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## Appendix 1 - Summary of studies investigating clinician role and perspective of self-management

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Method</th>
<th>Aim</th>
<th>Setting</th>
<th>Country</th>
<th>Participants</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ashworth &amp; Thompson</td>
<td>2011</td>
<td>Semi-structured interview</td>
<td>Health professionals’ perspectives on the management of long-term conditions</td>
<td>Primary health</td>
<td>New Zealand</td>
<td>n = 10 2 management 4 nurses 4 general practitioners</td>
<td>General inductive approach – themes and categories</td>
</tr>
<tr>
<td>Blakeman et al.</td>
<td>2006</td>
<td>Semi-structured interview</td>
<td>General practitioner role in facilitating self-management</td>
<td>Primary care trusts</td>
<td>Northern England</td>
<td>n = 16 general practitioners</td>
<td>Codes and categories based on Howie’s theoretical model for understanding general practice consultations</td>
</tr>
<tr>
<td>Blakeman et al.</td>
<td>2010</td>
<td>Semi-structured interviews and recorded consultations</td>
<td>Explore self-management support and communication</td>
<td>General practices</td>
<td>Northern England</td>
<td>n = 115 86 recorded primary care consultations 17 healthcare professionals (11 GPs, 5 Nurses, 3 podiatrist and health practitioners) 12 patients with LTC</td>
<td>Iterative process, constant comparison with resultant themes</td>
</tr>
<tr>
<td>Horsburgh et al.</td>
<td>2010</td>
<td>Web based survey</td>
<td>Determine use of Flinders Program™ and identify barriers and enablers of its use. Part of feasibility study</td>
<td>Primary health</td>
<td>New Zealand</td>
<td>n = 148 Practice nurses</td>
<td>Descriptive statistics and narrative</td>
</tr>
<tr>
<td>Hunt &amp; Arrar¹</td>
<td>2001</td>
<td>Open-ended ethnographic interview</td>
<td>Presentation of analytical framework contrasting provider and patient perspectives</td>
<td>Public clinics</td>
<td>South Texas, USA</td>
<td>n = 86 51 patients 35 providers (26 physicians, 5 physician’s assistants, 2 nurse practitioners, 2 registered nurses</td>
<td>Framework development - Contrasting Perspectives Model</td>
</tr>
</tbody>
</table>

¹ Same data as Hunt, Arrar and Larme 1998
### Appendix 1 – Summary of studies investigating clinician role and perspective of self-management - continued

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Method</th>
<th>Aim</th>
<th>Setting</th>
<th>Country</th>
<th>Participants</th>
<th>Analysis</th>
</tr>
</thead>
</table>
| Hunt, Arrar & Larme | 1998 | Open-ended interviews | Compare and contrast patient and provider goals of management, criteria for evaluating achievement of goals and strategies for meeting goals for type 2 DM | Public clinics                  | South Texas, USA     | n = 86  
51 patients  
35 providers (26 physicians, 5 physician’s assistants, 2 nurse practitioners, 2 registered nurses) | Content analysis                                           |
| Johnston, Liddy & Ives | 2011 | Semi-structured interview | Investigating provider perspectives of existing self-management support resources | Urban and rural general practices | Champlain health region, Canada | n = 38  
4 physicians  
2 nurse practitioners  
14 registered nurses  
13 programme managers  
2 healthcare consultants | Grounded theory approach. Themes presented to 145 providers and written and oral feedback sought. |
| Macdonald et al. | 2008 | Semi-structured interviews | To explore practice nurse involvement in facilitation of self-management | Two Primary Care Trusts         | Northern England     | n = 25 practice nurses | Constant comparative method with discursive analysis |
| McDonal d et al. | 2008 | Semi-structured interviews | To explore ways nurses engage in identity work and assess extent compatible with identities promoted by government policy | Two Primary Care Trusts         | Northern England     | n = 25 practice nurses | Thematic analysis |
| Oldroyd et al.  | 2003 | Focus groups          | Explore views on chronic disease care                                | Urban and rural general practice | New South Wales, Australia | n = 54 general practitioners | Thematic – themes only included if 100% agreement by four researchers |

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2 Study related to Blakeman et al., 2006. GPs recruited and then approached to ask if nurses could take part in separate study.

3 Same data as Macdonald et al., 2008 with different analysis to answer different question
<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Method</th>
<th>Aim</th>
<th>Setting</th>
<th>Country</th>
<th>Participants</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pill et al.</td>
<td>1999</td>
<td>Observation and interviews</td>
<td>To explore reasons behind poor continuation of an intervention designed to alter professional behaviour. Complementing an RCT</td>
<td>Fifteen general practices</td>
<td>Wales</td>
<td>n = 18 Practice nurses</td>
<td>Qualitative analysis</td>
</tr>
<tr>
<td>Pooley et al.</td>
<td>2001</td>
<td>Semi-structured interviews</td>
<td>To explore issues central to effective diabetes management</td>
<td>Health authorities</td>
<td>North West England</td>
<td>n = 85 38 health professionals 47 patients</td>
<td>Thematic</td>
</tr>
<tr>
<td>Rogers et al.</td>
<td>2005</td>
<td>Interviews</td>
<td>To illuminate quantitative results of RCT and explore physician and patient encounters</td>
<td>Multicentre</td>
<td>North West England</td>
<td>n = 39 11 consultants 28 patients</td>
<td>Thematic using NUD*IST</td>
</tr>
<tr>
<td>Roy et al.</td>
<td>2011</td>
<td>Focus groups, interviews, free text responses web survey</td>
<td>To understand experience of Flinders Program™ for clients and their nurses. Part of feasibility study</td>
<td>Primary health</td>
<td>New Zealand</td>
<td>n = 383 11 clients and their 4 nurses 13 nurses focus groups 355 free text responses from web based survey</td>
<td>Informed by interpretive description from focus group to inform interview and second focus group. Combined data analysed using thematic interpretive processes.</td>
</tr>
<tr>
<td>Wilson, Kendall &amp; Brooks</td>
<td>2006</td>
<td>Focus groups interviews &amp; observation</td>
<td>Explore health professional’s responses to expert patients</td>
<td>Community, primary and secondary care</td>
<td>England</td>
<td>n = 200 100 adults with LTC 100 nurses, doctors and physiotherapists</td>
<td>Categories from data collected with nurse were reported in this article. Constant comparative method – grounded theory</td>
</tr>
</tbody>
</table>

**Appendix 1 – Summary of studies investigating clinician role and perspective of self-management - continued**
Appendix 2 - Ethical approval letter - February 2010

24 February 2010

Mandy Wilkinson
Centre for Postgraduate Nursing Studies
University of Otago, Christchurch
PO Box 4345
Christchurch

Dear Mandy

Ethics ref: MEC/09/10/117
Study title: Rheumatology and reality of self-care in New Zealand: patient, practitioner and policy perspective
Investigators: Mandy Wilkinson, Dr. Lisa Whitehead, Dr Marie Crowe
Locality: Centre for Postgraduate Nursing Studies, Christchurch

The above study has been given ethical approval by the Multi-region Ethics Committee.

