my medicines every day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>It has happened (at least once) that I did not start taking a medicine that</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>was prescribed by my doctor (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>I sometimes take more medicines than prescribed by my doctor (R)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Self-management behaviours**

The self-management behaviour outcome was assessed with 14 questions addressing eating, exercise, foot care and smoking behaviours (Figure 5.19). The questions asked participants to recall their behaviour within the last week: the number of days during the last week on which they performed intended behaviours. If the participants mentioned any number of days, they were questioned further about the frequency of doing the behaviour within a day. If the participants responded that they never performed such behaviour within the last week, the zero (0) was circled, and the questioning process was continued to the following number.
The following questions ask about what you usually do for managing your diabetes.

1. How many days in the last week did you eat a meal where rice filled at least a quarter of your plate?
   0 1 2 3 4 5 6 7
   When you did that, on average, how many times a day did you eat a meal where rice filled at least a quarter of your plate? ..........................

2. How many days in the last week did you eat a meal where vegetables and fruits filled at least half of your plate?
   0 1 2 3 4 5 6 7
   When you did that, on average, how many times a day did you eat a meal where green vegetables and fruits filled at least half of your plate? ..........................

3. How many days in the last week did you eat a meal where protein-containing food filled at least as much as a quarter of your plate?
   0 1 2 3 4 5 6 7
   When you did that, on average, how many times a day did you eat a meal where protein-containing food filled at least as much as a quarter of your plate? ..........................

4. How many days in the last week did you have food in your plate like this picture?
   0 1 2 3 4 5 6 7
   When you did that, on average, how many times a day did you have food in your plate like the picture above? ..........................

5. How many days in the last week did you substitute white rice with another type of carbohydrate?
   0 1 2 3 4 5 6 7
   When you did that, on average, how many times a day did you substitute white rice with another type of carbohydrate? ..........................

6. How many days in the last week did you eat fried snacks?
   0 1 2 3 4 5 6 7
   When you did that, on average, how many times a day did you eat fried snacks? ..........................

7. How many days in the last week did you drink coffee or tea with sugar?
   0 1 2 3 4 5 6 7
   When you did that, on average, how many cups a day did you drink coffee or tea with sugar? ..........................

8. How many days in the last week did you eat cookies and sweet snacks?
   0 1 2 3 4 5 6 7
   When you did that, on average, how many times a day did you eat cookies and sweet snacks? ..........................
Continued...

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>How many days in the last week did you exercise on your own (including walking)?</td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td></td>
<td>When you did that, on average, how long did you exercise on your own per day?</td>
<td>..........</td>
</tr>
<tr>
<td>10</td>
<td>How many days in the last week did you attend specific exercise programme such as “senam” or other group exercise?</td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>11</td>
<td>How many days in the last week did you exercise (including walking) for about 30 minutes a day?</td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>12</td>
<td>How many days in the last week did you take care of your feet, including washing, soaking and drying your feet?</td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>13</td>
<td>How many times in the last month did you visit your health professional for checking your diabetes?</td>
<td>..........</td>
</tr>
<tr>
<td>14</td>
<td>Do you smoke cigarettes?</td>
<td>..........</td>
</tr>
<tr>
<td></td>
<td>How many days in the last week did you smoke a cigarette – even one puff?</td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td></td>
<td>How many cigarettes did you smoke on an average day?</td>
<td>..........</td>
</tr>
</tbody>
</table>

**Figure 5.19: Questions for measuring self-management behaviours**

The questions about diet were developed based on the plate method dietary recommendation, carbohydrate substitution, and food restrictions. The plate method has been suggested as a simple alternative meal planning method using a visual plate, on which the portion of food is depicted [537]. This plate method is recommended for teaching diabetes patients, particularly those with low literacy levels [539]. The questions about carbohydrate substitution and food restriction were also developed based on local eating habits and conditions.

### 5.6.2.4 Training of the interviewers

The interviewers for the questionnaire were eight study assistants who were recruited from undergraduate students at the Faculty of Public Health, Nusa Cendana University (Figure 5.20). The criteria for their selection were: had experiences of interviewing the public, or conducting a survey; and were able to speak the local language for daily conversation. The selection process was helped by a lecturer from the Faculty of Public Health, Nusa Cendana University. The selected study assistants were provided with a half-day training. The training included explanation about the study, the process of collecting data, their roles, responsibilities, and the questionnaire. Related to the questionnaire, the meaning
of each question was explained, and acceptable ways of modifying the questions into local dialect or wording were also discussed.

After each data collection session, discussions with study assistants were also made to check the completeness of the data, and discuss their experiences in interviewing participants. As an appreciation for their time and covering travel cost, the study assistants were paid after each stage of data collection was completed.

Figure 5.20: Research assistants involved in the study with the researcher

5.7 Data collection

5.7.1 Baseline data

Baseline data of participants in both intervention and control groups were collected in four timeslots. During the data collection process, the researcher, the Prolanis team, the laboratory staff, and the research assistants, gathered at a designated place and time. The place and time selected were the usual place and timing of the Prolanis club activities (in order to facilitate the participants
attending) (Table 5.8). The blood sample was drawn from the participants by the laboratory staff. After having their blood sampled, the participants were interviewed by the research assistants. The amount of time needed for data collection process differed across participant groups. It depended on the number of participants, and the time of their attendance. In some places, the participants did not attend the data collection process at the same time, so we waited for them to come, as they had agreed to be involved.

### Table 5.8: The timing and the number of participants who attended baseline data collection

<table>
<thead>
<tr>
<th>Group of participants</th>
<th>Time and date of baseline data collection</th>
<th>Number of participants attended the session</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control group</td>
<td>Saturday, 8 October 2016, at 8 AM to 11 AM</td>
<td>32</td>
</tr>
<tr>
<td>First intervention group</td>
<td>Saturday, 15 October 2016, at 6 AM to 9 AM</td>
<td>16</td>
</tr>
<tr>
<td>Second intervention group</td>
<td>Saturday, 8 October 2016, at 6 AM to 8 AM</td>
<td>12</td>
</tr>
<tr>
<td>Third intervention group</td>
<td>Wednesday, 19 October 2016, at 7.30 AM to 10.00 AM</td>
<td>7</td>
</tr>
</tbody>
</table>

One participant involved in the third intervention group could not attend the data collection session as she had another activity on the date of data collection. This participant, however, agreed to come to the laboratory to get her blood sampled the day after. This participant therefore only completed the clinical outcome, and missed the questionnaire data. The researcher, along with the Prolanis team made attempts to contact her to have the questionnaire data collected, but we could not manage this until the intervention sessions were started. The number of participants who completed baseline data collection is described in Figure 5.21.

Figure 5.22 illustrated the data collection process at baseline.
Figure 5.22: Data collection process at baseline
Figure 5.23: Data collection process at follow up
5.7.1.1 Follow-up data collection

The follow-up data were collected approximately three months after the baseline data collection (Figure 5.23). As described previously, one participant in the control group was excluded after baseline data collection. A total of 67 participants, therefore, were invited to the follow-up data collection. Scheduled timing and participants’ attendance are listed in Table 5.9.

Table 5.9: Follow-up data collection

<table>
<thead>
<tr>
<th>Group of participants</th>
<th>Time and date of follow-up data collection</th>
<th>Number of participants attended the session</th>
<th>Number of participants who had data collected at different time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control group</td>
<td>Saturday, 14 January 2017, at 6 AM to 10 AM</td>
<td>27</td>
<td>3</td>
</tr>
<tr>
<td>First intervention group</td>
<td>Saturday, 21 January 2017, at 6 AM to 8 AM</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Second intervention group</td>
<td>Saturday, 21 January 2017, at 8 AM to 11 AM</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Third intervention group</td>
<td>Friday, 20 January 2017, at 8 AM to 9 AM</td>
<td>6</td>
<td>0</td>
</tr>
</tbody>
</table>

Figure 5.24: Torrential rain in Kupang
The process of collecting follow-up data was the same as the baseline data. The researcher, the Prolanis team, the research assistants, and the laboratory staff were gathered at the designated time and place. Participants in the intervention group were informed of the schedules for follow-up data collection at the last intervention session. The participants were also reminded about the session a day before by the researcher and/or the Prolanis team through a short message and/or a phone call. The participants in the control group were contacted through a short message and/or a phone call by the researcher and/or the Prolanis team a week before. For some of them who could not be contacted through phone, the Prolanis team asked the other participants who lived close to them to invite them.

During the follow-up data collection, however, a practical problem mainly caused by bad weather was encountered. The follow-up data were collected in January, the time of the year with the highest intensity of rainfall (Figure 5.24). This made it difficult for participants to come to the session.

Four participants involved in the control group did not attend the session: one participant went out of town; one was unwell; one had something else to do at the same time; and one did not offer a reason. The researcher along with the Prolanis team then made attempts to contact them and asked whether or not they were willing to have their data collected at other times. We finally managed to get the data collected from three out of four of the missing participants in the control group within two weeks after the data collection session: all but the one with no reason. These three participants agreed to come to the laboratory for blood sampling, and had the interview conducted at their house.

The follow-up data collection in the first and second intervention groups were conducted on the same day but different times. It was a heavy rainy day. Nine out of 12 participants in the first intervention group, and ten out of 16 participants in the second intervention group, attended the session. Three participants in the first intervention group did not come to the session because of the rain. Six participants in the second intervention group did not come: two went out of town; one was unwell; and the other three did not come because of the rain. Addressing this missing data, the researcher along with the Prolanis team contacted the
missing participants. We informed them that if they were willing to have their follow-up data collected, they may go to the laboratory or have the laboratory staff collect their blood at their home. Within a week after the scheduled data collection sessions, all three participants in the first intervention group agreed to have their blood sample collected at their home, and four participants in the second intervention group agreed to come to the laboratory to have their blood sampled. For the questionnaire data, all seven participants were interviewed at their homes by research assistants. This left two missing participants from the second intervention group: the one participant without any reason; and the one who was still out of town. All participants in the first intervention group had their data collected.

In the third intervention group, two participants did not come to the follow-up data collection session: one without any reason; and one who had haemoglobin variant which could not be measured for HbA1c. An attempt has also made to contact the missing participants. Both of them, however, were not willing to have their follow-up data collected. This resulted in a total of 62 participants who completed follow-up data, as can be seen in Figure 5.25.

![Figure 5.25: Follow up data completion](image)
5.8 Data management and analysis

5.8.1 Data management

During the study, all data collected were managed by the researcher, and securely stored in a locked filing cabinet and on a password-protected laptop. The HbA1c outcome results were collected by the researcher from the laboratory, and stored securely. Copies of these results were also distributed to the relevant participants and their health providers. The completed questionnaire files were also managed, compiled, and stored by the researcher. Although the study assistants interviewed the participants, the compilation of this data was done by the researcher, and the results were only known to the researcher.

After the research was completed, all primary data files including the original copy of HbA1c laboratory test results and the filled paper questionnaires were brought to New Zealand and stored in a locked container, and only the researcher and the supervisors had access to this data.

Health information generated from this study will be retained for at least five years in secure storage. Any personal information may be destroyed at the completion of the research even though the raw data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

Although the completed questionnaires have the participants’ names on them, for data analysis, they were de-identified. The participants’ names were also not presented in the thesis and publications derived from the thesis.

5.8.2 Data analysis

The outcomes data were recorded into Excel in their original language. The recorded data were checked and re-checked by the researcher. After inputting the original version of the data into Excel, this was then translated into English. The translated versions were used for analysis.
5.8.2.1 HbA1c outcome

The HbA1c test provided the results in two units: The National Glycohemoglobin Standardization Programme (NGSP) unit of percentage; and the International Federation of Clinical Chemistry (IFCC) unit of mmol/mol. However, only the NGSP unit of percent is presented in this thesis.

5.8.2.2 Socio-demographic and disease experiences data

Information about participants’ demographic characteristics and disease experiences was presented as given. No scoring was applied in analysing this data.

5.8.2.3 Knowledge outcome

As described previously, the 38 questions for measuring knowledge were divided into seven categories, and the questions consisted of nine positive and 29 negative types of questions. The positive questions were scored 1 for the ‘true’ answer, and 0 for the ‘false’ answer. In contrast, the negative or reverse questions were scored 1 for the ‘false’ answer, and 0 for the ‘true’ answer. In cases where respondents responded, ‘do not know’ the score given was 0. This scoring process provided ‘the raw score’. The raw scores were processed further for data analysis.

From the raw score, the total composite score was calculated by dividing the raw score of each participant by the number of total questions (38), and multiplying by 100. The total scores therefore ranged from 0 to 100. For comparing the knowledge score in each knowledge category, the raw score in each knowledge category was divided by the number of questions, and multiplying by 100. By doing this, the mean scores in each knowledge category are comparable.

5.8.2.4 Medication adherence outcome

The participants’ medication adherence outcome was measured with ProMAS developed by Kleppe, et al. [538]. It consists of 18 yes or no questions. The guideline for scoring these questions was also based on Kleppe, et al. [538], of which ‘yes’ is coded with 1, and ‘no’ is coded with 0 for the positive questions, and inversely, ‘yes’ is coded with 0 and ‘no’ is coded with 1 for the reversed questions.
5.8.2.5 **Self-management behaviours outcome**

The self-management behaviours outcomes were measured with 14 questions divided into two types of questions. The first type included ten questions (question number 1 - 9, and 14) which have two different questions for each number. These nine questions asked participants about how many days in the last week did the participant practised a specific behaviour. When the participants responded with a specific number of days, they were asked further about the frequency within a day of them doing the behaviour. In scoring this type of question, participants' answers of the number of days were multiplied by the frequency within a day of doing the behaviour. This calculation provided the score for behavioural activities.

Meanwhile, for the second type of question (question number 10 – 13) the participants were only asked about how many days in the last week. In scoring this type of question, the participants response of the number of the days were used as the final score of behaviour.

5.8.2.6 **Statistical analysis**

Descriptive statistics were applied to characterise participants in terms of demographics, and diabetes experiences. Statistical analyses using independent t-test, $X^2$ test and Mann-Whitney U test were applied to compare socio-demographic and diabetes experiences of participants between the control and the intervention group. Independent sample t-tests were performed to compare the differences between the control and intervention group at baseline.

To test our intervention, we used analysis of covariance (ANCOVA) for detecting differences in the outcomes measured between participants in the control and intervention groups. The ANCOVA analysis used the follow-up data as dependent variables and baseline data as covariates. Statistical analysis of correlation matrix and analysis of variance (ANOVA) were also performed to assess association of outcomes with participants' characteristics. Correlations were used for analysing the relationship of two continuous variables, while the ANOVA was performed for analysing association of continuous variable with categorical variables.
Validation of the Indonesian translation of the ProMAS questionnaire was done with Rasch scaling using the eRm package in R [540, 541]. Details of validity of the Indonesian translation of this measure are included in Appendix 8. In dealing with some missing data, the principle of intention to treat analysis was applied. Therefore, the missing data at follow up were replaced with the last measurement carried forward [542]. The significance level for all tests was set at p < 0.05. Jamovi [543], an open access statistical software was used in the data analysis.
6  Chapter 6: Results of the intervention study

6.1  Introduction

This chapter presents the results and discussions of the diabetes intervention pilot study including participants’ response and completion rates, demographic characteristics and diabetes experiences, clinical outcomes (HbA1c), and knowledge, medication adherence and self-management behaviour outcomes. Both participants’ and health professionals’ perspectives related to the implementation of the intervention programme are also explored. Lastly, this chapter also presents the discussions of the overall results of the intervention pilot study.

6.2  Participants’ response rate and completion rate

A total of 72 diabetes patients met the eligibility criteria for the intervention study: 32 potential participants registered in a health centre which was allocated to the control group; and 40 potential participants registered in three health centres which were allocated to the intervention group. These 72 potential participants were contacted and invited to attend the information session followed by baseline data collection. In the intervention group, four potential participants did not attend the information and baseline data collection sessions, leaving 36 participants who attended the session, signed the consent form, and completed baseline data. All 32 participants in the control group attended the information session, signed consent forms, and completed baseline data collection. A response rate of 94% was therefore calculated. After analysing the baseline data, however, one participant in the control group was excluded. This participant did not suffer from diabetes confirmed by HbA1c test result at baseline and interviewer-administered questionnaire. A total of 67 participants were therefore included in the study: 36 participants in the intervention group; and 31 participants in the control group.

At the follow up, one participant in the control group, and four participants in the intervention group did not complete data collection. A total of 30 participants in the control group and 32 participants in the intervention groups therefore
completed baseline and follow up data collection (Figure 6.1). Based on this, the drop-out rate was 7.5%.

Figure 6.1: CONSORT flow diagram of participants’ response and completion rate

6.3 Demographic characteristics and diabetes experiences

6.3.1 Demographic characteristics

Demographic characteristics of participants are presented in Table 6.1. Despite some minor variation between groups, no significant differences were observed at baseline.

In 2008, the Indonesian government declared that education would be compulsory for nine years, which included six years of elementary school and three years of junior high school [544]. All participants in the study had completed some form of formal education, and overall most participants were relatively well-educated.
### Table 6.1: Demographic characteristics of participants

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>Intervention group</th>
<th>Control group</th>
<th>Between-group p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>56%</td>
<td>65%</td>
<td>0.456a</td>
</tr>
<tr>
<td>Male</td>
<td>44%</td>
<td>35%</td>
<td></td>
</tr>
<tr>
<td>Age (mean ± SD in years)</td>
<td>58.8±7.98</td>
<td>55.9±6.30</td>
<td>0.101b</td>
</tr>
<tr>
<td>Education level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elementary School (ES)</td>
<td>17%</td>
<td>26%</td>
<td>0.595c</td>
</tr>
<tr>
<td>Junior High School (JHS)</td>
<td>11%</td>
<td>19%</td>
<td></td>
</tr>
<tr>
<td>Senior High School (SHS)</td>
<td>39%</td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>Tertiary level (UNI)</td>
<td>33%</td>
<td>39%</td>
<td></td>
</tr>
<tr>
<td>Monthly income IDR (USD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. &lt; 500,000 (&lt; 36)</td>
<td>19%</td>
<td>16%</td>
<td>0.562c</td>
</tr>
<tr>
<td>2. 500,000 – 1,499,999 (36 - 106)</td>
<td>31%</td>
<td>23%</td>
<td></td>
</tr>
<tr>
<td>3. 1,500,000 – 2,499,999 (107 - 178)</td>
<td>8%</td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>4. 2,500,000 – 4,999,999 (179 - 358)</td>
<td>33%</td>
<td>35%</td>
<td></td>
</tr>
<tr>
<td>5. ≥ 5,000,000 (≥ 359)</td>
<td>8%</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>89%</td>
<td>93%</td>
<td>0.801a</td>
</tr>
</tbody>
</table>

Notes:  
- a determined by X² test  
- b determined by Welch’s t test  
- c determined by Mann-Whitney U test

### 6.3.2 Diabetes experiences

During the interview process we asked participants about their experiences of diabetes, including duration, medication taking, participation in diabetes programmes, and visiting dietitians (Table 6.2). Age at diagnosis was calculated by subtracting duration of diabetes from participants’ age.

<table>
<thead>
<tr>
<th>Diabetes experiences</th>
<th>Intervention group</th>
<th>Control group</th>
<th>Between-Group p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration of diabetes c mean ± SD (year)</td>
<td>5.06 ± 5.10</td>
<td>4.04 ± 3.37</td>
<td>0.336a</td>
</tr>
<tr>
<td>Age at diagnosis mean ± SD (year)</td>
<td>53.9 ± 7.82</td>
<td>51.8 ± 6.74</td>
<td>0.257a</td>
</tr>
<tr>
<td>Taking medicines</td>
<td>83%</td>
<td>87%</td>
<td>0.632b</td>
</tr>
<tr>
<td>Prescribed with oral antidiabetics</td>
<td>90%</td>
<td>89%</td>
<td>0.222b</td>
</tr>
<tr>
<td>Taking traditional medicines</td>
<td>46%</td>
<td>36%</td>
<td>0.399b</td>
</tr>
<tr>
<td>Participating in diabetes programme</td>
<td>66%</td>
<td>48%</td>
<td>0.155b</td>
</tr>
<tr>
<td>Consulting dietitian</td>
<td>51%</td>
<td>65%</td>
<td>0.283b</td>
</tr>
</tbody>
</table>

Notes:  
- a determined by Welch’s t test;  
- b determined by X² test  
- c data on duration of diabetes was missing for one participant. At baseline, this participant did not answer the question about duration of having diabetes in a specific time frame, instead he answered qualitatively: ‘for a long time’. This participant also lost at follow up.
6.3.2.1  Duration of diabetes and age at diagnosis

Most participants in both groups suffered from diabetes for less than five years (Table 6.2), but the mean duration was relatively similar, the mean being pulled up by participants who had diabetes for longer. There was also more variation in the duration of diabetes in the intervention group, with two participants newly diagnosed, and two other participants having suffered from diabetes for 18 and 21 years. Most participants were diagnosed between the age of 50 to 59 years, and the mean age of diagnosis did not differ between groups.

6.3.2.2  Medication taking

Around 85% of participants were taking medicines, with no statistically significant variation between groups. Four participants in the control group and five participants in the intervention group reported that they did not take medicines. Among participants who did not take medicines, two of them said that they discontinued taking medicines in the last three months, and one other participant said that she took medicines for only a month, and discontinued taking them.

The majority of participants were prescribed oral antidiabetic medicines. Four participants were prescribed insulin, and two participants were prescribed both oral antidiabetics and insulin.

The questionnaire also asked about the number of types of tablets prescribed. In many cases, however, participants could not differentiate which medicines they got for diabetes, or for other comorbid conditions. This information was therefore missing in many cases, and if the information presented, we could not confirm its reliability. Metformin was mentioned by a number of participants as a medicine they were taking, followed by glibenclamide, and glimepiride. Addressing this problem, I tried to obtain access to patients’ medical records at the health centres. However, the medical records were often incomplete and poorly written. Information about the number of medicines taken by participants could not therefore be retrieved.
Somewhat less than half of participants were also taking herbal or traditional medicines. It appears that some participants took these traditional or herbal medicines either as an alternative to, or in combination with, medicines. The most commonly mentioned traditional medicines mentioned in the interviews were from leaves, such as the leaves of sirsak, salam, airnona, binahong, and marungga, trees or unspecified bitter leaves.

6.3.2.3  **Lifestyle interventions**

As can been seen in Table 6.2, although the number of participants attending specific diabetes programme and visiting a dietitian varied between the intervention and control groups, the differences were not statistically significant. Some participants also explained further that they attended a diabetes programme managed by the health centres, or community health education provided by health professionals. In contrast, slightly more participants in the control group than the intervention group reported that they had visited a dietitian.

6.3.3  **Discussion of demographic characteristics and diabetes experiences**

Overall, the demographic characteristics and diabetes experiences of participants in both groups did not differ statistically. More female than male participants were involved in the study, similar to other diabetes studies conducted in Indonesia [213, 217, 218, 505, 507, 509, 515, 545, 546]. This finding might be because the prevalence of diabetes in Indonesia is higher in women than men, and this has been consistent over time. In 2009, the prevalence of diabetes in women was 6.4% compared to 4.9% in men, and in 2013 it increased to 7.7% compared to 5.6% [89, 206, 547]. The higher prevalence of diabetes among women was also found in rural areas of Indonesia [493]. Further, Christiani, et al. [548] reported that risks factors for non-communicable diseases in Indonesia were higher in women [548]. Women have a higher prevalence of overweight, obesity, hypercholesterolemia [20, 548], and hypertension [205], which further led them to have a higher prevalence of pre-diabetes, and diabetes [202, 203] than their male counterparts. The higher prevalence of diabetes and its risk factors among women are also found in Thailand, Bangladesh, and Sri Lanka [549-551].
In terms of age, the mean age of participants was 57. The majority of diabetes studies in Indonesia also involved participants with mean age between 50 – 60 years old [209, 213, 215, 216, 218, 220, 497, 507, 509, 510, 545, 546, 552]. Most participants were diagnosed between 40 and 60, similar to a previous study which also demonstrated that the mean age of diabetes diagnosis was 49.68±6.8 years [213]. This figure is similar to the age distribution of diabetes prevalence in other Asian countries [549-551]. Diabetes affects people in Asia at a younger age than people in developed regions, with the highest prevalence in the 40 – 59 age group [194, 195, 388]. With the increasing prevalence of obesity at a younger age, diabetes prevalence in people aged 30 – 39 is also increasing [195]. Two participants in this study were diagnosed with diabetes at less than 40 years of age. Some previous studies about diabetes also involved participants aged less than 40 [516, 552].

The 2013 Basic Health Research survey reported that prevalence of diabetes was 1.1% for people aged 15 – 24 years old, and it rose dramatically to 11.5% for the age of 55 – 64 years, and peaked at 13.2% for people aged 65 or more [206]. A study on pre-diabetes in Indonesia also showed that pre-diabetes has been found in people aged 18 – 27 years old, and this increased along with increasing age, with the highest proportion in 38 – 47 age group [202]. The implication of these findings is that interventions for prevention or early detection of diabetes and its risk factors should target people before the age of 40.

In terms of income, less than 20% of participants had a very low monthly income (less than IDR 500,000/USD 36.65), and very few a had very high income (> IDR 5,000,000/USD 366.5). The Indonesian national poverty line is IDR 400,995 (USD 29.5) per month in urban areas and IDR 370,910 (USD 27.2) per month in rural areas [63]. The poverty line, however, differs among regions and districts within the country. In Kupang, the poverty line was set at IDR 482,857 (USD 35.5) [535], so less than 20% of participants in this study were below the poverty line. Most participants were in the middle-income bracket.

Since the beginning of the 21st century, there has been rapid socioeconomic development in Indonesia and many other Asian countries which may contribute
to the increasing prevalence of diabetes [194, 195, 388]. This socio-economic development was shown by the increasing proportion of people within the middle-income bracket [553]. Although the definition of middle-income class varied, Chun [554] defined it as people with daily expenditure of USD 2 – 20. This daily expenditure range is divided further into near poor (USD 2 - 4), lower middle-income class (USD 4- 10), and upper middle-income class (USD 10 - 20). Kupang is the biggest urban area of the province in which rapid urbanisation has occurred and there are increased job opportunities, and more tertiary education facilities available. These have further fuelled the economic growth of the city. These three factors have led to the rising number of people with mid-level incomes [60].

The distribution of participants by income is similar to the distribution of participants by level of education. Only a few participants had completed only the lowest level of education. Most participants had completed secondary education, and some of them attended tertiary education. Educational level often correlates with income, with the higher the education, the higher the income. In contrast to some developed countries, Balinese women who are wealthier and had a higher education level tended to be overweight and obese [555]. Moreover, risk factors of hypertension and obesity were found mostly among people residing in urban areas and among wealthy people living in more rural areas [200]. This is also similar to other studies which reported that diabetes was found more in people with a higher level of education and income [493]. This information may imply that diabetes in Indonesia affected more people with higher income and educational level. The disease burden for the poor is, however, higher than that for the wealthier counterparts.

In terms of medication taking behaviour, this intervention study reported similar findings to the qualitative study: the majority of participants reported taking medicines, with many of them combining or alternating the medicines with other herbal or traditional medicines. This finding is similar to other studies in Indonesia [227-229]. A high prevalence of complementary and alternative medicine use has also been found in other communities in developing countries.
The results of the qualitative study described in Chapter 3 explain diabetes patients’ behaviour in medication taking, including the patterns and the reasons for their behaviour.

Furthermore, some participants also reported that they had attended diabetes-specific programmes and dietitian consultations conducted at the healthcare facilities where they were registered. This implies that many participants have been exposed to information about diabetes, which further relate to the results of the knowledge, medication adherence, and self-management behaviour outcomes, which are described in a separate section of this chapter.

6.4 Outcome measures: HbA1c

6.4.1 HbA1c data completion

A total of 67 participants completed HbA1c measurement at baseline. As can be seen in Figure 6.2, one participant in the control and one in the intervention group had a haemoglobin variant which interfered with HbA1c analysis, as described in Chapter 5. Their HbA1c level could therefore not be measured, leaving data for 65 participants at baseline. Post-intervention, five participants were lost to follow up: one participant in the control group; and four participants in the intervention group. The participant in the intervention group who had a haemoglobin variant that interfered with HbA1c analysis at baseline was also lost at follow up. The HbA1c data for 61 participants was therefore obtained at follow up. Results of HbA1c measurement of participants in the intervention and control groups are included in Appendix 9.

The HbA1c levels at baseline and follow up were analysed using the intention to treat principle, and missing data were replaced with the last measurement carried forward. One participant who was lost at follow up had HbA1c measured in a time between baseline and follow-up data collection. The other three participants did not have their HbA1c level measured in between, however. During the study period, in December 2016, people with diabetes in Kupang who registered under the universal health insurance scheme were offered a complete biological measurement including HbA1c. This was not part of the regular service provided
by the insurance; HbA1c analysis had never been done in Kupang prior to the study period. In analysing the HbA1c outcomes, therefore, four missing data at follow up were replaced by the baseline values for three participants, and HbA1c value measured in between for one participant.

![Diagram](image)

**Figure 6.2: CONSORT flow diagram of HbA1c outcome completion**

### 6.4.2 HbA1c outcomes

As shown in Table 6.3, HbA1c did not differ between groups at baseline. To test the effectiveness of the intervention, ANCOVA analysis was performed with HbA1c at follow up as an independent variable, and HbA1c baseline as a covariate. There was no difference between the control and intervention groups $F(1,62) = 0.02, p = 0.9$ (Table 6.3). As can be seen in Figure 6.3, the intervention did not provide statistically significant difference in HbA1c outcome compared to the control (usual care).

<table>
<thead>
<tr>
<th>Groups</th>
<th>Baseline Mean ± SD</th>
<th>Between group p value at baseline</th>
<th>Follow up Mean ±SD</th>
<th>Between group p value at follow up</th>
<th>P-value between group difference over time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>8.26 ± 1.89</td>
<td>0.872 (^a)</td>
<td>7.84 ± 1.82</td>
<td>0.839 (^a)</td>
<td>0.897 (^b)</td>
</tr>
<tr>
<td>Control</td>
<td>8.35 ± 2.60</td>
<td></td>
<td>7.95 ± 2.53</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes: \(^a\) determined by Welch’s t-test;  
\(^b\) determined by ANCOVA test
6.4.2.1 Exploratory analyses

However, as Figure 6.3 makes obvious, participants in both groups made improvements in HbA1c outcome as shown in decreasing trends of HbA1c over time. Further statistical analysis using paired independent t-test (Table 6.4) comparing the HbA1c level of all participants at baseline and follow-up shows groups improved significantly from baseline. Similarly, a Bayesian t-test provides strong evidence that HbA1c had decreased at follow-up.

| Table 6.4: Paired t-test comparing HbA1c at baseline and at follow up |
|-----------------|-----------------|-------------|---|-----|--------|---|
| HbA1c at baseline | HbA1c at follow-up | Student’s t | ±% | df | p     | Cohen’s d |
|                  |                  | 2.91        | 64.0 | 0.005 | 0.361 |
|                  |                  | Bayes factor | 6.31 | 1.05e-8 |

Although my planned analyses revealed no evidence of an effect for the interaction, I further looked to see whether there was any information in the data that could be useful for guiding future interventions. In Figure 6.4, participants HbA1c levels were categorised based on cut points at 7.0 and 8.0. The percentage of participants in the control group at each specific range of HbA1c at baseline and follow-up did not differ. In contrast, in the intervention group, the percentage of participants with poorly controlled glycaemic level of 8% or more dropped from 51% to 40%, and the participants achieving HbA1c value of less than 7% increased from 26% to 37%.
Figure 6.4: Participants’ outcome at baseline and follow-up based on HbA1c range

Figure 6.5: Percentage of participants by the level of HbA1c change
Further, across both groups, the HbA1c levels of most participants improved: 63% of participants in the control group, and 71% of participants in the intervention group. A few participants experienced no change in their HbA1c value, and glycaemic control deteriorated in some participants. The level of HbA1c change of participants can be seen in Figure 6.5.

More participants in the intervention group than those in the control group achieved a decrease in HbA1c value of 0.5% or more, 43% compared to 30%, respectively. More participants in the intervention group, however, also experienced a high increase in their HbA1c value of 1% or more, 11% compared to 3%. These participants attended the intervention sessions less frequently compared to the others.

6.4.3 Association of HbA1c outcomes and socio-demographic characteristics of participants

Table 6.5: Statistical tests associating HbA1c at baseline with demographic characteristics

<table>
<thead>
<tr>
<th></th>
<th>HbA1c at baseline</th>
<th>HbA1c at follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender a</td>
<td>F (1,63) = 0.411</td>
<td>F (1,59) = 0.330</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.524</td>
<td>p-value = 0.568</td>
</tr>
<tr>
<td>Age b</td>
<td>Pearson’s r = -0.390</td>
<td>Pearson’s r = -0.279</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.001*</td>
<td>p-value = 0.030*</td>
</tr>
<tr>
<td>Education level a</td>
<td>F (3,61) = 0.520</td>
<td>F (3,57) = 1.23</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.670</td>
<td>p-value = 0.308</td>
</tr>
<tr>
<td>Income a</td>
<td>F (4,60) = 0.490</td>
<td>F (4,56) = 0.619</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.743</td>
<td>p-value = 0.651</td>
</tr>
<tr>
<td>Duration of diabetes b</td>
<td>Pearson’s r = -0.087</td>
<td>Pearson’s r = 0.022</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.495</td>
<td>p-value = 0.869</td>
</tr>
</tbody>
</table>

Notes: a determined by ANOVA
       b determined by correlation matrix analysis with Pearson’s r
       * statistically significant (p-value <0.05)

Statistical tests were performed to analyse associations between HbA1c outcome at baseline and follow-up, and change in HbA1c with participants’ characteristics including gender, age, education level, income, and duration of diabetes. Correlation matrix analysis was performed to test between HbA1c and continuous
variables of age and duration of having diabetes, and ANOVA test was applied for analysing the correlation between HbA1c and categorical variables of gender, educational level, and income. Table 6.5 and Figure 6.6 show that HbA1c level decreased with increasing age, about both baseline and follow-up. There were no other statistically significant associations between HbA1c and demographic variables.

![Graph showing correlation between HbA1c at baseline and age](image)

**Figure 6.6: Negative association between HbA1c at baseline and age**

6.4.4 Discussion of HbA1c outcome

Participants in both study groups experienced a very similar level of HbA1c improvement. This is surprising because typically people with diabetes tend to stay the same or get worse with time, as discussed below. Although more participants in the intervention group experienced an improvement of HbA1c level of equal to or more than 0.5% than those in the control group (44% compared to 31%), statistically the change of HbA1c in both groups did not differ. Baseline condition of participants – their demographic characteristics, diabetes experiences, and clinical outcome – did not differ statistically. This suggests that the project might have indirectly triggered more intensive diabetes management in the study area.
The literature review (Chapter 4) showed that there have been few intervention studies for diabetes patients in Indonesia. This study was the first experimental study with control measuring the effect of intensive group-based self-management education, conducted regularly for three months, on participants’ clinical outcomes as well as knowledge, medication adherence and behavioural outcomes. An intervention study evaluating the effects of a single session of counselling and providing a medication booklet on diabetes patients’ medication adherence and HbA1c outcomes was conducted in Banten Province [515]. The study applied pre- and post-test a single group design, and reported a huge improvement of HbA1c from 11.3±2.95% to 8.1±2.79% after 10 weeks. The mean of baseline HbA1c level from 30 participants involved in the study by Presetiawati, et al. [515] was higher compared to that of the participants in this study. A systematic review showed that interventions involving poorly controlled diabetes participants with HbA1c levels of over 9.5% resulted in a greater effect [558].