Approved Documents
- Participants with Long-term condition Interview Telephone Screening Sheet, version 1, dated February 2010
- Nurse Interview Telephone Screening Sheet, version 1, dated February 2010
- Information Sheet for Participants with Long-term condition, version 3, dated December 2009
- Information Sheet for Nurses, version 3, dated December 2009
- Consent Form for Participants with Long-term Condition, version 2, dated November 2009
- Consent Form for Nurse Participants, version 2, dated November 2009
- Interview Guide for Participants with Long-term Condition, version 2, dated November 2009
- Interview Guide for Nurses, version 2, dated November 2009
- Interview Prompt for individuals living with Chronic Long-term Condition, version 2, dated November 2009
- Advertisement / Flyer – Interviews for Individuals with a Long-term Condition, version 3, dated December 2009
- On-line Invitation for Individuals with a Long-term Condition, version 3, dated December 2009
- Advertisement / Flyer – Interviews for Nurses, version 3, dated December 2009
- On-line Invitation for Nurses, version 3, dated December 2009
- On-line Questionnaire for Individuals with Long-term Condition, version 1, dated November 2009
- On-line Questionnaire for Nurses, version 1, dated November 2009

We look forward to receiving and approving your updated Questionnaires once the interviews have taken place.

Administered by the Ministry of Health
Approved by the Health Research Council
http://www.ethicscommittee.health.govt.nz
Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports
The study is approved until 9th of December 2012. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator’s responsibility to forward a progress report covering all sites prior to ethical review of the project. The report form is available at http://www.ethicscommittees.health.govt.nz. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Amendments
It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

We wish you well with your study.

Yours sincerely,

Claire Lindsay
Administrator
Multi-region
Email: claire_lindsay@moh.govt.nz
Appendix 3 - Ethical approval letter – July 2010

Health
and
Disability
Ethics
Committees

15 July 2010

Ms Mandy Wilkinson
University of Otago - Christchurch School of Medicine
Centre for Postgraduate Nursing Studies
University of Otago, Christchurch
PO Box 4345
Christchurch

Dear Mandy

Ethics ref: MEC/09/10/117 (please quote in all correspondence)
Study title: Rhetoric and reality of self-care in New Zealand: patient, practitioner and policy perspective

Thank you for your letter dated the 24th of June 2010 outlining amendments that are to be made to the above named study. This Information and the related documentation has been reviewed and approved by the Chairperson of the Multi-region Ethics Committee under delegated authority.

Approved amendments:

- Ask permission of participants enrolled in the study if they are happy for nurses to participate in an interview
- Invite nurses who are attending a study block for a paper facilitated at the Centre for Postgraduate Nursing Studies to participate in a focus group

Approved documents:

- Amended advertisement, Verelon 5, dated July 2010
- Contact Permission Sheet, Version 1, dated June 2010
- Focus Group Invite for Nurses, Verelon 2, dated July 2010
- Information Sheet for Nurses, Verelon 1, dated June 2010

Please do not hesitate to contact me should you have any queries.

Yours sincerely,

Claire Lindsay
Administrator
Multi-region Ethics Committee
Email: Claire_Lindsay@moh.govt.nz

Administered by the Ministry of Health
Approved by the Health Research Council
http://www.ethicscommittees.health.govt.nz
6 May 2011

Ms Mandy Wilkinson
University of Otago - Christchurch School of Medicine
Centre for Postgraduate Nursing Studies
University of Otago, Christchurch
PO Box 4345
Christchurch

Dear Ms Wilkinson -

Ethics ref: MEC/09/10/117 (please quote in all correspondence)
Study title: Rhetoric and reality of self-care in New Zealand: patient, practitioner and policy perspective

Thank you for your letter dated the 15th of April 2011 enclosing documentation relating to the above named study. This documentation has been reviewed and approved by the Chairperson of the Multi-region Ethics Committee under delegated authority.

Approved Documents

- On-line questionnaire for individuals living with long-term conditions (Version 2)

Please do not hesitate to contact me should you have any queries.

Yours sincerely

Elise Agostino
Administrator
Multi-Region Ethics Committee
Email: Multiregion_ethicscommittee@MOH.govt.nz
Appendix 5 – Participant consent form

Self-care in New Zealand: patient and nurse perspectives

CONSENT FORM FOR
PARTICIPANTS WITH LONG TERM CONDITION

I have read the Information Sheet concerning this study and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I understand that:-

• My participation in the study is entirely voluntary;
• I am free to withdraw from the study at any time without any disadvantage;
• The audio-tapes will be destroyed at the conclusion of the study but any raw data on which the results of the study depend will be retained in secure storage for ten years, after which it will be destroyed;
• I understand this study involves an open-questioning technique where the precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which the interview develops. In the event that 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 study without any disadvantage of any kind.
• I may have a friend, family or whanau support to help me understand the risks and/or benefits of this study and any other explanation I may require. If I have any queries or concerns about my rights as a participant in this study, I may contact a Health and Disability Services Consumer Advocate;
• The results of the study may be published but my anonymity will be preserved.

I agree to take part in this study.

...........................................................................................................(Signature of participant and date)

I would also like to receive information about the results of this study when it is complete

☐ Yes  ☐ No

Contact postal address or email:

.................................................................................................................................
.................................................................................................................................
.................................................................................................................................

Thank you ☺

Self-care in New Zealand: Patient and nurse perspectives
Version 2, December 2009
Appendix 6 – Nurse participant consent form

Self-care in New Zealand: patient and nurse perspectives

CONSENT FORM FOR NURSE PARTICIPANTS

I have read the Information Sheet concerning this study and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I understand that:

- My participation in the study is entirely voluntary;
- I am free to withdraw from the study at any time without any disadvantage;
- The audio-tapes will be destroyed at the conclusion of the study but any raw data on which the results of the study depend will be retained in secure storage for ten years, after which it will be destroyed;
- I understand this study involves an open-questioning technique where the precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which the interview develops. In the event that 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 study without any disadvantage of any kind.
- I may have a friend, family or whanau support to help me understand the risks and/or benefits of this study and any other explanation I may require. If I have any queries or concerns about my rights as a participant in this study, I may contact a Health and Disability Services Consumer Advocate;
- The results of the study may be published but my anonymity will be preserved.

I agree to take part in this study.

.......................................................................................................................................................................................................................... ...............................

(Signature of participant and date)

I would also like to receive information about the results of this study when it is complete

☐ Yes  ☐ No

Contact postal address or email:

..........................................................................................................................................................................................................................

..........................................................................................................................................................................................................................

Thank you ☺

Self-care in New Zealand: Patient and nurse perspectives
Version 2, December 2009
INFORMATION SHEET FOR PARTICIPANTS
WITH LONG-TERM CONDITION

Study title: Self-care in New Zealand: patient and nurse perspectives

Primary Investigator: Mandy Wilkinson, PhD Student at Centre for Postgraduate Studies, University of Otago, Christchurch, 72 Oxford Terrace, Christchurch. Telephone 03 364 3856

Supervisor: Dr Lisa Whitehead, Senior Lecturer, Centre for Postgraduate Nursing Studies, 72 Oxford Terrace, Christchurch. Telephone: 03 364 3858.

What is the aim of the study?

You are invited to take part in a research study that will explore current understanding of the term self-care/management within the New Zealand setting from the perspectives of an individual living with long-term condition/s, nurses and policy directives. The study has three parts:

• The first part is a review of government (social, economic and health) and education documents to explore how these policies and reports shape and portray self-care/management within the New Zealand context.
• The second part involves interviews. These aim to explore how individual expertise in self-care/management is defined and experienced by individuals living with long-term conditions and nurses and to explore beliefs that enhance or impede the development of an individual’s ability to self-care/manage.
• The third part involves a New Zealand wide survey of individual’s living with chronic disease and healthcare professionals to explore attitudes, beliefs, knowledge and readiness for self-care/management.

Who can take part in this study?

The study is seeking adult English speaking participants (aged 18 years and over) who have a long-term chronic condition (eg: asthma, heart failure, diabetes, bipolar disorder, arthritis).

What will participants be asked to do?

Should you agree to take part in this study, you will be invited to attend a one-on-one interview with the primary researcher and it is anticipated this interview will take up to one hour of your time at a mutually agreed venue and time to suit. This interview will explore how your expertise in self-care/management is defined and experienced and will explore factors that enhance or impede the development of your ability to self-care/manage.

You may have a friend, family or whanau support to help you understand the risks and/or benefits of this study and any other explanation you may require. If you have any queries or concerns about your rights as a participant in this study, you may wish to contact a Health and Disability Services Consumer Advocate,

• 0800 555 050 or
• Free fax 0800 2787 7678
Or email advocacy@hdc.org.nz

Please be aware that you may decide not to take part in the study without any disadvantage to yourself of any kind.
What data or information will be collected and what use will be made of it?

This study involves an open-questioning technique where the precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which the interview conversation develops. Consequently, although the Ethics Committee is aware of the general areas to be explored in the interview, the Committee has not been able to review the precise questions to be used.

In the event that the line of questioning does develop in such a way that you feel hesitant or uncomfortable you are reminded of your right to decline to answer any particular question(s) and also that you may withdraw from the study at any stage without any disadvantage to yourself of any kind.

The data is being collected as part of a PhD research thesis and only the primary researcher, supervisors and the bio-statistician will have access to the data. Results of this study may be published but your confidentiality is assured and no material, which could personally identify you, will be used in any reports on this study. The data will be coded and all files will be stored on a secure computer and paper copies will be stored in a locked filing cabinet in a secure office. At the end of the study any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the study depend will be retained in secure storage for ten years, after which it will be destroyed. You are most welcome to request a copy of the results of the study should you wish. This study has received ethical approval from the Multi-region Ethics Committee, New Zealand.

Please feel free to contact the researchers Mandy Wilkinson or Lisa Whitehead at the address and phone numbers given at the top of page one if you have any questions about this study. Thank you for taking the time to read this information sheet.
Appendix 8 – Nurse interview information sheet

INFORMATION SHEET FOR NURSES - INTERVIEWS

Study title: Self-care in New Zealand: patient and nurse perspectives

Primary Investigator: Mandy Wilkinson, PhD Student at Centre for Postgraduate Studies, University of Otago, Christchurch, 72 Oxford Terrace, Christchurch. Telephone 03 364 3856

Supervisor: Dr Lisa Whitehead, Senior Lecturer, Centre for Postgraduate Nursing Studies, 72 Oxford Terrace, Christchurch. Telephone: 03 364 3858.

What is the aim of the study?

You are invited to take part in a research study that will explore current understanding of the term self-care/management within the New Zealand setting from the perspectives of individuals living with long-term condition/s, nurses and policy directives. The study has three parts:

- The first part is a review of government (social, economic and health) and education documents to explore how these policies and reports shape and portray self-care/management within the New Zealand context.
- The second part involves interviews. These aim to explore how individual expertise in self-care/management is defined and experienced by individuals living with long-term conditions and nurses and to explore beliefs that enhance or impede the development of an individual’s ability to self-care/manage.
- The third part involves a New Zealand wide survey of individual’s living with long-term conditions and healthcare professionals to explore attitudes, beliefs, knowledge and readiness for self-care/management.

Who can take part in this study?

The study is seeking primary healthcare nurses and nurse specialists working with individuals living with long-term conditions (eg: asthma, heart failure, diabetes, bipolar disorder, arthritis).

What will participants be asked to do?

Should you agree to take part in this study, you will be invited to attend a one-on-one interview with the primary researcher and it is anticipated this interview will take up to one hour of your time at a mutually agreed venue and time to suit. This interview will explore how individual expertise in self-care/management is defined and experienced by yourself and will explore beliefs that enhance or impede the development of an individual’s ability to self-care/manage.

You may have a friend, family or whanau support to help you understand the risks and/or benefits of this study and any other explanation you may require. If you have any queries or concerns about your rights as a participant in this study, you may wish to contact a Health and Disability Services Consumer Advocate,

- 0800 555 050 or
- Free fax 0800 2787 7678

Or email advocacy@hdc.org.nz
Please be aware that you may decide not to take part in the study without any disadvantage to yourself of any kind.

What data or information will be collected and what use will be made of it?