The result that HbA1c outcomes of participants in both groups improved also contrasted with similar studies conducted in developed and developing countries. Systematic reviews evaluating the effectiveness of similar diabetes intervention studies demonstrated favourable outcomes of HbA1c improvement compared to control or usual care services [457, 458, 467, 468, 559-562]. As an example, Chrvala, et al. [458] reported that among 118 diabetes self-management interventions, about 62% of them demonstrated significant changes in HbA1c with an absolute improvement of 0.57%. A systematic review conducted by Fan and Sidani [457] published in 2010 reported a lower reduction of HbA1c value of 0.36%. The possible explanations for the findings of this study are presented in the final section of this chapter.

Our participants’ baseline HbA1c level (8.30 ± 2.23%) was similar to two national Indonesian studies published in 2010 and 2009 that found uncontrolled blood glucose means of 8.1 ± 2% [213], and 8.1 ± 2.1% [218]. The participants in our study were selected based on inclusion criteria of having no diabetes related complications. Studies involving diabetes patients with complications showed higher HbA1c levels. Pemayun and Naibaho [216], for example, examined the
profile of diabetes patients with foot ulcers admitted to a hospital in Central Java and found that the mean HbA1c was 11.3 ± 2.8%. Yusuf, et al. [217] also showed that diabetes participants with diabetic foot ulcers had a considerably higher HbA1c compared to those without complications, 8.95 ± 2.07% compared to 7.86 ± 2.61%. Rianita, et al. [503] also found a mean of HbA1c of 9.1 ± 2.4% in diabetes patients with vision complications. A study by Pranoto, et al. [552] who specifically recruited diabetes patients with uncontrolled blood glucose found a mean HbA1c of 11.60 ± 2.03%. Newly diagnosed diabetes patients also tended to have higher levels of HbA1c with a mean value of 10.5 ± 4.9% [563].

Further, the majority of participants had uncontrolled glycaemic levels with HbA1c levels of more than 7%. A study that recruited diabetes participants from three hospitals in three different cities in Indonesia showed that 49% of their participants had uncontrolled blood glucose, i.e. more than 7% [499]. Soegondo, et al. [218] found that 60% of diabetes patients did not reach the target of a HbA1c less than 7%. Markum and Galastri [505] found 73% of diabetes patients had HbA1c levels more than or equal to 7%.

In our study, participants were recruited from lists of diabetes patients registered at primary care facilities. Most studies on diabetes in Indonesia also recruited participants from healthcare facilities. This implies that the people with diabetes involved in studies have reached medical care and are being treated by health professionals. Most of them, however, still experienced uncontrolled blood glucose levels. This finding is similar to studies conducted in other developing countries: although the diabetes patients have been treated by healthcare professionals, the majority of them had uncontrolled glycaemic levels [549, 564]. An implication of this finding is that management of diabetes patients in healthcare facilities should be evaluated and monitored.

This current study also found interesting points related to the participants’ HbA1c outcome in association with their characteristics. The statistical analysis revealed that the HbA1c level was not correlated with duration of having diabetes. Previous studies in Indonesia have found that HbA1c levels are correlated positively with the duration of having diabetes: that the longer the duration, the higher the level
of HbA1c [213, 514]. Furthermore, the current study demonstrated a negative correlation between HbA1c measured both at baseline and follow up with the participants’ age: the older the age, the lower the HbA1c level. This result differs from that of another study in Indonesia which reported that HbA1c level was not associated with participants’ age [514].

6.5 Outcome measures: knowledge

6.5.1 Knowledge questionnaire data completion and scoring

![CONSORT flow diagram of participants’ completion of knowledge questionnaire]

Knowledge was evaluated with a 38 item yes-or-no interviewer-administered questionnaire. From a total of 67 participants involved in the study, one participant involved in the intervention group missed the baseline interview. As a result, we have baseline knowledge data from 66 participants: 31 from the control group; and 35 from the intervention group. At follow-up, one participant in the control group and four participants in the intervention group were lost to follow up. This leaves a total of 61 participants; 30 in the control group and 31 in the
intervention group who had a completed knowledge outcome measured at baseline and at follow up (Figure 6.7).

6.5.2 Knowledge scores at baseline and follow-up
There were no differences in baseline knowledge of participants between groups (Table 6.6).

<table>
<thead>
<tr>
<th>Groups</th>
<th>Baseline Mean ± SD</th>
<th>Between group p value at baseline</th>
<th>Follow up Mean ±SD</th>
<th>Between group p value at follow up</th>
<th>P-value between group difference over time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>56.6 ± 9.03</td>
<td>0.394 (^a)</td>
<td>58.9 ± 11.8</td>
<td>0.507 (^a)</td>
<td>0.544 (^b)</td>
</tr>
<tr>
<td>Control</td>
<td>54.3 ± 12.1</td>
<td></td>
<td>56.8 ± 13.9</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes: \(^a\) determined by Welch's t test; \(^b\) determined by ANCOVA test

To evaluate differences in knowledge changes of participants in the control and intervention groups, ANCOVA was conducted with knowledge score at follow up as the independent variable, groups as fixed factor, and knowledge score at baseline as covariate. As Figure 6.8 shows, both groups experienced a similar increase in the total knowledge score from baseline. This increase was confirmed with a paired t-test, \(t(65) = -2.02, p = 0.047\).
6.5.3 Association of knowledge score with demographic characteristics of participants

Statistical analysis was also performed to explore associations between knowledge with participants’ characteristics and HbA1c outcome. The ANOVA test showed that there was significant association of knowledge score at baseline and follow up with participants’ education level, and income (Table 6.7). This association demonstrated that the higher the education level and income, the higher the mean knowledge score (Figure 6.9). Knowledge scores at baseline did not, however, correlate with participants’ gender, age, duration of having diabetes, or HbA1c.

Table 6.7: Statistical analysis of association of total knowledge score and participants’ demographic characteristics and HbA1c outcome

<table>
<thead>
<tr>
<th></th>
<th>Total knowledge score at baseline</th>
<th>Total knowledge score at follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender a</td>
<td>F (1,64) = 0.144, p-value = 0.706</td>
<td>F (1,60) = 8.93, p-value = 0.004*</td>
</tr>
<tr>
<td>Age b</td>
<td>Pearson’s r = 0.051, p-value = 0.684</td>
<td>Pearson’s r = 0.143, p-value = 0.269</td>
</tr>
<tr>
<td>Education level a</td>
<td>F (3,62) = 6.35, p-value = &lt;0.001*</td>
<td>F (3,58) = 8.27, p-value = &lt;0.001*</td>
</tr>
<tr>
<td>Income a</td>
<td>F (4,62) = 2.70, p-value = 0.039*</td>
<td>F (4,57) = 4.09, p-value = 0.006*</td>
</tr>
<tr>
<td>Duration of diabetes b</td>
<td>Pearson’s r = 0.119, p-value = 0.345</td>
<td>Pearson’s r = 0.199, p-value = 0.120</td>
</tr>
<tr>
<td>HbA1c b</td>
<td>Pearson’s r = -0.023, p-value = 0.856</td>
<td>Pearson’s r = 0.094, p-value = 0.471</td>
</tr>
</tbody>
</table>

Notes: 

a determined by ANOVA
b determined by correlation matrix analysis with Pearson’s r
* statistically significant (p-value < 0.05)

At follow-up, knowledge scores were significantly associated with gender. Male participants had significantly higher knowledge level at follow up than their female counterparts (Figure 6.10).

Further association analysis of knowledge change also revealed that the change in knowledge was significantly associated with gender. The male participants experienced a notable improvement in their level of knowledge (mean change of score of 6.82) while their female counterparts did not experience an improvement in knowledge score (mean change of score of 0.065).
Figure 6.9: Association of participants’ total knowledge score at baseline and education level and income

Figure 6.10: Descriptive plot of knowledge scores at follow up based on gender

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6.5.4 Participants knowledge scores based on knowledge categories

Statistical analysis showed that the knowledge outcome for participants in the intervention group did not differ statistically from participants who received usual care in the control group. The knowledge level of participants in both groups improved. We then analysed this further by breaking down the scores into categories of diabetes knowledge: causes; risk factors; medications; complications; symptoms; and diabetes self-management, including diet, exercise and smoking. We wanted to get a better understanding of participants’ knowledge in each category. This information will be useful in designing future studies aiming at improving diabetes knowledge.

Figure 6.11 illustrates the mean scores of participants’ knowledge based on knowledge categories at baseline. It shows that mean scores in each knowledge category of participants in both groups were quite similar. The highest score was on knowledge about risk factors, followed by knowledge about exercise and smoking for diabetes management. Knowledge about diet was the lowest. Knowledge scores were similar at follow-up (Figure 6.12). There was no evidence of change between experimental groups, F (1,64) <2.8, p> 0.1.

On average, about half of the questions about causes of diabetes were answered correctly. Most participants (78%) understood that diabetes is not transmitted through sharing food, eating equipment or clothing. A lot of participants (67%) also understood that diabetes can be prevented. About half of participants responded that having contact with unhealed wounds of participants and unhealthy environments increased their risk of getting diabetes, however, and only about 30% of participants believed that diabetes is a disease that currently cannot be cured. This implies that most participants were still confused about the causes of diabetes.

Knowledge about risk factors had the highest mean score compared to other categories. The vast majority of participants understood that diabetes is not only suffered by people who have family history, are obese, and older people. About two third of participants were also aware that having high blood pressure increases their risk of having diabetes.
Figure 6.11: Mean score of knowledge divided into categories at baseline

Figure 6.12: Mean score of knowledge divided into categories at follow-up
Participants’ score on knowledge about diabetes medication was also relatively high. Most of them were aware that regular check-ups are important to assess effectiveness of the medications. Most participants were also aware that they had to apply a healthy diet although they were on diabetes medications. Some participants, however, believed that long-term use of medicines may cause kidney damage, and more than a half of them also believed that they could stop taking medicines if their blood sugar was normal or if they were feeling better. This provided evidence that some participants had limited understanding of the role of medications in diabetes management, and the importance of continuation of taking medications. The belief that taking medicines for a long time increased the risk of kidney damage needs to be addressed.

In terms of knowledge about complications, mean scores at baseline and follow up were similar. Most participants understood that heart disease is a complication of diabetes. About half of them, however, also thought that diabetes might increase their risk of cancer, rheumatoid arthritis, and lung problems.

In recognising diabetes symptoms, most participants acknowledged that feeling weakness is an early symptom of diabetes. Almost all participants also responded that always feeling sleepy was also a symptom of having diabetes. This lay knowledge might come from the participants’ experiences of fatigue which was interpreted as sleepiness.

Knowledge about diet for diabetes had the lowest mean score compared to the other categories. This showed that most participants had limited knowledge related to diet for diabetes. The term ‘sugar disease’ let them think that diabetes is caused by any sweet food so that they believe anything sweet was restricted for diabetes patients. Most of them also had limited knowledge in recognising the sources of food containing carbohydrate. Most of them responded that potato was free from carbohydrate. Some of them also thought that taro, sweet potato and corn also could not substitute for white rice as a source of carbohydrate. Furthermore, although the majority of them recognised that reducing rice portions is part of managing diabetes, most of them believed that skipping dinner is part of a healthy diet for diabetes.
Moreover, related to diabetes management, more than two thirds of participants acknowledged that stopping smoking is part of managing diabetes. In terms of exercise, most participants were aware that walking regularly is recommended for diabetes patients, and recognised the importance of a combination of exercise and a healthy diet for managing diabetes.

6.5.5 Discussion of knowledge results

This current study showed that participants in both groups experienced an improvement in their knowledge scores. The improvement, however, was not remarkable, only an increase of 3.06 from the total score of 100, or about one question item. Furthermore, ANCOVA analysis confirmed that the change of knowledge scores of participants did not differ between groups. These findings contrasted to other studies assessing the impact of diabetes interventions. A systematic review of diabetes self-management interventions showed that the most notable improvement was on knowledge outcomes, followed by clinical outcomes, and the least was on behavioural outcomes [457].

A likely explanation of these findings might be that participants in both groups had relatively high knowledge scores at baseline. The mean knowledge scores at baseline was 55, which means that most participants had an average level of knowledge. Only a few participants had knowledge scores of lower than 20. The participants were recruited from selected healthcare facilities in the study location, so that most of them had reached medical care. During the usual consultation with health professionals, information and education were often provided. Some participants had also attended specific diabetes related programmes. Most participants had therefore already gained a better understanding about diabetes. This finding is similar to other studies assessing diabetes patients’ knowledge, attitudes and practice in Dhaka, Bangladesh [565, 566]. Studies focused on knowledge of diabetes patients in other developing countries reported a variety of levels of participants’ knowledge. A limited knowledge about diabetes was reported in studies conducted in Pakistan [567], Nepal [568], and the Democratic Republic of Congo [569]. In contrast, a high level
of knowledge was also reported in some other settings including Sri Lanka [570], Bangladesh [564], and Iran [571]. It is difficult, however, to compare the results to those studies because the nature of the study population and the instruments used were dissimilar.

This study found that participants’ knowledge about diabetes was associated with their education level and income, with the higher the education level and income, the more knowledgeable the participants. Most participants involved in this study were relatively well-educated and had a better income, with only about 20% participants in the lowest education and income levels. This might also explain why most participants had an average knowledge about diabetes. It is highly recognised that knowledge level of diabetes patients is associated with education level [564, 565, 568-570, 572, 573]. Other studies have also found an association of knowledge with income [564, 565, 569].

The knowledge scores of the participants in this study were not associated with age, and duration of diabetes. Age and duration of diabetes have often been reported to be associated with knowledge [564, 568, 571, 572]. Herath, et al. [570] also found that there was no association between knowledge and age, however. Interestingly, our study revealed that the participants’ knowledge score at follow up was associated with gender, which was not shown at baseline. Further analysis showed that the change of knowledge was also associated with gender, with male participants experiencing some increase in their knowledge scores, while the knowledge scores of female participants were unchanged. Some studies conducted in Bangladesh, the Democratic Republic of Congo, and the United Arab Emirates also reported an association of knowledge and gender with the males significantly better than females [564, 565, 569, 573]. Those studies did not evaluate the association of change of knowledge with gender, however, but may provide evidence that the learning abilities of male participants were higher than their female counterparts. Another likely explanation for this is that the women tended to receive false information from lay sources. Studies found that women more actively sought health-related information [574, 575]; however, women also reported receiving more informal health-related information from lay others,
including relatives, or friends [575]. This may imply that the women learnt as much false information from others as information from trusted health professionals.

It was widely acknowledged that a sufficient level of knowledge was a pre-requisite for a better attitude to, and outcomes of diabetes management. In the Indonesian context for example, Adriono, et al. [546] found that lack of knowledge about the vision complications of diabetes was associated with less practice of eye examination, and Primanda, et al. [509] reported that there was a positive correlation between knowledge related to diet and dietary behaviour.

This current study, however, found no correlation between knowledge scores and the clinical outcomes of HbA1c. Similar findings were also observed in studies conducted in Bangladesh [564] and the United Arab Emirates [573]. It was also suggested that knowledge level did not predict self-management behaviours of people with diabetes in East Java Province, Indonesia [510], and knowledge did not associate with attitude and the practice of diabetes patients in Sri Lanka [570]. This finding implies that improving knowledge may not be enough to improve outcomes.

In terms of knowledge categories, this study revealed that most participants had a relatively good understanding of diabetes risk factors, and exercise and smoking cessation for managing diabetes. Most participants, however, seemed to be confused in terms of knowledge related to diet and medications. This further implies areas of diabetes education that should be strengthened: knowledge that relates to behaviours including diet and medications. Participants’ medicine taking was hindered by their belief that long term use of medication might cause kidney damage, and that the medication taking could be stopped when their condition improved. Participants’ dietary behaviour might also be affected by their limited ability to recognise carbohydrate-containing food.
6.6 Outcome measures: medication adherence

6.6.1 Data completion on medication adherence questionnaire

A total of 67 participants completed baseline data collection. In medication adherence outcome, however, nine participants reported that they did not take any medicines for diabetes, so that they were not able to answer questions related to medication adherence. Some of them mentioned that they discontinued taking medicines for diabetes. Another participant missed being interviewed at baseline. Data on medication adherence outcome at baseline were therefore gathered from 57 participants.

Figure 6.13: CONSORT flow diagram of data completion of medication adherence questionnaire
At follow up, the medication adherence data were completed by 58 participants. Five participants were lost at follow up. Two participants, who reported taking medicines at baseline, reported not taking medicines at follow up. Seven participants, who reported not taking medicines at baseline, took medicines at follow up. Meanwhile, two participants reported not taking medicines both at baseline and follow up. Because of the differences in participants’ medication-taking behaviour at baseline and follow up, 50 participants completed medication adherence questionnaire both at baseline and follow up (Figure 6.13).

6.6.2 Medication adherence

The medication adherence outcome was assessed with the Probabilistic Medication Adherence Scale (ProMAS) [538]. Table 6.8 shows that there were no differences in medication adherence scores between groups at baseline or follow-up.

<table>
<thead>
<tr>
<th>Groups (N)</th>
<th>Baseline Mean ± SD</th>
<th>Between group p value at baseline</th>
<th>Follow up Mean ±SD</th>
<th>Between group p value at follow up</th>
<th>P-value between group difference over time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>9.97 ± 3.54</td>
<td>0.628 a</td>
<td>10.4 ± 4.24</td>
<td>0.569 a</td>
<td>0.928 b</td>
</tr>
<tr>
<td>Control</td>
<td>10.4 ± 3.84</td>
<td></td>
<td>10.9 ± 3.26</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes:  

a determined by Welch’s t test;  
b determined by ANCOVA test

Both groups experienced a similar increase in the medication adherence score from baseline; however, this increase was not statistically significant as shown by the ANCOVA analysis.

6.6.3 Association of medication adherence score with demographic characteristics and other outcomes

Associations between medication adherence score and participants’ characteristics and other outcomes were also explored. As can be seen in Table 6.9, the medication adherence score at baseline was associated with education level and income. Interestingly, these associations demonstrated that the higher the education level, and the higher the income, the less adherent participants were (Figure 6.14). These associations, however, were not found at follow up.

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Table 6.9: Association of medication adherence with sociodemographic characteristics and other outcomes

<table>
<thead>
<tr>
<th></th>
<th>Medication adherence score at baseline</th>
<th>Medication adherence score at follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong> <em>a</em></td>
<td>F (1, 55) = 1.52</td>
<td>F (1,56) = 0.087</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.223</td>
<td>p-value = 0.769</td>
</tr>
<tr>
<td><strong>Age</strong> <em>b</em></td>
<td>Pearson’s r = 0.023</td>
<td>Pearson’s r = 0.193</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.865</td>
<td>p-value = 0.146</td>
</tr>
<tr>
<td><strong>Education level</strong> <em>a</em></td>
<td>F (3,53) = 6.06</td>
<td>F (3,54) = 1.07</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.001 *</td>
<td>p-value = 0.370</td>
</tr>
<tr>
<td><strong>Income</strong> <em>a</em></td>
<td>F (4,52) = 3.60</td>
<td>F (4,53) = 1.84</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.012 *</td>
<td>p-value = 0.135</td>
</tr>
<tr>
<td><strong>Duration of diabetes</strong> <em>b</em></td>
<td>Pearson’s r = -0.104</td>
<td>Pearson’s r = 0.110</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.444</td>
<td>p-value = 0.413</td>
</tr>
<tr>
<td><strong>HbA1c</strong> <em>b</em></td>
<td>HbA1c at baseline</td>
<td>HbA1c at follow up</td>
</tr>
<tr>
<td></td>
<td>Pearson’s r = -0.113</td>
<td>Pearson’s r = -0.343</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.410</td>
<td>p-value = 0.009 *</td>
</tr>
<tr>
<td><strong>Knowledge score</strong> <em>b</em></td>
<td>Knowledge score at baseline</td>
<td>Knowledge score at follow up</td>
</tr>
<tr>
<td></td>
<td>Pearson’s r = -0.108</td>
<td>Pearson’s r = -0.091</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.426</td>
<td>p-value = 0.498</td>
</tr>
</tbody>
</table>

Notes:  
* a determined by ANOVA  
* b determined by correlation matrix analysis with Pearson’s r  
* s statistically significant (p-value < 0.05)

Figure 6.14: Association of medication adherence score at baseline with participants’ educational level and income
At follow-up, higher HbA1c was associated with lower medication adherence (Figure 6.15), which suggests that poorer self-reported adherence is associated with poorer glycaemic control. The medication adherence scores both at baseline and follow up were not associated with other participants’ characteristics and outcomes (Table 6.9).

![Figure 6.15: Association of medication adherence score at follow up with HbA1c at follow up](image)

### 6.6.4 Discussion of medication adherence

Our study found that although participants in both groups experienced a similar improvement in medication adherence, we could not detect statistically significant differences in medication adherence scores between groups over time. A systematic review assessing the impact of interventions for people with diabetes on medication adherence, conducted by Sapkota, et al. [576], revealed that among fifty-two studies reviewed, only twenty-two studies showed improvement in medication adherence. Similarly, Williams, et al. [577] also systematically reviewed twenty-seven studies of diabetes interventions, and thirteen of them showed statistically significant change in medication adherence. Although the results might be incomparable as the instruments used for measuring adherence varied, these findings indicated that the effect of diabetes interventions on participants’ adherence to medication might be limited.

Adherence to medications in chronic diseases is a complex phenomenon. The results of the qualitative study described in Chapter 3 showed that medication taking behaviours of people with diabetes underlined the concept of resistance to
medicines taking, which means that the people try to take the medicines as little as possible. With the availability of other alternative therapies, people compared the effect of both types of medications. Numerous qualitative studies have also been conducted to identify factors influencing diabetes patients’ medication taking behaviour. It was found that reluctance to initiate therapy was prevalent, as they believed that once they started taking it, they could not stop doing it [557, 578, 579]. Beliefs about traditional medicines, stigma, and relationship with doctors also influenced adherence to medicines [579-581]. Moreover, with the asymptomatic nature of the disease, patients often adjusted dosage and timing of taking medicines [578]. These findings suggested that patients have a key role in making decisions related to their medication. It is therefore suggested that the key step to improving adherence to medication is to identify individual barriers to medication taking and develop personalised strategies [577, 582]. Inconsistent results among studies implementing similar strategies were also found, however, suggesting that there is no specific formula for the interventions to be effective in improving adherence to medications [576, 583].

On the other hand, measuring adherence to medication is also challenging. In our study, some participants reported that they discontinued taking medicines for a long time, therefore they were not able to answer the questions on adherence to medications. Most of these participants, however, reported taking medicines at follow up. The study has therefore triggered the participants to start taking the medications they discontinued before, but we could not detect this change statistically. Furthermore, in measuring adherence we relied on self-reported data. Various methods are available to measure adherence to medications [584]; however, most studies applied self-report tools [576, 577, 585]. There is no gold standard of methods in measuring medication adherence; however, triangulation, or using a combination of methods, is suggested to increase validity of the results [584, 585].

No association was found between medication adherence score and HbA1c level at baseline, but a relationship was observed at follow-up. This provides some
preliminary evidence for the validity of the translated ProMAS in an Indonesian diabetes population.

From the studies reviewed by Sapkota, et al. [576], only nine out of 52 studies reported improvement in both adherence score and HbA1c. This may suggest that adherence to medication is not the only contributor to glycaemic control [577]. Poor glycaemic control of diabetes patients is, however, associated with poor adherence to treatment [586, 587]. Poor adherence to diabetes medication increased disease progression [588], and led to higher healthcare costs [589]. A current systematic review of type 2 diabetes medicines adherence revealed that only 22% of studies reported adherence of ≥80% among their study participants [590]. Studies in Indonesia also found that only about 30% of diabetes patients showed high adherence to diabetes medications, and they also frequently took alternative and complementary medicines [227, 228]. Strategies to improve medication adherence need to be developed [582]. Other studies found that the interventions led by pharmacists and focusing on medication, led to an improvement in adherence to medications [577, 591]. This may imply that pharmacist involvement in diabetes interventions is crucial, particularly for improving adherence to medications.

6.7 Outcome measures: self-management behaviours

In measuring self-management behaviours, the participants were asked about their diet, exercise, foot care, visits to health professionals and smoking behaviour within the last week. Dietary behaviour was assessed with four questions about portion control, one question about carbohydrate substitution, and three questions about food restriction. Exercise behaviour was measured with three questions: total minutes of exercising; days of attending an exercise programme; and days of exercising for 30 minutes or more. Foot care and smoking behaviours were gathered with one question each: number of days in the last week of taking care of feet; and whether or not they had smoked in the last week. The number of health professionals visited during the last month was also asked.
Some data about self-management behaviours were missing as the participants found it difficult to answer the questions. A few participants, for example, could not answer the questions about portion control because their way of putting food on a plate was different – they did not put vegetables on the same plate but in a separate bowl. In another example, they mentioned that they never calculated the time they spent doing exercise. Some of them also found it difficult to recall what they had done during the last week. The number of participants who provided data about each behaviour is described in each section below.

6.7.1 Dietary behaviour

6.7.1.1 Data completion

![CONSORT flow diagram of data on dietary behaviour completion at baseline and follow up]

At baseline, from the total of 67 participants, completed data were gathered from 63 participants. Three participants were unable to respond to the questions. Although the study assistants tried to elaborate the questions, some participants
remained unable to answer them. One other participant missed the baseline interview. At follow up, three of those participants who had missing data at baseline, responded to the questions as expected. One participant could not answer the questions on self-management behaviour because of time constraints: she was about to go out of town (this participant responded to knowledge and medication adherence questions). Five other participants were lost to follow up, leaving 61 participants who completed questions on self-management behaviour at follow up. A total of 58 participants completed dietary behaviour questions at baseline and follow up (Figure 6.16).

6.7.1.2 Dietary behaviour analysis

Dietary behaviour was divided into two categories: portion control and carbohydrate substitution; and food restriction. A higher score for portion control and carbohydrate substitution is desirable, which means that the participants applied desirable behaviour more frequently. In contrast, the higher score for food restriction is undesirable, because it means that participants more frequently consumed food which should be restricted.

<table>
<thead>
<tr>
<th>Table 6.10: Statistical test of dietary behaviour scores</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Portion control and carbohydrate substitution</strong></td>
</tr>
<tr>
<td>Baseline Mean ± SD Between group p-value</td>
</tr>
<tr>
<td>Base</td>
</tr>
<tr>
<td>Follow up Mean ± SD Between group p-value</td>
</tr>
<tr>
<td>P-value between group difference over time</td>
</tr>
<tr>
<td><strong>Food restriction</strong></td>
</tr>
<tr>
<td>Baseline Mean ± SD Between group p-value</td>
</tr>
<tr>
<td>Follow up Mean ± SD Between group p-value</td>
</tr>
<tr>
<td>P-value between group difference over time</td>
</tr>
</tbody>
</table>

Notes: \(^a\) determined by Welch’s t test; \(^b\) determined by ANCOVA test
No differences were however found between intervention and control at baseline, or following the intervention (Table 6.10). This meant that dietary behaviour of all participants at baseline was similar to that at follow up, and that the intervention did not change participants’ behaviour.

6.7.1.3 Description of dietary behaviour of participants

No differences were found for dietary behaviour. We further explored the participants’ dietary behaviours by looking at the mean score of questions asking the number of days within the last week they were practising the recommended behaviour at baseline. This better describes the behaviours that have been applied by the participants, and this may be important in designing future projects. We included eight questions on dietary habits: portion control (question 1 - 4), carbohydrate substitution (question 5), and food restriction (question 6 - 8) (Table 6.11).

Table 6.11: The mean number of days within the last week the participants applied dietary behaviours at baseline

<table>
<thead>
<tr>
<th>The mean number of days within the last week the participants applied the behaviours</th>
<th>Q1</th>
<th>Q2</th>
<th>Q3</th>
<th>Q4</th>
<th>Q5</th>
<th>Q6</th>
<th>Q7</th>
<th>Q8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>4.49</td>
<td>4.65</td>
<td>3.48</td>
<td>3.60</td>
<td>1.85</td>
<td>1.20</td>
<td>1.86</td>
<td>1.69</td>
</tr>
<tr>
<td>Median</td>
<td>7</td>
<td>6</td>
<td>3.00</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Standard deviation</td>
<td>3.01</td>
<td>2.68</td>
<td>2.78</td>
<td>2.90</td>
<td>2.12</td>
<td>1.72</td>
<td>2.81</td>
<td>1.98</td>
</tr>
<tr>
<td>Minimum</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Maximum</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>7</td>
</tr>
</tbody>
</table>

Q1 = how many days in the last week they had meals with about a quarter portion of rice
Q2 = how many days in the last week they had meals that were half vegetables and fruit
Q3 = how many days within the last week the participants had meals that were a quarter lauk
Q4 = how many days within the last week the participants had meals with combination of those three portions
Q5 = how many days within the last week the participants substituted rice with other type of carbohydrate
Q6 = how many days within the last week the participants ate fried snacks
Q7 = how many days within the last week the participants drink coffee or tea with sugar
Q8 = how many days within the last week the participants ate cookies or sweet snacks

In portion control, many participants reported that they had reduced the amount of rice, and added more vegetables in their meals. As can be seen in Table 6.11, on average, within the last week, participants had their meals with a quarter of rice and a half portion of vegetables and fruit for about 4.5 days. Only 16 and 10
participants, respectively, reported that they had not applied the recommended portion of rice, and vegetables and fruit portion within the last week. Some participants, however, added some comments on the vegetables and fruit question. They said that they ate fruits less frequently than the vegetables. Some said that they only had fruit once a day and some also said that they had fruit only some days of the week. Meanwhile, for the protein or 'lauk' portion (Q3), the mean number of days that participants had meals with protein for one quarter of their plate was less than the rice and vegetable portions. This meant the number of days within the last week that the participants had a combination of previous three questions (Q4) was similar to the protein portion. In this case, some participants added comments that 'lauk' was less than a quarter portion of what they ate.

Although this information in some cases may not be accurate (as many participants said that it was difficult to answer the question as the way they plated meals was different), it does show that many participants were aware about controlling portions of their meal, particularly by reducing the rice portion and adding more vegetables.

The question about carbohydrate substitution (Q5) had a lower mean of the number of days than the portion control (only about 1.8 days). This implies that carbohydrate substitution was less frequently applied by participants than portion control as part of dietary management for diabetes.

The questions about food restriction (Q6 – Q8) are negative, which means that the higher score was undesirable. Table 6.11 shows that the mean of days within the last week of food restriction behaviours was about two days, with Q6 (eating fried snacks) having the lowest mean days (1.2 days). This implies that many participants restricted eating fried snacks. Some participants also mentioned that they had substituted non-calorie sweetener for white cane sugar in their tea or coffee.
6.7.2  Exercise behaviour

Exercise behaviours were measured with three main questions: the number of days during the last week the participants exercised independently; attended a specific exercise programme; and exercised for 30 minutes or more. At baseline, one participant missed being interviewed as explained previously, while at follow up five participants were lost.

At baseline, as can be seen from Table 6.12, the mean scores of exercise behaviours of participants in the control group were similar to those of participants in the intervention group. At follow up, for the number of days attending specific exercise programme, participants in the intervention group had a higher mean score than those in the control group, as confirmed by ANCOVA and depicted in Figure 6.17. No other effects of the intervention were observed for exercise.

<table>
<thead>
<tr>
<th>Exercise behaviours</th>
<th>Statistics</th>
<th>Intervention group (N = 36)</th>
<th>Control group (N = 31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of days doing independent exercise</td>
<td>Baseline Mean ± SD Between group p-value</td>
<td>3.69 ± 3.03</td>
<td>3.81 ± 3.22</td>
</tr>
<tr>
<td></td>
<td>Follow up Mean ± SD Between group p-value</td>
<td>4.17 ± 2.77</td>
<td>4.03 ± 3.04</td>
</tr>
<tr>
<td></td>
<td>P-value between group difference over time</td>
<td></td>
<td>0.714 b</td>
</tr>
<tr>
<td>Number of days attending specific programme</td>
<td>Baseline Mean ± SD Between group p-value</td>
<td>0.686 ± 0.676</td>
<td>0.677 ± 0.653</td>
</tr>
<tr>
<td></td>
<td>Follow up Mean ± SD Between group p-value</td>
<td>1.17 ± 1.61</td>
<td>0.548 ± 0.506</td>
</tr>
<tr>
<td></td>
<td>P-value between group difference over time</td>
<td></td>
<td>0.042 b*</td>
</tr>
<tr>
<td>Number of days doing exercise for 30 minutes or more</td>
<td>Baseline Mean ± SD Between group p-value</td>
<td>2.94 ± 2.79</td>
<td>3.39 ± 3.21</td>
</tr>
<tr>
<td></td>
<td>Follow up Mean ± SD Between group p-value</td>
<td>3.03 ± 2.90</td>
<td>2.87 ± 3.11</td>
</tr>
<tr>
<td></td>
<td>P-value between group difference over time</td>
<td></td>
<td>0.939 b</td>
</tr>
</tbody>
</table>

Notes:  
* a determined by Welch’s t test;  
* b determined by ANCOVA test  
* statistically significant (p-value < 0.05)
6.7.2.1 Description of participants’ exercise behaviour

Most participants exercised for some days during the last week (Table 6.12). Following the question about the number of days that the participants did independent exercise, the participants were also asked for ‘how long they did the independent exercise for’. Most participants, however, failed to answer the second question.

Some of them mentioned that they did not calculate the time spent exercising. Others said that they exercised on random days and at random times, so they could not recall the duration. At baseline, 40 participants - 21 in the control group and 19 in the intervention group - responded to this question, while at follow up, 49 participants - 23 in the control group and 26 in the intervention group - responded to this question. A total of only 29 participants - 14 in the control group and 15 in the intervention group - responded to the question about duration of doing independent exercise. These data showed a variety of duration of exercise, with most doing exercise for about 30 minutes. Some participants elaborated further: they did gardening as part of their daily routine; or they walked regularly in the morning.

In terms of attending a specific exercise programme, at baseline, some participants reported that they attended exercise programmes held by health facilities. At follow up, participants in the intervention group reported a significant
improvement in attending a routine exercise programme compared to the participants in the control group. The intervention has encouraged the participants to attend the exercise programme regularly.

### 6.7.3 Other self-management behaviours

Other self-management behaviours included the number of days that the participants took care of their feet within the last week, visits to health professionals within the last month, and smoking behaviour (Table 6.13).

<table>
<thead>
<tr>
<th>Other self-management behaviours</th>
<th>Statistics</th>
<th>Intervention group (N = 36)</th>
<th>Control group (N = 31)</th>
<th>Between group p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of days taking care of feet</td>
<td>Baseline Mean ± SD</td>
<td>1.56 ± 2.84</td>
<td>1.90 ± 2.90</td>
<td>0.631&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Between group p-value</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.248&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.264&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Follow up Mean ± SD</td>
<td>1.74 ± 2.79</td>
<td>1.00 ± 2.38</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Between group p-value</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>P-value between group difference over time</td>
<td>0.062&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.342&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>Number of visiting health professionals within the last month</td>
<td>Baseline Mean ± SD</td>
<td>0.794 ± 0.641</td>
<td>1.39 ± 1.61</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Between group p-value</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.877&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Follow up Mean ± SD</td>
<td>1.43 ± 1.22</td>
<td>1.74 ± 1.41</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Between group p-value</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.918&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>P-value between group difference over time</td>
<td>0.468&lt;sup&gt;c&lt;/sup&gt;</td>
<td>0.468&lt;sup&gt;c&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>Smoking behaviour</td>
<td>Baseline Percentage YES/NO</td>
<td>5.6%/94.4%</td>
<td>6.5%/93.5%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Between group p-value</td>
<td></td>
<td></td>
<td>0.877&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Follow up Percentage YES/NO</td>
<td>2.8%/97.2%</td>
<td>6.5%/93.5%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Between group p-value</td>
<td></td>
<td></td>
<td>0.468&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

Notes:  
<sup>a</sup>determined by Welch’s t test;  
<sup>b</sup>determined by ANCOVA test;  
<sup>c</sup>determined by X² test

### 6.7.3.1 Foot care

Foot care behaviour was measured with one question about the number of days in the last week they cared for their feet including washing, soaking, and drying. Table 6.13 shows this did not differ at baseline, with participants taking care their feet only for about two days on average in the last week. Some participants who
practised foot care elaborated further, that they always drain their feet when they got wet. Some others said that they took care of their feet when they became itchy. The participants who reported not taking care of their feet said that they had no wounds on them, so they thought that foot care was not needed. At follow-up, the mean number of days decreased for the control group, and remained almost the same for the intervention group. However, this change was not significant statistically.