This study involves an open-questioning technique where the precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which the interview conversation develops. Consequently, although the Ethics Committee is aware of the general areas to be explored, the Committee has not been able to review the precise questions to be used.

In the event that the line of questioning does develop in such a way that you feel hesitant or uncomfortable you are reminded of your right to decline to answer any particular question(s) and also that you may withdraw from the study at any stage without any disadvantage to yourself of any kind.

The data is being collected as part of a PhD research thesis and only the primary researcher, supervisors and the bio-statistician will have access to the data. Results of this study may be published but your confidentiality is assured and no material, which could personally identify you, will be used in any reports on this study. The data will be coded and all files will be stored on a secure computer and paper copies will be stored in a locked filing cabinet in a secure office. At the end of the study any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the study depend will be retained in secure storage for ten years, after which it will be destroyed. You are most welcome to request a copy of the results of the study should you wish. This study has received ethical approval from the Multi-region Ethics Committee, New Zealand.

Please feel free to contact the researchers Mandy Wilkinson or Lisa Whitehead at the address and phone numbers given at the top of page one if you have any questions about this study. Thank you for taking the time to read this information sheet.

Self-care in New Zealand: Patient and nurse perspectives
Version 3, December 2009
Page 2 of 2
Appendix 9 – Nurse focus group information sheet

INFORMATION SHEET FOR NURSES – Focus Group

Study title: Self-care in New Zealand: patient and nurse perspectives

Primary Investigator: Mandy Wilkinson, PhD Student at Centre for Postgraduate Studies, University of Otago, Christchurch, 72 Oxford Terrace, Christchurch. Telephone 03 364 3856

Supervisor: Dr Lisa Whitehead, Senior Lecturer, Centre for Postgraduate Nursing Studies, 72 Oxford Terrace, Christchurch. Telephone: 03 364 3858.

What is the aim of the study?

You are invited to take part in a research study that will explore current understanding of the term self-care/management within the New Zealand setting from the perspectives of individuals living with long-term condition/s, nurses and policy directives. The study has three parts:

- The first part is a review of government (social, economic and health) and education documents to explore how these policies and reports shape and portray self-care/management within the New Zealand context.
- The second part involves interviews. These aim to explore how individual expertise in self-care/management is defined and experienced by individuals living with long-term conditions and nurses and to explore beliefs that enhance or impede the development of an individual’s ability to self-care/manage.
- The third part involves a New Zealand wide survey of individual’s living with long-term conditions and healthcare professionals to explore attitudes, beliefs, knowledge and readiness for self-care/management.

Who can take part in this study?

The study is seeking nurses working with individuals living with long-term conditions (eg: asthma, heart failure, diabetes, bipolar disorder, arthritis etc).

What will participants be asked to do?

Should you agree to take part in this study, you will be invited to attend a focus group interview with the researchers for up to one hour of your time. This focus group will explore how expertise in self-care/management is defined and beliefs that enhance or impede the development of an individual’s ability to self-care/manage.

You may have a friend, family or whanau support to help you understand the risks and/or benefits of this study and any other explanation you may require. If you have any queries or concerns about your rights as a participant in this study, you may wish to contact a Health and Disability Services Consumer Advocate,

- 0800 555 050 or
- Free fax 0800 2787 7678
Or email advocacy@hdc.org.nz

Please be aware that you may decide not to take part in the study without any disadvantage to yourself of any kind.
What data or information will be collected and what use will be made of it?

This study involves an open-questioning technique where the precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which the interview conversation develops. Consequently, although the Ethics Committee is aware of the general areas to be explored, the Committee has not been able to review the precise questions to be used.

In the event that the line of questioning does develop in such a way that you feel hesitant or uncomfortable you are reminded of your right to decline to answer any particular question(s) and also that you may withdraw from the study at any stage without any disadvantage to yourself of any kind.

The data is being collected as part of a PhD research thesis and only the primary researcher, supervisors and the bio-statistician will have access to the data. Results of this study may be published but your confidentiality is assured and no material, which could personally identify you, will be used in any reports on this study. The data will be coded and all files will be stored on a secure computer and paper copies will be stored in a locked filing cabinet in a secure office. At the end of the study any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the study depend will be retained in secure storage for ten years, after which it will be destroyed. You are most welcome to request a copy of the results of the study should you wish. This study has received ethical approval from the Multi-region Ethics Committee, New Zealand.

Please feel free to contact the researchers Mandy Wilkinson or Lisa Whitehead at the address and phone numbers given at the top of page one if you have any questions about this study. Thank you for taking the time to read this information sheet.
Appendix 10 - Individual interview guide

INTERVIEW GUIDE FOR PARTICIPANTS WITH LONG-TERM CONDITION

I’d like to find out about your experience of living with a long-term condition and how you feel the doctors, nurses and therapists listen to and interact with you.

Tell me a little about yourself and your condition such as are you married, do you work, what condition do you have and when did you find out?

Medical details – what is your condition? How long have you had it? What problems does it cause you and how do you manage these? What other help do you need? Who gives this help?

How well do you feel that you understand your condition? Signs and symptoms, its treatment, management plan, medication and use?

How confident do you feel you are at managing your long-term condition? How do you develop your ability to manage? What strengthens/improves your confidence? What weakens/decreases your confidence?

What other things/people in your life enable you to manage your long-term condition? Which health care professionals do you deal with?

Who has been most helpful, and what areas have you experienced problems? How often do you see your G.P.? How long have you known them? Do you feel he/she takes your viewpoint into consideration? Do you feel you share in decisions made about your health condition? Please explain.

Who do you see at the hospital? How long have you known them? Do you see a medical consultant for your care? If so, how often do you attend? How long have you known them?

Do you feel he/she takes your viewpoint into consideration? Do you feel you share in decisions made about your health condition? Please explain. Which other people do you see regarding your condition? How long have you known them?

Do you feel he/she takes your viewpoint into consideration? Do you feel you share in decisions made about your health condition? Please explain.
How do you think interactions between yourself and the healthcare professionals you have mentioned could be improved?

Are there any changes you’d like to see in the interactions between healthcare professionals and individuals with long-term conditions within the hospital system?

Are there particular “tricks” you have learned that help you manage your condition? How comfortable are you at discussing these with your doctor, nurse etc.

Where have you learned about your long-term condition?
   Has anyone given you information about ........? 
   If so, who, when and what information.

Friends, family, other patients, internet, libraries (books or medline), media, health education leaflets, support groups?