6.7.3.2 *Health professional visits*

The majority of participants had visited their health professionals at least once within the last month, and this did not differ between groups (Table 6.13). The health facilities in the study location commonly scheduled patient visits once a month. Only a few participants visited their health professionals more than once a month. Some participants mentioned further that they visited a physician at *Puskesmas* (community health centres), or came to *Posyandu Lansia* (community-based health services for the elderly). Two participants also mentioned that they were visited at home by health professionals. Some participants – five in the control group and eleven in the intervention group – did not visit a health professional within the last month. Two of them said that they had not had their diabetes checked in the last four and two months respectively.

At follow up, more participants in both groups reported visiting health professionals at least once within the last month. Only nine participants - three in control and six in the intervention - reported that they did not visit health professionals within the last month. At follow up, the number of participants who visited their doctors more than once in a month increased. These changes were not statistically significant, however.

6.7.3.3 *Smoking behaviour*

The majority of participants reported that they did not smoke at both baseline and follow-up data collection. The participants who reported smoking were all male. Only four participants – two in the control group and two in the intervention group – reported smoking at baseline. At follow up, one participant in the control
group who previously reported smoking stated that he had not smoked within the last week at follow up. Moreover, one participant who reported not smoking at baseline mentioned that he smoked at follow-up. One other participant in the control group mentioned that he smoked at both baseline and follow up with an increased number of cigarettes on an average day from 10 to 20. In the intervention group, one participant who reported smoking at baseline was lost at follow up, and one other participant reported not smoking at follow up. Smoking status did not differ statistically at baseline or follow-up.

6.7.4 Combined score of self-management behaviours and its association with demographic characteristics and other outcomes

The combined scores of self-management behaviour were calculated by adding the scores of all behaviour categories, except for the dietary behaviour on food restriction. The score for food restriction behaviour was subtracted as the questions were negative. Table 6.14 shows statistical tests of total behavioural score of participants in the control and intervention groups at baseline, and at follow up. There were no differences at baseline or follow-up.

<table>
<thead>
<tr>
<th>Groups</th>
<th>Baseline</th>
<th>Follow up</th>
<th>P-value between group difference over time</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean ± SD</td>
<td>Between group p-value</td>
<td>Mean ± SD</td>
</tr>
<tr>
<td>Intervention</td>
<td>41.1 ± 28.3</td>
<td>0.131 a</td>
<td>51.9 ± 29.0</td>
</tr>
<tr>
<td>Control</td>
<td>52.0 ± 29.3</td>
<td></td>
<td>49.7 ± 29.9</td>
</tr>
</tbody>
</table>

Notes:  
a determined by Welch's t test;  
b determined by ANCOVA test

Self-management behaviour was not associated with gender, age, duration of diabetes, or education, or with other outcomes of knowledge and HbA1c (Table 6.15). Participants with the lowest and the highest income had higher self-management scores than those in the middle income group. No effect was found at follow-up.
Table 6.15: Association analysis of self-management behaviour score at baseline and participants demographic characteristics, and other outcomes

<table>
<thead>
<tr>
<th></th>
<th>Total self-management behaviour score at baseline</th>
<th>Total self-management behaviour score at follow up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender a</td>
<td>F (1,64) = 0.147</td>
<td>F (1,59) = 0.451</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.702</td>
<td>p-value = 0.504</td>
</tr>
<tr>
<td>Age b</td>
<td>Pearson’s r = -0.034</td>
<td>Pearson’s r = -0.017</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.785</td>
<td>p-value = 0.895</td>
</tr>
<tr>
<td>Education level a</td>
<td>F (3,62) = 0.295</td>
<td>F (3,57) = 2.88</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.829</td>
<td>p-value = 0.044</td>
</tr>
<tr>
<td>Income a</td>
<td>F (4,61) = 2.66</td>
<td>F (4,56) = 0.402</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.041</td>
<td>p-value = 0.807</td>
</tr>
<tr>
<td>Duration of diabetes b</td>
<td>Pearson’s r = -0.112</td>
<td>Pearson’s r = 0.048</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.373</td>
<td>p-value = 0.713</td>
</tr>
<tr>
<td>HbA1c b</td>
<td>Pearson’s r = 0.026</td>
<td>Pearson’s r = -0.075</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.841</td>
<td>p-value = 0.570</td>
</tr>
<tr>
<td>Knowledge score b</td>
<td>Pearson’s r = -0.227</td>
<td>Pearson’s r = -0.233</td>
</tr>
<tr>
<td></td>
<td>p-value = 0.067</td>
<td>p-value = 0.071</td>
</tr>
</tbody>
</table>

Notes:  
a determined by ANOVA  
b determined by Pearson correlation  
c statistically significant (p value < 0.05)

6.7.5 Discussion of self-management behaviour outcomes

The study found that there were no significant differences in self-management behaviours between participants in the control and intervention groups. Analysis of specific self-management behaviours (dietary habits, exercise, and other self-management behaviours) also showed that there were no differences between participants in the intervention and control groups. The behaviour scores were statistically unchanged, except in the number of days attending exercise programme, where participants in the intervention did participate more in structured exercise activities, relative to control.

Studies of diabetes interventions have reported positive results on HbA1c and knowledge outcomes, but showed more conflicting results on behavioural outcomes. A systematic review of diabetes intervention studies in Iran showed that most studies have positive effects on knowledge and HbA1c outcomes, but the effects on attitude and behavioural outcomes varied [592]. Most diabetes interventions conducted in other developing countries also reported favourable outcomes of HbA1c, however, only a minority of them had small impacts on other outcomes measured including knowledge and behaviours [560]. Furthermore, Fan
and Sidani [457] reported that the diabetes self-management interventions produced the lowest effect size on behavioural outcomes compared to knowledge and HbA1c [457]. Hawthorne, et al. [467] also conducted a systematic review of diabetes interventions in socially disadvantaged ethnic minority communities living in developed countries, and found that the interventions improved clinical outcome of HbA1c and knowledge. The interventions, however, resulted in no significant improvement in the other patient-centred outcomes including attitude, quality of life, and self-efficacy [467]. A systematic review of diabetes interventions conducted in China also showed that most of the interventions improved participants’ knowledge and glycaemic control, while only limited interventions resulted in positive effect on behaviour [593].

This accumulating evidence suggests two likely explanations of why some people with diabetes have their clinical outcome improved but with limited improvement in behavioural outcomes: firstly, it may relate to measurement issues; and secondly, it may relate to the intervention not being able to change participants’ behaviour.

Measuring adherence to self-management behaviours of people with diabetes is complicated as it includes a wide ranges of activities: from dietary control to foot care [594]. Some methods are recommended, including clinical outcome indicators, behavioural observation, pill counts, and patients’ self-reports. Patient self-report is regarded as the most reliable approach compared to the others, as this method enables the researcher to detect specific behaviours they implemented that may contribute to their clinical outcome [594]. Self-reported data are, however, subject to bias which may come from over-reporting [595]. In our study, we asked participants at baseline and follow up to recall their behaviour within the last week. The statistical analysis showed no changes in behavioural scores over time. Bias from over-reporting behaviours at the baseline measurement may provide a likely explanation on this result. Furthermore, recalling data may also be influenced by memory error. Johnson [594], therefore, suggested it is possible to gather good quality self-report data on self-management behaviour when the participants were asked about a very specific behaviour, so
that it more understandable. Further, in order to improve quality of recall data, short term recall (for example, one day) or multiple sources of recall including both patients and their caregiver are recommended [594].

Issues of reliability of measurement tools also emerged. Previous studies have attempted to develop and measure reliability of self-management or self-care behaviours. As an example, Toobert, et al. [596] developed The Summary of Diabetes Self-Care Activities Measure, and reviewed its validity; and Schmitt, et al. [597] developed the 16 item Diabetes Self-Management Questionnaire and evaluated its relationship with glycaemic control. Applying previously developed and validated questionnaires in different community contexts is however problematic. Both of those questionnaires, for example, asked participants about their behaviour related to self-monitoring of blood glucose. In the Indonesian context, this is less applicable. Most people with diabetes in Indonesia do not have their own blood glucose measurement tools. Most previously validated questionnaires are also developed in a western community context, so that their questions about dietary control might not be appropriate in the Indonesian context. In our study we therefore did not use a previously validated questionnaire; instead we developed the questionnaire based on knowledge gathered at the qualitative study. This study did not, however, aim to measure the validity and reliability of this questionnaire. Future study needs to be conducted in this area, so that a valid and reliable questionnaire for measuring self-management behaviour applicable in the Indonesian context is established.

Secondly, it is widely recognised that behavioural change is the most challenging part of diabetes management. At the last intervention session, some participants expressed "iya, kita ini sudah pintar kalau ditanya disini bias jawab, tapi begitu sampai dirumah susah sekali kita laksanakan" (yes, we now knew a lot about diabetes and how to manage it, and we could respond well when we were asked questions related to that. However, when we get home, it is really difficult to apply what we know).

The Social Cognitive Theory (SCT) explains that behaviour is a result of a complex interplay between individual characteristics and environmental support [280].
The central determinant of SCT is self-efficacy, which is the perceived ability to perform such behaviour. The intervention sessions in this study focused not only on improving knowledge, but also increasing participants’ self-efficacy by providing encouragement, and facilitation for them to practise the recommended behaviours. The likely explanation for this failure in improving behaviour, however, is the short-term duration of the intervention which was only for three months. This allowed limited time for monitoring and giving feedback to the participants. Fan and Sidani [457] suggested that diabetes interventions conducted over a longer duration (>24 weeks) resulted in larger effects for clinical, knowledge, and behavioural outcomes.

Furthermore, Baker, et al. [598] identified a number of strategies employed by some successful diabetes prevention programmes in changing lifestyle behaviours. Among the strategies implemented was that the methods of delivering counselling and education for behavioural change was face-to-face interaction, individually or in small groups after an initial individual counselling, with the duration of delivery of around a year. Those explanations imply that interventions to change behaviour need to be conducted more intensively, involving individual assessment of barriers and problems in applying recommended behaviour, and developing individual strategies to implement the recommended behaviours. Interventions for behavioural change also need a longer time to have an effect, as behaviour change needs to be a gradual process.

The other important component of behaviour change is environmental support [280]. Changing individual behaviour is likely to be successful when environmental factors are also taken into account [599]. The qualitative study revealed that the implementation of dietary control and physical activity were challenged by unsupportive family members, and cultural practices. Family’s attitude has shown to have an important impact on diabetes self-management [600]. This implies that interventions for changing lifestyle should not only target individuals, but also the influence of family members and cultural practices on the behaviours. In the absence of these supports, the outcome of behavioural change would likely to be minimal. The intervention applied in the study has
acknowledged the importance of support. However, we only included peer support from other diabetes patients through peer-modelling. This may not be enough in encouraging participants to change behaviours.

6.8 Acceptability of the intervention programme to participants and health professionals

Four individual interviews and a focus group were conducted with participants involved in the intervention group after the intervention sessions were completed. Individual interviews with two Prolanis (programme for managing chronic illnesses) team leaders in the intervention groups were also conducted. The interviews and focus group aimed to gather participants' and health professionals’ opinions about the implementation of the intervention.

From the interviews with participants, most perceived benefit from the intervention: that the intervention improved their knowledge about diabetes and their conditions. Some participants also suggested that health professionals’ attitude toward the patients is important in encouraging the participants to adopt the recommended actions. Interactive and continuing communication improved health professionals-patient relationships, and the good relationship supported participants to attend the session regularly.

The activities help us ... I mean our health is getting better ... controlled ... because we exercised routinely, as we rarely do it at home [individually] (Individual interview).

We really like to come here as the health professionals always smile to us, and provide the best health services to us. So, we really appreciated them (Group discussions).

The activities really help us, and I wish that this is continued, and I also wish that my friends here come to the programme regularly, and not absent... for our [better] health (Group discussion).

She, my friend [who also has diabetes] doesn't want to come, what can I do, she will know the impact later... (why she doesn't want to come?) She is so lazy to wake up early in the morning” (individual interview).
The participants also wished that the members of the groups would routinely come and participate in the activities in the future. They said that level of individual awareness of the importance of the sessions, and time constraints hindered some of their friends with diabetes from attending the programme.

From the Prolanis teams’ perspectives, the intervention improved participants’ attendance at the programme, compared to the usual Prolanis activities. The Prolanis teams also mentioned that the intervention sessions increased participants’ enthusiasm about being actively involved in the activities, particularly in educational sessions. The continued and structured education sessions, and the individual tasks and small rewards increased the participants’ motivation to attend the sessions and practise the recommended actions. The HbA1c measurement also increased participants’ enthusiasm to know more about their conditions. These new initiatives implemented in the intervention session were perceived positively by the Prolanis teams, and will be continued in their usual Prolanis activities. The Prolanis team in Puskesmas Oebobo - who have increased the frequency of their Prolanis activities from fortnightly to once a week - reported that more intensive activities increased not only the enthusiasm of the participants to come to the sessions, but also improved the personal relationship among the participants. In this intervention group, the members of the group initiated establishing a social self-managed group, which was not only concerned with improving health, but also other social activities.

Participants’ attendance improved. And the participants were also enthusiastic in the education sessions, as usually we rarely provided education for them. With this intervention, the education was done regularly with more structured material. This encouraged them to come to the session. And the glucose measurement … (Prolanis team Oepoi).

Usually we performed Prolanis activities once in two weeks, because of limited health professionals’ availability to manage the programme, but then we observed the participants’ enthusiasm with this intensified programme [once a week], so we will do our best to continue the activities once a week (Prolanis team Oebobo).

Yes, probably because of more frequently they meet, the participants then feel that the programme belongs to them, so increase their belonging to the programme, so they then also have other ideas for social activities (Prolanis team Oebobo).
6.9 Discussion of overall results of type 2 diabetes intervention study

The findings of the current study showed that outcomes for the participants in each of the study arms did not differ statistically. A significant overall reduction of HbA1c level from $8.3 \pm 2.23\%$ to $7.9 \pm 2.16\%$ within three months of study duration was a welcome finding, however, and was observed in both groups. Participants’ knowledge outcomes also improved, although their medication adherence and self-management behaviours did not change statistically.

These results, however, were in contrast to the majority of type 2 diabetes self-management intervention studies. Systematic reviews of diabetes self-management interventions conducted in both developed and developing countries’ contexts mostly reported favourable outcomes of knowledge, metabolic, and behavioural improvement [457, 458, 465, 468, 477, 559-562, 592, 593]. Most diabetes intervention studies implemented a Randomised Controlled Trial (RCT) design. A quasi-experimental non-equivalent control group, and pre-experimental pre-and-post single group were applied more often in developing countries’ contexts [559, 560, 592].

An RCT is widely recognised as the most robust design for measuring a ‘true experiment’ effect, as randomisation prevents selection bias. In clinical practice, however, randomisation might not be possible. In the context of this study’s location, randomisation was neither practical nor feasible (detailed in Chapter 5). The quasi-experimental design is regarded as the most powerful alternative in cases where randomisation cannot be undertaken [601]. The addition of a control group in the quasi-experimental design, even if the control group is un-matched or non-equivalent, greatly reduces equivocality (ambiguous findings) resulting from single group pre-and post-test [602]. Further, Campbell [602] underlined that the control group in the quasi-experimental design is more effective when more similarities are found between the two groups confirmed by the score at pre-test [602]. In this study, statistical analysis showed no significant differences in demographic characteristics and outcomes measured at baseline between participants in the control and intervention groups. The control group, therefore,
although it was not matched and non-equivalent, can effectively act as the comparison group.

A few studies on type 2 diabetes interventions published in peer-reviewed journals reported unfavourable outcomes, or non-significant differences of outcomes between group arms. Sperl-Hillen, et al. [603], Sperl-Hillen, et al. [604] compared three study arms: individual education; group education; and usual care of poorly controlled type 2 diabetes patients in Minnesota. They found that participants in all group arms experienced an improvement in HbA1c, with the highest reduction in the individual education group. The HbA1c reduction of participants in the group education cohort was similar to that in usual care. They concluded that the individual education was more effective in their setting. Rygg, et al. [605] evaluated the effectiveness of an ongoing diabetes programme conducted in local hospitals and included poorly controlled type 2 diabetes patients in Norway. The results showed that the programme prevented the patients’ diabetes deteriorating: participants in the intervention group experienced a small reduction of HbA1c while those in the control group showed an increase in HbA1c value. Further, Partapsingh, et al. [606] implemented a diabetes intervention guided by the Stages of Change model in patient-physician consultations in Trinidad. With an RCT design, this study found that there was an overall increase in HbA1c level of participants in both groups, with those in the control group experiencing a higher increase of HbA1c. The authors attributed the worsening conditions of the study participants to the harsh economic condition in the study location at the time of the study.

Frosch, et al. [607] evaluated the effectiveness of ongoing telephone support for poorly controlled type 2 diabetes patients compared to only providing an educational booklet. The study reported that there was a significant overall reduction of HbA1c from baseline to six months, but there were no differences observed between groups, with the higher improvement in the control group. There were also no significant differences between groups for other outcomes. Skelly, et al. [608] also reported that tailored home-visit diabetes intervention for older African American women resulted in non-significant differences among
study arms in HbA1c, and other physiological and behavioural outcomes. Participants in both study groups experienced an improvement in all outcomes measured. They assumed that multiple extraneous factors might have affected the internal validity of the study. Cooper, et al. [609], Gary, et al. [610] also found a small improvement of participants in the intervention group. Cooper, et al. [609] found that HbA1c level at 12 months correlated negatively with attendance rates with the higher attendance rates predicting the greater level of HbA1c reduction. Anderson, et al. [611] also reported that both control and intervention participants showed an improvement in outcomes during six weeks of intervention activities focused on problem-based empowerment education. They attributed the findings to volunteer bias, study effect, and intervention impact.

The possible causes of improvement in both intervention and control groups in an experimental study is explained by Becker, et al. [612], including reactivity of measurement, contamination, maturation, and history. Further, Campbell [602] listed history, maturation, and testing effect among eight extraneous variables which may influence internal validity of experimental study design. We believe that measurement reactivity, contamination, and history contributed to the lack of differences observed between intervention and control in our study.

6.9.1 Measurement reactivity

Reactivity of measurement is defined as the change of participants' outcomes simply as a result of being measured [612, 613]. Measurement reactivity has been shown to influence participants' behaviour, emotion, and cognition [613]. Measurement reactivity is similar to the Hawthorne effect [614, 615], testing effect [602, 615], and mere measurement effect [616]. The Hawthorne effect is defined as the impact of merely participating in the study which results in increasing awareness and behaviour [614, 615]. The testing effect explains that the participants experienced an improvement in the second testing as they learned from the first one [602]. Similarly, mere measurement effect describes the change in actual behaviour as a result of being asked. The mere measurement effect has been studied by comparing the self-reported intention to the actual behaviour [616, 617].
In this study, we believe that measurement reactivity provides a likely explanation of the significant improvement of some outcomes in both groups. We assume that the HbA1c measurement, providing the results of the HbA1c to both participants and health professionals, and interview-type questionnaire triggered more intensive diabetes management in the study location.

This intervention study provided participants their first experience of HbA1c measurement. The HbA1c test has not been included in the standard diabetes care in the health facilities involved in the study. People with diabetes commonly received fasting or random blood glucose tests with a point of care device. The frequency of blood glucose measurement, however, also depended on the health facility’s capability and financial support to conduct the measurement. In measuring the HbA1c, this study also collaborated with a private clinical laboratory in the city, which was perceived by most people as a highly qualified clinical laboratory, that differed from what the participants usually received. This may have further increased their enthusiasm about the measurement itself. Further, providing information about the study, and that they would have their HbA1c measured at baseline and three months after, may also have made the participants aware of being evaluated over time, and encouraged participants to better manage the disease.

Furthermore, the HbA1c test results were reported both to participants and health professionals soon after the baseline data collection was completed. Providing the results early provided feedback for both participants and health professionals about how well their diabetes was managed. It has been found that providing a report of a comprehensive diabetes evaluation to participants and health professionals, can be a form of intervention that affects diabetes outcomes [611, 618]. The measurement of HbA1c and providing the results to both participants and their health professionals might therefore trigger the participants to more intensively self-manage the disease, and trigger health professionals to more intensively manage the patients. This study did not prohibit participants in either group from attending self-management education or programmes provided by
usual healthcare providers. This study also did not prohibit the participants seeking or being involved in any other education programme.

This study was not, however, able to record and evaluate changes in treatment provided by health professionals that the participants experienced during the study period. The only data source we had about changes in treatment was the questionnaire. One question asked about the number of medications for diabetes the participants received at baseline and at follow-up. In many cases, however, the participants could not differentiate between the medicines for diabetes or other comorbid conditions. These self-reported data were therefore less reliable. Attempts were made to collect data about participants' treatment changes over time through medical records. In some cases, however, the medical records were poorly written, so that we could not retrieve that data. The impact of treatment changes given by the healthcare providers on the outcomes could not therefore be evaluated.

Measurement reactivity might also come from the questions asked of the participants. Capellan, et al. [619], for example, found that the participants in the control group learned about how to better manage catheter-related problems through questions asked in repeated interviews, so that their self-monitoring behaviour improved [619]. This effect of asking questions has also been studied in relation to physical activity behaviour with a Solomon four-group design [595, 620]. These two studies suggested that participants' self-reported walking behaviour increased as a result of completing a questionnaire or wearing a pedometer. Completing the questionnaire did not, however, affect the actual (not self-reported) walking behaviour [595]. In our study, the participants' reactivity may also come from the questions covering knowledge, medication adherence, and self-management behaviour administered face-to-face by the research assistants. It has been previously found that merely administering a questionnaire resulted in higher self-reported behaviour, and this effect was often higher when the questions were asked by an interviewer [595, 620]. In the interview process, two-way communication cannot be avoided. It was observed during the data collection that the participants clarified the questions asked, or asked for the
correct answer for the questions afterwards. This process might also act as knowledge-enhancing intervention. The questions on medication adherence and self-management behaviours may also increase people's awareness of the recommended behaviours for managing diabetes.

We found, however, that the self-management behaviour scores at baseline and follow up did not change statistically. This means that in this study we did not obtain a higher score for self-management behaviour at follow up. This may preclude the possibility of the questionnaire as a source of measurement reactivity. Interestingly, participants' HbA1c outcome improved. This may imply that the participants experienced a change in their diabetes management; however, we were unable to identify the change.

### 6.9.2 History

History effects, defined as contextual changes occurring between the first and follow up measurements, might also explain some of the improvement in both control and intervention groups [602, 612]. Two contextual changes in the healthcare environment in the study location were observed during the study period. Firstly, the healthcare facility from which the control participants were recruited (Puskesmas Sikumana) intensified their activities in the *Prolanis* programme (a programme for managing diabetes and hypertension patients) from once a month to once a week. This intensified *Prolanis* activity might also have provided more intensive care for participants involved in the control group. Secondly, during the study period the universal health coverage management (*BPJS Kesehatan*) in the study location provided more health services to people with diabetes and hypertension, including participants involved in both intervention and control groups. The insurance management (*BPJS Kesehatan*) provided a complete blood check including HbA1c and total cholesterol level in December 2016, and centralised *Prolanis* activities twice in the three month period of the study. These activities had not been conducted before the study period. These changes may have increased the diabetes participants' involvement in diabetes programmes, which further facilitated improvement of their outcomes.
6.9.3 Contamination

Contamination of the control group means that the participants in the control group actively or passively received the intervention programme from the other participants involved in the intervention group [612]. To avoid contamination, we designed the study so that the intervention and control participants were allocated based on the health centres they were registered in. The people in the study location commonly registered with the health facility closest to their home, so that the transportation problem is minimised. With this design, participants in both groups were geographically separated, so that the contamination of information about the intervention was minimised.

This may not have been enough to ensure that participants from both groups did not interact, however. Most participants in the study were registered under the universal health coverage (UHC) scheme. We observed that during the intervention period, the management of the health insurance (BPJS Kesehatan) conducted integrated education and health check activities for all diabetes patients in the city. During this session, all diabetes patients under the UHC management, including those involved in the intervention and control groups, were invited to a designated place and time to have their blood drawn, and received standard diabetes education. This event provides an example of a chance for participants in the intervention and the control groups to interact. Although effort was made to minimise contamination bias, we could not therefore ensure that there were no interactions between the participants in both groups.

Based on this explanation, we believe that we developed an effective intervention but employed a method that did not allow us to ascertain the relative effect of extraneous forces of measurement reactivity, history, and contamination. The most effective approach to minimise this threat to internal validity is to conduct a study for a longer period, during which neither patients nor physicians receive any study data. The longer time would allow us to ascertain whether the change was as a result of the intervention or merely as reactivity of the participants to the measurement. It did not seem ethical to withhold data, however, particularly on
the results of blood glucose measurement, from either participants or physician. Although the participants involved in the study were registered at healthcare facilities, most healthcare facilities provided blood glucose monitoring services once a month, and most participants did not have a device for self-blood glucose monitoring. Most participants therefore wanted to know about the results of their blood glucose measurement, so that withholding the results seemed to disadvantage them.

Regardless of issues about study design, the intervention programme in our study provided a positive impact through increasing the management of diabetes in the intervention group, and stimulating local healthcare providers to more intensively manage their diabetes patients. The intervention activities in our study were conducted based on availability of the health professionals in the study location; therefore, this can be applied in other similar settings.
Section D – Discussion and conclusion

7 Chapter 7: Discussion and conclusion

7.1 Introduction

This study was prompted by the fact that there are few studies in the Indonesian context that address the problem of child immunisation and diabetes, as explained in Chapter 1. The goal set for the thesis was to investigate whether it was possible to improve health indicators and outcomes. The literature study in Chapter 2 shows that understanding people’s behaviours related to health problems is crucial in developing acceptable and effective interventions. Understanding lay people’s perspectives enables researchers to tailor interventions based on community needs and preferences. Literature on lay people’s perspectives and health behaviour related to child immunisation and diabetes in Indonesia, however, is very limited. The qualitative study with focus group discussions presented in Chapter 3 was therefore performed as an attempt to gather information on Indonesian people’s behaviour related to child immunisation and diabetes. The questions were developed based on Kroeger’s framework of factors determining choice of health providers, including characteristics of the individual, the disease, and the health providers [279]. Findings from the qualitative study directed the focus and design of the major study, which was an intervention pilot study for type 2 diabetes patients in Kupang, the capital city of East Nusa Tenggara Province. A literature review on diabetes interventions described in Chapter 4 provided further guidelines in developing the intervention study. The methodology of the intervention study is detailed in Chapter 5. A quasi-experimental design was applied to compare the effectiveness of intensive group-based intervention to usual care for people with diabetes. The intervention activities were conducted in collaboration with the Prolanis programme in primary healthcare facilities. With this collaboration, the intervention was conducted based on available resources in the study location, which further enabled the intervention to be continued even after the project ended. The results of the intervention study are explained in Chapter 6.
Chapter 7 summarises the thesis findings, describes lessons learned, the strengths and limitations of the study, and suggests implication, recommendations, and future research directions. The chapter ends with the conclusions of the thesis.

7.2 Summary of the thesis findings

7.2.1 The qualitative study

The qualitative study aimed to answer three research questions: 1) What are people’s perceptions, beliefs, and experiences related to child immunisation and diabetes?; 2) What are the individual and social factors that may influence people’s behaviour related to child immunisation and diabetes?; and 3) What are the health provider factors that may determine people’s behaviour in seeking care?

The study revealed that characteristics of the individual, characteristics of the health problems and how they are perceived, and characteristics of the health providers determined health-related behaviours of people in Indonesia (Figure 7.1). These findings underline the importance and applicability of the framework developed by Kroeger [279] in understanding people’s behaviour in the context of study location. Focusing on two different health problems, child immunisation and diabetes, enabled us to understand the extent to which each factor that determines people’s behaviours may vary.

7.2.1.1 Child immunisation

We found that most mothers utilised Posyandu for child immunisation. When the children were considered sick on the day of Posyandu service, they were referred to other immunisation services. This study also highlighted issues related to the implementation of Posyandu. Financial issues and lack of community participation often hindered Posyandu implementation. Potential missed opportunities were also often noted. In overcoming these, increasing the skills of community-based health workers is crucial.

Moreover, the most notable factors influencing mothers’ behaviour were the characteristics of the subject, and the characteristics of the immunisation service.
Within the characteristics of the subject, the qualitative study underlined the importance of mothers’ interaction with the family, including their status in the household in making decisions related to child immunisation. As has been detailed previously, the most frequent reason mentioned by mothers for refusing immunisation was that the fathers did not agree. Although the mothers are responsible for taking care of the children, decisions related to health services utilisation therefore depended on the fathers as the leader and the decision maker in the family. Most mothers who participated in the study were housewives. This may imply that the housewife mothers have less power in their family in the decision-making process.

Characteristics of the immunisation services, namely relationships between mothers and community-based health workers influenced their behaviours. The relationships facilitated the mothers to perform recommended behaviours, not
only in child immunisation, but also in engaging with other health services including maternal and child care. This underlined the importance of health professionals’ attitudes and communication in improving the acceptability of health services.

Characteristics of the disorder and its perception were also found to influence child immunisation behaviours. It seemed, however, that this factor was not strongly associated with behaviour. Most mothers participating in the child immunisation programme, for example, kept immunising their children despite limited understanding about immunisation and the diseases the vaccines protected against. Only a few participants mentioned that they did not immunise their children as they perceived no benefit from having immunisation.

7.2.1.2 Diabetes

Participants experienced late diagnosis, uncontrolled blood glucose levels, and diabetes related complications. Diabetes patients’ behaviours in managing the disease were determined mostly by individual lay perceptions, evaluation and experiences of their disease and its treatment. Based on the Kroeger's framework [279], this factor is categorised as characteristics of the disorder and perceptions of it. Diabetes patients perceived the disease in their own explanations of aetiological model, and expected benefit of treatment. Because diabetes is a chronic disease, lay evaluation is a continuing process over time.

The results of the lay evaluation of the disease and the effectiveness of its treatment further influenced the appeal and acceptability of specific health services. Diabetes patients, who perceived that medicines could not cure the disease, for example, chose traditional medicines for treating diabetes. In the lay evaluation process, the diabetes patients sought and received recommendations from significant others. Unlike those in the topic of child immunisation, in the case of diabetes, the significant others were other people with diabetes including family members or friends. As an example, the diabetes patients decided to take traditional medicines based on success stories of other diabetic friends.
Other factors categorised as characteristics of subject, including cultural beliefs and practices also influenced people's behaviour in managing the disease. Diabetes participants in the study saw the disease in a broader cultural context. Their perceived ability in managing the disease was therefore challenged by these cultural beliefs and practices.

7.2.2 Findings of the intervention pilot study

The intervention pilot study failed to show statistically significant differences in outcomes between participants in the intervention and control groups. Participants in both groups, however, experienced an improvement in clinical outcome and knowledge. Therefore, we believe that we developed an intervention that was effective in improving outcomes, but we were not able to detect the relative effect of extraneous forces including measurement reactivity, contamination, and history.

Participants in the quasi-experimental study were 60% female, mean age 57, and had diabetes for an average of 4.5 years. Baseline HbA1c did not differ (control mean 8.35%, SD 2.60; intervention 8.26%, SD 1.89). Post-intervention, both groups showed improvement in HbA1c (control mean 7.95%, SD 2.53; intervention 7.84%, SD 1.82). Although more intervention than control participants achieved an HbA1c reduction of 0.5%, 43% compared to 31%, change between groups was not different (p = 0.9).

In terms of knowledge, most participants had a moderate level of knowledge at baseline. The highest score was on knowledge about risk factors, and the lowest score was on knowledge about diet. The mean of total knowledge was 54.3 (SD 12.1) for participants in the control group, and 56.6 (SD 9.03) for participants in the intervention group. At follow up, the knowledge score of participants in both groups had improved, 56.8 (SD 13.9) in the control group, and 58.9 (SD 11.8) in the intervention group. Statistical analysis of ANCOVA showed that there was no significant difference in the knowledge score change between participants in the control and intervention groups (p=0.54). Most participants were aware that diabetes can be prevented and that high blood pressure is one of risk factors for developing diabetes. Most of them also acknowledged the importance of
controlling diet and performing exercise in managing the disease. Participants involved in the study had suffered from diabetes for some period and had experience of attending specific programme for diabetes. Their level of knowledge may not therefore be similar to the general population or newly diagnosed diabetes patients. With this level of understanding, a small knowledge gain was observed within three months.

In the outcome of medication adherence, the study did not find statistically significant differences over time between participants in the control and the intervention group. The mean score of medication adherence for participants in the control group was 10.4 ± 3.84 at baseline, and 10.9 ± 3.26 at follow up. Meanwhile, participants in the intervention group had a mean score of 9.97 ± 3.54 at baseline, and 10.4 ± 4.24 at follow up. Although the intervention was not able to significantly improve adherence to medication of the participants, it has increased awareness about the importance of taking medicines. Nine participants reported discontinuing taking medicines at baseline, and seven of them reported taking medicines at follow up.

Furthermore, the study found that participants’ self-management behaviours did not change during the three months of the study period, except for the number of days attending an exercise programme during the last week. Within the exercise behaviour, the number of days attending an exercise programme during the last week improved significantly for participants in the intervention group, compared to the control group. At baseline, the mean total behavioural score of participants in the control group was 52.0 (SD 29.3), and those in the intervention group was 41.1 (SD 29.3). At follow up, the mean of total behavioural score of participants in the control group decreased to 49.7 (SD 29.9), while the mean score of participants in the intervention group increased to 51.9 (SD 29). Statistical analysis of ANCOVA, however, showed that the change of the scores of participants in both groups did not differ with p=0.9. Many participants reported that they had reduced the portion of rice, and added a greater portion of vegetables in their meals. They, however, reported eating less fruits and protein-containing food. Most participants also responded that they had restricted fried snacks. In terms of
exercise, some of them also mentioned that they exercised on some days during the last week. Foot care has not been commonly practised yet. A few male participants reported that they smoked during the last week.

The association analysis revealed that the HbA1c outcome was not associated with any participant’s characteristics, diabetes experiences, and outcomes measured. Follow-up data, however, showed that higher HbA1c was associated with lower medication adherence, which suggests that poorer self-reported adherence is associated with poorer glycaemic control. The knowledge outcome was statistically associated with participants’ education level and income. Interestingly, knowledge gain was associated with gender with male participants having their knowledge level improved significantly, while the female participants did not experience an improvement in knowledge.

7.3 Lessons learned

Discussions on results of the qualitative and intervention studies have been presented above. This chapter presents the lessons learned from the study overall including the importance of understanding people’s behaviour in designing the intervention, the challenges in the implementation of diabetes interventions and evaluation of their effectiveness.

7.3.1 Importance of understanding people’s behaviour before designing the intervention

The thesis shows the importance of understanding people’s perspectives in designing an intervention. This understanding enabled the researcher to tailor the design of the intervention, develop the content of the intervention, and modify delivery methods for it. This contextual understanding may also facilitate people’s acceptance of the intervention.

Findings from the qualitative study on diabetes highlights that the characteristics of the individual, particularly the individuals’ interactions with other diabetes patients, greatly influenced patients’ behaviour. Acknowledging this, the intervention for diabetes was designed for patients as a group, so that the group
members acted as support for each other and also provided positive role models for others.

Furthermore, in the study location, diabetes patients interacted with each other, and this interaction would likely increase for those who visit the same health providers, those who have familial relationships, or those who are living nearby. Because of this, we believed that individual randomisation would result in significant cross contamination from participants in the intervention group to those in the control group. A quasi-experimental study with non-randomised participants was therefore used.

Findings from the qualitative study also highlighted that diabetes patients’ behaviour was influenced by the characteristics of the disorder and their perception. As described previously, the nature of diabetes as a chronic disease led the patients to perform lay evaluation of their disease and the results of the treatment. It is therefore important that the content of the intervention focused on assisting individuals in the process of lay evaluation, and in facilitating positive experiences from practising the recommended treatment. In addressing this, the principles of self-regulatory processes, facilitation, and intensive motivation were applied in the intervention.

During the research process, intervention activities were also modified based on the characteristics of people in the study location. As an example, we initially planned that healthy potluck meals would be included in the activities of the intervention; however, we decided not to do this. This was because the participants ranged widely in term of socio-economic status – from low, middle, to high income. This income variation affected their ability to prepare food to share. Culturally, people would be ashamed if they cannot provide a good and proper meal for others. As this activity would burden the poor more, we excluded this activity from the intervention sessions.

The studies reviewed in Chapter 4 show that culturally tailored interventions for diabetes patients are more acceptable and effective in influencing behaviour. The education content and mode of delivery should be tailored based on the
participants' language and level of understanding. As an example, in the context of
the study location, educating people on carbohydrate and calorie counting would
be difficult. Most people in Kupang cook their meals from raw ingredients which
are locally grown or available in the local market. Information on the number of
calories for specific local food does not exist. The number of dietitians available in
the study location is also limited. The plate method and recognising which food
sources are recommended or should be restricted are therefore the most practical
and feasible ways to educate people about diet. Furthermore, people in the study
location felt appreciated when they were given time to share their experiences. In
delivering the education, interactive methods were therefore used.

Interventions focused on diabetes should also address the patients’ problems in
practising recommended self-management behaviour. In terms of medication, for
example, the most common problem of non-adherence to medication was the
feeling of getting fed up with taking medicines. Effort should therefore be focused
on overcoming the psychological problem of getting fed up, and facilitating
participants to improve their adherence to diabetes medication.

Indonesia has a culturally diverse population. This suggests that interventions for
diabetes patients should be specifically tailored based on understanding about
local culture. This study found that diabetes participants in West Sumatera
mentioned the types of their traditional cuisine challenged them to practise
healthy eating. Meanwhile, in East Nusa Tenggara, it is not the traditional cuisine,
but the frequent ethnic feasts that challenged diabetes patients in adhering to the
recommended diet. With these differences, different approaches should be
established to facilitate diabetes patients practising recommended behaviour.

7.3.2 Challenges in implementing the intervention study on diabetes

7.3.2.1 Participation rates

Based on experiences in delivering the intervention sessions, the most substantial
challenge was to improve participants' uptake and engagement with the activities,
and to create active participation rather than passive participation. This challenge
was also shared by the health professionals responsible for the *Prolanis*
programme: that the participants’ attendance at the Prolanis programme fluctuated and tended to decrease over time. This may relate to Indonesian people’s beliefs about health and illness. Indonesian people consider themselves healthy if they can perform their everyday activities without disruption. Thus, people generally went to healthcare facilities when symptoms prevented this. This also applied to managing disease, and some participants shared that they had no symptoms of diabetes so they thought that their disease was controlled.

Other studies on diabetes self-management education reported that the main challenge of delivering interventions was low participants’ retention to the programme [459]. Further, Lepard, et al. [621] reviewed studies focusing on diabetes interventions for people residing in rural areas of the United States, and reported that the retention rate for interventions which were delivered to the participant’s home were higher than those that required participants to travel to the intervention site.

The intervention sessions in this study were conducted in the health facilities closest to the participants’ home. This aimed to facilitate the participants coming to the sessions. In the study location context, limited transportation systems and the cost of travel to the intervention site may hinder participants from coming. The motorbike was the main method of transport in the study location. Public transport is available in connecting people to and from the main roads, so that people residing far from the main road are unable to access it. The motorbike taxis are the main transportation system for people far from the main road; however, they are more expensive. Some participants relied on their other family members to take them to the intervention site. Participants who regularly attended the sessions, therefore, were those who had no problem with transport to the intervention site.

Weather also challenged the intervention programme. The intervention study was conducted from September 2016 to January 2017. In the study location, heavy-rain season starts in December and continues until January. The participation rate decreased during the rainy period. In one health facility, the sessions were performed outdoors, and the place turned into a muddy field after rain. It also
rained heavily at the day of follow-up data collection session, so that many participants could not come to the session. An individual approach, however, was successful for collecting data from some missing participants.

7.3.2.2 Health professional availability for managing diabetes patients

The government has introduced Prolanis, a specific programme for managing chronic illnesses. Implementation of this programme, however, depends on the availability of health professionals in healthcare facilities to manage the programme. Some health facilities have Prolanis activities conducted once a week, while the others are only able to manage it once a month. Our intervention study showed that intensified group activities increase people’s participation and engagement with the programme. Further, intensified group activities also increase interaction and integration of health professionals with the people. By doing this, a trusted relationship is established. It has been widely acknowledged that relationships between patients and health providers based on trust improve patients’ adherence and continuation with health interventions [374-376]. Based on the fieldwork experience, increasing health professional-patient relationships improved patients’ engagement with intervention activities. In the Indonesian context, however, health professionals’ availability to manage the programme is often limited as they are commonly often over burdened by the high number of patients and other administrative tasks.

Studies have also shown that interventions for diabetes patients are best conducted by a team involving multidisciplinary health professionals [461]. The role of a pharmacist in diabetes interventions has been studied and pharmacist involvement has been found to improve patients’ outcomes [591]. Findings from the current study imply that the involvement of pharmacist and dietitian in managing diabetes patients is needed. Many participants in the study discontinued taking medicines, or alternated and/or combined medicines with traditional therapeutics for various reasons. Limited understanding about medicines also hindered participants from adhering to their medication regimen. These findings and experiences imply that the role of pharmacist and pharmaceutical care are crucial in diabetes management. At the time of study, however, there was no
pharmacist employed in the *Puskesmas* and other primary healthcare facilities in Kupang. The medicines were commonly dispensed by pharmacy technicians, and the information about medications provided to the patients was limited to instruction about medicine taking, and how many times a day to take it. The involvement of dietitians in diabetes management was also limited, which further led to limited information about the proper diet for diabetes. The diabetes patients often evaluated the effect of certain local foods to their blood glucose level, subjectively or objectively. Collaborative work involving multidisciplinary health professionals is therefore needed. Availability of some specific health professionals in the study locations was limited, however.

### 7.3.3 Evaluating effectiveness of the diabetes intervention

This study provided substantial knowledge in designing a study aimed at assessing the effectiveness of diabetes intervention in the Indonesian context. In this study, we believe that external factors precluded us from finding statistically significant differences in outcomes between participants in the intervention group and those in the control group. The strongest external factors interfering with the study outcomes were likely to be measurement reactivity, and cross-contamination. This implies that measuring the ‘true experiment’ effect is more challenging in the context of study location.

Addressing the problem of measurement reactivity, Solomon [622] recommended designing an intervention with four groups, after randomising participants into control and intervention groups. This allows both the control and intervention group to have a group with pre-testing, and a group without pre-testing. This design enables researcher to detect the pre-testing effect. Furthermore, due to the social nature of the communities, cluster randomisation would be appropriate in a larger sample to minimise cross contamination bias. In the Indonesian context, the cluster should be defined in the larger geographical areas, for example, different cities or provinces.

Acknowledging these sources of threat to internal validity, a simple design is also suggested. As explained in Chapter 6, we believed that the HbA1c measurement and providing the results of the measurement to both the participants and health
professionals has led to more intensive diabetes management. To minimise the effect of measurement reactivity, therefore, the study needs to be designed for a longer period, without providing the results to both participants and their health professionals. This seems unethical, however. A possible alternative is measuring the effect of the intervention as part of the ongoing diabetes programme at the healthcare facilities, without changing the type of clinical measurement that is normally provided.

Furthermore, in evaluating secondary outcomes of knowledge, medication adherence and self-management behaviours, an interviewer-administered questionnaire was applied. The questionnaire asked participants to self-report their behaviour. The self-reported questions increased people’s chance to over-estimate or over-report [595, 620]. To minimise this problem, self-reported measurement should be combined with more objective measurement, particularly in behavioural-related outcomes. In evaluating medication adherence, for example, the questionnaire may be supplemented by medicines counting or timeliness of participants in refilling the medication. In evaluating dietary and exercise behaviour outcomes, a daily food and exercise log may also be implemented. When technology is available, photos and/or videos may also be used for evaluating the behavioural outcomes.

### 7.4 Strengths and limitations

#### 7.4.1 Strength of the study

A number of strengths may be attributed to the current research. Firstly, this study implemented an intervention that was developed based on understanding of the community's perspectives and local context. It has been widely recognised that understanding community behaviour is important before developing an intervention, and understanding health behaviour may have no direct impact without applying that understanding to an action for improving people's health.
Secondly, the intervention study provided comprehensive self-management education aimed at improving not only knowledge, but also skills and self-efficacy through facilitation, and peer modelling. The content of the education also covered most recommended self-management behaviours for diabetes including dietary control, medication adherence, exercise, and foot care behaviour. For assessing the effectiveness of the intervention, a combination of clinical outcome measures (HbA1c) and self-reported data from questionnaires was used. The clinical outcome of HbA1c provided objective results of the effect of the intervention.

Thirdly, the intervention was conducted in collaboration with an existing programme of Prolanis. This collaboration enabled the intervention to be conducted with available resources, and continued after the project was ended. The intervention could also be further implemented in other locations, particularly in East Nusa Tenggara Province, with similar participants’ characteristics and environmental context.

Lastly, this research was performed in areas outside Java Island, which addresses geographical disparities in health research in Indonesia.

7.4.2 Limitations of the study

7.4.2.1 Qualitative study

The qualitative study included a small number of participants in East Nusa Tenggara, and West Sumatera provinces. Therefore, the results may be different in other culturally different contexts, or in areas of Indonesia with different characteristics. Furthermore, in investigating child immunisation, the qualitative study was also limited by the methods of recruiting participants, who were mothers involved in the Posyandu programme. It may therefore not be able to capture behaviours of mothers who are employed or who used other immunisation services. Gathering data from these mothers, however, revealed problems within the Posyandu programme, the long-established outreach programme for increasing mother and child health. For the study on diabetes, participants were only those who had been diagnosed with diabetes by healthcare
professionals, so that it may not represent people with undiagnosed diabetes or people who did not utilise formal health services.

Furthermore, limitations of the qualitative study may come from the methods of gathering data through focus group discussions. Within the discussions, participants may have felt ashamed to express their individual opinion if it was different from the group opinion. In one discussion, the participants involved in the discussion were divided into two groups based on their individual opinion: those who only took medicines from the doctors; and those who also took traditional medicines. The role of facilitator was important in directing the discussions.

Lastly, the qualitative study was also limited by the involvement of two or more languages. The discussion questions were first developed in English and translated into Bahasa Indonesia, whereas the transcripts were first written in Bahasa Indonesia, and translated into English. Although during this process I was assisted by persons who were fluent in both languages, there remains a risk that some meaning was lost in some cases. Furthermore, the qualitative study was also conducted in two different cultures, neither of which is the culture that I come from. The discussions were conducted mainly in Bahasa Indonesia, and most participants spoke Bahasa Indonesia. In some cases, particularly in more rural areas, most participants used a combination of local language and Bahasa Indonesia. Although I was assisted by research assistants who were native speakers of the participants’ local language, and efforts were made to reduce the risk of losing meaning, it is inevitable that the process of translation involving multiple languages may have resulted in some loss of integrity of the data.

7.4.2.2 Quantitative intervention study

The intervention study also has some limitations. Firstly, the intervention study was developed in response to the lack of literature on diabetes interventions in the Indonesian context. The design and content of the intervention were therefore developed solely based on the findings and experiences gathered from the qualitative study, and information from the literature review of intervention
studies conducted in other developed or developing country contexts. The intervention study also involved a relatively small number of participants for the experimental design. Increasing the sample size would potentially increase the chance that the effect would be detectable.

Secondly, the intervention sessions were conducted in collaboration with health professionals at the healthcare facilities who agreed to be involved in the study. The sessions in each group were therefore delivered by different health professionals. Although the content and instruments for the education sessions were developed by the researcher, and discussions with the health professionals were also held, there were differences in style and ability to perform education activities between health professionals. These differences may further impact on the differences in information received by participants, which may also impact on their outcomes. This method, however, represented natural differences in the real clinical settings.

The study may also be limited by the use of research assistants in interviewing participants to gather data on knowledge, adherence to medications, and self-management behaviours. Although criteria were applied in recruiting the research assistants, and training was also conducted, differences in communication style and ability to convey the meaning of the questions between research assistants remained. This may impact on the quality of the data collected. In the context of people’s characteristics in the study location, however, self-administered questionnaires were not feasible.

Another limitation of the study was the lack of medical record data for diabetes patients in the study locations. We were therefore not able to gather participants’ history of the disease and treatment changes provided by their health professionals during the intervention period. Information about disease experiences, for example duration of having diabetes and type of medicines they were taking, were retrieved from self-report data in the questionnaire. In some cases, we found a remarkable difference in their answers at baseline and at follow up. As an example, one participant mentioned that she had diabetes for about three years at baseline, but responded that she had diabetes for one year at follow
up. With this limitation, we solely relied on the information available from the questionnaire output, and in case there was a remarkable difference, we used the information at the baseline. These experiences, however, may also suggest that in Indonesian context, particularly in the study location, self-reported data should ideally be supplemented by objective data.

### 7.5 Implications of and recommendations from the study

#### 7.5.1 Child immunisation programme

The findings from the qualitative study about child immunisation provide three main implications and recommendations. Firstly, mothers’ behaviour in immunising their child is shaped and influenced by the fathers as the decision makers. This implies that family support is crucial in improving immunisation uptake. Interventions should therefore be established by involving not only mothers, but also their families. Although the study found that limited understanding about immunisation and the diseases the vaccines protected against did not always correlate with negative behaviour towards immunisation, interventions for improving understanding are important to avoid vague conceptualisation and unrealistic expectations. Improving family members’ and wider communities’ understanding and awareness of immunisation would therefore be beneficial in supporting mothers to immunise their children.

Secondly, although Posyandu is a long-established community-based programme focused on maternal and child health including child immunisation, it still faces some practical challenges in its implementation. These practical problems decreased opportunities for the children to receive immunisation, and discouraged mothers from utilising the Posyandu service. The roles of community-based health workers are crucial in addressing the practical problems and facilitating the success of Posyandu implementation. The implication of this finding would be for the health system to focus on improving the skills and capacity of community-based health workers. Basic training and routine
supervision have been acknowledged as factors determining the effectiveness of programmes involving community-based health workers [623].

Lastly, participation of all community stakeholders is important for the sustainability of community-based programmes. Community support and participation in the Posyandu programme seemed to be lacking. Efforts should therefore be made to involve community stakeholders to improve participation and support for the programme. The role of the government is also important to minimise disparities in health services in the community-based programme because of differences in the community capability to support the programme.

7.5.2 Diabetes
The current research on the topic of diabetes implies that the problem of diabetes in Indonesia is alarming. This thesis therefore recommends the health system in Indonesia makes diabetes a priority disease to focus on. Efforts should be made to prevent the diabetes epidemic in the country.

This study found that most diabetes patients were diagnosed late when they experienced a very high level of blood glucose, or had diabetes related complications. Some of them also detected diabetes accidentally when they went to health facilities for other health complaints. This showed limited awareness about diabetes in the community. This problem is complicated by people’s beliefs related to health and illness. Indonesian people commonly consider themselves to be healthy when they perceive no symptoms that disrupted their daily activities. This implies that efforts should be made to improve people’s awareness and understanding about the asymptomatic nature of diabetes, and encourage them to detect diabetes risk factors early. On the other hand, from the health providers’ perspective, early diabetes screening programmes need to be intensified. A study revealed that health professionals in Indonesia showed low adherence to the guideline, including detecting risk factors and early screening. The doctors tended not to advise their patients to be screened for diabetes unless several cardiovascular risk factors had emerged [241].
Secondly, the current research involved diabetes patients who had been diagnosed and were being managed by health professionals. The majority of them, however, experienced uncontrolled blood glucose levels. This evidence has implications from both patients’ and health providers’ perspectives. From the patients’ perspective, the uncontrolled blood glucose level may be a result of not implementing recommended actions in managing diabetes, including diet, exercise, and medication taking. On the other hand, this problem of uncontrolled blood glucose level may also be caused by insufficient or ineffective treatment provided by health professionals. Interventions should therefore be conducted on both sides: interventions focused on improving diabetes patients’ self-management behaviours; and interventions focused on evaluating and improving diabetes management practices of the health professionals.

Thirdly, this study highlights that diabetes in Indonesia not only affects people in urban areas, but also people in more rural areas. Diabetes burdened the people and the health system more in areas with lower socio-economic status. It has been acknowledged that the risk of developing diabetes is higher in people with a history of stunting in early childhood [15]. Diabetes in East Nusa Tenggara may provide evidence for this correlation. The prevalence of undernutrition and stunting in children under five in East Nusa Tenggara province were reported to be the highest in the country [22]. More research should be conducted in this area. This implies that interventions for preventing the diabetes epidemic in the context of East Nusa Tenggara Province need to also address the problems of undernutrition and stunting in children under five.

Lastly, primary prevention of diabetes should also be initiated. The cost of treating diabetes, particularly those with complications, is high. This burdens not only the patients and their family, but also the community and the country, particularly in the universal health coverage era. Programmes focusing on non-communicable diseases including diabetes have been implemented. Evaluation of those programmes, however, is lacking, and the implementation of the health programmes also differs depending on the capacity and capability of health professionals in the health facilities. This suggests that the existing programmes
on non-communicable diseases need to be empowered and evaluated to achieve the target of improving people’s health and general wellbeing.

7.6 Future research direction

The current study directed the future research agenda in the topic of child immunisation and diabetes. In general, literature study found that there are disparities in health research across the regions in Indonesia. Most available studies were concentrated in Java Island, the most developed region in the country. This implies that more research on health should be conducted outside of Java.

7.6.1 Child immunisation

Although the qualitative study investigated health behaviours in child immunisation and diabetes, the study was only able to develop and implement an intervention focused on diabetes. Intervention studies aiming at improving immunisation uptake, based on the results of child immunisation programmes need be established. To gather richer information about child immunisation behaviour, studies on immunisation behaviour involving a broader cross-section of the community, including mothers who are not housewives and do not use Posyandu for immunisation services are also needed.

7.6.2 Diabetes

Studies aimed at understanding diabetes patients’ views and behaviour in managing the disease are needed in other communities with different characteristics and cultural backgrounds. These studies would inform a variety different interventions in these various context. This is important in informing the design, content, and delivery methods for diabetes interventions. To increase the richness of the information on people’s behaviours related to diabetes, studies involving the general population, people with undiagnosed diabetes, people with newly-diagnosed diabetes, and diabetes patients who do not utilise formal healthcare providers are also needed.
The results of the qualitative study also showed that diabetes patients experienced different problems and differing ability to cope with the disease. The group-based intervention conducted in this study was unable to address individual problems in managing diabetes. Instead, we addressed the common problems of diabetes patients in the study location based on information gathered from the qualitative study. Future interventions for diabetes patients should be designed to combine both individual and group-based approaches. Previous research has reported that the combination of a group-based and an individual approach resulted in the largest improvement in outcomes [458].

Although this current study detected no differences in outcomes between the intervention and usual care groups, the improvement in clinical outcomes experienced by most participants was a welcome finding. The external factors that potentially interfered with the results of the study should be acknowledged and minimised in the future study. Future research should be conducted also by escalating the study in terms of sample size and duration of intervention. This current study detected an improvement of HbA1c in a short period of time, so the sustainability of this outcome improvement needs to be evaluated.

The results of the current study showed that the participants experienced an improvement in the clinical and knowledge outcomes. There was no improvement observed in the medication adherence and self-management behaviours outcomes, however. Participants in the current study mentioned that their self-management behaviour in managing the disease was influenced by support from their family members, and their cultural practices. Intervention studies targeting not only the individual, but also social and environmental determinants of behaviours are therefore also needed to facilitate patients to implement the recommended behaviours.

Lastly, future research needs to be conducted to evaluate the effectiveness of existing programmes in non-communicable diseases in achieving their goals. Efforts should also be made to maximise health resources currently available to improve diabetes patients’ outcomes.
7.7 Conclusions

The thesis revealed a number of factors influencing mothers’ behaviours in immunising children, and factors influencing diabetes patients in managing the disease. The findings add substantial value to the existing literature, particularly in Indonesia, and in a developing country context. The findings also help to fill the gap created by the limited qualitative studies for understanding health problems from the communities’ perspectives in Indonesia, particularly in the case of child immunisation and diabetes.

The thesis demonstrated that an intervention that was developed based on an understanding of community was able to improve diabetes patients’ clinical, knowledge, and medication adherence outcomes. Although the effect of the intervention was statistically insignificant compared to the usual care, we believe that external factors contributed to this. The findings of this intervention study also add to knowledge about diabetes interventions in Indonesia. The literature review has shown that although research about diabetes has been widely conducted, those focusing on improving patients’ outcomes were very limited.

The findings of the current study recommend that the government and related stakeholders implement interventions to improve health outcomes by acknowledging factors influencing communities’ behaviours in these health-related problems. In the topic of diabetes, specifically, the thesis recommends that the government and related stakeholders focus on primary prevention, early detection, and outcomes improvement. The diabetes epidemic is threatening the country, and with continuing socio-economic development and genetic predisposition, risk factors for diabetes in Indonesia are increasing significantly.
REFERENCES


38. Seeberg J, Pannarunothai S, Trisnantoro L, Barua N, Pandav CS. Treatment seeking and health financing in selected poor urban


74. The President of Indonesia. The President’s regulation No 12 Year 2013 about Health Insurance (Jaminan Kesehatan), 2013.


90. Health Department of West Sumatera Province. Health profile of West Sumatera Province 2012: Health Department of West Sumatera Province, 2013.


126. Central Bureau of Statistics Indonesia, State Ministry of Population/National Family Planning Coordinating Board Indonesia, Ministry of Health, Macro


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260. Shea B, Andersson N, Henry D. Increasing the demand for childhood vaccination in developing countries: a systematic review. BMC


307. Erlyana E, Damrongplasit KK, Melnick G. Expanding health insurance to increase health care utilization: will it have different effects in rural vs. urban areas? *Health Policy.* 2011;100(2-3):273-81.


312. D’Ambruoso L, Byass P, Qomariyah SN. 'Maybe it was her fate and maybe she ran out of blood': final caregivers’ perspective on access to care in obstetric emergencies in rural Indonesia. *Journal of Biosocial Science.* 2010;42(2):213-41. doi: http://dx.doi.org/10.1017/S0021932009990496.


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543. Jamovi (version 0.9) [Computer Software] [program], 2018.


562. Rawal LB, Tapp RJ, Williams ED, Chan C, Yasin S, Oldenburg B. Prevention of Type 2 Diabetes and Its Complications in Developing Countries: A Review.


607. Frosch DL, Uy V, Ochoa S, Mangione CM. Evaluation of a behavior support intervention for patients with poorly controlled diabetes. *Archives of*


Appendices
## Appendix 1 – Articles included in the literature review about health-seeking behaviour of people in Indonesia