In your mind, what is the most important thing we have talked about today?
Is there anything else you would like to say about your experiences?
Appendix 11 - Nurse focus group guide

Focus group Wednesday 28 July, 2010

Introduce self – I am Mandy and I would like to thank you very much for agreeing to participate in this focus group. I am doing a PhD here at the Centre and my research question aims to explore knowledge perceptions and readiness for self-care in New Zealand. It is a mixed method study with a review of government (social, economic and health) and education documents, interviews with individuals with long-term conditions and nurses and NZ wide online questionnaire.

- Ground rules - confidentiality, tape recording, 1 person to speak at a time, finish time
- Introduce themselves
- First name,
- Area working
- Types of long term condition they encounter.

Questions;

1. Describe a patient who you think has “good” self-care

2. Thinking about the individual with “good” self-care, which of these attributes do you think are important for self-care?

3. Describe an individual who you think has “poor” self-care

4. Thinking about this individual with “poor” self-care, how do you gauge their readiness for “self-care” education?

5. How do you go about encouraging this individual with ‘poor’ self-care to self-manage?

6. What things do you think make it difficult for your patients to self-care?

7. How do you promote self-care with your patients?
   What things make it difficult to promote self-care with your patients?

8. What things make it difficult to engage with the idea of self-care?
   What things make it easy to engage with the idea of self-care?

9. What do you think are the problems with the idea of self-care?
   What do you think are the strengths of the idea of self-care?

10. What do you think are the most important issues regarding self-care?

Thanks and close at 1310hrs.
INTERVIEW GUIDE - NURSE

I would like to talk to you about how you feel people with long-term conditions should be managed and gain your views on the idea of self-care/management.

Bibliographical data – training dates, years of experience, time in current position

Caseload/clinic data – number and types of individuals with a long-term condition on the caseload or seen at clinic. Primary care locations – practice profile

When interacting with individuals living with a long-term condition such as (e.g. asthma), how would you describe your role?

What are the particular challenges working with this group?

Has this changed over time and if so, how?

How do you help individuals to develop their knowledge?

Decision making– how do you go about this? Barriers? Facilitators?

What is your understanding of the term self-care/management?

Are there any potential problems with the idea of self-care/management?

What do you think are the strengths of this idea?

Knowledge and confidence in delivering self-management education, how confident are you? What barriers do you experience? Facilitators?

How do you gauge readiness for self-management?

How supportive is the structure of your organisation for self-management by individuals living with a long-term condition? Barriers? Facilitators?

What other constraints do you experience? Time, resources?

What are your top 3 priorities when working with this group?
Can you describe an individual that you feel has developed significant knowledge in their condition?

Can you describe whether this has caused any difficulties?

Could you describe an individual who you feel thinks they know more about their condition than they actually do?

How do you deal with this?

Is there anything else that I have not asked that you feel is relevant to say about how individuals living with long-term conditions self-care/manage?
Appendix 13 - E-survey introductory email

Dear Sir/Madam

I am a PhD student with the Centre for Postgraduate Nursing Studies, University of Otago, Christchurch. I am undertaking a study investigating self-care of long-term conditions in within NZ, specifically exploring knowledge, perceptions and readiness for self-care with adults who have a long-term condition and nurses who work with these individuals. Part of my study includes an online NZ wide questionnaire for individuals living with a long-term condition.

I am emailing to find out if ORGANISATION has a community newsletter and if it does, how often is it produced or if you have another means of communicating with your community?

If you have either of these, I would also like to know if it would be possible to advertise my questionnaire and provide a link to the questionnaire in your newsletter/website. The questionnaire has Multi-region ethical approval, has been constructed for online use and will be hosted on a website by the Centre for Postgraduate Nursing Studies.

I am happy to provide further information and answer any questions you may have.

I look forward to hearing from you.

With thanks

Mandy Wilkinson
PhD Student
Centre for Postgraduate Nursing Studies
University of Otago, Christchurch
PO Box 4345
Christchurch
Do you have a long-term condition?

Are you aged 18 and over and live with a long-term condition? (e.g.: asthma, arthritis, diabetes, bipolar disorder, emphysema, COPD, other lung disease, heart disease or other long-term conditions.)

You are invited to complete an online survey which will take approximately 20 minutes of your time.
If you would like to take part please go to www.selfcarenz.co.nz for more information.
Appendix 15 - E-survey advertising: Organisation approached and responses

### Organisations approached for advertising e-survey

<table>
<thead>
<tr>
<th>Replied - Yes</th>
<th>Replied - No</th>
<th>Sent info &amp; no reply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arthritis NZ – web</td>
<td>Auckland DHB</td>
<td>Asthma New Zealand</td>
</tr>
<tr>
<td>Asthma Society – Blenheim</td>
<td>Hawkes Bay DHB</td>
<td>Asthma &amp; Respiratory HB</td>
</tr>
<tr>
<td>Asthma Waikato</td>
<td>Lakes DHB</td>
<td>Services Trust – Napier</td>
</tr>
<tr>
<td>Coffee News - NZ wide</td>
<td>MidCentral DHB</td>
<td>Asthma &amp; Respiratory</td>
</tr>
<tr>
<td>Diabetes Ref Group WGT - email</td>
<td>Northland DHB</td>
<td>Management BOP -</td>
</tr>
<tr>
<td>Disability Information Service</td>
<td>South Canterbury DHB</td>
<td>Tauranga</td>
</tr>
<tr>
<td>Timaru – email network</td>
<td>Tairawhiti DHB</td>
<td>Asthma Society – Canterbury,</td>
</tr>
<tr>
<td>Health Navigator - web</td>
<td>Taranaki DHB</td>
<td>Napier, Nelson, Rotorua,</td>
</tr>
<tr>
<td>Heart Foundation NZ – web</td>
<td></td>
<td>Tauranga</td>
</tr>
<tr>
<td>Lower South Island Primary Health Nurses - email list</td>
<td></td>
<td>Balance NZ</td>
</tr>
<tr>
<td>Nelson Bays Primary Health - newsletter</td>
<td>Waitemata DHB</td>
<td>Bay of Plenty DHB</td>
</tr>
<tr>
<td>Support Works – newsletter</td>
<td>Whanganui DHB</td>
<td>Canterbury DHB – newsletter</td>
</tr>
<tr>
<td>Waikato DHB - web</td>
<td>Asthma &amp; Respiratory Foundation of NZ Inc – Head Office</td>
<td>Capital and Coast DHB</td>
</tr>
<tr>
<td>Wairarapa DHB – web</td>
<td>Asthma Society - Dunedin, Oamaru, South Canterbury, Whangarei</td>
<td>College of Nurses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Counties/Manukau DHB</td>
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<tr>
<td></td>
<td></td>
<td>Diabetes New Zealand</td>
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<td></td>
<td></td>
<td>Diabetes Chch Inc</td>
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<tr>
<td></td>
<td></td>
<td>Hutt Valley DHB</td>
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<tr>
<td></td>
<td></td>
<td>Nelson/Marlborough DHB</td>
</tr>
<tr>
<td></td>
<td></td>
<td>West Coast DHB</td>
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<tr>
<td></td>
<td></td>
<td>Southern DHB</td>
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</table>
Appendix 16 - E-survey response rate over 9 months