Table A1.1 Studies included in the review gathered from peer-reviewed journals

<table>
<thead>
<tr>
<th>No.</th>
<th>Studies</th>
<th>Type</th>
<th>Participants</th>
<th>Focus</th>
<th>Study design</th>
<th>Study location</th>
<th>Important findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Suswardany, et al. [281]</td>
<td>Secondary data of 2010 Basic Health Research</td>
<td>Focus on data retrieved from 12,226 adults aged 15 years and above who resided in high-risk malaria-endemic provinces</td>
<td>Malaria</td>
<td>Quantitative analysis of data from a cross-sectional household survey. Data were collected by interviewing household heads and household members based on structured questionnaires.</td>
<td>28 provinces out of 33 provinces</td>
<td>Concept of health and illness- will seek care if the symptoms hinder daily activities. Determinant of health provider choices: socio demographic characteristics, socio-cultural beliefs</td>
</tr>
<tr>
<td>2</td>
<td>Probandari, et al. [282]</td>
<td>Community based</td>
<td>Mothers with postnatal complications (8), family members (6), and village midwives (5)</td>
<td>Postnatal care</td>
<td>A qualitative study with in-depth interviews as method for gathering data</td>
<td>Klaten district, Central Java</td>
<td>Determinant of health provider choices: socio-cultural beliefs (the use of herbal remedies during pregnancy)</td>
</tr>
<tr>
<td>3</td>
<td>Kurniawan, et al. [283]</td>
<td>Community health centre based</td>
<td>Adults aged ≥18 year old visited community health centre (400).</td>
<td>Antibiotics use</td>
<td>Quantitative cross-sectional design with a questionnaire-structured interview.</td>
<td>North Sulawesi</td>
<td>Self-medication with antibiotics</td>
</tr>
<tr>
<td>4</td>
<td>Fles, et al. [284]</td>
<td>Hospital based</td>
<td>12 newly diagnosed nasopharyngeal carcinoma (NPC) patients between March-June 2014 at Dr. Sardjito Hospital.</td>
<td>NPC</td>
<td>Qualitative research. Patients were interviewed using semi-structured interview guidelines.</td>
<td>Dr. Sardjito Hospital, Yogyakarta</td>
<td>Concept of health and illness- will seek care if the symptoms hinder daily activities, believe that illness were form God, either God's gift, or punishment. Determinant of health provider choices: significant others, socio-cultural beliefs, experiences with medical services including negative experiences, and cost (indirect cost of medical treatment), complex insurance systems. Care pathway</td>
</tr>
<tr>
<td>5</td>
<td>Brooks, et al. [285]</td>
<td>Analysis of secondary data, and a community based study</td>
<td>Quantitative analysis: DHS 2012 data gathered from poor women who had a live birth 5 years preceding the survey. Qualitative: poor women who had a live birth between 2010 and 2012 (n = 20), midwives (n = 12), and government representatives (n = 19).</td>
<td>Birth delivery</td>
<td>Mixed-methods design, utilising data from the 2012 Indonesian Demographic and Health Survey for quantitative analysis, supplemented by in-depth interview for qualitative analysis.</td>
<td>All provinces for DHS. Qualitative: Jakarta and Banten</td>
<td>Pattern of health care utilization, determinant of health provider choices: socio demographic determinants, socio-cultural beliefs, perceptions about health care systems: negative experiences with medical care and quality of care, cost: indirect cost, complex insurance systems.</td>
</tr>
<tr>
<td>6</td>
<td>Ariyanto and Wati [286]</td>
<td>Community based</td>
<td>38 Tuberculosis (TB) patients chosen randomly based on the PHC’s records.</td>
<td>TB</td>
<td>Quantitative, a cross-sectional study with Social Network Analysis (SNA) to get seeking treatment behaviour pattern of TB patients and supporting treatment pattern among neighbourhood.</td>
<td>Jember district, East Java</td>
<td>Determinant of health provider choices: significant others. Care pathway. Self-medications for tuberculosis</td>
</tr>
<tr>
<td>7</td>
<td>Suhariadi, et al. [287]</td>
<td>Community based,</td>
<td>5 newly diagnosed pulmonary TB patients</td>
<td>TB</td>
<td>Explorative qualitative research, with semi-structured interview.</td>
<td>East Java Province</td>
<td>Determinant of health provider choices: significant others</td>
</tr>
<tr>
<td>8</td>
<td>Rahmawati and Bajorek [288]</td>
<td>Community based</td>
<td>11 older persons with hypertension and 3 lay health workers from a local Puskesmas</td>
<td>Hypertension</td>
<td>Qualitative with semi-structured interviews.</td>
<td>Bantul district, Yogyakarta</td>
<td>Determinant of health provider choices: socio-cultural beliefs (reasons for choosing alternative treatment).</td>
</tr>
<tr>
<td>9</td>
<td>Praptiningsih, et al. [289]</td>
<td>Household survey</td>
<td>Individuals who self-identified as the most knowledgeable about the health conditions of household members from 2520 households</td>
<td>Acute respiratory illness</td>
<td>Quantitative, cross-sectional survey with face-to-face interviews using a structured questionnaire in East Jakarta municipality, and Bogor district.</td>
<td>Jakarta and West Java Province</td>
<td>Determinant of health provider choices: perception of medical services.</td>
</tr>
<tr>
<td>10</td>
<td>Nasir, et al. [290]</td>
<td>Community-based</td>
<td>110 participants were interviewed. 7 FGDs with men, village midwives and TBA.</td>
<td>Birth delivery</td>
<td>Explorative qualitative approach, with semi-structured interviews, and focus group discussions in 8 villages in Southwest Sumba, and 8 villages in Cianjur.</td>
<td>East Nusa Tenggara, and West Java</td>
<td>Determinant of provider choices: significant others, traditional beliefs and cultural practices, accessibility, and cost (indirect cost of medical treatment).</td>
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<tr>
<td>No</td>
<td>Study Authors</td>
<td>Study Type</td>
<td>Study Population</td>
<td>Setting</td>
<td>Research Design</td>
<td>Data Collection</td>
<td>Findings</td>
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<td>11</td>
<td>Marthoenis, et al. [291]</td>
<td>Hospital based</td>
<td>16 family members of 17 patients who accompanied the patients to the hospital</td>
<td>Psychosis</td>
<td>Qualitative. Data were collected via in-depth interviews at the outpatient clinic of the Aceh Psychiatric Hospital in Banda Aceh.</td>
<td>Aceh Province</td>
<td>Determinant of provider choices: significant others, causality beliefs, cost (indirect cost of medical treatment), accessibility, negative perception of medical services. Care pathway: for illnesses attributed to supernatural causes</td>
</tr>
<tr>
<td>12</td>
<td>Marchira, et al. [292]</td>
<td>Hospital based</td>
<td>100 patients with early psychosis and their caregivers at Sardjito Hospital, Grhasia Mental Hospital, Jogjakarta District Hospital and Furi Nirmala Mental Hospital.</td>
<td>Psychosis</td>
<td>A descriptive analytic study with cross-sectional design. Respondents were in-depth interviewed, and the data were analysed and coded to allow quantitative analysis.</td>
<td>Yogyakarta Province</td>
<td>Determinant of health provider choices: perception about disease and causality. Care pathway: for illnesses attributed to supernatural causes</td>
</tr>
<tr>
<td>13</td>
<td>Kreslake, et al. [293]</td>
<td>Households survey, and clinic based physician surveys</td>
<td>Adult of 2520 households who was most knowledgeable about the health conditions of household members. N = 554 physicians from in various types of health care facilities</td>
<td>HPAI H5N1 signs/symptoms</td>
<td>All community respondents, regardless of illness history, were asked questions about perceptions of health care services and intentions to seek treatment in hypothetical scenarios where they developed HPAI H5N1 signs/symptoms. A survey of physicians with face-to-face structured interviews.</td>
<td>Jakarta and Bogor district in West Java</td>
<td>Determinant of health provider choices: perception of medical services and health systems</td>
</tr>
<tr>
<td>14</td>
<td>Karyana, et al. [294]</td>
<td>Households survey</td>
<td>825 households. The survey was conducted with the head of the household or another suitable adult</td>
<td>Malaria</td>
<td>A randomised cross-sectional household survey. The survey was conducted using a structured questionnaire. Quantitatively analysed.</td>
<td>Mimika Regency, southern Papua Province.</td>
<td>Concept of health and illness- will seek care if the symptoms hinder daily activities. Determinant of health provider choices: perception of medical services</td>
</tr>
<tr>
<td>15</td>
<td>Irwan, et al. [295]</td>
<td>Community-based</td>
<td>People over 60 years of age (140)</td>
<td>General health of older people</td>
<td>Quantitative cross-sectional study with questionnaires. The questionnaires were read aloud to ensure a clear understanding of the study.</td>
<td>Makassar, South Sulawesi Province</td>
<td>Concept of health and illness: older people went to health services when perceived symptoms that disrupted their daily activities</td>
</tr>
<tr>
<td></td>
<td>First Name and Last Name, et al. [Reference]</td>
<td>Setting</td>
<td>Participants</td>
<td>Health Care Research Area</td>
<td>Methodology</td>
<td>Setting</td>
<td>Determinant of Health Provider Choices</td>
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<tr>
<td>16</td>
<td>Handaya ni, et al. [296]</td>
<td>Hospital based</td>
<td>Parents of 145 children with cancer</td>
<td>Childhood cancer</td>
<td>Quantitative cross-sectional study using semi-structured questionnaires</td>
<td>Dr Sardjito Hospital in Yogyakarta Province</td>
<td>Determinant of health provider choices: significant others, cultural beliefs, negative perception of medical care, accessibility</td>
</tr>
<tr>
<td>17</td>
<td>Dewi, et al. [297]</td>
<td>Community based intervention for TB</td>
<td>In total, 50 participants: 17 TB patients, 16 ex-TB patients, 8 village TB volunteers, and 9 village leaders across six villages, and also were between 18 – 30 TB leadership group members who participated in the FGD.</td>
<td>TB</td>
<td>Qualitative study with descriptive analysis. Data collection included interviews, group discussions, observations, field notes and audit of records. Intervention: Tuberculosis leadership groups were only established in the three villages that received the asset-based intervention.</td>
<td>Six villages in Sikka District Flores, East Nusa Tenggara Province</td>
<td>Concept of health and illness: will seek care if the symptoms hinder daily activities</td>
</tr>
<tr>
<td>18</td>
<td>Widayati, et al. [298]</td>
<td>Community-based</td>
<td>25 adults &gt;18 years old with experience of using non-prescribed antibiotics including leftover antibiotics</td>
<td>Self-medication with antibiotics</td>
<td>Qualitative study as part of a mixed-methods study examining self-medication with antibiotics based on the TPB in Yogyakarta City, Indonesia. Face-to-face interviews were used to collect data. An exploratory sequential design was applied.</td>
<td>Urban areas of Yogyakarta Province</td>
<td>Determinant of health provider choices: negative experiences with medical services</td>
</tr>
<tr>
<td>19</td>
<td>Prabawan ti, et al. [299]</td>
<td>Specific transgender community-based</td>
<td>209 waria (male to female transgender)</td>
<td>HIV</td>
<td>The study was part of a broader study that covered condom use and HIV-related health seeking behaviours. Cross-sectional data were gathered through face-to-face structured interviews. Quantitatively analysed.</td>
<td>Jakarta Province</td>
<td>Determinant of provider choices: perception of health care systems</td>
</tr>
<tr>
<td>20</td>
<td>Pitaloka and Hsieh [223]</td>
<td>Community-based</td>
<td>30 women with type 2 diabetes recruited from PERSADIA-Indonesia Diabetes Association</td>
<td>Type 2 Diabetes</td>
<td>Qualitative, with in-depth interview as method for collecting data. The study applied grounded theory, and a constant comparative analysis for data analysis.</td>
<td>Central Java Province</td>
<td>Determinant of health provider choices: perception about disease</td>
</tr>
<tr>
<td></td>
<td>Authors</td>
<td>Setting</td>
<td>Sample Size</td>
<td>Research Area</td>
<td>Methodology</td>
<td>Location</td>
<td>Care Pathway</td>
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<tr>
<td>21</td>
<td>Seeberg, et al. [300]</td>
<td>Household surveys</td>
<td>203 households in round 1, 221 household in round 2, 220 households in round 3 and 219 households in round 4.</td>
<td>General health</td>
<td>Mixed methods. This article presents a comparative analysis of socio-economic disparities in relation to treatment seeking strategies and healthcare expenditures in poor neighbourhoods in four cities in India, Indonesia and Thailand. In Yogyakarta, the study was conducted in two poor neighbourhoods, with a total of 8105 households.</td>
<td>Yogyakarta Province</td>
<td>Care pathway: treatment effectiveness is a matter of being &quot;suited&quot;</td>
</tr>
<tr>
<td>22</td>
<td>Murhandarwati, et al. [33]</td>
<td>Community based</td>
<td>Qualitative behaviour study: 24 respondents who had experienced malaria during the outbreaks or had contracted malaria in the previous three years, and three malaria health officers.</td>
<td>Malaria</td>
<td>A mix method study presents a case of malaria resurgence after five years of low endemicity. Cross-sectional survey to map each malaria cases during the malaria outbreak, and qualitative study to describe the community perceptions and health services delivery situation that contribute to the outbreak.</td>
<td>Koleap Subdistrict Yogyakarta Province.</td>
<td>Determinant of health provider choices: socio-cultural beliefs (the use of herbal remedies for malaria)</td>
</tr>
<tr>
<td>23</td>
<td>Iskandar yah, et al. [301]</td>
<td>Hospital based</td>
<td>50 breast cancer patients at Hasan Sadikin Hospital in Bandung</td>
<td>Breast cancer</td>
<td>Qualitative study with semi-structured interviews to explore patients’ experiences during their diagnosis and treatment. Interviews were conducted in the clinic waiting room while participants waited for their appointment.</td>
<td>Bandung, West Java Province</td>
<td>Concept of health and illness: will seek care if the symptoms hinder daily activities. Determinant of health provider choices: cultural beliefs: traditional healer provide comprehensive services, significant others, cost (indirect cost of medical treatment). Care pathway</td>
</tr>
<tr>
<td>24</td>
<td>Peters, et al. [302]</td>
<td>Community based</td>
<td>53 participants were interviewed, and 20 FGD were conducted.</td>
<td>Leprosy</td>
<td>A Qualitative study with in-depth interviews with people currently under treatment for leprosy or already cured and focus groups discussions with neighbours of those who had leprosy, community and religious leaders, mothers of children affected, teachers, and health workers.</td>
<td>Cirebon District of West Java Province</td>
<td>Concept of health and illness: believe that illness were form God, either God’s gift, or punishment. Determinant of health provider choices: socio-cultural beliefs, causality beliefs (supernatural causes). Care pathway: for illnesses attributed to supernatural causes</td>
</tr>
<tr>
<td>25</td>
<td>Ahmad, et al. [303]</td>
<td>Community and household survey</td>
<td>A total of 746 individuals age ≥15 years with cough for &gt;2 weeks</td>
<td>TB</td>
<td>Quantitative: A cross-sectional survey to assess determinants of care-seeking behaviour among patients with suspected TB at the population level. Patients were interviewed using a structured quantitative questionnaire.</td>
<td>Three districts in Yogyakarta Province</td>
<td>Concept of health and illness- will seek care if the symptoms hinder daily activities. Determinant of health provider choices: significant others, socio demographic, socio-cultural beliefs,</td>
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<tr>
<td>26</td>
<td>Bennett, et al. [304]</td>
<td>Hospital based</td>
<td>212 infertile women recruited through invitations posted at three infertility clinics</td>
<td>Infertility</td>
<td>Quantitative research with interviewer-administered survey. Data was subject to descriptive statistical analysis.</td>
<td>Jakarta, Surabaya and Denpasar</td>
<td>Determinants of health provider choices: accessibility, perceived effectiveness of therapy, cost.</td>
</tr>
<tr>
<td>27</td>
<td>Agus and Horiuchi [305]</td>
<td>Community based</td>
<td>145 married women who were pregnant or had experienced birth</td>
<td>Antenatal care</td>
<td>Quantitative cross sectional study with self-administered questionnaire. Questionnaire was distributed to the participants by midwives.</td>
<td>Tanah Datar regency West Sumatera</td>
<td>Determinants of health provider choices: cultural beliefs, and socio-demographic characteristics.</td>
</tr>
<tr>
<td>28</td>
<td>Wulandari and Whelan [306]</td>
<td>Community health centre based</td>
<td>18 pregnant women aged 20–35 years</td>
<td>Pregnancy related health</td>
<td>Qualitative study as part of a mixed methods study investigating women’s adherence to iron supplementation in pregnancy in Bali. Data was collected with interview.</td>
<td>South Kuta, Bali Province</td>
<td>Socio-cultural beliefs (the use of herbal remedies during pregnancy)</td>
</tr>
<tr>
<td>29</td>
<td>Widayati, et al. [41]</td>
<td>Population survey</td>
<td>Adults over 18 years old living in Yogyakarta City. A total of 559 questionnaires were analysed (response rate = 90%).</td>
<td>Self-medication with antibiotics</td>
<td>Quantitative: This cross-sectional population-based survey used a pretested questionnaire which was self-administered to randomly selected respondents.</td>
<td>Yogyakarta city, Yogyakarta</td>
<td>Self-medication with antibiotics</td>
</tr>
<tr>
<td>30</td>
<td>Lock, et al. [40]</td>
<td>Clinic based</td>
<td>194 TB suspects (coughing lasted for at least 2 weeks) that registered at the lung clinics.</td>
<td>TB</td>
<td>Quantitative: Cross-sectional data were gathered with a structured questionnaire in which psychosocial determinants were based on an extended version of the theory of planned behaviour (TPB).</td>
<td>Yogyakarta Province</td>
<td>Concept of health and illness- will seek care if the symptoms hinder daily activities. Determinant of health provider choices: socio-cultural beliefs, perception of medical services and healthcare systems. Care pathway: combining or alternating medicines from different providers. Self-medication for TB</td>
</tr>
<tr>
<td>ID</td>
<td>Reference</td>
<td>Study Type</td>
<td>Participants</td>
<td>Setting</td>
<td>Data Source</td>
<td>Study Object</td>
<td>Data Collected</td>
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<tr>
<td>31</td>
<td>Erlyana, et al. [307]</td>
<td>Secondary data of Indonesian Family Life Survey 2000</td>
<td>The data gathered from 10,857 (4202 urban and 6673 rural) uninsured adults aged ≥15 years who report having had some kind of illness during the past one month</td>
<td>General illnesses</td>
<td>Quantitative with secondary data from Indonesian Family Life Survey 2000 to investigate the importance of medical fee and distance to health care provider on individual's decision to seek care in developing countries.</td>
<td>The IFLS were carried out in 13 Provinces</td>
<td>determinant of health providers choices: cost, and health insurance: people in more rural areas sensitive to indirect cost of medical services.</td>
</tr>
<tr>
<td>32</td>
<td>Ahmad, et al. [308]</td>
<td>Clinic based</td>
<td>253 newly diagnosed TB patients in 89 DOTS facilities.</td>
<td>TB</td>
<td>Quantitative cross-sectional survey amongst newly diagnosed TB patients. The history of care-seeking was reconstructed through retrospective interviews. Patients were interviewed using a structured questionnaire.</td>
<td>Jogjakarta, Kulonprogo and Gunung Kidul districts, Yogyakarta</td>
<td>Determinant of health provider choices: socio demographic characteristics did not associated with seeking behaviour.</td>
</tr>
<tr>
<td>33</td>
<td>Titaley, et al. [309]</td>
<td>Community based</td>
<td>In total 295 participants: 119 mothers of children aged 40 days to four months, 40 fathers, 26 health professionals, 20 village cadres, 37 traditional birth attendants, 42 community and religious leaders, and 11 health office staff.</td>
<td>Antenatal and postnatal care</td>
<td>A qualitative study FGDs and in-depth interviews to explore community members’ perspectives on antenatal and postnatal care services, including reasons for using or not using these services, the services received during antenatal and postnatal care, and cultural practices during antenatal and postnatal periods.</td>
<td>Garut, Ciamis, and Sukabumi districts in West Java</td>
<td>Determinants of health provider choices: cost, including indirect cost, limited availability and accessibility of services.</td>
</tr>
<tr>
<td>34</td>
<td>Titaley, et al. [310]</td>
<td>Community based</td>
<td>Same as above (No 33)</td>
<td>Birth delivery</td>
<td>A qualitative study FGDs and in-depth interviews to explore reasons for using a trained or a traditional birth attendant and reasons for having a home or an institutional delivery.</td>
<td>Garut, Ciamis, and Sukabumi districts in West Java</td>
<td>Determinant of health provider choices: significant others, socio-cultural beliefs, complex insurance systems,</td>
</tr>
<tr>
<td>35</td>
<td>Norris, et al. [44]</td>
<td>Community based</td>
<td>11 persons with stroke (aged 32-69 years) and 18 of their caregivers.</td>
<td>Stroke</td>
<td>Qualitative study informed by both hermeneutic phenomenology and ethnography. Data were gathered through interviews, photographs and observations with participants.</td>
<td>Two districts of Aceh Province</td>
<td>Concept of health and illness- will seek care if the symptoms hinder daily activities. determinant of health provider choices: socio cultural beliefs,</td>
</tr>
<tr>
<td>No.</td>
<td>Author(s)</td>
<td>Setting</td>
<td>Methodology</td>
<td>Data Analysis</td>
<td>Location</td>
<td>Health Provider Choices</td>
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<tr>
<td>36</td>
<td>Dewi, et al. [311]</td>
<td>Community-based</td>
<td>Involving lay people with high and low socio-economic status, and government health officers.</td>
<td>Qualitative study with a combination of 2 individuals interview and 8 FGDs (78 informants). Data were analysed with content analysis.</td>
<td>Yogyakarta Province</td>
<td>Lay concept of health and illness: maintain balance and harmony.</td>
<td></td>
</tr>
<tr>
<td>37</td>
<td>D’Ambruoso, et al. [312]</td>
<td>Community-based</td>
<td>A total of 104 cases of women who had died during pregnancy were purposively selected.</td>
<td>A mixed methods. A routine health surveillance of verbal autopsy with 75 closed questions was used to generate cause-specific mortality profiles. In the second part, respondents were asked about the circumstances and events surrounding the death in a semi-structured format with free dialogue. Descriptive statistics and qualitative analysis.</td>
<td>Serang and Pandeglang districts of Banten province,</td>
<td>Determinant of health provider choices: complex insurance systems, and insurance problem from health provider perspectives.</td>
<td></td>
</tr>
<tr>
<td>38</td>
<td>Rintiswati, et al. [313]</td>
<td>Community-based, patients recruited from health care providers.</td>
<td>In total, 67 newly diagnosed or diagnosed a maximum of 3 months before the data collection TB patients and 22 family members were interviewed and 6 FGDs were performed.</td>
<td>Qualitative study with in-depth interviews with TB patients and members of their family and through Focus Group Discussions (FGD) with community members</td>
<td>Kulon Progo district, and Yogyakarta city, located in Yogyakarta</td>
<td>Determinant of health provider choices: significant others, socio-cultural beliefs, causality beliefs (lay perception of causality), perception of medical services and healthcare systems. Care pathway. Self-medication for tuberculosis</td>
<td></td>
</tr>
<tr>
<td>40</td>
<td>Utarini, et al. [315]</td>
<td>Community-based</td>
<td>All 3746 clinical malaria cases aged 6 months to 92 years treating by Village Malaria Worker during the study period.</td>
<td>Mixed study. A year longitudinal study of all clinical malaria cases treated by Village Malaria Workers (VMWs). Data on health seeking behaviour during 7 days illness period were collected using diary, 24 interaction were audiotaped. Data analysed qualitatively.</td>
<td>Jepara district, Central Java Province.</td>
<td>Determinant of health provider choices: socio-cultural beliefs. Self-medication for malaria</td>
<td></td>
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<tr>
<td></td>
<td>Authors</td>
<td>Study Type</td>
<td>Methodology</td>
<td>Disease</td>
<td>Setting</td>
<td>Provider Choice Determinants</td>
<td>Care Pathway</td>
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<tr>
<td>41</td>
<td>Sanjana, et al.</td>
<td>Household survey</td>
<td>Quantitative with a pre-tested survey instrument consisting of 93 questions</td>
<td>Malaria</td>
<td>Purworejo District, Central Java</td>
<td>Determinant of health provider choices: socio-cultural beliefs (the use of herbal remedies for malaria). Care pathway: Self-medication for malaria</td>
<td></td>
</tr>
<tr>
<td>42</td>
<td>Kurihara, et al.</td>
<td>Community based</td>
<td>Quantitative analysis to provide statistical evidence of Balinese beliefs related to mental disorders. Data collected through interview with patients accompanied by other family members.</td>
<td>Psychiatric illness</td>
<td>Bali Province</td>
<td>Determinant of health provider choices: significant others, causality beliefs. Care pathway: for illnesses attributed to supernatural causes</td>
<td></td>
</tr>
<tr>
<td>43</td>
<td>Kurihara, et al.</td>
<td>Community based</td>
<td>Quantitative study with a questionnaire developed by the authors that listed 15 possible causes of schizophrenia was used to examine the respondents' beliefs.</td>
<td>Schizophrenia</td>
<td>Bali Province</td>
<td>Care pathway: for illnesses attributed to supernatural causes</td>
<td></td>
</tr>
<tr>
<td>44</td>
<td>Thind</td>
<td>Secondary data of DHS 1997</td>
<td>Quantitative analysis of the data for understanding patterns and predictors of health services utilisation for respiratory illness in children.</td>
<td>Respiratory illnesses in children</td>
<td>National wide covering 27 Provinces.</td>
<td>Determinant of health provider choices: socio demographic characteristics, perception of medical services and healthcare systems,</td>
<td></td>
</tr>
<tr>
<td>46</td>
<td>Watkins and Plant</td>
<td>Community based</td>
<td>An exploratory qualitative design with in-depth interview to study the issues associated with treatment-seeking behaviour for TB in Bali from patients' perspective.</td>
<td>TB</td>
<td>Bali Province</td>
<td>Concept of health and illness- will seek care if the symptoms hinder daily activities. Determinant of health provider choices: significant others, socio-cultural beliefs, causality beliefs, perception of health care systems. Care pathway: combining or alternating medicines from different providers. Care pathway: for illnesses attributed to supernatural causes. Self-medication for TB</td>
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<tr>
<td>No.</td>
<td>Author et al.</td>
<td>Study Type</td>
<td>Study Details</td>
<td>Disease</td>
<td>Data Collection Method</td>
<td>Study Location</td>
<td>Key Findings</td>
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<tr>
<td>47</td>
<td>Simanjuntak et al. [321]</td>
<td>Census</td>
<td>The total population enumerated by the study was 160,261 individuals, living in 34,503 households.</td>
<td>Diarrhoea</td>
<td>Quantitative with A de jure census: all members living in a household for more than six months and planning to stay in the household were included in the census. Data were collected through a structured interview with a household member, preferably the household head.</td>
<td>North Jakarta, Jakarta Province</td>
<td>Care pathway: if the sick person is a child.</td>
</tr>
<tr>
<td>48</td>
<td>Utarini et al. [322]</td>
<td>Community based</td>
<td>The main subgroups were: pregnant women (10), caretakers of the under-fives (10), traditional health providers (6), formal and informal leaders (10), cases or caretakers of cases (13). FGD: 7 involving 54 participants.</td>
<td>Malaria</td>
<td>Qualitative method with Rapid Assessment Procedures or RAP during a 3-month intensive data collection period. Data were retrieved from 38 free-listings, 28 in-depth interviews, seven focus group discussions and unstructured observation.</td>
<td>Jepara district, Central Java Province.</td>
<td>Determinant of health provider choices: socio-cultural beliefs (the use of herbal remedies for malaria), lay term, and lay perception of disease and its causality. Care pathway, treatment effectiveness is a matter of being &quot;suited&quot;. Self-medication for malaria.</td>
</tr>
<tr>
<td>49</td>
<td>Susanti et al. [323]</td>
<td>Hospital based</td>
<td>Quantitative: 124 patients, consisted of 38 patients with early stage and 86 patients with advanced stage. Qualitative: 6 patients, 1 midwife, and husband of 1 patient.</td>
<td>Cervical cancer</td>
<td>This research employs cross sectional quantitative and qualitative methods.</td>
<td>Jakarta Province</td>
<td>Determinants of delay in seeking treatment: limited knowledge, and limited availability of services.</td>
</tr>
<tr>
<td>50</td>
<td>Eeuwijk [324]</td>
<td>Community based</td>
<td>150 households for household study, 75 people for cohort study, 42 people suffered from chronic illness selected from cohort sample.</td>
<td>Elderly related health and chronic diseases</td>
<td>Mixed qualitative and quantitative research methods. Semi-structured interviews with the cohort sample have yielded general and unspecified statements on experience and meaning of chronic illnesses.</td>
<td>Three towns in North Sulawesi</td>
<td>Concept of health and illness- will seek care if the symptoms hinder daily activities.</td>
</tr>
<tr>
<td>51</td>
<td>Caprara et al. [325]</td>
<td>Community based</td>
<td>In total, 28 focus groups with community members, 42 open-ended interviews with community leaders, and 28 in-depth interviews with TB patients' family members were conducted.</td>
<td>TB</td>
<td>Qualitative methods including participant observation, case studies, focus groups, and open-ended, in-depth interviews.</td>
<td>Aceh Province</td>
<td>Determinant of health provider choices: significant others, socio-cultural beliefs, cost: payment for traditional health can be made with food for example, causality beliefs. Care pathway, for illnesses attributed to supernatural causes.</td>
</tr>
<tr>
<td>52</td>
<td>Sclafar, et al. [326]</td>
<td>Secondary data of household survey on self-medication</td>
<td>The survey was conducted in 1993 involving 2429 randomly selected households. The data were collected by structured interview.</td>
<td>Self-medication</td>
<td>Quantitative and descriptive analysis of the data aiming at developing methodology and evaluating appropriateness of self-medication.</td>
<td>Jakarta, East Java, and Yogyakarta Provinces.</td>
<td>Care pathway: if the sick person is a child. Self-medication</td>
</tr>
<tr>
<td>54</td>
<td>Sutrisna, et al. [328]</td>
<td>Household survey</td>
<td>Cases: 141 deaths in children less than 5 years of age</td>
<td>Fatal illness in children</td>
<td>Method: Cohort study with repeat visits to every household every 3 months. Subsequently, whenever a death was reported, a &quot;verbal autopsy&quot;, and also a questionnaire were used to collect data.</td>
<td>Indramayu, West Java Province</td>
<td>Determinant of health provider choices: duration of illness, and mothers’ participations in Posyandu. Socio-demographic characteristics were not associated with choices of health providers.</td>
</tr>
<tr>
<td>55</td>
<td>Darmawan, et al. [329]</td>
<td>Population based survey</td>
<td>Adults over 15 years old including 2499 women and 2184 men from two villages and total of 590 women and 481 men from two city neighbourhoods (response rate 96%)</td>
<td>Musculoskeletal pain</td>
<td>Quantitative survey with house to house interviews to collect data.</td>
<td>Central Java Province</td>
<td>Determinant of health provider choices: socio-cultural beliefs. Self-medication for muscular-skeletal pain</td>
</tr>
<tr>
<td>56</td>
<td>Berman, et al. [330]</td>
<td>Household survey</td>
<td>The household survey yielded data on 2697 households (17 375 individuals).</td>
<td>General health</td>
<td>Quantitative: Household members were asked a wide range of questions about utilisation of curative, preventive and community-based health care. The illness care data were responses to two-week recall of perceived illnesses.</td>
<td>Two regencies in West Java Province</td>
<td>Concept of health and illness- will seek care if the symptoms hinder daily activities. Care pathway: combining or alternating medicines from different providers</td>
</tr>
</tbody>
</table>
Table A1.2 Studies included in the review gathered from Indonesian journals

<table>
<thead>
<tr>
<th>No.</th>
<th>Studies</th>
<th>Type</th>
<th>Participants</th>
<th>Illness</th>
<th>Methods</th>
<th>Location</th>
<th>Important findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Widayati [331]</td>
<td>Community based</td>
<td>Adults over 18 years old, 640 respondents with 90% response rate.</td>
<td>General illness</td>
<td>A cross-sectional survey using a pre-tested questionnaire.</td>
<td>Yogyakarta</td>
<td>Determinant of health provider choices: socio demographic characteristics did not associated with seeking behaviour. Care pathway: combining or alternating medicines from different providers</td>
</tr>
<tr>
<td>2</td>
<td>Safitri, et al. [332]</td>
<td>Traditional clinic based</td>
<td>88 People who sought care to leeches therapy</td>
<td>Illnesses treated with leeches therapy</td>
<td>This research was conducted quantitatively, a cross-sectional study design.</td>
<td>Tuban, East Java</td>
<td>Determinant of health provider choices: socio-cultural beliefs for alternative treatment with leeches</td>
</tr>
<tr>
<td>3</td>
<td>Ngambut and Sila [333]</td>
<td>Household survey</td>
<td>Head of the 185 household or adults over 18 years old living in that households</td>
<td>Malaria</td>
<td>Cross sectional survey, data was collected through direct observation and interview with respondents. The data presented descriptively.</td>
<td>Kupang, East Nusa Tenggara</td>
<td>Self-medication for malaria</td>
</tr>
<tr>
<td>4</td>
<td>Kristiono and Wardani [334]</td>
<td>Community based</td>
<td>750 People suffered from cough more than two weeks, aged 15 or older.</td>
<td>TB</td>
<td>Cross sectional survey in Bantul district, Sleman district, and Yogyakarta city.</td>
<td>Yogyakarta Province</td>
<td>Determinant of health provider choices: socio demographic characteristics did not associated with seeking behaviour.</td>
</tr>
<tr>
<td>5</td>
<td>Kurnia [335]</td>
<td>Traditional clinic based</td>
<td>34 People sought care to alternative treatment for bone fracture</td>
<td>Bone fracture</td>
<td>Quantitative, descriptive study with questionnaire developed based on Health Belief Model.</td>
<td>Sumedang, West Java</td>
<td>Determinant of health provider choices: socio-cultural beliefs for alternative treatment from traditional bone setters</td>
</tr>
<tr>
<td>6</td>
<td>Triratnawati [336]</td>
<td>Community based</td>
<td>54 adults working as peasant and fisherman who experienced any illness</td>
<td>General illness</td>
<td>Qualitative, ethnography study using observation and in-depth interview</td>
<td>Yogyakarta and Central Java</td>
<td>Determinant of health provider choices: socio-cultural beliefs for alternative treatment with coin scratching</td>
</tr>
<tr>
<td>7</td>
<td>Supardi and Susyanty [337]</td>
<td>Data from National survey</td>
<td>Participants: people who were ill during the past month and took traditional medicines for self-medication (280,000 households).</td>
<td>Traditional medicine’s use</td>
<td>The data derived from Susenas 200) consist of 280,000 households in 33 provinces in Indonesia. Quantitatively analysed.</td>
<td>33 Provinces</td>
<td>Determinant of health provider choices: socio demographic characteristics</td>
</tr>
<tr>
<td>No</td>
<td>Authors</td>
<td>Location</td>
<td>Study Design</td>
<td>Setting</td>
<td>Data Collection Methods</td>
<td>Findings</td>
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<td>8</td>
<td>Ningsi, et al. [338]</td>
<td>Central Sulawesi</td>
<td>Community based</td>
<td>Community leaders, and people positive malaria based on blood test (the number of participants were not explained)</td>
<td>A qualitative study include observation, in depth interview with community leaders, and some informants.</td>
<td>Determinant of health provider choices: socio-cultural beliefs (the use of herbal remedies for malaria)</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Kamaluddin [339]</td>
<td>Banyumas district, Central Java</td>
<td>Traditional clinic based</td>
<td>6 Hypertension patients who did cupping therapy in An-Nahl, and Natura traditional therapy clinics</td>
<td>Descriptive phenomenological qualitative design. Data were obtained through in-depth interviews.</td>
<td>Determinant of health provider choices: socio-cultural beliefs for alternative treatment of cupping therapy</td>
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<tr>
<td>10</td>
<td>Jauhari, et al. [340]</td>
<td>Pontianak, West Kalimantan</td>
<td>Traditional clinic based</td>
<td>12 Patients, 6 sinhe(s) (Chinese traditional healers), 1 staff of health office, 1 doctor, and 1 leader of Chinese ethnic community</td>
<td>A qualitative study using grounded theory approach with observation guide and in depth interview.</td>
<td>Determinant of health provider choices: socio-cultural beliefs, reasons for choosing alternative treatments (sinhe) : safe, natural,</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Budijanto and Rooshermiatie [341]</td>
<td>Surabaya, East Java</td>
<td>Community based</td>
<td>6 FGD of 8 – 10 respondents each involving women in their reproductive age and men in their working age.</td>
<td>A qualitative study with FGD involving 8 – 10 people in each group.</td>
<td>Care pathways: self-medication first, and if symptoms persist visited health workers. But if the sick person is their child/children, they directly went to medical services.</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Supardi, et al. [342]</td>
<td>27 provinces</td>
<td>National survey data</td>
<td>People who took medicine, traditional medicine and or traditional methods on self-medication during the last one month before the survey (225,057)</td>
<td>Quantitative analysis of The National Socio-Economic Survey data 2001 to obtain information on the pattern of the use of medicine, traditional medicine and traditional methods on self-medication.</td>
<td>Determinant of health provider choices: socio demographic characteristics</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Shinta and Sukowati [343]</td>
<td>Purworejo, Central Java</td>
<td>Community-based</td>
<td>100 People resided in the area</td>
<td>Quantitative cross sectional descriptive study. Data were gathered with structured questionnaire.</td>
<td>Determinant of health provider choices: socio-cultural beliefs (the use of herbal remedies for malaria)</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Hendarwan [344]</td>
<td>Serang district, Banten</td>
<td>Community health centre based</td>
<td>101 Mothers who have child/ren under 5 with pneumonia related symptoms</td>
<td>A quantitative cross sectional study with questioner which was interviewed to the respondents.</td>
<td>Care pathway: if the sick person is a child</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Zalbawi and Santoso [345]</td>
<td>Traditional clinic based</td>
<td>72 Rheumatism patients who sought care to traditional healers, 15 traditional healers, and 6 traditional Chinese healers.</td>
<td>Rheumatoid</td>
<td>This paper is part of study on traditional medication for diabetes, hypertension and rheumatism conducted by Health Ecology and Development Centre in 1998/1999. The research used mixed methods. Quantitative: structured interview with rheumatism patients who sought care to traditional healer. Qualitative: in depth interview with traditional healers.</td>
<td>Jakarta, Yogyakarta, and Surabaya</td>
<td>Determinant of health provider choices: socio-cultural beliefs, reasons for choosing alternative treatments; safe, natural</td>
</tr>
<tr>
<td>16</td>
<td>Santoso, et al. [346]</td>
<td>Traditional clinic based</td>
<td>103 Hypertension patients who sought care to traditional healers</td>
<td>Hypertension</td>
<td>The research used mixed methods. Quantitative data: structured interview with hypertension respondents who sought care to traditional healers. Qualitative data: in depth interview with other hypertensive patients</td>
<td>Jakarta, Yogyakarta, and Surabaya</td>
<td>Determinant of health provider choices: socio-cultural beliefs, reasons for choosing alternative treatments: seeking for cure</td>
</tr>
</tbody>
</table>
Appendix 2 – Ethics and local government letter of approvals to conduct the qualitative study

Appendix 2.1: The University of Otago ethics approval to conduct the qualitative study

H15/057

Dear Professor Norris,

I am again writing to you concerning your proposal entitled “Health seeking behaviour of people in Indonesian communities”. Ethics Committee reference number H15/057.

Thank you for your e-mail of 3rd July 2015 addressing the issues raised by the Committee.

Thank you for providing further clarification in respect of the process the student investigator, Anna Wahyuni Widayanti, will undertake to obtain approval from both the Provincial Government and District Government. The Committee understands that once approval has been obtained that Anna will then approach the research departments of each hospital with the approval letters to request to conduct the research. Thank you for providing the list of hospitals and primary health centres that will be approached.

The Committee thanks you for the further comment provided relating to the support available for Anna while she is in Indonesia.

Once approval has been granted from the Provincial Government and District Government, please provide copies for our files.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

The standard conditions of approval for all human research projects reviewed and approved by the Committee are the following:

Conduct the research project strictly in accordance with the research proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee.
Inform the Human Research Ethics Committee immediately of anything which may warrant review of ethics approval of the research project, including: serious or unexpected adverse effects on participants; unforeseen events that might affect continued ethical acceptability of the project; and a written report about these matters must be submitted to the Academic Committees Office by no later than the next working day after recognition of an adverse occurrence/event. Please note that in cases of adverse events an incident report should also be made to the Health and Safety Office:

http://www.otago.ac.nz/healthandsafety/index.html

Advise the Committee in writing as soon as practicable if the research project is discontinued.

Make no change to the project as approved in its entirety by the Committee, including any wording in any document approved as part of the project, without prior written approval of the Committee for any change. If you are applying for an amendment to your approved research, please email your request to the Academic Committees Office:

gary.witte@otago.ac.nz

jo.farrondediaz@otago.ac.nz

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval or an extension of approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

Yours sincerely,

Mr Gary Witte
Manager, Academic Committees
Tel: 479 9256
Email: gary.witte@otago.ac.nz

c.c. Professor S B Duffull Dean School of Pharmacy
Appendix 2.2: The provincial government letter of approval to conduct the qualitative study in Kupang Municipality, East Nusa Tenggara Province

PEMERINTAH PROVINSI NUSA TENGGARA TIMUR
KANTOR PELAYANAN PERIZINAN TERPADU SATU PINTU
Jalan Teratai No. 10 – Telp / Fax. (0380) 833213
Email : kptspprovntt@yahoo.co.id; Website : www.kptsp-provntt.org

Kupang, 07 September 2015

Nomor : 070/3631/KPPTSP/2015
Sifat : Blasa
Lampiran : -
Hal : Izin Penelitian

Yth. Walikota Kupang
Cq. Kepala Badan Kesbang dan Linmas Kota Kupang

Kepada

KUPANG

Menindaklanjuti Surat Dekan Fakultas Farmasi Universitas Gadjah Mada Nomor : UGM/FA/3195/M/03/02 tanggal 04 September 2015, perihal Permohonan Izin Penelitian dan setelah mempelajari rencana kegiatan/proposal yang diajukan, maka dapat diberikan Izin Penelitian kepada mahasisawa :

Nama : ANNA WAHYUNI WIDAYANTI
NIM : 1236769
Jurusan/Prodi : Farmasi
Kebangsaan : Indonesia

Untuk melakukan penelitian dengan judul:

"HEALTH SEEKING BEHAVIOR OF PEOPLE IN INDONESIAN COMMUNITIES: A PRELIMINARY STUDY"

Lokasi : Kota Kupang
Pengikut : -
Lamanya Penelitian : 1 (satu) Bulan
Penanggung Jawab : Dekan Fakultas Farmasi Universitas Gadjah Mada

Peneliti berkerjasama menghormati/mentaati peraturan dan tata tertib yang berlaku di daerah setempat dan melaporkan hasil penelitian kepada Gubernur Nusa Tenggara Timur Cq. Kepala Kantor Peelayanan Perizinan Terpadu Satu Pintu Provinsi Nusa Tenggara Timur dan Walikota Kupang.

Demikian pemberitahuan ini dan atas perhatian disampaikan terima kasih.

Tembusan:
1. Gubernur Nusa Tenggara Timur di Kupang (sebagai laporan);
2. Wakil Gubernur Nusa Tenggara Timur di Kupang (sebagai laporan);
3. Sekretaris Daerah Provinsi Nusa Tenggara Timur di Kupang (sebagai laporan);
4. Kepala Badan Kesbangpol Provinsi NTT di Kupang;
5. Kepala Badan Pelayanan Perizinan Terpadu Kota Kupang di Kupang;
6. Dekan Fakultas Farmasi Universitas Gadjah Mada di Yogyakarta;
7. Yang bersangkutan di Tempat (asli untuk yang bersangkutan).
Appendix 2.3: The provincial government letter of approval to conduct the qualitative study in Kupang district, East Nusa Tenggara Province

PEMERINTAH PROVINSI NUSA TENGGARA TIMUR
KANTOR PELAYANAN PERIZINAN TERPADU SATU PINTU
Jalan Teratai No. 10 – Telp / Fax. (0380) 833213
Email : kpptspprovntt@yahoo.co.id; Website : www.kppts-provntt.org

Kupang, 07 September 2015

Yth. Bupati Kupang
Cq. Kepala Badan Penanaman Modal dan Pelayanan Perizinan Terpadu Kabupaten Kupang
di –

OELAMASI

Menindaklanjuti Surat Dekan Fakultas Farmasi Universitas Gadjah Mada Nomor : UGM/FA/3195/M/03/02 tanggal 04 September 2015, perihal Permohonan Izin Penelitian dan setelah mempelajari rencana kegiatan/proposal yang diajukan, maka dapat diberikan Izin Penelitian kepada mahasiswa :

Nama : ANNA WAHYUNI WIDAYANTI
NIM : 1236769
Jurusan/Prodi : Farmasi
Kebangsaan : Indonesia

Untuk melakukan penelitian dengan judul:

"HEALTH SEEKING BEHAVIOR OF PEOPLE IN INDONESIAN COMMUNITIES:
A PRELIMINARY STUDY"

Lokasi : Kabupaten Kupang
Pengikut : -
Lamanya Penelitian : 1 (satu) Bulan
Penanggung Jawab : Dekan Fakultas Farmasi Universitas Gadjah Mada


Demikian pemberitahuan ini dan atas perhatian disampaikan terima kasih.

a.n. GUBERNUR NUSA TENGGARA TIMUR
KEPALA KPTSP PROVINSI NTT,

Demikian pemberitahuan ini dan atas perhatian disampaikan terima kasih.