<table>
<thead>
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<th>Date Checked</th>
<th>Full*</th>
<th>Incomplete**</th>
<th>Total</th>
</tr>
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</tr>
<tr>
<td>8/6</td>
<td>50</td>
<td>31</td>
<td>81</td>
</tr>
<tr>
<td>29/6</td>
<td>121</td>
<td>65</td>
<td>186</td>
</tr>
<tr>
<td>4/7</td>
<td>129</td>
<td>66</td>
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<td>13/7</td>
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<td>70</td>
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</tr>
<tr>
<td>1/8</td>
<td>179</td>
<td>81</td>
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</tr>
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<td>9/8</td>
<td>186</td>
<td>83</td>
<td>269</td>
</tr>
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<td>29/8</td>
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<td>7/9</td>
<td>191</td>
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</tr>
<tr>
<td>2/11</td>
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<td>87</td>
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<td>283</td>
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<td>23/1/12</td>
<td>204</td>
<td>96</td>
<td>300</td>
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<td>7/2</td>
<td>209</td>
<td>96</td>
<td>305</td>
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Deactivated 10/2/12
### Appendix 17 - E-survey CHERRIES Part A: Design, IRB approval, development etc.

<table>
<thead>
<tr>
<th>Part A: Checklist for Reporting Results of Internet E-surveys (CHERRIES)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Design</strong></td>
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<tr>
<td><strong>Institutional Review Board approval &amp; informed consent process</strong></td>
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<tr>
<td><strong>Data protection</strong></td>
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<tr>
<td><strong>Development &amp; pretesting</strong></td>
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<tr>
<td><strong>Recruitment process &amp; description of sample having access to questionnaire</strong></td>
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<tr>
<td><strong>Survey administration</strong></td>
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</tbody>
</table>
Appendix 18 – E-survey unique visitors by month, number of visits etc.

<table>
<thead>
<tr>
<th>Month</th>
<th>Unique visitors</th>
<th>Visits/visitor</th>
<th>#pages</th>
<th>Pg/visit</th>
<th>Visit duration</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0-30sec 30s-2min 2-5min 5-15min 15-30min 30min-1hr 1hr + Visit time (Ave all #visits) Visit time (Ave 15min-1hr+)</td>
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<tr>
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<td>167</td>
<td>227</td>
<td>1.35</td>
<td>903</td>
<td>21.59</td>
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<tr>
<td>July</td>
<td>99</td>
<td>126</td>
<td>1.27</td>
<td>2352</td>
<td>18.66</td>
</tr>
<tr>
<td>Aug</td>
<td>31</td>
<td>35</td>
<td>1.12</td>
<td>581</td>
<td>16.60</td>
</tr>
<tr>
<td>Sept</td>
<td>13</td>
<td>13</td>
<td>1.00</td>
<td>52</td>
<td>4.00</td>
</tr>
<tr>
<td>Oct</td>
<td>34</td>
<td>38</td>
<td>1.11</td>
<td>93</td>
<td>2.44</td>
</tr>
<tr>
<td>Nov</td>
<td>23</td>
<td>29</td>
<td>1.26</td>
<td>180</td>
<td>6.20</td>
</tr>
<tr>
<td>Dec</td>
<td>35</td>
<td>71</td>
<td>2.02</td>
<td>359</td>
<td>5.05</td>
</tr>
<tr>
<td>Jan 12</td>
<td>42</td>
<td>69</td>
<td>1.64</td>
<td>638</td>
<td>9.24</td>
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<tr>
<td>10 Feb</td>
<td>20</td>
<td>28</td>
<td>1.40</td>
<td>238</td>
<td>8.50</td>
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<tr>
<td></td>
<td>464</td>
<td>636</td>
<td>5396</td>
<td>5396</td>
<td>327</td>
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</tbody>
</table>

Data from [http://nativespace-jupiter.its-jupiter.com](http://nativespace-jupiter.its-jupiter.com)
Appendix 19 - E-survey welcome message and questions

Welcome message at commencement of E-survey

Thank you for your interest in this survey.

I am a PhD student with the Centre for Postgraduate Nursing Studies and this survey forms part of my research project. The aim of the survey is to obtain a picture of what it is like to live with a long-term condition (e.g.: asthma, arthritis, diabetes, bipolar disorder, emphysema, COPD, other lung disease, heart disease or other long-term conditions) in New Zealand.

I am seeking adults, aged 18 and over, living with a long-term condition to participate in this survey. Your participation in this survey is entirely voluntary (your choice) and the online survey takes approximately 20 minutes to complete. The survey has received ethical approval from the Multi-region Ethics Committee, New Zealand.

The answers from all survey participants will be gathered together and analysed. Results from the survey may be published and no material that could personally identify you will be used in any reports about this survey. The data from the survey will be retained in secure storage for ten years, after which it will be destroyed.

To take part in this survey, please click on the “NEXT” button at bottom of this page.

Kind regards and thank you

Mandy
PhD Student

Section 3 message
This section contains eight open ended questions. Please type your response in the free text box provided.

End Message
Thank you very much for taking the time to answer this survey and helping to find out more about living with a long-term condition in New Zealand. Your participation is appreciated. 😊
If you are interested, a link to results from this survey will be posted on the Centre for Postgraduate Nursing Studies website: http://www.otago.ac.nz/christchurch/departments/nursing/research/ in December 2012.
Appendix 19 – E-survey welcome message and questions

Section 1 – Demographics
These questions help us to understand more about the characteristics of those people taking part in our research project.

1. Are you:
   □ Male
   □ Female

2. Which ethnic group do you belong to? (Mark the space or spaces that apply to you)
   □ New Zealand European
   □ Maori
   My iwi is: ________________________________
   □ Samoan
   □ Cook Island Maori
   □ Tongan
   □ Niuean
   □ Chinese
   □ Indian
   □ Other (such as Dutch, Japanese, Tokelauan) Please state: __________________________________________________________

3. Country of current residence – (Drop box with choice of countries ie; NZ, AUS, USA, UK etc) this question is included to ensure inclusion criteria are met

4. What is your age? (Drop down box with numbers from 18 upwards)

5. Please indicate below which long-term condition(s) you are living with:
   Diabetes
   Asthma
   Emphysema or COPD
   Other lung disease – Type of lung disease: ________________________________
   Heart disease – Type of heart disease: ________________________________
   Arthritis or other rheumatic disease – Specify type: _____________________________
   Cancer – Type of cancer: ________________________________
   Other long-term condition: Specify ________________________________

6. For how many months/years since diagnosis by a doctor or specialist, have you lived with your long-term condition?
Appendix 19 – E-survey welcome message and questions - continued

Section 2 – Stanford Scales

General Health *(Stanford Self-Rated Health)*

1. In general, would you say your health is: *(Tick one)*

<table>
<thead>
<tr>
<th>Health Level</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>1 □</td>
</tr>
<tr>
<td>Very good</td>
<td>2 □</td>
</tr>
<tr>
<td>Good</td>
<td>3 □</td>
</tr>
<tr>
<td>Fair</td>
<td>4 □</td>
</tr>
<tr>
<td>Poor</td>
<td>5 □</td>
</tr>
</tbody>
</table>

Symptoms *(Stanford Health Status/Health Distress scale)*

1. How much time during the past 2 weeks … *(choose a number for each question)*

<table>
<thead>
<tr>
<th>Time Duration</th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>A good bit of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Were you discouraged by your health problems?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>b Were you fearful about your future health?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>c Was your health a worry in your life?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>d Were you frustrated by your health problems?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Confidence about doing things *(Stanford Self-Efficacy 6-item scale)*

For each of the following questions, please *choose* the number that corresponds with your confidence that you can do the tasks regularly at the present time.

How confident are you that you can...

1. Keep the physical discomfort or pain of your disease from interfering with the things you want to do?

<table>
<thead>
<tr>
<th>Confidence Level</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
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<td>totally</td>
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</tbody>
</table>

2. Keep the emotional distress caused by your disease from interfering with the things you want to do?

<table>
<thead>
<tr>
<th>Confidence Level</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
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<tr>
<td>not at all</td>
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<td>2</td>
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<td>4</td>
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<td>6</td>
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<td>totally</td>
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</tr>
</tbody>
</table>
3. Keep any other symptoms or health problems you have from interfering with the things you want to do? 

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>

4. Do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor? 

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>

5. Keep the fatigue caused by your disease from interfering with the things you want to do? 

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>

6. Do things other than just taking medication to reduce how much your illness affects your everyday life? 

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>

(Stanford Original Scale – Get information about disease item)

7. Get information about your disease from community resources? 

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>

(Stanford Original Scale – Obtain help from community, family and friends scale)

8. Get family and friends to help you with the things you need (such as household chores like shopping, cooking or transport)? 

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>

9. Get emotional support from friends and family (such as listening or talking over your problems)? 

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>
10. Get emotional support from resources other than friends or family, if needed?

11. Get help with your daily tasks (such as housecleaning, yard work, meals, or personal hygiene) from resources other than friends or family, if needed?

(Stanford Original Scale – Communicate with physician scale)

12. How confident are you that you can ask your doctor things about your illness that concerns you?

13. How confident are you that you can discuss openly with your doctor any personal problems that may be related to your illness?

14. How confident are you that you can get work out differences with your doctor when they arise?

(Stanford Original Scale - General Self-Efficacy – Managing disease in general scale)

15. Having an illness often means doing different tasks and activities to manage your condition. How confident are you that you can do all the things necessary to manage your condition on a regular basis?
Appendix 19 – E-survey welcome message and questions - continued

16. How confident are you that you can judge when the changes in your illness mean you should visit a doctor?

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>

17. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>

18. How confident are you that you can reduce the emotional distress caused by your health condition so that it does not affect your everyday life?

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>

19. How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>

(Stanford Original Scale – Self-efficacy to achieve outcomes – do chores scale)

20. How confident are you that you can complete your household chores, such as vacuuming and yard work, despite your health problems?

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>

21. How confident are you that you can get your errands done despite your health problems?

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>

22. How confident are you that you can get your shopping done despite your health problems?

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>
## Appendix 19 – E-survey welcome message and questions - continued

*(Stanford Original Scale – Self-efficacy to achieve outcomes – social/recreation activities scale)*

23. **How confident are you that you can continue to do your hobbies and recreation?**

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>

24. **How confident are you that you can continue to do the things you like to do with friends and family (such as social visits and recreation)?**

<table>
<thead>
<tr>
<th>not at all confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>totally confident</th>
</tr>
</thead>
</table>

### Daily Activities *(Stanford – Social/role activities limitations)*

During the **past 2 weeks**, how much... *(Choose one number for each question)*

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Almost totally</th>
</tr>
</thead>
</table>

1. **Has your health interfered with your normal social activities with family, friends, neighbors or groups?**

| 0 | 1 | 2 | 3 | 4 |

2. **Has your health interfered with your hobbies or recreational activities?**

| 0 | 1 | 2 | 3 | 4 |

3. **Has your health interfered with your household chores?**

| 0 | 1 | 2 | 3 | 4 |

4. **Has your health interfered with your errands and shopping?**

| 0 | 1 | 2 | 3 | 4 |
Medical Care (Stanford – Communication with physicians scale)

When you visit your doctor, how often do you do the following (please choose one number for each question):

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Almost</th>
<th>Sometimes</th>
<th>Fairly</th>
<th>Very</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Prepare a list of questions for your doctor</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Ask questions about the things you want to know and things you don’t understand about your treatment</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Discuss any personal problems that may be related to your illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Section 3 – Open-ended questions

Each of the following questions will have a free text space for the participants to respond in if they wish.