Tembusan:
1. Gubernur Nusa Tenggara Timur di Kupang (sebagai laporan);
2. Wakil Gubernur Nusa Tenggara Timur di Kupang (sebagai laporan);
3. Sekretaris Daerah Provinsi Nusa Tenggara Timur di Kupang (sebagai laporan);
4. Kepala Badan Kesbangpol Provinsi NTT di Kupang;
5. Kepala Kantor Kesbangpol Kabupaten Kupang di Oelamasi;
6. Dekan Fakultas Farmasi Universitas Gadjah Mada di Yogyakarta;
7. Yang bersangkutan di Tempat (astik untuk yang bersangkutan ).
Appendix 2.4: The provincial government letter of approval to conduct the qualitative study in Manggarai district, East Nusa Tenggara Province

PEMERINTAH PROVINSI NUSA TENGGARA TIMUR
KANTOR PELAYANAN PERIZINAN TERPADU SATU PINTU
Jalan Teratai No.10 – Telp./Fax. (0380) 833213
Email: kpptsprovntt@yahoo.co.id; Website: www.kpptsp-provntt.org

Kupang, 07 September 2015

Kepada
Yth. Bupati Manggarai
Cq. Kepala Badan Kesbang Linmas
Kabupaten Manggarai
di –

RUTENG

Menindaklanjuti Surat Dekan Fakultas Farmasi Universitas Gadjah Mada Nomor: UGM/FA/3195/M/03/02 tanggal 04 September 2015, perihal Permohonan Izin Penelitian dan setelah mempelajari rencana kegiatan/proposal yang diajukan, maka dapat diberikan Izin Penelitian kepada mahasiswa:

Nama : ANNA WAHYUNI WIDAYANTI
NIM : 1236769
Jurusan/Prodi : Farmasi
Kebangsaan : Indonesia

Untuk melakukan penelitian dengan judul:

"HEALTH SEEKING BEHAVIOR OF PEOPLE IN INDONESIAN COMMUNITIES: A PRELIMINARY STUDY"

Lokasi : Kabupaten Manggarai
Pengikut : -
Lamanya Penelitian : 1 (satu) Bulan
Penanggung Jawab : Dekan Fakultas Farmasi Universitas Gadjah Mada


Demikian pemberitahuan ini dan atas perhatian disampaikan terima kasih.

[Signature]

GUBERNUR NUSA TENGGARA TIMUR
KEPALA KPPS Provinsi NTT

Tembusan:
1. Gubernur Nusa Tenggara Timur di Kupang (sebagai laporan);
2. Wakil Gubernur Nusa Tenggara Timur di Kupang (sebagai laporan);
3. Sekretaris Daerah Provinsi Nusa Tenggara Timur di Kupang (sebagai laporan);
4. Kepala Badan Kesbangpol Provinsi NTT di Kupang;
5. Kepala Kantor Pelayanan Perizinan Terpadu Satu Pintu Kabupaten Manggarai di Ruteng;
6. Dekan Fakultas Farmasi Universitas Gadjah Mada di Yogyakarta;
7. Yang bersangkutan di Tempat ( asli untuk yang bersangkutan ).
Appendix 2.5: The provincial government letter of approval to conduct the qualitative study in Manggarai Timur district, East Nusa Tenggara Province

PEMERINTAH PROVINSI NUSA TENGGARA TIMUR
KANTOR PELAYANAN PERIZINAN TERPADU SATU PINTU
Jalan Teratai No. 10 – Telp / Fax: (0380) 833213
Email: kpptspprovntt@yahoo.co.id; Website: www.kpptspprovntt.org

Kupang, 07 September 2015

Kepada

Yth. Bupati Manggarai Timur
Ct. Kepala Badan Kesbang Linnmas
Kabupaten Manggarai Timur
di –

BORONG

Menindaklanjuti Surat Dekan Fakultas Farmasi Universitas Gadjah Mada
Nomor : UGM/FA/3195/M/03/02 tanggal 04 September 2015, perihal Permohonan Izin
Penelitian dan setelah mempelajari rencana kegiatan/proposal yang diajukan, maka
dapat diberikan Izin Penelitian kepada mahasiswa :

Nama : ANNA WAHYUNI WIDAYANTI
NIM : 1236769
Jurusan/Prodi : Farmasi
Kebangsaan : Indonesia

Untuk melakukan penelitian dengan judul:

“HEALTH SEEKING BEHAVIOR OF PEOPLE IN INDOENSIAN COMMUNITIES:
A PRELIMINARY STUDY”

Lokasi : Kabupaten Manggarai Timur
Pengikut : -
Lamanya Penelitian : 1 (satu) Bulan
Penanggung Jawab : Dekan Fakultas Farmasi Universitas Gadjah Mada

Peneliti berkewajiban menghormati/menatai peraturan dan tata tertib yang berlaku
di daerah setempat dan melaporkan hasil penelitian kepada Gubernur Nusa Tenggara
Timur Ct. Kepala Kantor Pelayanan Perizinan Terpadu Satu Pintu Provinsi Nusa Tenggara
Timur dan Bupati Manggarai Timur.

Demikian pemberitahuan ini dan atas perhatian disampaikan terima kasih.

b.n. GUBERNUR
PEMENDANG PROVINSI NTT

[Signature]

Demikian pemberitahuan ini dan atas perhatian disampaikan terima kasih.

1. Gubernur Nusa Tenggara Timur di Kupang (sebagai laporan);
2. Wakil Gubernur Nusa Tenggara Timur di Kupang (sebagai laporan);
3. Sekretaris Daerah Provinsi Nusa Tenggara Timur di Kupang (sebagai laporan);
4. Kepala Badan Kesbangpol Provinsi NTT di Kupang;
5. Kepala Badan Perencanaan Daerah dan Pelayanan Perizinan Kabupaten Manggarai Timur di Borong;
6. Dekan Fakultas Farmasi Universitas Gadjah Mada di Yogyakarta;
7. Yang bersangkutan di Tempat ( asli untuk yang bersangkutan ).
Appendix 2.6: The provincial government letter of approval to conduct the qualitative study in West Sumatera Province

PEMERINTAH PROVINSI SUMATERA BARAT
BADAN KESATUAN BANGSA DAN POLITIK
Jln. Kuning No.79 A Telp / Fax. 0751 - 31554 Padang
Website : http://www.sumbarprov.go.id e-mail: ksbangpolprov.co.id

REKOMENDASI PENELITIAN,
No. B.070/ 658 Was-BKPol / 2015

Latar
1. Undang-Undang Republik Indonesia Nomor 18 Tahun 2002 tentang Nisien Nasional Penelitian,
Pengembangan dan Penerapan Ilmu Pengembangan dan Teknologi;
2. Undang-Undang Republik Indonesia Nomor 32 Tahun 2004 tentang Pemerintah Daerah sebagaimana telah diubah beberapa kali, terakhir dengan Undang-Undang Nomor 12 Tahun 2008;

b. Bahwa untuk tertib administrasi dan pengendalian pelaksanaan penelitian dan pengendalian rekomendasi penelitian;

Kepada Badan Kesbangpol Provinsi Sumatera Barat, memberikan Surat Rekomendasi Penelitian kepada :

Pekerjaan : PNS Dosen UGM
Alamat : Pupur Sumar Putri Wayang KT 063/001 Pupir Purworejo Java Tengah.
Maissal/Adul : “HEALTH SEEKING BEHAVIOR OF PEOPLE IN INDONESIAN COMMUNITIES”
Waktu Penelitian : 1 Bulan

Dengan Ketentuan sebagai berikut:
1. Wajib Menghormati dan Menata Tata Teriti di Lokasi Tempat Penelitian sesuai dengan peraturan perundang-undangan yang berlaku;
2. Pelaksanaan Penelitian jangan disalahgunakan untuk kepentingan yang dapat mengganggu ketertiban dan ketertiban umum;
3. Melaporkan hasil penelitian apabila telah selesai kepada Gubernur melalui Badan Kesatuan Bangsa dan Politik Provinsi Sumatera Barat dengan secepatnya;
4. Bila terjadi penyimpangan dari maksud semula, maka surat rekomendasi ini dinyatakan tidak berlaku lagi.

Demikianlah disampaikan agar dapat dipergunakan dengan sepelemanis, akses keputusan ini dinyatakan tidak berlaku lagi.

Pada : 20 November 2015
PLH KEPALA BANGSA DAN POLITIK
PROVINSI SUMATERA BARAT

Tersebut kepada Yth:
1. Bapak Gubernur Sumatera Barat (sebagai laporan)
6. Yang bersangkutan.
7. Pernah dari...
Appendix 3 – Participant information sheets and consent forms for the qualitative study

Appendix 3.1: Participant information sheet for the qualitative study about child immunisation in English

Participant Information Sheet

<table>
<thead>
<tr>
<th>Study title:</th>
<th>Immunisation Behaviour of Indonesian Communities</th>
</tr>
</thead>
</table>
| Principal investigator: | Name: Prof. Pauline Norris  
Department: Pharmacy | Contact phone number:  
+64 274 80 95 95 |

Introduction
Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this research project?
This project aims to understand people’s perspective, beliefs, experiences and opinions about immunisation how the people decide whether or not to immunise their children. This understanding is very important in helping the government to create specific programmes on immunisation that may be well-accepted and afforded by the people. It also helps the government to improve the quality of immunisation-related health services.

Who is funding this project?
This project is funded by New Zealand Ministry of Foreign Affairs and Trade through New Zealand ASEAN Scholarship and the University of Otago, New Zealand.

Who are we seeking to participate in the project?
Mothers aged at least 17 years who have child or children aged 12 – 24 months will be chosen from primary health centres data and community-based child care organisations. The selection criteria are: has no formal health education background, does not work for a formal health provider, and has agreed to participate and shared their experience in immunisation. This project involves about 60 participants from different locations with 4 – 10 participants in each discussion.

If you participate, what will you be asked to do?
Should you agree to take part in this project, you will be asked to answer questions in group discussion. There is no right or wrong in your answer and we will not evaluate your answer as right or wrong. We just asked you to answer based on your personal opinion. Every of your answer is meaningful and very important. We will respect to any information that you have given. The discussion will take about 1 – 2 hours. You may decide not to involve or to stop or leave the discussion at any time you wish without any disadvantage to yourself at any kind.

Is there any risk of discomfort or harm from participation?
Any of your information that you have given will only be used for academic purposes. There will be no physical or psychological risk or harm as every effort will be made to keep your personal identification safely and preserve your anonymity. However, as the nature of discussion, your shared information may be known by other person involved in the discussion. Should you disagree with such question, or your answer of such question is very confidential, you may refuse to answer it or answer it in a written format.

What data or information will be collected, and how will they be used?
The questions that we will ask to you are about your experiences, beliefs, opinions, perception about immunisation and how you make decisions whether or not to immunise your children. We will also collect your personal information such as name, age, job and address.
If you agree, I will record our discussion in order to avoid missing any information that you have given. The recording will be transcribed and this transcript will be a raw data. This raw data will be retained for at least 5 years in secure storage. Any personal information may be destroyed at the completion of the research even though the raw data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

Then, we will analyse the raw data and include it in the final result of the project. Your information may be appear in the form of quotes in the report and publication, but you will not be identified by name anywhere in the reports or published information. Every effort will be made to make secure any personal information.

The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve your anonymity. If you wish, you can request to the final report.

**What about anonymity and confidentiality?**
I will give you a copy of the transcript for you to check whether or not it represents your opinion accurately. After your checking process, the transcript will be translated into English with the help of research assistants.

The audio recording and the transcript will be securely stored in such a way that only I, my supervisors and research assistants will be able to access it. The research assistants will only have access to the data until the translation process is finished.

You will not be identified by name anywhere in the research reports or published information. Every effort will be made to make secure any personal information.

**If you agree to participate, can you withdraw later?**
You may withdraw from participation in the project at any time and without any disadvantage to yourself.

Any questions?
If you have any questions now or in the future, please feel free to contact:

<table>
<thead>
<tr>
<th>Name: Anna Wahyuni Widayanti</th>
<th>Nomor telepon: +62 81328685900</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position: Mahasiswa peneliti</td>
<td></td>
</tr>
<tr>
<td>Departement: Pharmacy, University of Otago, New Zealand</td>
<td></td>
</tr>
</tbody>
</table>

This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.
Appendix 3.2: Participant information sheet for the qualitative study about child immunisation in Indonesian

Lembar Informasi untuk partisipan

<table>
<thead>
<tr>
<th>Judul penelitian:</th>
<th>Perilaku terhadap imunisasi pada masyarakat di Indonesia.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ketua peneliti:</td>
<td>Nama: Prof. Pauline Norris Departemen: Farmasi</td>
</tr>
<tr>
<td></td>
<td>Kontak: +64 274 80 95 95</td>
</tr>
</tbody>
</table>

Pendahuluan

Apakah tujuan dari penelitian ini?
Penelitian ini bertujuan untuk memahami persepsi, kepercayaan, pengalaman dan pendapat masyarakat mengenai imunisasi. Pemahaman ini sangat penting dalam membantu pemerintah untuk memperbaiki program imunisasi, sehingga dapat diterima dengan baik, dan terjangkau oleh masyarakat. Hal tersebut juga membantu pemerintah untuk meningkatkan kualitas pelayanan imunisasi.

Siapakah yang membiayai penelitian ini?
Penelitian ini dibayai oleh Kementerian Perdagangan dan Urusan Luar Negeri New Zealand melalui beasiswa New Zealand ASEAN dan Universitas Otago, New Zealand.

Siapa saja yang kami cari untuk berpartisipasi dalam penelitian ini?

Jika anda berpartisipasi, apa yang anda akan lakukan?

Apakah ada resiko ketidaknyamanan atau bahaya dari keterlibatan dalam penelitian?
Semua informasi yang anda sampaikan hanya akan kami gunakan untuk kepentingan akademik. Tidak ada ada resiko atau bahaya fisik atau psikologis sebagai hasil dari keterlibatan anda dalam penelitian. Kami mengupayakan segala usaha yang akan menjadi identitas diri anda dengan aman. Kami juga meminta semua partisipan dalam diskusi untuk menghormati kerahasiaan informasi yang disampaikan oleh orang lain, tetapi dalam sebuah diskusi kami tidak bisa sepenuhnya menjamin bahwa partisipan lain pasti akan menjaga kerahasiaan informasi yang akan anda sampaikan. Jika anda tidak ingin menjawab sebuah atau beberapa pertanyaan, atau anda merasa jawaban anda adalah rahasia untuk partisipan lain dalam diskusi, anda dapat menolak untuk menjawabnya atau dapat juga menjawabnya secara tertutus.
Data atau informasi apa yang diinginkan dan bagaimana data atau informasi tersebut akan digunakan?
Kami akan bertanya kepada anda mengenai pengalaman, kepercayaan, pendapat dan persepsi anda mengenai imunisasi untuk anak anda. Kami juga akan bertanya mengenai bagaimana anda memutuskan untuk melakukan imunisasi untuk anak anda atau tidak. Kami juga akan mengumpulkan data nama, jenis kelamin, usia, pekerjaan dan alamat anda.

Selanjutnya, kami akan menganalisis transkrip ini dan memasukkannya dalam laporan akhir hasil penelitian. Informasi yang anda sampaikan mungkin muncul dalam hasil laporan penelitian tersebut, tetapi identitas diri anda tidak akan pernah disebutkan dimanapun dalam laporan hasil penelitian. Segala usaha akan kami lakukan untuk menjaga kerahasiaan identitas anda.


Bagaimana dengan kerahasiaan nama dan informasi?
Transkrip salinan rekaman akan diterjemahkan ke dalam Bahasa Inggris dengan bantuan asisten peneliti. Hasil rekaman dan salinan transkrip ini akan kami simpan di tempat yang aman sehingga hanya peneliti, pembimbing peneliti dan asisten peneliti yang dapat mengaksesnya. Asisten peneliti hanya dapat mengakses data hanya sampai proses penerjemahan selesai. Identitas diri anda tidak akan teridentifikasi dimanapun dalam laporan atau publikasi hasil penelitian. Segala upaya akan kami lakukan untuk menjaga keamanan informasi dan data identitas pribadi anda.

Jika anda setuju untuk berpartisipasi, dapatkah anda berhenti untuk berpartisipasi di setiap saat?
Anda dapat memutuskan untuk mengundurkan diri dari berpartisipasi kapanpun, dan tanpa konsekuensi atau resiko apapun terhadap diri anda.

Ada pertanyaan?
Jika anda mempunyai pertanyaan saat ini atau di kemudian hari, anda dapat mengontak peneliti:

<table>
<thead>
<tr>
<th>Nama : Anna Wahyuni Widayanti</th>
<th>Nomor telepon: 0 81328685900</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jabatan dalam penelitian : Mahasiswa peneliti</td>
<td></td>
</tr>
<tr>
<td>Departemen : Farmasi, Universitas Otago, New Zealand</td>
<td></td>
</tr>
</tbody>
</table>

Penelitian ini telah disetujui oleh komite etik Universitas Otago. Jika anda mempunyai pertanyaan atau keluhan yang berkaitan dengan etik penelitian, anda dapat menghubungi komite melalui bagian administrasi komite etik, Universitas Otago, dengan nomor telepon +64 34798256 atau melalui email ke alamat: gary.witte@otago.ac.nz. Semua permasalahan yang anda kemukakan akan diperlakukan dan diinvestigasi secara rahasia dan anda akan diberikan informasi mengenai hasil investigasi tersebut.
Appendix 3.3: Participant information sheet for the qualitative study about diabetes in English

Participant Information Sheet

Study title: Health Seeking Behaviour of Indonesian Communities for diabetes and common cold

Principal investigator: Name: Prof. Pauline Norris
Department: Pharmacy

Introduction
Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this research project?
This project aims to understand people’s perspective, beliefs, experiences and opinions about diabetes and the common cold and how the people decide to choose any mode of treatment. This understanding is very important in helping the government to create specific programmes on diabetes and the common cold that may be well-accepted and afforded by the people. It also helps the government to improve the quality of health services.

Who is funding this project?
This project is funded by New Zealand Ministry of Foreign Affairs and Trade through New Zealand ASEAN Scholarship and the University of Otago, New Zealand.

Who are we seeking to participate in the project?
Adult aged at least 30 years, both males and females. Participants are chosen from hospitals or primary health centres data. The selection criteria are: has been diagnosed with diabetes for at least one year, has no formal health education background, does not work in any health services, and has agreed to participate and share their experience in managing diabetes and the common cold. This project will involve about 60 participants from different locations with 4 – 10 participants in each discussion.

If you participate, what will you be asked to do?
Should you agree to take part in this project, you will be asked to answer questions in group discussion. There is no right or wrong in your answer and we will not evaluate your answer as right or wrong. We just asked you to answer based on your personal opinion. Every of your answer is meaningful and very important. We will respect to any information that you have given. The discussion will take about 1 – 2 hours. You may decide not to involve or to stop or leave the discussion at any time you wish without any disadvantage to yourself at any kind.

Is there any risk of discomfort or harm from participation?
Any of your information that you have given will only be used for academic purposes. There will be no physical or psychological risk or harm as every effort will be made to keep your personal identification safely and preserve your anonymity. However, as the nature of discussion, your shared information may be known by other person involved in the discussion. Should you disagree with such question, or your answer of such question is very confidential, you may refuse to answer it or answer it in a written format.

What data or information will be collected, and how will they be used?
The questions that we will ask to you are about your experiences, beliefs, opinions, perception about diabetes and the common cold and how you make decisions in choosing any treatment available. We also will collect your personal information such as name, gender, age, job and address. If you agree, I will record our discussion in order to avoid missing any information that you have given. The recording will be transcribed and this transcript will be a raw data. This raw data will be retained for at least 5 years in secure storage. Any personal information may be destroyed at the completion of the
research even though the raw data derived from the research will, in most cases, be kept for much longer or possibly indefinitely. Then, we will analyse the raw data and include it in the final result of the project. Your information may be appear in the form of quotes in the report and publication, but you will not be identified by name anywhere in the reports or published information. Every effort will be made to make secure any personal information.

The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve your anonymity. If you wish, you can request to the final report.

**What about anonymity and confidentiality?**
I will give you a copy of the transcript for you to check whether or not it represents your opinion accurately. After your checking process, the transcript will be translated into English with the help of research assistants. The audio recording and the transcript will be securely stored in such a way that only I, my supervisors and research assistants will be able to access it. The research assistants will only can have access to the data until the translation process is finished. You will not be identified by name anywhere in the research reports or published information. Every effort will be made to make secure any personal information.

**If you agree to participate, can you withdraw later?**
You may withdraw from participation in the project at any time and without any disadvantage to yourself.

**Any questions?**
If you have any questions now or in the future, please feel free to contact:

<table>
<thead>
<tr>
<th>Name: Anna Wahyuni Widayanti</th>
<th>Nomor telepon:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position: Mahasiswa peneliti</td>
<td>+62 81328685900</td>
</tr>
<tr>
<td>Departemen: Pharmacy, University of Otago, New Zealand</td>
<td></td>
</tr>
</tbody>
</table>

*This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8236 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.*
Appendix 3.4: Participant information sheet for the qualitative study about diabetes in Indonesian

<table>
<thead>
<tr>
<th>Judul penelitian:</th>
<th>Perilaku pencarian pengobatan pada masyarakat Indonesia terkait dengan diabetes dan flu</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ketua peneliti:</td>
<td>Nama: Prof. Pauline Norris Departemen: Farmasi Kontak: +64 274 80 95 95</td>
</tr>
</tbody>
</table>

**Pendahuluan**

Terima kasih atas ke tertarikan anda untuk terlibat dalam penelitian ini. Mohon bacalah lembar informasi ini dengan seksama. Luangkan waktu untuk berpikir, dan jika anda inginkan, bicaralah dengan teman atau saudara, sebelum memutuskan bersedia atau tidak untuk berpartisipasi dalam penelitian ini.

Jika anda memutuskan untuk berpartisipasi, kami sangat berterima kasih. Jika anda memutuskan untuk tidak berpartisipasi, tidak akan ada konsekuensi apapun, dan kami juga berterima kasih anda telah mempertimbangkan permohonan kami.

**Apakah tujuan dari penelitian ini?**

Penelitian ini bertujuan untuk memahami persepsi, kepercayaan, pengalaman dan pendapat masyarakat mengenai diabetes dan flu. Pemahaman ini sangat penting dalam membantu pemerintah untuk membuat program diabetes dan flu yang dapat diterima dengan baik, dan terjangkau oleh masyarakat. Hal tersebut juga membantu pemerintah untuk meningkatkan kualitas pelayanan kesehatan.

**Siapakah yang membiayai penelitian ini?**

Penelitian ini dibiayai oleh Kementerian Perdagangan dan Urusan Luar Negeri New Zealand melalui beasiswa New Zealand ASEAN dan Universitas Otago, New Zealand.

**Siapa saja yang kami cari untuk berpartisipasi dalam penelitian ini?**

Masyarakat dewasa, berusia paling rendah 30 tahun, baik laki-laki maupun perempuan. Calon partisipan dipilih dari data pasien di rumah sakit atau puskesmas. Kriteria seleksi untuk calon partisipan adalah:

- telah didiagnosis diabetes selama minimal 1 tahun, tidak memiliki latar belakang pendidikan bidang kesehatan, tidak bekerja di tempat pelayanan kesehatan, dan bersedia untuk berpartisipasi dan membagi pengalamannya dalam mengatasi diabetes dan flu. Penelitian ini akan melibatkan kurang lebih 60 partisipan dari lokasi penelitian yang berbeda-beda dengan 4 – 10 partisipan dalam setiap kali diskusi.

**Jika anda berpartisipasi, apa yang anda akan lakukan?**


**Apakah ada resiko ketidakh Garyamanan atau bahaya dari keterlibatan dalam penelitian?**

Semua informasi yang anda sampaikan hanya akan kami gunakan untuk kepentingan akademik. Tidak akan ada resiko, bahaya fisik atau psikologis sebagai hasil dari keterlibatan anda dalam penelitian ini. Kami mungkin akan segala usaha yang akan menjaga identitas diri anda dengan aman. Kami juga meminta semua partisipan dalam diskusi untuk menghormati kerahasiaan informasi yang disampaikan.
oleh orang lain, tetapi dalam sebuah diskusi kami tidak bisa sepenuhnya menjamin bahwa partisipan lain pasti akan menjaga kerahasiaan informasi yang akan anda sampaikan. Jika anda tidak ingin menjawab sebuah atau beberapa pertanyaan, atau anda merasa jawaban anda adalah rahasia untuk partisipan lain dalam diskusi, anda dapat menolak untuk menjawabnya atau dapat juga menjawabnya secara tertulis.

**Data atau informasi apa yang diinginkan dan bagaimana data atau informasi tersebut akan digunakan?**


Selanjutnya, kami akan menganalisis transkrip ini dan memasukkannya dalam laporan akhir hasil penelitian. Informasi yang anda sampaikan mungkin muncul dalam laporan penelitian tersebut, tetapi nama anda tidak akan pernah disebutkan dimanapun dalam laporan hasil penelitian. Segala usaha akan kami lakukan untuk menjaga kerahasiaan identitas anda.

Hasil penelitian ini akan kami publikasikan secara luas, namun segala upaya akan kami lakukan untuk menjaga kerahasiaan identitas diri anda. Jika anda berkeinginan, anda dapat juga meminta fotokopi dari laporan akhir penelitian.

**Bagaimana dengan kerahasiaan nama dan informasi?**
Transkrip salinan rekaman akan diterjemahkan ke dalam Bahasa Inggris dengan bantuan asisten peneliti. Hasil rekaman dan salinan transkrip ini akan kami simpan di tempat yang aman sehingga hanya peneliti, pembimbing peneliti dan asisten peneliti yang dapat mengaksesnya. Asisten peneliti hanya dapat mengakses data sampai proses penerjemahan selesai.
Identitas diri anda tidak akan teridentifikasi dimanapun dalam laporan atau publikasi hasil penelitian. Segala upaya akan kami lakukan untuk menjaga keamanan informasi dan data identitas pribadi anda.

**Jika anda setuju untuk berpartisipasi, dapatkah anda berhenti untuk berpartisipasi di setiap saat?**
Anda dapat memutuskan untuk mengundurkan diri dari berpartisipasi kapanpun, dan tanpa konsekuensi atau resiko apapun terhadap diri anda.

**Ada pertanyaan?**
Jika anda mempunyai pertanyaan saat ini atau di kemudian hari, anda dapat mengontak peneliti:

| Nama : Anna Wahyuni Widayanti  
| Jabatan dalam penelitian : Mahasiswa peneliti  
| Departemen : Farmasi, Universitas Otago, New Zealand | Nomor telepon: 0 81328685900 |

Penelitian ini telah disetujui oleh komite etik Universitas Otago. Jika anda mempunyai pertanyaan atau keluhan yang berkaitan dengan etik penelitian, anda dapat menghubungi komite melalui bagian administrasi komite etik, Universitas Otago, dengan nomor telepon +64 34798256 atau melalui email ke alamat: gary.witte@otago.ac.nz. Semua permasalahan yang anda kemukakan akan diperlakukan dan diinvestigasi secara rahasia dan anda akan diberikan informasi mengenai hasil investigasi tersebut.
Appendix 3.5: Consent form for participants involved in the qualitative study about child immunisation in English

Immunisation Behaviour of Indonesian Communities

Principal Investigator: Prof. Pauline Norris (pauline.norris@otago.ac.nz, +64274809595)

CONSENT FORM FOR PARTICIPANTS

Following signature and return to the research team this form will be stored in a secure place for ten years.

Name of participant:…………………………………………..

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project at any time without disadvantage.
6. I know that as a participant I will involve in a group discussion.
7. I know that the discussion will explore the perspective, beliefs, experiences and opinions about immunisation and how the people decide whether or not to immunising the children and that if the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s), and/or may withdraw from the project without disadvantage of any kind.
8. I understand the nature and size of the risks of discomfort or harm which are explained in the Information Sheet.
9. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from the project, and that these will be placed in secure storage and kept for at least ten years.
10. I understand that the results of the project may be published and be available in the University of Otago Library, but that I agree that any personal identifying information will remain confidential between myself and the researchers during the study, and will not appear in any spoken or written report of the study.
11. I know that there is no remuneration offered for this study, and that no commercial use will be made of the data.

1) Signature of participant: ___________________________ Date: ___________________________
Appendix 3.6: Consent forms for participants involved the qualitative study about child immunisation in Indonesian

Perilaku terhadap imunisasi pada masyarakat di Indonesia

Ketua peneliti: Professor Pauline Norris (pauline.norris@otago.ac.nz, +64 274809595)

Lembar persetujuan untuk partisipan

Mohon untuk ditandatangani dan dikembalikan kepada tim peneliti. Lembar ini akan disimpan dengan aman, dalam kurun waktu sepuluh tahun.

Nama partisipan: ……………………………………………..

1. Saya telah membaca Lembar Informasi yang berkaitan dengan penelitian ini dan memahami tujuan dari penelitian ini.
2. Saya telah diberi cukup waktu untuk mempertimbangkan dan berbicara dengan orang lain terkait keputusan saya untuk terlibat dalam penelitian ini.
3. Saya menyatakan bahwa saya memenuhi kriteria sebagai partisipan yang telah dijelaskan dalam Lembar Informasi.
4. Semua pertanyaan saya terkait penelitian telah dijawab dengan memuaskan, dan saya memahami bahwa saya berhak untuk meminta informasi lebih lanjut kapanpun.
5. Saya mengerti bahwa partisipasi saya dalam penelitian sepenuhnya adalah sukarela, dan saya bebas untuk mengundurkan diri dari berpartisipasi dalam penelitian ini kapanpun tanpa adanya resiko apapun.
6. Saya memahami bahwa sebagai partisipan, saya akan terlibat dalam sebuah diskusi kelompok.
7. Saya mengetahui bahwa dalam diskusi kelompok tersebut, saya akan diberi pertanyaan mengenai persepsi, kepercayaan, pengalaman dan pendapat saya terkait imunisasi untuk anak saya, dan bagaimana saya memutuskan mengimunisasi anak saya atau tidak. Saya juga memahami bahwa jika pertanyaan dapat berkembang ke arah yang membuat saya enggan atau tidak nyaman untuk menjawab, saya dapat menolak untuk menjawab pertanyaan tertentu tersebut, dan/atau dapat juga mengundurkan diri dari berpartisipasi dalam penelitian tanpa adanya resiko apapun.
8. Saya memahami tentang kemungkinan resiko atau ketidaknyamanan yang telah dijelaskan dalam Lembar Informasi.
9. Saya mengetahui bahwa ketika penelitian telah selesai, semua data identitas diri saya akan dihapus dari transkrip atau salinan rekaman dan juga dari data elektronik. Saya juga mengetahui bahwa data lain akan disimpan di tempat yang aman selama paling tidak sepuluh tahun.
10. Saya memahami bahwa hasil penelitian ini dapat dipublikasikan dan juga tersedia di perpustakaan Universitas Otago, tapi saya mengetahui bahwa semua informasi terkait data identitas diri saya akan tetap dirahasiakan dan tidak akan muncul dalam laporan penelitian baik secara lisan ataupun tertulis.
11. Saya mengetahui bahwa tidak akan ada imbalan dalam bentuk uang yang diberikan kepada saya atas keterlibatan saya dalam penelitian, dan saya juga mengetahui bahwa data penelitian juga tidak akan digunakan untuk kepentingan komersial.

Tanda tangan partisipan

Tanggal
Appendix 3.7: Consent form for participants involved the qualitative study about diabetes in English

Health-seeking behaviour of Indonesian communities for diabetes and common cold

Principal Investigator: Professor Pauline Norris (pauline.norris@otago.ac.nz, +64 274 80 95 95)

CONSENT FORM FOR PARTICIPANTS

Following signature and return to the research team this form will be stored in a secure place for ten years.

Name of participant:…………………………………………..

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project at any time without disadvantage.
6. I know that as a participant I will involve in a group discussion.
7. I know that the discussion will explore the perspective, beliefs, experiences and opinions about diabetes and the common cold and how the people decide to choose any mode of treatment and that if the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s), and /or may withdraw from the project without disadvantage of any kind.
8. I understand the nature and size of the risks of discomfort or harm which are explained in the Information Sheet.
9. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from the project, and that these will be placed in secure storage and kept for at least ten years.
10. I understand that the results of the project may be published and be available in the University of Otago Library, but that I agree that any personal identifying information will remain confidential between myself and the researchers during the study, and will not appear in any spoken or written report of the study.
11. I know that there is no remuneration offered for this study, and that no commercial use will be made of the data.

4) Signature of participant: ___________________________ Date: ___________________________
Appendix 3.8: Consent form for participants involved in the qualitative study about diabetes in Indonesian

Perilaku pencarian pengobatan pada masyarakat Indonesia terkait dengan diabetes dan flu

Ketua peneliti: Professor Pauline Norris (pauline.norris@otago.ac.nz, +64 274 80 95 95)

Lembar persetujuan untuk partisipan

Mohon untuk ditandatangani dan dikembalikan kepada tim peneliti. Lembar ini akan disimpan dengan aman, dalam kurun waktu sepuluh tahun.

Nama partisipan: ……………………………………………..
1. Saya telah membaca Lembar Informasi yang berkaitan dengan penelitian ini dan memahami tujuan dari penelitian ini.
2. Saya telah diberi cukup waktu untuk mempertimbangkan dan berbicara dengan orang lain terkait keputusan saya untuk terlibat dalam penelitian ini.
3. Saya menyatakan bahwa saya memenuhi kriteria sebagai partisipan yang telah dijelaskan dalam Lembar Informasi.
4. Semua pertanyaan saya terkait penelitian telah dijawab dengan memuaskan, dan saya memahami bahwa saya berhak untuk meminta informasi lebih lanjut kapanpun.
5. Saya mengerti bahwa partisipasi saya dalam penelitian sepenuhnya adalah sukarela, dan saya bebas untuk mengundurkan diri dari berpartisipasi dalam penelitian ini kapanpun tanpa adanya resiko apapun.
6. Saya memahami bahwa dalam diskusi kelompok tersebut, saya akan diberi pertanyaan mengenai persepsi, kepercayaan, pengalaman dan pendapat saya terkait dengan diabetes dan flu, dan bagaimana saya memutuskan untuk mencari pengobatan untuk diabetes dan flu. Saya juga memahami bahwa jika pertanyaan dapat berkembang ke arah yang membuat saya enggan atau tidak nyaman untuk menjawab, saya dapat menolak untuk menjawab pertanyaan tersebut, dan/atau dapat mengundurkan diri dari berpartisipasi dalam penelitian ini kapanpun tanpa adanya resiko apapun.
7. Saya memahami tentang kemungkinan resiko atau ketidaknyamanan yang telah dijelaskan dalam Lembar Informasi.
8. Saya mengetahui bahwa ketika penelitian ini dapat dipublikasikan dan juga tersedia di perpustakaan Universitas Otago, tapi saya mengetahui bahwa semua identitas diri saya akan dihapus dari transkrip atau salinan rekaman dan juga dari data elektronik. Saya juga mengetahui bahwa data lain akan disimpan di tempat yang aman selama paling tidak sepuluh tahun.
9. Saya mengetahui bahwa hasil penelitian ini dapat dipublikasikan dan juga tersedia di perpustakaan Universitas Otago, tapi saya mengetahui bahwa semua informasi terkait data identitas diri saya akan tetap dirahasiakan dan tidak akan muncul dalam laporan penelitian baik secara lisan ataupun tertulis.
10. Saya mengetahui bahwa tidak akan ada imbalan dalam bentuk uang yang diberikan kepada saya atas keterlibatan saya dalam penelitian, dan saya juga mengetahui bahwa data penelitian juga tidak akan digunakan untuk kepentingan komersial.

Tanda tangan partisipan

Tanggal

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Appendix 4 – Ethics and local government letters of approval to conduct the intervention study

Appendix 4.1: The University of Otago ethics approval to conduct the intervention study

Professor P Norris
School of Pharmacy

29 July 2016

Dear Professor Norris,

I am again writing to you concerning your proposal entitled "Community-based intervention for type 2 diabetes patients in East Nusa Tenggara, Indonesia". Ethics Committee reference number H16/076.

Thank you for your letter of 25th July 2016, addressing the issues raised by the Committee.

The Committee notes that once the research permit has been provided a copy will be sent for our records.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

The standard conditions of approval for all human research projects reviewed and approved by the Committee are the following:

Conduct the research project strictly in accordance with the research proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee.

Inform the Human Research Ethics Committee immediately of anything which may warrant review of ethics approval of the research project, including: serious or unexpected adverse effects on participants; unforeseen events that might affect continued ethical acceptability of the project; and a written report about these matters must be submitted to the Academic Committees Office by no later than the next working day after recognition of an adverse occurrence/event. Please note that in cases of adverse events an incident report should also be made to the Health and Safety Office:

http://www.otago.ac.nz/healthandsafety/index.html

Advise the Committee in writing as soon as practicable if the research project is discontinued.
Make no change to the project as approved in its entirety by the Committee, including any wording in any document approved as part of the project, without prior written approval of the Committee for any change. If you are applying for an amendment to your approved research, please email your request to the Academic Committees Office:

gary.witte@otago.ac.nz

jo.farrousmediaz@otago.ac.nz

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval or an extension of approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

The Human Ethics Committee (Health) asks for a Final Report to be provided upon completion of the study. The Final Report template can be found on the Human Ethics Web Page [http://www.otago.ac.nz/council/committees/committees/HumanEthicsCommittees.html](http://www.otago.ac.nz/council/committees/committees/HumanEthicsCommittees.html)

Yours sincerely,

\[Signature\]

Mr Gary Witte
Manager, Academic Committees
Tel: 479 8256
Email: gary.witte@otago.ac.nz

\[C.C. Assoc. Prof. N J Medlicott Acting Dean School of Pharmacy\]
Appendix 4.2: The provincial government letter of approval to conduct the intervention study in Kupang, East Nusa Tenggara
Appendix 4.3: The Kupang city government letter of approval to carry out the intervention study

PEMERINTAH KOTA KUPANG
BADAN KESATUAN BANGSA
DAN POLITIK
Jl. S. K. Lekik
Telp. (0380) 826573

SURAT KETERANGAN MELAKUKAN PENELITIAN / SURVEI
Nomor : BKB. 070 /3734/ III/07/ 2016

Perihal Permohonan ijin Penelitian.

Menimbang : Bahwa demi kelancaran tugas dimaksud, perlu dikeluarkan suatu rekomendasi.

WALIKOTA KUPANG

Dengan ini menerangkan: ----- TIDAK KEBERATAN ----- kepada :

Nama : Anna Wahyuni Widayanti
NIM : 123456789
Pekerjaan : Mahasiswa
Jurusan : Farmasi
Alamat : Kei.Kayu Putih
Untuk : Melakukan penelitian dengan judul :

"COMMUNITY-BASED INTERVENTION FOR TYPE 2 DIABETES PATIENTS IN EAST NUSA TENGGARA, INDONESIA"

Lama : 1 (Tahun) Bulan, Terhitung Mulai Tanggal Surat ini
Lokasi : Wilayah Kota Kupang, Puskesmas se Kota Kupang
Pengikut :

Dengan ketentuan :
1. Wajib memberitahukan maksud dan tujuan kepada Instansi Pemerintah / Swasta yang hendak diteliti.
2. Selama melakukan penelitian/Survey, tidak diijinkan melakukan kegiatan di bidang lain yang mengganggu ketertiban masyarakat.
4. Ijin Penelitian/Survey ini akan dicabut dan dinyatakan tidak berlaku lagi apabila Pihak Peneliti melanggar ketentuan tersebut di atas.

Demikian Surat Keterangan ini diberikan untuk dipergunakan sebagaimana mestinya dan diharapkan agar pihak - pihak yang mendapat bantuan sesuai dengan ketentuan peraturan yang berlaku.

Kupang, 28 Juli 2016

an. Walikota Kupang
Kepala Badan Kesatuan Bangsa & Politik
Kota Kupang
Ub. Kabid Kesatuan Bangsa,

MULYADI, S.GUNAWAN, S.Sos,MM
Pembina IV/A
NIP: 196704151998031014
Appendix 4.4: The Kupang city health department letter of approval to conduct the intervention study

PEMERINTAH KOTA KUPANG
DINAS KESEHATAN
Jalan S.K Lerik, Kelapa Lima Telp. (0380) 825769, Fax. (0380) 825730
Website: www.dinkes-kotakupang.web.id. Email: sekretariat@dinkes-kotakupang.web.id

Lampiran : -
Perihal : Persetujuan Melakukan Penelitian

Kepada
Yth.
Kepala Puskesmas se-Kota Kupang
di –
Kupang


Demikian untuk maklum, dan atas perhatian saudara disampaikan terima kasih.

a.n SEKRETARIS DINAS KESEHATAN
KOTA KUPANG
Kasubag taman & Kepegawaian

Tembusan : disampaikan dengan hormat kepada :
1. Kepala Badan Kesbangpol Kota Kupang di Kupang
2. Dekan Fakultas Farmasi Universitas Gajahmada di Yogyakarta
3. Yang Bersangkutan

Yenny Arani, SH
Penata Ti.: 1
NIP. 16000206 200112 2 005
Appendix 5 – Participant information sheet and consent form for the intervention study

Appendix 5.1: Participant information sheet for the intervention study in English

Participant Information Sheet

<table>
<thead>
<tr>
<th>Study title:</th>
<th>Community-based intervention for type 2 diabetes patients in East Nusa Tenggara, Indonesia</th>
</tr>
</thead>
</table>
| Principal investigator: | Name: Pauline Norris  
Department: Pharmacy  
Position: Professor |
| Contact phone number: | +64 274 80 95 95 |

**Introduction**

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

**What is the aim of this research project?**

This study aims to compare the effectiveness of two diabetes intervention: an intensive community-based care and standard care. This is crucial in order to establish the best strategy for managing diabetes, and improve patients’ outcome in diabetes management.

**Who is funding this project?**

This study is funded by New Zealand Ministry of Foreign Affairs and Trade through New Zealand ASEAN Scholarship and the University of Otago, New Zealand.

**Who are we seeking to participate in the project?**

Adults aged 20 – 65 years old, both males and females. The selection criteria are: 1) diagnosed with type 2 diabetes mellitus, 2) on diabetes medication, 3) able to understand and comprehend information, 4) without major organ complication of diabetes, 5) not pregnant, and 6) willing to participate in the study. This research will involve about 66 participants in total selected from 2 sub-districts in Kupang municipality.

**If you participate, what will you be asked to do?**

Should you agree to participate, you will be in one of the two groups of participants: 1) participants who will be involved in an intensive community-based diabetes intervention, and 2) participants who will receive standard care. You may not choose to be in either first or second groups as it has been designed based on your home location.

Duration of your participation is 4 months. Before and after the study is started, you will be asked to complete a questionnaire with the help of a researcher. Your sugar level control, blood pressure, weight, and waist circumference will also be measured. A whole blood sample, and fingertip blood samples will be taken for measuring your sugar levels control. These measurements will show how your diabetes is progressing.

Then, if you are in the first group, you will be asked to arrange a small group consisting of 8 – 10 participants with a group leader. You will be asked to attend regular group session once a week for 4 months. The group session will be held in a place that is arranged by group members. Activities in each group session will include outcomes measurement (fasting blood glucose, blood pressure and weight), giving encouragement and motivation, sharing experiences, giving education, goal setting, physical activity and healthy diet.

If you are in the second group, you will be asked to visit your health providers regularly for monitoring your condition. After completing the study, you will be given NZD 10, as reimbursement of expenses for participation, for example travel cost.
Is there any risk of discomfort or harm from participation?
There will be no significant risk as a result of participating in this study. In completing questionnaire, you may complete by yourself or ask research staff to read the questions for you. The questionnaire is not a test for your level of knowledge as individual, but will be evaluated to understand the common knowledge about diabetes in your community. It will be evaluate as group, not individually. If you feel hesitant or uncomfortable, you may decline to answer any particular question(s), and /or may withdraw from the project without disadvantage of any kind.

The risks associated with blood sample taking will be minimal, as we will ensure that safety procedure in taking and handling blood sample will be strictly followed. If you feel uncomfortable, you may refuse to have your blood sample taken, and may withdraw from participation at any time without any disadvantages.

If you decided to withdraw you will still have a standard medical care from your usual health providers.

What specimens, data or information will be collected, and how will they be used?
We will collect your personal information such as name, gender, age, job and address, and also information related to diabetes from your medical records. We will also ask you questions about your understanding of diabetes, medication, and what you usually do to treat your diabetes. Apart from that, we will also collect your sugar levels control, blood pressure, weight, and waist circumference. For measuring your sugar levels control, we will take your blood sample from your fingertips and from your arms.

All data generated from the study will only be used for academic purposes. Health information generated from this study will be retained for at least 5 years in secure storage. Your name will not be stored. Any personal information may be destroyed at the completion of the research even though the raw data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

The results of the project may be published but every attempt will be made to preserve your anonymity. If you wish, you can request to the results.

What about anonymity and confidentiality?
The data collected in this study will be securely stored in such a way that only I, my supervisors and research team will be able to access it.
You will not be identified by name anywhere in the research reports or published information. Every effort will be made to make secure any personal information.

If you agree to participate, can you withdraw later?
You may withdraw from participation in the project at any time and without any disadvantage to yourself.

Any questions?
If you have any questions now or in the future, please feel free to contact:

<table>
<thead>
<tr>
<th>Name</th>
<th>Contact phone number:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anna Wahyuni Widayanti</td>
<td>+64220286499</td>
</tr>
<tr>
<td>Position: Student investigator</td>
<td>+6281328685900</td>
</tr>
<tr>
<td>Department: Pharmacy</td>
<td></td>
</tr>
</tbody>
</table>

This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone 643 479 8236 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.
Appendix 5.2: Participant information sheet for the intervention study in Indonesian

Lembar informasi untuk partisipan

<table>
<thead>
<tr>
<th>Judul penelitian</th>
<th>Intervensi berbasis komunitas untuk pasien diabetes mellitus tipe 2 di Nusa Tenggara Timur, Indonesia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peneliti utama</td>
<td>Nama : Pauline Norris Departemen : Farmasi Jabatan : Profesor Nomor telepon: +64 274 80 95 95</td>
</tr>
</tbody>
</table>

Pendahuluan
Terima kasih atas ketertarikan anda terhadap penelitian ini. Mohon bacalah lembar informasi ini dengan seksama. Luangkan waktu untuk berpikir, dan jika anda inginkan, bicaralah dengan teman atau saudara, sebelum memutuskan bersedia atau tidak untuk berpartisipasi dalam penelitian ini.

Jika anda memutuskan untuk berpartisipasi, kami sangat berterima kasih. Jika anda memutuskan untuk tidak berpartisipasi, tidak akan ada konsekuensi apapun, dan kami juga berterima kasih anda telah mempertimbangkan permohonan kami.

Apakah tujuan dari penelitian ini?
This study aims to compare the effectiveness of two diabetes intervention: an intensive community-based care and standard care. This is crucial in order to establish the best strategy for managing diabetes, and improve patients’ outcome in diabetes management.


Siapakah yang membiayai penelitian ini?
Penelitian ini dibiayai oleh Kementerian Perdagangan dan Urusan Luar Negeri New Zealand melalui beasiswa New Zealand ASEAN dan Universitas Otago, New Zealand.

Siapakah yang kami cari untuk berpartisipasi dalam penelitian ini?
Masyarakat dewasa berusia antara 20 – 65 tahun, baik laki-laki maupun perempuan, dengan kriteria: 1) mempunyai penyakit gula atau diabetes melitus tipe 2, 2) menerima pengobatan untuk diabetes dari dokter, 3) mampu mengerti dan memahami informasi, 4) tidak mempunyai komplikasi berat dari diabetes, 5) tidak sedang mengandung, dan 6) bersedia untuk berpartisipasi. Penelitian ini akan melibatkan sekitar 66 partisipan yang berasal dari 2 kecamatan di wilayah kota Kupang, yakni kecamatan Kelapa Lima dan Alak.

Jika anda berpartisipasi, hal apa saja yang akan anda lakukan?
Jika anda setuju untuk berpartisipasi, anda akan kami masukkan ke dalam satu dari 2 kelompok partisipan: 1) partisipan yang akan menerima pengelolaan diabetes berbasis komunitas, dan 2) partisipan yang akan menerima pengelolaan diabetes standar dari tempat pelayanan kesehatan. Anda mungkin tidak bias memilih untuk dimasukkan dalam kelompok yang mana karena hal tersebut sudah kami pilih berdasarkan lokasi tempat tinggal anda.


Lalu, jika anda dalam kelompok partisipan pertama, anda akan kami minta untuk membentuk grup kecil beranggotakan sekitar 8 – 10 partisipan per grup dengan satu orang ketua grup. Kemudian setiap grup kami minta untuk berkumpul secara rutin sekali seminggu selama 4 bulan. Mengenai tempat untuk berkumpul akan didiskusikan bersama anggota grup. Aktivitas dalam grup tersebut meliputi pengukuran kadar gula darah, berbagi pengalaman dalam mengatasi diabetes, saling memotivasi antar anggota.
kelompok, pemberian penjelasan mengenai diabetes, senam bersama, dan program makanan sehat untuk diabetes.

Jika anda termasuk dalam kelompok partisipan yang kedua, anda akan kami mohon untuk datang secara rutin ke Puskesmas atau rumah sakit tempat anda memeriksa kesehatan secara untuk memmonitor perkembangan diabetes anda.

Setelah menyelesaikan seluruh rangkaian keterlibatan dalam penelitian, anda akan menerima uang sejumlah Rp 100.000,00 sebagai ganti biaya transportasi.

**Apakah ada resiko atau bahaya dari keterlibatan anda dalam penelitian?**


**Spesimen, data, atau informasi apa saja yang akan kami kumpulkan, dan bagaimana hal tersebut akan kami gunakan?**


Hasil penelitian ini akan kami publikasikan secara luas, namun segala upaya akan kami lakukan untuk menjaga kerahasiaan identitas diri anda. Jika anda berkeinginan, anda dapat juga meminta fotokopi dari laporan akhir penelitian.

**Bagaimana dengan kerahasiaan nama dan informasi?**

Semua data yang kami kumpulkan dalam penelitian ini akan kami simpan di tempat penyimpanan yang aman sehingga hanya saya, pembimbing, dan tim peneliti yang dapat mengaksesnya. Anda tidak akan teridentifikasi dimanapun dalam laporan atau publikasi hasil penelitian. Segala upaya akan kami lakukan untuk menjaga keamanan informasi dan data identitas pribadi anda.

**Jika anda setuju untuk berpartisipasi, dapatkah anda berhenti untuk berpartisipasi setiap saat?**

Anda dapat memutuskan untuk mengundurkan diri dari berpartisipasi kapanpun, dan tanpa konsekuensi atau resiko apapun terhadap diri anda.

**Ada pertanyaan?**

Jika anda mempunyai pertanyaan saat ini atau di kemudian hari, anda dapat mengontak peneliti:

<table>
<thead>
<tr>
<th>Nama</th>
<th>Anna Wahyuni Widayanti</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jabatan dalam penelitian</td>
<td>Mahasiswa peneliti</td>
</tr>
<tr>
<td>Departemen</td>
<td>Farmasi, Universitas Otago, New Zealand</td>
</tr>
<tr>
<td>Nomor telepon</td>
<td>0 81328685900</td>
</tr>
</tbody>
</table>

Penelitian ini telah disetujui oleh komite etik Universitas Otago. Jika anda mempunyai pertanyaan atau keluhan yang berkaitan dengan etik penelitian, anda dapat menghubungi komite etik Sekolah Administrasi Komite Etik, Universitas Otago, dengan nomor telepon +64 34798256 atau melalui email ke alamat: gary.witte@otago.ac.nz. Semua permasalahan yang anda kemukakan akan diperlakukan dan ditinjau secara rahasia dan anda akan diberikan informasi mengenai hasil investigasi tersebut.
Appendix 5.3: Consent form for participants involved in the intervention study in English

Community-based intervention for type 2 diabetes patients in East Nusa Tenggara, Indonesia
Principal Investigator: Professor Pauline Norris
(pauline.norris@otago.ac.nz phone +64 274 80 95 95)

CONSENT FORM FOR PARTICIPANTS

Following signature and return to the research team this form will be stored in a secure place for ten years.
Name of participant:…………………………………………..

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project at any time without disadvantage.
6. I know that as a participant I will receive either an intensive community-based diabetes care or standard care. I will also complete a questionnaire, and my sugar levels control, blood pressure, weight, and waist circumference will be measured. My blood sample will be taken for measuring sugar control levels.
7. I know that the questionnaire will ask my understanding about diabetes, my medication and what I usually do for treating my diabetes. If the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s), and/or may withdraw from the project without disadvantage of any kind.
8. I understand the nature and size of the risks of discomfort or harm which are explained in the Information Sheet.
9. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from the project, and that these will be placed in secure storage and kept for at least ten years.
10. I understand that the results of the project may be published, and I agree that any personal identifying information will remain confidential between myself and the researchers during the study, and will not appear in any spoken or written report of the study
11. I know that, after completing the study, I will receive NZD 10 as a reimbursement of expenses for participation such as travel cost. I also understand that no commercial use will be made of the data.

Signature of participant: ______________________ Date: ______________________
Appendix 5.4: Consent form for participants involved in the intervention study in Indonesian

Intervensi berbasis komunitas untuk pasien diabetes mellitus tipe 2 di Nusa Tenggara Timur, Indonesia
Peneliti utama: Professor Pauline Norris
(pauline.norris@otago.ac.nz, +64 274 80 95 95)

Lembar persetujuan untuk partisipan
Mohon untuk ditandatangani dan dikembalikan kepada tim peneliti. Lembar ini akan disimpan dengan aman, dalam kurun waktu sepuluh tahun.

Nama partisipan: ……………………………………………

1. Saya telah membaca Lembar Informasi yang berkaitan dengan penelitian ini dan memahami tujuan dari penelitian ini.
2. Saya mempunyai cukup waktu untuk berbicara dengan orang lain terkait keputusan saya untuk terlibat dalam penelitian ini.
3. Saya menyatakan bahwa saya memenuhi kriteria sebagai partisipan yang telah dijelaskan dalam Lembar Informasi.
4. Semua pertanyaan saya terkait penelitian telah dijawab dengan memuaskan, dan saya memahami bahwa saya berhak untuk meminta informasi lebih lanjut kapanpun.
5. Saya mengerti bahwa partisipasi saya dalam penelitian sepenuhnya adalah sukarela, dan saya bebas untuk mengundurkan diri dari berpartisipasi dalam penelitian ini kapanpun tanpa adanya resiko apapun.
7. Saya memahami bahwa pertanyaan pertanyaan dalam kuesioner adalah mengenai pemahaman saya terhadap diabetes, pengobatan yang saya lakukan, dana apa yang biasa saya lakukan terkait diabetes saya. Jika pertanyaan berkembang ke arah yang membuat saya enggan atau tidak nyaman untuk menjawab, saya dapat menolak untuk menjawab pertanyaan tersebut, dan/atau dapat juga mengundurkan diri dari berpartisipasi dalam penelitian tanpa adanya resiko apapun.
8. Saya memahami tentang kemungkinan resiko atau ketidaknyamanan yang telah dijelaskan dalam Lembar Informasi.
9. Saya mengetahui bahwa ketika penelitian telah selesai, semua data identitas diri saya akan dihapus dari transkrip atau salinan rekaman dan juga dari data elektronik. Saya juga mengetahui bahwa data lain akan disimpan di tempat yang aman selama paling tidak sepuluh tahun.
10. Saya mengetahui bahwa hasil penelitian ini dapat dipublikasikan, tapi saya menyetujui bahwa semua informasi terkait data identitas diri saya akan tetap dirahasiakan dan tidak akan muncul dalam laporan penelitian baik secara lisan ataupun tertulis.
11. Saya mengetahui bahwa setelah menyelesaikan seluruh keterlibatan dalam penelitian, saya akan menerima Rp 100,000,00 sebagai ganti biaya transportasi. saya juga mengetahui bahwa data penelitian juga tidak akan digunakan untuk kepentingan komersial.

Tanda tangan partisipan

Tanggal

390
Appendix 6 – Education materials used in the intervention study

Appendix 6.1: Mengenal diabetes (understanding diabetes)

MENGENAL DIABETES

Apa itu diabetes?
Adalah suatu penyakit yang menyebabkan peningkatan kadar gula dalam darah. Sering disebut dengan penyakit gula atau kencing manis.

Apa penyebabnya?
Disebabkan oleh gangguan fungsi insulin atau kurangnya jumlah insulin yang diproduksi tubuh.

Apa itu insulin?
Hormon yang mengatur gula dalam darah.

Apa akibatnya?
Ketidakberesan insulin menyebabkan gula dalam darah tidak bisa digunakan oleh tubuh untuk menghasilkan energi.

Mengapa kelebihan gula dalam darah menjadi berbahaya?
- Karena gula tidak bisa digunakan oleh tubuh untuk menghasilkan energi.
- Menyebabkan aliran darah terhambat dan tidak lancar.

Apa gejala awal diabetes?
Seringkali gejala awal sering kali tidak begitu mudah terdeteksi, diantaranya:
- Merasa sangat haus
- Merasa sangat lapar – meskipun baru saja makan
- Sering buang air kencing
- Pandangan mata kabur
- Luka yang lama sembuh
- Kesemutan, nyeri atau mati rasa di ujung jari kaki atau tangan.

Apa saja faktor yang dapat mencetus terjadinya diabetes?
- Pola makan
- Kurang olahraga
- Mempunyai riwayat tekanan darah tinggi
- Kegemukan
- Riwayat keluarga dengan diabetes
- Merokok
- Bertambahnya usia.

Berapa kadar gula darah normal?
Gula darah puasa (tidak makan selama 8 jam, boleh minum air putih)

<table>
<thead>
<tr>
<th>Kadar Gula Darah</th>
<th>Unit</th>
<th>Deskripsi</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal</td>
<td>&lt; 100 mg/dL</td>
<td></td>
</tr>
<tr>
<td>Pre-diabetes</td>
<td>100 – 125 mg/dL</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>≥126 mg/dL</td>
<td></td>
</tr>
</tbody>
</table>

Apa saja gejala yang anda alami bila kadar gula darah meningkat?
- Sering merasa haus
- Sering merasa lapar
- Sering buang air kencing lebih banyak
- Pandangan mata kabur
- Luka yang lama sembuh
- Kesemutan, nyeri atau mati rasa di ujung jari kaki atau tangan
- Merasa lelah atau penurunan berat badan
- Gangguan pencernaan

Ada berapa jenis diabetes?
1. Diabetes tipe 1: biasanya terjadi sejak usia muda, terkait kelainan genetic.
3. Diabetes gestasional: kadar gula tinggi selama kehamilan.

Gula darah puasa (tidak makan selama 8 jam, boleh minum air putih)

<table>
<thead>
<tr>
<th>Kadar Gula Darah</th>
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Apa saja gejala yang anda alami bila kadar gula darah meningkat?
- Sering merasa haus
- Sering merasa lapar
- Sering buang air kencing lebih banyak
- Pandangan mata kabur
- Luka yang lama sembuh
- Kesemutan, nyeri atau mati rasa di ujung jari kaki atau tangan
- Merasa lelah atau penurunan berat badan
- Gangguan pencernaan

Gula darah puasa (tidak makan selama 8 jam, boleh minum air putih)

<table>
<thead>
<tr>
<th>Kadar Gula Darah</th>
<th>Unit</th>
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<tbody>
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<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>≥126 mg/dL</td>
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</tr>
</tbody>
</table>

Apa saja gejala yang anda alami bila kadar gula darah meningkat?
- Sering merasa haus
- Sering merasa lapar
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- Kesemutan, nyeri atau mati rasa di ujung jari kaki atau tangan
- Merasa lelah atau penurunan berat badan
- Gangguan pencernaan

Gula darah puasa (tidak makan selama 8 jam, boleh minum air putih)

<table>
<thead>
<tr>
<th>Kadar Gula Darah</th>
<th>Unit</th>
<th>Deskripsi</th>
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<tr>
<td>Normal</td>
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</tr>
<tr>
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</tr>
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</table>

Apa saja gejala yang anda alami bila kadar gula darah meningkat?
- Sering merasa haus
- Sering merasa lapar
- Sering buang air kencing lebih banyak
- Pandangan mata kabur
- Luka yang lama sembuh
- Kesemutan, nyeri atau mati rasa di ujung jari kaki atau tangan
- Merasa lelah atau penurunan berat badan
- Gangguan pencernaan
Appendix 6.2: Apa arti hasil kadar gula darah anda? (What is the meaning of your blood glucose level?)

**APA ARTI HASIL KADAR GULA DARAH ANDA?**

Untuk apa cek kadar gula darah?
- Deteksi dini:
  - Normal
  - Prediabetes
  - Diabetes
- Bagi yang sudah terdiagnosis dengan diabetes:
  Untuk menjaga nya pada rentang target → Mengapa? Mencegah komplikasi.

Apa itu pre diabetes?
Pre diabetes adalah kondisi kadar gula darah di atas normal tapi belum sampai kepada diabetes. → LAMPU KUNING

**Gula Darah Puasa**

Deteksi dini

<table>
<thead>
<tr>
<th>Hasil</th>
<th>Mencegah komplikasi (bagi yang sudah DM)</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥ 126 mg/dL</td>
<td>Diabetes</td>
</tr>
<tr>
<td>100-125 mg/dL</td>
<td>Prediabetes</td>
</tr>
<tr>
<td>80-99 mg/dL</td>
<td>Normal</td>
</tr>
</tbody>
</table>

Target: 80 – 130 mg/dL

**Gula Darah 2 jam setelah makan**

Deteksi dini

<table>
<thead>
<tr>
<th>Hasil</th>
<th>Mencegah komplikasi (bagi yang sudah DM)</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥ 180 mg/dL</td>
<td>Diabetes</td>
</tr>
<tr>
<td>140-179 mg/dL</td>
<td>Prediabetes</td>
</tr>
<tr>
<td>&lt; 140 mg/dL</td>
<td>Normal</td>
</tr>
</tbody>
</table>

Target: dibawah 180 mg/dL

Apa komplikasi diabetes?
- Masalah Penglihatan
- Stroke
- Penyakit jantung
- Kerusakan ginjal
- Kerusakan jaringan saraf
- Aliran darah ke kaki terhambat
- Permasalahan di kaki
Appendix 6.3: Tahukah anda obat diabetes atau hipertensi yang anda minum? (Do you know about diabetes and/or hypertension medicines you are taking?)

2. Tepat waktu
Kapan waktu paling tepat minum obat?
Obat gula → sebagian besar diminum pada saat makan, sesaat sebelum makan, atau segera setelah makan.
Glibenclamide: biasanya satu kali sehari diminum bersama dengan makan pagi.
Obat hipertensi, tergantung jenis obatnya.
Captopril → diminum saat perut kosong, atau 1 jam sebelum makan.
Amlodipin, 1 kali sehari, pada jam yang sama setiap hari.

Contohnya?

![Diagram showing diabetes and hypertension management]

Mengapa diperlukan?

Apa perubahan gaya hidup saja tidak mampu untuk mengatasi tingginya gula darah atau tekanan darah.

Mengapa harus diminum rutin?

Diabetes melitus (type 2) dan hipertensi, disebabkan oleh penurunan fungsi atau kerja organ-organ tubuh.
Obat → membantu memperbaiki fungsi nya, tetapi tidak mengganti organ nya.

Apa artinya?

Obat tidak menyembuhkan penyakit nya tetapi membantu tubuh untuk tetap berfungsi dengan baik.

Sering lupa? Bosan?

Tak kenal maka tak sayang
- kenali obat anda, apa fungsinya, bagaimana cara penggunaan yang tepat

Alah bisa kerena biasa
- Anggapan minum obat sebagai rutinitas yang biasa anda lakukan seperti rutinitas lain, makan, gosok gigi

Menulis menghilangkan lupa
- Tulis yang sudah diminum

Siaga. Siap kapan saja
- Letakkan obat sebagian di tas bepergian

Teringat bila terlihat
- letakkan obat di tempat yang mudah terlihat, misal di mejakan

Bagaimana untuk mendapat manfaat maksimal dari obat?

1. Tepat dosis
   Misal: 3 kali sehari 1 tablet
Appendix 6.4: Diet sehat, bagaimana caranya? (Healthy diet, how to do that?)

**PENTING...!!**

Untuk orang dengan diabetes: Makan teratur: jadwal, jenis dan jumlah makanan.

Jadwal: 3 kali sehari, 2 kali selingan.
Jenis: kurangi karbohidrat, lemak jahat dan sumber gula.
Jumlah: sesuai kebutuhan kalori, atur porsi.

<table>
<thead>
<tr>
<th>Haritgl</th>
<th>Yang saya makan</th>
</tr>
</thead>
</table>

**DIET SEHAT? BAGAIMANA CARANYA?**

Apakah itu diet sehat?
Pola makan yang seimbang, rendah lemak jahat, rendah gula dan garam, cukup protein, karbohidrat, dan banyak sayuran dan buah.

Apakah diet sehat hanya untuk orang orang yang terkena diabetes atau hipertensi saja?
Tidak, diet sehat dirajuk untuk semua orang, tidak hanya yang sudah terkena diabetes atau hipertensi saja.

Bagaimana caranya?
Coba lihat apa yang bisa anda makan. Mulailah dengan mengontrol jenis, jam makan, dan mengatur porsinya.

**Bagaimanakah porsi yang dianjurkan?**


Seperempat piring, sumber protein : Daging (tanpa lemak), ayam tanpa kulit, kacang-kacangan, tahu, tempe, telur, ikan, udang.

Minuman, tanpa gula. Perbanyak minum air putih sekitar 8 gelas per hari.
Appendix 6.5: Sudahkah anda berolahraga hari ini? (Have you been exercising today?)

Berani menerima tantangan?
Mari katong mulai BESOK PAGI..!!

Betul sudah olahraga:

<table>
<thead>
<tr>
<th>Hari</th>
<th>Jenis olahraga</th>
<th>Lamanya</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minggu</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Senin</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selasa</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rabu</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kamis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jumat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sabtu</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

"Setiap langkah berat selalu dimulai dengan langkah pertama" ---- Mari melangkah ----

Apa manfaat olahraga?

Sudahkah anda berolahraga hari ini??

- Menjaga berat badan
- Mengurangi peredaran darah
- Mencegah penurunan kolesterol
- Menurunkan risiko penyakit jantung & stroke
- Memperkuat tulang, otot, sendi
- Menghilangkan stress
- Mengontrol gula darah, tekanan darah, kolesterol

Apa saja contoh olahraga yang dianjurkan?

Bagaimana untuk mendapat manfaat maksimal dari olahraga?

30 menit sebapi hari..!!

Sulit memulai?

Bermotivasi: BETA PASTI BISA
Lakukan olahraga yang paling mudah dan murah
Mulai secara bertahap.
Ajak anggota keluarga, tetangga atau kawan.

SEMANGAT!
Appendix 6.6: Perawatan kaki untuk diabetes (Foot care for diabetes)

7. Periksa kaki secara seksama termasuk bagian telapak

8. Jangan berjalan tanpa alas kaki

9. Sebelum dipakai, bersihkan sepatu dari kotoran yang mengganggu

“Kaki kita yang mengantarkan kita kemana-mana, maka mari jaga dengan baik.”

Bagaimana mencegahnya?

1. Jaga kadar gula darah sesuai target.
2. Lakukan perawatan kaki setiap hari.
3. Lakukan senam kaki.

Bagaimana cara merawat kaki?

1. Cuci kaki dengan air hangat

2. Keringkan kaki dengan handuk termasuk sela-sela jari kaki

3. Gunting kuku secara lurus dengan hati-hati, jangan terlalu pendek.

4. Jaga kelembaban kaki dengan lotion

5. Bila memakai kaos kaki, pilihlah yang tidak terlalu ketat, dan ganti setiap hari

6. Gunakan alas kaki yang nyaman, sesuai dengan ukuran kaki, tidak terlalu kecil.
Appendix 6.7: Komplikasi, apa dan bagaimana mencegahnya? (Diabetes complications, what and how to prevent them?)

MINUM OBAT TERATUR

HINDARI STRESS

NO PROBLEM!

BERHENTI MEROKOK

STOP

KONTROL TERATUR

Komplikasi hipertensi

BERAPA KADAR GULA DAN TEKANAN DARAH TARGET?

GULA PUASA : 80 – 130 Mg/dL
TEKANAN DARAH : < 140/90 mmHg

Bagaimana menjaga kadar gula darah dan tekanan darah sesuai target?

POLA MAKAN

OLAHARAGA

Bagaimana mencegahnya?

MENJAGA KADAR GULA DARAH DAN TEKANAN DARAH PADA RENTANG TARGET/NORMAL
Appendix 7 – The questionnaire used in the intervention study

**Appendix 7.1: The questionnaire used in the intervention study in English**

**QUESTIONNAIRES**

This questionnaire is strictly confidential. Please assist us by answering all questions.

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your name</td>
<td>: .............................................</td>
</tr>
<tr>
<td>Gender</td>
<td>: ☐ Male</td>
</tr>
<tr>
<td></td>
<td>☐ Female</td>
</tr>
<tr>
<td>What is your age?</td>
<td>: ............................................. Years</td>
</tr>
<tr>
<td>What is your gender?</td>
<td>☐ Male</td>
</tr>
<tr>
<td></td>
<td>☐ Female</td>
</tr>
<tr>
<td>How long have you had diabetes?</td>
<td>: ............................................. years or ....... Months or .......days</td>
</tr>
<tr>
<td>Do you take medicines from doctors for your diabetes?</td>
<td>☐ Yes</td>
</tr>
<tr>
<td></td>
<td>☐ No</td>
</tr>
<tr>
<td>If yes, what type of your medicines from doctors?</td>
<td>☐ Tablets</td>
</tr>
<tr>
<td></td>
<td>and/or</td>
</tr>
<tr>
<td></td>
<td>☐ injection</td>
</tr>
<tr>
<td>If you use injection, how many injections per day?</td>
<td>☐ 1</td>
</tr>
<tr>
<td></td>
<td>☐ 2</td>
</tr>
<tr>
<td></td>
<td>☐ 3</td>
</tr>
<tr>
<td></td>
<td>☐ 4</td>
</tr>
<tr>
<td></td>
<td>☐ other, please specify ......................</td>
</tr>
<tr>
<td>If you use tablets, how many different tablets?</td>
<td>☐ 1</td>
</tr>
<tr>
<td></td>
<td>☐ 2</td>
</tr>
<tr>
<td></td>
<td>☐ 3</td>
</tr>
<tr>
<td></td>
<td>☐ other, please specify ......................</td>
</tr>
<tr>
<td>Do you also take herbals for your diabetes?</td>
<td>☐ Yes</td>
</tr>
<tr>
<td></td>
<td>☐ No</td>
</tr>
<tr>
<td>Have you ever attended specific diabetes programme?</td>
<td>☐ Yes</td>
</tr>
<tr>
<td></td>
<td>☐ No</td>
</tr>
<tr>
<td>Have you ever seen a dietitian?</td>
<td>☐ Yes</td>
</tr>
<tr>
<td></td>
<td>☐ No</td>
</tr>
<tr>
<td>Income per month:</td>
<td>☐ &lt; 500,000</td>
</tr>
<tr>
<td></td>
<td>☐ 500,000 – 1,499,999</td>
</tr>
<tr>
<td></td>
<td>☐ 1,500,000 – 2,499,999</td>
</tr>
<tr>
<td></td>
<td>☐ 2,500,000 – 4,999,999</td>
</tr>
<tr>
<td></td>
<td>☐ &gt; 5,000,000</td>
</tr>
<tr>
<td>Marital status</td>
<td>☐ Married</td>
</tr>
<tr>
<td></td>
<td>☐ Not married</td>
</tr>
<tr>
<td></td>
<td>☐ Widowed</td>
</tr>
<tr>
<td>Highest education level</td>
<td>☐ Elementary school</td>
</tr>
<tr>
<td></td>
<td>☐ Junior high school</td>
</tr>
<tr>
<td></td>
<td>☐ Senior high school</td>
</tr>
<tr>
<td></td>
<td>☐ University</td>
</tr>
</tbody>
</table>
Dear participant,
The following questions ask about what you know about diabetes. I will read these statements, and please choose either true or false based on your opinion or understanding.

<table>
<thead>
<tr>
<th>Number</th>
<th>Statement</th>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Diabetes is a condition that can be cured by adopting a healthy lifestyle</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Diabetes is a condition that can be cured with medicines</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Diabetes is a condition that currently not curable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Diabetes is a disease that cannot be prevented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Diabetes is only suffered by people who have family history with it.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>Diabetes is only suffered by obese people</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Diabetes is a disease only suffered by older people</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>If your blood sugar levels are normal or if you feel better, you can stop taking medicines from your doctor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>Long-time use of medicines from the doctors may cause kidney damage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Regular medical check-ups are necessary to assess whether to adjust diabetes medicines.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>People taking diabetes medicines from doctors do not need to worry about healthy eating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>If your diabetes is getting worse, you might get cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>If your diabetes is getting worse, you might get rheumatoid arthritis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>If your diabetes is getting worse, you might get lung problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>If your diabetes is getting worse, you might get heart disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Feeling weakness is early symptom of diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Headache is early symptom of diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>Feeling pain at the back of your neck is early symptom of diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>Always feeling sleepy is early symptom of diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>Avoid carbohydrates food is part of managing diabetes.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>Taking food supplement is part of managing diabetes.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>Stop smoking is part of managing diabetes.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>Having high blood pressure makes you more likely to get diabetes.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td>Having contact with unhealed wound of diabetic patients makes you more likely to get diabetes.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td>Sharing your food, eating equipment or clothing with diabetes patients makes you more likely to get diabetes.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26.</td>
<td>Unhealthy environment makes you more likely to get diabetes.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27.</td>
<td>People with diabetes must not eat anything sweet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28.</td>
<td>Potato is a vegetable, so it is carbohydrate free</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29.</td>
<td>Taro, sweet potato, and corn cannot substitute white rice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30.</td>
<td>Diet recommendations for people with diabetes are the same as healthy diet recommended for general people.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31.</td>
<td>Skipping dinner is as part of healthy diet for people with diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>32.</td>
<td>Eat specific food product designed for diabetes is as part of healthy diet for people with diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>33.</td>
<td>Reduce the rice portion in every meal is as part of healthy diet for people with diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34.</td>
<td>No meat diet is as part of healthy diet for people with diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35.</td>
<td>Exercise for diabetes patients has to be done in a specific exercise class with an instructor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36.</td>
<td>Walking regularly is a form of exercise for diabetes patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>37.</td>
<td>Exercise for diabetes patients should be avoided in people with high blood sugar and hypertension</td>
<td></td>
<td></td>
</tr>
<tr>
<td>38.</td>
<td>It is OK to eat more after doing exercise to replace energy used</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The following questions ask about how you usually take your medicines from your doctor for diabetes. Please respond Yes or No to each statement.

<table>
<thead>
<tr>
<th>No.</th>
<th>Statements</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>It has happened at least once that I forgot to take (one of) my medicines</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>It happens occasionally that I take (one of) my medicines later than usual.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>I have never (temporarily) stopped taking (one of my) medicines.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>It has happened at least once that I did not take (one of) my medicines for a day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I am positive that I have taken all the medication that I should have taken in the previous year.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I take my medicines exactly at the same time every day.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>I have never change my medicine use myself.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>In the past month, I forgot to take my medicine at least once</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I faithfully follow my doctor’s prescription concerning the time I take my medicines</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>I sometimes take (one of) my medicines at a different time than prescribed (e.g., with breakfast or in the evening)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>In the past, I once stopped taking (one of) my medicines completely.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>When I am away from home, I occasionally do not take (one of) my medicines.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>I sometimes take less medicines than prescribed by my doctor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>It has happened (at least once) that I changed the dose of (one of) my medicines without discussing this with my doctor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>It has happened (at least) once that I was too late with filling a prescription at the pharmacy.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>I take my medicines every day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>It has happened (at least once) that I did not start taking a medicine that was prescribed by my doctor.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>I sometimes take more medicines than prescribed by my doctor.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The following questions ask about what you usually do for managing your diabetes

1. How many days in the last week did you eat a meal where rice filled at least a quarter of your plate?

   0 1 2 3 4 5 6 7

   When you did that, on average, how many times a day did you eat a meal where rice filled at least a quarter of your plate? 

2. How many days in the last week did you eat a meal where vegetables and fruits filled at least half of your plate?

   0 1 2 3 4 5 6 7

   When you did that, on average, how many times a day did you eat a meal where green vegetables and fruits filled at least half of your plate? 

3. How many days in the last week did you eat a meal where protein-containing food filled at least as much as a quarter of your plate?

   0 1 2 3 4 5 6 7

   When you did that, on average, how many times a day did you eat a meal where protein-containing food filled at least as much as a quarter of your plate? 

401
4. How many days in the last week did you have food in your plate like this picture?

![Diagram of food plate]

0 1 2 3 4 5 6 7

When you did that, on average, how many times a day did you have food in your plate like the picture above? ............................

5. How many days in the last week did you substitute white rice with another type of carbohydrate?

0 1 2 3 4 5 6 7

When you did that, on average, how many times a day did you substitute white rice with another type of carbohydrate? ............................

6. How many days in the last week did you eat fried snacks?

0 1 2 3 4 5 6 7

When you did that, on average, how many times a day did you eat fried snacks? ......................

7. How many days in the last week did you drink coffee or tea with sugar?

0 1 2 3 4 5 6 7

When you did that, on average, how many cups a day did you drink coffee or tea with sugar? ..............

8. How many days in the last week did you eat cookies and sweet snacks?

0 1 2 3 4 5 6 7

When you did that, on average, how many times a day did you eat cookies and sweet snacks? ..................

9. How many days in the last week did you exercise on your own (including walking)?

0 1 2 3 4 5 6 7

When you did that, on average, how long did you exercise on your own per day? .......

10. How many days in the last week did you attend specific exercise programme such as “senam” or other group exercise?

0 1 2 3 4 5 6 7

11. How many days in the last week did you exercise (including walking) for about 30 minutes a day?

0 1 2 3 4 5 6 7
12. How many days in the last week did you take care of your feet, including washing, soaking and drying your feet?

0 1 2 3 4 5 6 7

13. How many times in the last month did you visit your health professional for checking your diabetes? ............

14. How many days in the last week did you smoke a cigarette – even one puff?

0 1 2 3 4 5 6 7

How many cigarettes did you smoke on an average day?

Number of cigarettes: ..........................
Appendix 7.2: The questionnaire used in the intervention study in Indonesian

KUESIONER

Kuesioner ini bersifat sangat rahasia. Mohon bantuannya untuk menjawab semua pertanyaan, sepenergetahuan bapak/ibu dan sesuai dengan kondisi bapak/ibu.

Nama bapak/ibu : …………………………………
Jenis kelamin : L / P
Berapakah usia bapak/ibu? : ………………… tahun
Berapa lama bapak/ibu mempunyai diabetes?…… tahun, …….bulan, atau …….hari

Apakah bapak/ibu menggunakan obat (dari dokter) untuk diabetes? □ Ya □ Tidak
Jika iya, apakah jenis obat (dari dokter) yang bapak/ibu gunakan?
□ Tablet/pil dan/atau □ Suntik
(bila menggunakan kedua jenis obat, mohon dicentang keduanya)
Jika bapak/ibu menggunakan obat yang disuntik, berapa kali sehari bapak/ibu menggunakan?
□ 1 □ 2 □ 3 □ 4 □ lebih dari 4, mohon sebutkan………..
Jika bapak/ibu menggunakan obat jenis tablet atau pil, berapa jenis tablet yang bapak/ibu gunakan
□ 1 □ 2 □ 3 □ lebih dari 3, mohon sebutkan ……………..
Apakah bapak/ibu menggunakan obat diabetes selain dari dokter, seperti misalnya obat tradisional atau ramuan herbal?
□ Ya □ Tidak
Apakah bapak/ibu pernah menghadiri program khusus untuk diabetes?
□ Ya □ Tidak
Pernahkah bapak/ibu berkonsultasi kepada ahli gizi?
□ Ya □ Tidak

Pendapatan per bulan:
□ < 500.000 □ 1.500.000 – 2.499.999 □ > 5.000.000
□ 500.000 – 1.499.999 □ 2.500.000 – 4.999.999

Status pernikahan:
□ Menikah □ Tidak/belum menikah □ Janda/duda

Tingkat pendidikan terakhir
□ Tidak sekolah
□ Sekolah Dasar
□ Sekolah Menengah Pertama atau yang sederajat
□ Sekolah Menengah Atas atau yang sederajat
□ Perguruan Tinggi atau yang sederajat
Bapak/ibu yang terhormat,
Pernyataan pernyataan berikut adalah tentang apa yang bapak/ibu ketahui tentang diabetes. Mohon pilihlah benar atau salah dari setiap pernyataan yang saya bacakan berikut, menurut sepengetahuan bapak/ibu.

<table>
<thead>
<tr>
<th>No.</th>
<th>Pernyataan</th>
<th>Benar</th>
<th>Salah</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Diabetes adalah suatu kondisi yang dapat disembuhkan dengan melakukan pola hidup sehat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Diabetes adalah suatu kondisi yang dapat disembuhkan dengan obat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Diabetes adalah suatu kondisi yang saat ini tidak dapat disembuhkan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Diabetes adalah suatu kondisi yang tidak dapat dicegah</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Diabetes hanya dapat dialami oleh orang-orang yang mempunyai riwayat keluarga dengan diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>Diabetes hanya dapat dialami oleh orang-orang yang gemuk</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Diabetes hanya dapat dialami oleh orang-orang yang sudah tua</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>Jika kadar gula darah bapak/ibu sudah normal atau jika bapak/ibu sudah merasa membaik, bapak/ibu dapat berhenti menggunakan obat yang diberikan oleh dokter</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>Penggunaan obat diabetes yang diberikan oleh dokter dalam jangka waktu lama dapat menyebabkan kerusakan ginjal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Melakukan kontrol atau pengecekan rutin sangat penting untuk menilai perlu tidaknya perubahan obat diabetes yang digunakan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Orang yang menggunakan obat diabetes tidak perlu melakukan pola makan sehat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>Jika diabetes bapak/ibu memburuk, bapak/ibu beresiko untuk mengalami komplikasi berupa penyakit kanker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>Jika diabetes bapak/ibu memburuk, bapak/ibu beresiko untuk mengalami komplikasi berupa penyakit rematik</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Jika diabetes bapak/ibu memburuk, bapak/ibu beresiko untuk mengalami komplikasi berupa penyakit paru paru</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Jika diabetes bapak/ibu memburuk, bapak/ibu beresiko untuk mengalami komplikasi berupa penyakit jantung</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Merasa lemah merupakan gejala awal dari diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Sakit kepala merupakan gejala awal dari diabetes</td>
<td></td>
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<tr>
<td>18.</td>
<td>Pegal pegal di tengkuk merupakan gejala awal dari diabetes</td>
<td></td>
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</tr>
<tr>
<td>19.</td>
<td>Selalu merasa mengantuk merupakan gejala awal dari diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>Menghindari makan nasi atau makanan yang mengandung karbohidrat merupakan bagian dari pengelolaan diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>Mengkonsumsi suplemen makanan merupakan bagian dari pengelolaan diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>Berhenti merokok merupakan bagian dari pengelolaan diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>Mempunyai tekanan darah tinggi akan membuat seseorang lebih beresiko terkena diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td>Bersentuhan dengan luka yang belum sembuh dari penderita diabetes akan membuat seseorang lebih beresiko terkena diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td>Berbagi makanan, peralatan makan, atau pakaian dengan penderita diabetes akan membuat seseorang lebih beresiko terkena diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26.</td>
<td>Lingkungan yang tidak sehat akan membuat seseorang lebih beresiko terkena diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27.</td>
<td>Orang dengan diabetes tidak boleh memakan makanan manis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28.</td>
<td>Kentang termasuk sayur mayur, sehingga tidak mengandung karbohidrat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29.</td>
<td>Umbi umbian dan jagung tidak bisa menggantikan nasi putih</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30.</td>
<td>Pola makan yang dianjurkan untuk orang dengan diabetes sama dengan pola makan sehat yang dianjurkan untuk orang-orang lain pada umumnya</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31.</td>
<td>Tidak makan malam merupakan bagian dari pola makan sehat untuk orang dengan diabetes</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
32. Makan produk khusus untuk penderita diabetes merupakan bagian dari pola makan sehat untuk orang dengan diabetes

33. Mengurangi pori nasi setiap kali makan merupakan bagian dari pola makan sehat untuk orang dengan diabetes

34. Tidak makan daging merupakan bagian dari pola makan sehat untuk orang dengan diabetes

35. Olahraga untuk pasien diabetes harus dilakukan secara khusus dengan seorang pelatih

36. Jalan kaki secara teratur juga merupakan olahraga yang baik untuk pasien diabetes

37. Olahraga tidak boleh dilakukan oleh orang dengan kadar gula dan tekanan darah tinggi

38. Setelah berolahraga, orang dengan diabetes diperbolehkan makan lebih banyak untuk mengganti tenaga yang digunakan

Pertanyaan berikut tentang bagaimana bapak/ibu biasanya meminum atau menyuntikkan obat diabetes dari dokter. Jawablah sesuai dengan kondisi bapak/ibu, ya atau tidak.

<table>
<thead>
<tr>
<th>No.</th>
<th>Pernyataan</th>
<th>Ya</th>
<th>Tidak</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Pernah terjadi setidaknya sekali, bapak/ibu lupa untuk meminum atau menyuntikkan (satu dari) obat.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Kadang-kadang bapak/ibu meminum atau menyuntikkan (satu dari) obat bapak/ibu lebih lambat dari jadwal biasanya.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Pernah terjadi setidaknya sekali, bapak/ibu tidak meminum atau menyuntikkan (satu dari) obat bapak/ibu seharian penuh.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Bapak/ibu yakin bahwa tahun lalu, bapak/ibu telah meminum atau menyuntikkan semua obat yang harus bapak/ibu gunakan.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>Dalam sebulan terakhir, bapak/ibu pernah lupa meminum atau menyuntikkan obat saya setidaknya satu kali.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Di waktu lalu, bapak/ibu pernah berhenti sama sekali meminum atau menyuntikkan (satu dari) obat bapak/ibu.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Pernah terjadi (setidaknya sekali), bapak/ibu mengubah dosis (satu dari) obat bapak/ibu tanpa mendiskusikannya dengan dokter.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Pernah terjadi (setidaknya) sekali, bapak/ibu sangat terlambat mengambil/menebus obat di apotek.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Bapak/ibu meminum/menyuntikkan obat setiap hari</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Pernah terjadi (setidaknya sekali), bapak/ibu tidak memulai meminum atau menyuntikkan obat yang sudah diresepkan oleh dokter.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Pertanyaan berikut menanyakan tentang hal yang biasa bapak/ibu lakukan untuk pengelolaan diabetes bapak/ibu:

1. Dalam seminggu terakhir, berapa hari bapak/ibu makan dengan porsi nasi sekitar seperempat dari isi piring?
   
   Pada hari bapak/ibu melakukan hal tersebut diatas, rata-rata berapa kali sehari bapak/ibu makan dengan porsi nasi seperempat dari isi piring? ................

2. Dalam seminggu terakhir, berapa hari bapak/ibu makan dengan porsi sayuran dan buah sekitar setengah dari isi piring?
   
   Pada hari bapak/ibu melakukan hal tersebut diatas, rata-rata, berapa kali sehari bapak/ibu makan dengan porsi sayuran dan buah setengah dari isi piring? .............

3. Dalam seminggu terakhir, berapa hari bapak/ibu makan dengan porsi lauk sekitar seperempat dari isi piring?
   
   Pada hari bapak/ibu melakukan hal tersebut diatas, rata-rata, berapa kali sehari bapak/ibu makan dengan porsi lauk sekitar seperempat dari isi piring? .............

4. Dalam seminggu terakhir, berapa hari bapak/ibu makan dengan isi piring seperti terlihat dalam gambar ini?

   ![Diagram piring makanan]

   Pada hari bapak/ibu melakukan hal tersebut diatas, rata-rata, berapa kali sehari bapak/ibu makan dengan isi piring seperti terlihat dalam gambar seperti diatas? ........

5. Dalam seminggu terakhir, berapa hari bapak/ibu mengganti nasi dengan sumber karbohidrat lain seperti jagung atau umbi-umbian?

   Pada hari bapak/ibu melakukan hal tersebut diatas, rata-rata, berapa kali sehari bapak/ibu makan sumber karbohidrat lain seperti jagung, atau umbi umbian sebagai pengganti nasi? .................
6. Dalam seminggu terakhir, ada berapa hari bapak/ibu makan gorengan?
    0 1 2 3 4 5 6 7
    Pada hari bapak/ibu melakukan hal tersebut diatas, rata-rata, berapa kali sehari bapak/ibu makan gorengan? ............

7. Dalam seminggu terakhir, ada berapa hari bapak/ibu minum kopi manis atau teh manis?
    0 1 2 3 4 5 6 7
    Pada hari bapak/ibu melakukan hal tersebut diatas, rata-rata, berapa gelas bapak/ibu minum kopi manis atau teh manis dalam sehari? ............

8. Dalam seminggu terakhir, ada berapa hari bapak/ibu makan kue-kue atau makanan kecil yang manis?
    0 1 2 3 4 5 6 7
    Pada hari bapak/ibu melakukan hal tersebut diatas, rata-rata, berapa kali sehari bapak/ibu makan kue-kue atau makanan kecil yang manis? ............

9. Dalam seminggu terakhir, ada berapa hari bapak/ibu berolahraga mandiri (termasuk berjalan kaki)?
    0 1 2 3 4 5 6 7
    Ketika bapak/ibu melakukan karyanya, rata-rata, berapa lama bapak/ibu berolahraga sendiri tiap harinya? ............

10. Dalam seminggu terakhir, ada berapa hari bapak/ibu datang ke acara olahraga seperti senam bersama, atau olahraga dalam kelompok lainnya?
    0 1 2 3 4 5 6 7

11. Dalam seminggu terakhir, ada berapa hari bapak/ibu berolahraga (termasuk berjalan) selama sekitar 30 menit per hari atau lebih?
    0 1 2 3 4 5 6 7

12. Dalam seminggu terakhir, ada berapa hari bapak/ibu merawat kaki bapak/ibu, termasuk mencuci, merendam, dan mengeringkan kaki bapak/ibu?
    0 1 2 3 4 5 6 7

13. Dalam sebulan terakhir, berapa kali bapak/ibu datang ke dokter untuk mengecek kondisi diabetes bapak/ibu? ............

14. Apakah bapak/ibu merokok?     Ya     Tidak
    Jika iya, dalam seminggu terakhir, ada berapa hari bapak/ibu merokok – meskipun hanya sekali hisap?
    0 1 2 3 4 5 6 7
    Dalam sehari, berapa rata-rata jumlah batang rokok yang bapak/ibu hisap? ............
Appendix 8 – Rasch analysis output

Rasch analysis was performed using the eRM package\textsuperscript{19} in R. For survey-type scales, Mean Square values between 0.6 and 1.4 are considered reasonable. Infit mean squares for our translated Indonesian ProMAS ranged from 0.729 to 1.285, while outfit mean squares ranged from 0.508 to 2.185. Lower values suggest some degree of redundancy, so overall, the model fit well, with some evidence for redundant items. Item fit, Indonesian language version and English translation of the items are presented in Table A.1 and Table A2.

Table A8.1. ProMAS item fit information and Indonesian translation (baseline data)

<table>
<thead>
<tr>
<th>Indonesian (translated)</th>
<th>English version</th>
<th>Difficulty (Indonesian)</th>
<th>Difficulty (English)</th>
<th>Chisq</th>
<th>df</th>
<th>p-value</th>
<th>Outfit MSQ</th>
<th>Infit MSQ</th>
<th>Outfit t</th>
<th>Infit t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pernah terjadi setidaknya sekali, saya lupa untuk meminum (satu dari) obat saya (R).</td>
<td>It has happened at least once that I forgot to take (one of) my medicines (R).</td>
<td>1.845838</td>
<td>2.03</td>
<td>44.11</td>
<td>53</td>
<td>0.803</td>
<td>0.817</td>
<td>0.942</td>
<td>-0.46</td>
<td>-0.25</td>
</tr>
<tr>
<td>Kadang kadang saya meminum (satu dari) obat saya lebih lambat dari jadwal biasanya (R).</td>
<td>It happens occasionally that I take (one of) my medicines at a later moment than usual (R)</td>
<td>1.201612</td>
<td>1.93</td>
<td>59.038</td>
<td>53</td>
<td>0.264</td>
<td>1.093</td>
<td>1.015</td>
<td>0.47</td>
<td>0.16</td>
</tr>
<tr>
<td>Saya tidak pernah (untuk sementara) berhenti meminum (satu dari) obat saya.</td>
<td>I have never (temporarily) stopped taking (one of my) medicines</td>
<td>0.48649</td>
<td>1.56</td>
<td>67.596</td>
<td>53</td>
<td>0.086</td>
<td>1.252</td>
<td>1.208</td>
<td>1.51</td>
<td>1.78</td>
</tr>
<tr>
<td>Pernah terjadi setidaknya sekali, saya tidak meminum (satu dari) obat saya sehari penuh (R).</td>
<td>It has happened at least once that I did not take (one of) my medicines for a day. (R)</td>
<td>1.201612</td>
<td>1.23</td>
<td>46.496</td>
<td>53</td>
<td>0.724</td>
<td>0.861</td>
<td>0.909</td>
<td>-0.56</td>
<td>-0.66</td>
</tr>
<tr>
<td>Saya yakin bahwa tahun lalu, saya telah meminum semua obat yang harus saya minum.</td>
<td>I am positive that I have taken all the medication that I should have taken in the previous year.</td>
<td>0.400917</td>
<td>1.09</td>
<td>66.163</td>
<td>53</td>
<td>0.106</td>
<td>1.225</td>
<td>1.116</td>
<td>1.38</td>
<td>1.04</td>
</tr>
<tr>
<td>Saya selalu meminum obat dalam waktu yang sama persis setiap harinya.</td>
<td>I take my medicines exactly at the same time every day</td>
<td>0.400917</td>
<td>0.86</td>
<td>57.49</td>
<td>53</td>
<td>0.313</td>
<td>1.065</td>
<td>1.02</td>
<td>0.45</td>
<td>0.21</td>
</tr>
<tr>
<td>Saya tidak pernah mengubah aturan penggunaan obat atas keinginan sendiri.</td>
<td>I have never change my medicine use myself</td>
<td>-0.11815</td>
<td>0.86</td>
<td>74.604</td>
<td>53</td>
<td>0.027</td>
<td>1.382</td>
<td>1.285</td>
<td>2.05</td>
<td>2.18</td>
</tr>
<tr>
<td>Dalam sebulan terakhir, saya pernah lupa meminum obat saya setidaknya satu kali (R).</td>
<td>In the past month, I forgot to take my medicine at least once. (R)</td>
<td>0.923251</td>
<td>0.39</td>
<td>40.263</td>
<td>53</td>
<td>0.901</td>
<td>0.746</td>
<td>0.831</td>
<td>-1.38</td>
<td>-1.43</td>
</tr>
<tr>
<td>Saya mengikuti aturan waktu meminum obat dengan tepat sesuai anjuran dari dokter.</td>
<td>I faithfully follow my doctor’s prescription concerning the time I take my medicines</td>
<td>-2.2403</td>
<td>0.29</td>
<td>41.242</td>
<td>53</td>
<td>0.88</td>
<td>0.764</td>
<td>0.846</td>
<td>-0.24</td>
<td>-0.39</td>
</tr>
<tr>
<td>Saya kadang kadang meminum (satu dari) obat dalam waktu yang berbeda dengan yang diresepkan (misalnya bersamaan dengan waktu sarapan atau pada sore hari) (R).</td>
<td>I sometimes take (one of) my medicines at a different time than prescribed (e.g., with breakfast or in the evening). (R)</td>
<td>1.106758</td>
<td>-0.05</td>
<td>47.627</td>
<td>53</td>
<td>0.683</td>
<td>0.882</td>
<td>0.983</td>
<td>-0.5</td>
<td>-0.09</td>
</tr>
<tr>
<td>Di waktu lalu, saya pernah berhenti sama sekali meminum (satu dari) obat saya (R).</td>
<td>In the past, I once stopped taking (one of) my medicines completely. (R)</td>
<td>-0.11815</td>
<td>-0.35</td>
<td>56.06</td>
<td>53</td>
<td>0.361</td>
<td>1.038</td>
<td>1.048</td>
<td>0.28</td>
<td>0.43</td>
</tr>
<tr>
<td>Ketika saya tidak berada di rumah, saya kadang kadang tidak meminum (satu dari) obat saya (R).</td>
<td>When I am away from home, I occasionally do not take (one of) my medicines. (R)</td>
<td>0.658729</td>
<td>-0.37</td>
<td>37.221</td>
<td>53</td>
<td>0.951</td>
<td>0.689</td>
<td>0.768</td>
<td>-2</td>
<td>-2.17</td>
</tr>
<tr>
<td>Saya kadang kadang mengurangi jumlah obat yang saya minum dari yang diresepkan oleh dokter (R).</td>
<td>I sometimes take less medicines than prescribed by my doctor. (R)</td>
<td>-0.89379</td>
<td>-0.98</td>
<td>43.452</td>
<td>53</td>
<td>0.822</td>
<td>0.805</td>
<td>0.888</td>
<td>-0.69</td>
<td>-0.65</td>
</tr>
<tr>
<td>Pernah terjadi (setidaknya sekali) saya mengubah dosis (satu dari) obat saya tanpa mendiskusikannya dengan dokter (R).</td>
<td>It has happened (at least once) that I changed the dose of (one of) my medicines without discussing this with my doctor. (R)</td>
<td>-1.0056</td>
<td>-1.09</td>
<td>52.433</td>
<td>53</td>
<td>0.496</td>
<td>0.971</td>
<td>0.945</td>
<td>-0.01</td>
<td>-0.26</td>
</tr>
<tr>
<td>Indonesian</td>
<td>English</td>
<td>p-value</td>
<td>z-score</td>
<td>T-score</td>
<td>N</td>
<td>r</td>
<td>95% CI</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pernah terjadi (setidaknya sekali), saya sangat</td>
<td>It has happened (at least) once that I was too late with filling a</td>
<td>0.48649</td>
<td>-1.31</td>
<td>45.791</td>
<td>53</td>
<td>0.748</td>
<td>0.453 to 0.935</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>terlambat mengambil atau menebus obat di apotek</td>
<td>prescription at the pharmacy. (R)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(R)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Saya menimum obat setiap hari.</td>
<td>I take my medicines every day</td>
<td>-1.83793</td>
<td>-1.44</td>
<td>27.441</td>
<td>53</td>
<td>0.999</td>
<td>0.789 to 1.000</td>
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</tr>
<tr>
<td>Pernah terjadi (setidaknya sekali), saya tidak</td>
<td>It has happened (at least once) that I did not start taking a</td>
<td>0.315426</td>
<td>-1.94</td>
<td>48.049</td>
<td>53</td>
<td>0.667</td>
<td>0.543 to 0.782</td>
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<tr>
<td>memulai meminum obat yang sudah diresepkan oleh</td>
<td>medicine that was prescribed by my doctor. (R)</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>dokter (R).</td>
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</tr>
<tr>
<td>Saya kadang kadang menimum obat dengan jumlah</td>
<td>I sometimes take more medicines than prescribed by my doctor. (R)</td>
<td>-2.81414</td>
<td>-2.47</td>
<td>62.82</td>
<td>53</td>
<td>0.167</td>
<td>0.088 to 0.245</td>
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<tr>
<td>lebih banyak dari yang diresepkan dokter (R).</td>
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</table>

(R) reverse scored
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<tr>
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<th>Difficulty (English)</th>
<th>Chisq</th>
<th>df</th>
<th>p-value</th>
<th>Outfit MSQ</th>
<th>Infit MSQ</th>
<th>Outfit t</th>
<th>Infit t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pernah terjadi setidaknya sekali, saya lupa untuk meminum (satu dari) obat saya (R).</td>
<td>It has happened at least once that I forgot to take (one of) my medicines (R).</td>
<td>1.933766</td>
<td>2.03</td>
<td>40.807</td>
<td>56</td>
<td>0.937</td>
<td>0.716</td>
<td>0.905</td>
<td>-0.74</td>
<td>-0.51</td>
</tr>
<tr>
<td>Kadang kadang saya meminum (satu dari) obat saya lebih lambat dari jadwal biasanya (R).</td>
<td>It happens occasionally that I take (one of) my medicines at a later moment than usual (R)</td>
<td>1.82257</td>
<td>1.93</td>
<td>56.577</td>
<td>56</td>
<td>0.453</td>
<td>0.993</td>
<td>1.122</td>
<td>0.09</td>
<td>0.77</td>
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<tr>
<td>Saya tidak pernah (untuk sementara) berhenti meminum (satu dari) obat saya.</td>
<td>I have never (temporarily) stopped taking (one of my) medicines</td>
<td>0.521866</td>
<td>1.56</td>
<td>58.717</td>
<td>56</td>
<td>0.376</td>
<td>1.03</td>
<td>1.07</td>
<td>0.22</td>
<td>0.6</td>
</tr>
<tr>
<td>Pernah terjadi setidaknya sekali, saya tidak meminum (satu dari) obat saya sehari penuh (R).</td>
<td>It has happened at least once that I did not take (one of) my medicines for a day. (R)</td>
<td>0.521866</td>
<td>1.23</td>
<td>37.425</td>
<td>56</td>
<td>0.973</td>
<td>0.657</td>
<td>0.745</td>
<td>-1.94</td>
<td>-2.23</td>
</tr>
<tr>
<td>Saya yakin bahwa tahun lalu, saya telah meminum semua obat yang harus saya minum.</td>
<td>I am positive that I have taken all the medication that I should have taken in the previous year.</td>
<td>-0.37533</td>
<td>1.09</td>
<td>78.283</td>
<td>56</td>
<td>0.026</td>
<td>1.373</td>
<td>1.103</td>
<td>1.4</td>
<td>0.74</td>
</tr>
<tr>
<td>Saya selalu meminum obat dalam waktu yang sama persis setiap harinya.</td>
<td>I take my medicines exactly at the same time every day</td>
<td>1.227274</td>
<td>0.86</td>
<td>47.218</td>
<td>56</td>
<td>0.792</td>
<td>0.828</td>
<td>0.937</td>
<td>-0.65</td>
<td>-0.43</td>
</tr>
<tr>
<td>Saya tidak pernah mengubah aturan penggunaan obat atas keinginan sendiri.</td>
<td>I have never change my medicine use myself</td>
<td>0.521866</td>
<td>0.86</td>
<td>71.569</td>
<td>56</td>
<td>0.079</td>
<td>1.256</td>
<td>1.161</td>
<td>1.27</td>
<td>1.28</td>
</tr>
<tr>
<td>Dalam sebulan terakhir, saya pernah lupa meminum obat saya setidaknya satu kali (R).</td>
<td>In the past month, I forgot to take my medicine at least once. (R)</td>
<td>0.694761</td>
<td>0.39</td>
<td>41.374</td>
<td>56</td>
<td>0.928</td>
<td>0.726</td>
<td>0.839</td>
<td>-1.45</td>
<td>-1.34</td>
</tr>
</tbody>
</table>
Saya mengikuti aturan waktu meminum obat dengan tepat sesuai anjuran dari dokter. | I faithfully follow my doctor’s prescription concerning the time I take my medicines | -1.25896 | 0.29 | 57.197 | 56 | 0.43 | 1.003 | 1.188 | 0.15 | 0.95 |
---|---|---|---|---|---|---|---|---|---|
Saya kadang kadang meminum (satu dari) obat dalam waktu yang berbeda dengan yang diresepkan (misalnya bersamaan dengan waktu sarapan atau pada sore hari) (R). | I sometimes take (one of) my medicines at a different time than prescribed (e.g., with breakfast or in the evening). (R) | 1.32033 | -0.05 | 57.326 | 56 | 0.426 | 1.006 | 1.058 | 0.11 | 0.46 |
Di waktu lalu, saya pernah berhenti sama sekali meminum (satu dari) obat saya (R). | In the past, I once stopped taking (one of) my medicines completely. (R) | 0.174054 | -0.35 | 35.952 | 56 | 0.983 | 0.631 | 0.729 | -2.05 | -2.3 |
Ketika saya tidak berada di rumah, saya kadang kadang tidak meminum (satu dari) obat saya (R). | When I am away from home, I occasionally do not take (one of) my medicines. (R) | 0.261704 | -0.37 | 56.466 | 56 | 0.457 | 0.991 | 1.047 | 0.02 | 0.41 |
Saya kadang kadang mengurangi jumlah obat yang saya minum dari yang diresepkan oleh dokter (R). | I sometimes take less medicines than prescribed by my doctor. (R) | -1.13109 | -0.98 | 50.085 | 56 | 0.697 | 0.879 | 0.882 | -0.2 | -0.58 |
Pernah terjadi (setidaknya sekali) saya mengubah dosis (satu dari) obat saya tanpa mendiskusikannya dengan dokter (R). | It has happened (at least once) that I changed the dose of (one of) my medicines without discussing this with my doctor (R). | -2.06589 | -1.09 | 38.425 | 56 | 0.965 | 0.674 | 0.763 | -0.35 | -0.77 |
Pernah terjadi (setidaknya sekali), saya sangat terlambat mengambil atau menebus obat di apotek (R). | It has happened (at least) once that I was too late with filling a prescription at the pharmacy. (R) | -0.00375 | -1.31 | 57.875 | 56 | 0.406 | 1.015 | 1.057 | 0.14 | 0.47 |
Saya minum obat setiap hari. | I take my medicines every day | -1.00987 | -1.44 | 53.396 | 56 | 0.574 | 0.937 | 1.03 | -0.06 | 0.23 |
Pernah terjadi (setidaknya sekali), saya tidak memulai meminum obat yang sudah diresepkan oleh dokter (R). | It has happened (at least once) that I did not start taking a medicine that was prescribed by my doctor. (R) | -0.27983 | -1.94 | 46.074 | 56 | 0.825 | 0.808 | 0.912 | -0.77 | -0.6 |
Saya kadang kadang meminum obat dengan jumlah lebih banyak dari yang diresepkan dokter (R). | I sometimes take more medicines than prescribed by my doctor. (R) | -2.87534 | -2.47 | 124.525 | 56 | 0 | 2.185 | 1.076 | 1.23 | 0.32 |

(R) reverse scored
Appendix 9 – Results of HbA1c measurement of participants in the intervention study at baseline and follow-up

Table A9.1 Results of HbA1c measurement of participants in control and intervention groups at baseline and follow-up

<table>
<thead>
<tr>
<th>Participant ID</th>
<th>Control group Baseline (%)</th>
<th>Control group Post-intervention (%)</th>
<th>Intervention group Participant ID</th>
<th>Intervention group Baseline (%)</th>
<th>Intervention group Post-intervention (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<td>8.4</td>
<td>32</td>
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<td>5.7</td>
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</tr>
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<td>6.7</td>
<td>34</td>
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<td>11.5</td>
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<td>10.5</td>
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<td>8.2</td>
<td>6.2</td>
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<td>58</td>
<td>8.9</td>
<td>7.9</td>
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<td>16.1</td>
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Notes:
* Have a haemoglobin variant interfere with HbA1c measurement
** Lost at follow up