- What do you think of the statement “a long-term condition is a lonely journey?” Please explain.
- What has helped you to accept that you have a long-term condition? Please explain.
- How has the impact of your long-term condition affected your partner and/or family relationships?
- Sometimes people with long-term conditions feel a sense of loss or limitations, what has been your experience of this?
- Someone has expressed the opinion that looking after your long-term condition is a “moral duty”. How would you respond to this statement?
- What are the main issues for you when managing your long-term condition?
- How would you explain self-care to someone else?
- Please share in your own words what you understand by the term “self-management”.
- Any additional comments you would like to add:
- Thank you for taking the time to answer this questionnaire 😊

Self-care in New Zealand: Patient and nurse perspectives
Version 2, May 2011
Appendix 20 - Flinders Program™ slides evidencing NPH discourse

**History of The Flinders Model**
- WHO Identify chronic conditions as major health impact 2002-2003
- National Primary Care Collaboratives from 2004
- Australian Better Health Initiative 2005 - present
- SA Chronic Disease Strategy 2004

**Why Do We Need To Change?**
- Disease burden has changed towards chronic conditions around the world. Health systems have not.
- Effective interventions exist for most chronic conditions, yet patients/clients do not receive them.
- Current health systems are designed to provide episodic, acute health care and fail to address self-management, prevention and follow up.
- Chronic conditions require a different kind of health care (mismatch)

**Cost of chronic conditions not sustainable (financial and social)**
- Strokes direct medical costs $150 million/year (Auckland University, 2005)
- Arthritis direct costs $2.35 billion in 2005 (Access Economics Pty Ltd, 2005)
- Asthma $825 direct costs million/year (Asthma and Resp. Foundation, NHC, 2007)

**Leading cause of preventable morbidity, mortality and unequal health outcomes in New Zealand**
- Coronary heart or valve problem (14 adults)
- Mental illness (1.5 adults)
- Asthma (1-6 aged 15 to 44 yrs)
- Arthritis (1.6 adults)
- Heart disease (1.5 adults)
- COPD (1.4)
- Diabetes (1.3, similar number undiagnosed)
- Aging Population in New Zealand, by 2051 25-45% will be 60+ yrs (an increase in co-morbidity and complexity of disease associated with aging)
- Prevalence of diabetes predicted to increase by 149% for P1 and 132% among Maori by 2011

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## Appendix 21 - Flinders Program™ Learning Objectives

### Learning Objectives

<table>
<thead>
<tr>
<th>KNOWLEDGE</th>
<th>COMPETENCIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understand the concept and principles of self-management</td>
<td>• Accesses information on the evidence and research that supports the theory and practice of self-management</td>
</tr>
<tr>
<td>Knowledge of self-management strategies and interventions that can assist a client to improve their self-management skills</td>
<td>• Works effectively with community groups, Non-government Organisations (NGOs), and government agencies</td>
</tr>
<tr>
<td>• Accesses and maintains up-to-date information on relevant resources that support self-management</td>
<td>• Promotes change in client health behaviours</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SKILLS</th>
<th>COMPETENCIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be able to assess a client’s self-management capacity using the Partners in Health Scale (PIH) and Cue and Response (C&amp;R) Interview</td>
<td>• Administers the Partners in Health Scale</td>
</tr>
<tr>
<td>• Conducts a Cue &amp; Response interview</td>
<td>• Identifies self-management issues</td>
</tr>
<tr>
<td>Be able to conduct a ‘Problems and Goals’ Assessment</td>
<td>• Uses a Problem and Goal Assessment process</td>
</tr>
<tr>
<td>Be able to review and monitor the Care Plan</td>
<td>• Writes a Problem and Goal Statement with a patient</td>
</tr>
<tr>
<td>Be able to use Self-management Tools</td>
<td>• Plans systems and structures to support regular review of the Care Plan</td>
</tr>
<tr>
<td>Routinely uses tools to support self-management</td>
<td>• Symptom Action Plans</td>
</tr>
<tr>
<td>• Monitoring Diaries</td>
<td>• Patient Self-Management Handbook</td>
</tr>
<tr>
<td>• Patient Checklist</td>
<td>• Identify patients “stage of change” in relation to their identified self-management issues</td>
</tr>
<tr>
<td>Be able to assess a client’s ‘stage of change’</td>
<td>• Uses appropriate strategies dependent on the client’s ‘stage of change’.</td>
</tr>
<tr>
<td>Be able to use Motivational Interviewing</td>
<td>• Uses Motivational Interviewing with clients to encourage change</td>
</tr>
<tr>
<td>Be able to assist a client to problem solve</td>
<td>• Teaches structured problem solving to clients for use in their everyday lives.</td>
</tr>
</tbody>
</table>

### ATTITUDES | COMPETENCIES |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Be aware of the importance of client autonomy, self-efficacy and partnership in the management of chronic disease</td>
<td>• Uses a ‘client-centred’ practice model</td>
</tr>
<tr>
<td></td>
<td>• Enhances the role of the client in shared decision making by encouraging clients to be confident in their partnership with health professionals</td>
</tr>
</tbody>
</table>
Appendix 22 - Flinders Program™ slides evidencing consumerist discourse

Characteristics of Successful Self-Management Support

3. Self-Management Training and Support Services
   (includes instruction on disease management, behavioral support, & addresses physical & emotional demands of living a chronic condition)

4. Active and Sustained Follow-up
   (tailored follow-up leads to better outcomes)

Self-Management: Who’s Responsible?
Self-management is what the person with a chronic condition does by taking action to cope with the impacts of their condition.
Self-management support is what others such as services, health professionals, family, friends and carers do to support the person to self-manage. They may do this by providing physical, social or emotional support to the person.

Activity — Brainstorm
What are the characteristics of people who self-manage well?
What barriers might they experience?

Characteristics of Successful Self-Management Support
1. Collaborative Problem Definition (between client and health professional)
2. Targeting, Goal Setting & Planning (target the issues of greatest importance to the client, set realistic goals and develop a personal care plan)

Definition of a Good Self-Manager
The Centre for Advancement in Health (1996) proposes the following definition:
"[the person with the chronic disease] engaging in activities that promote and protect health, monitoring and managing of symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes."

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Appendix 23 - Flinders Program™ slides evidencing consumerist discourse

**Definition of a Good Self-Manager**
Kate Lorig (1993) states that self-management is also about enabling:

"Participants to make informed choices, to adapt new perspectives and generic skills that can be applied to new problems as they arise, to practice new health behaviours, and to maintain or regain emotional stability."

**Principles of Self-Management**
- K: Knowledge
- I: Involvement
- C: Care Plan
- M/R: Monitor and Respond
- I: Impact
- L: Lifestyle

**Six Principles of Self-Management**
1. Know your condition
2. Have active Involvement in decision-making with the GP or health workers
3. Follow the Care Plan that is agreed upon with the GP and other health professionals
4. Monitor symptoms associated with the condition(s) and Respond to, manage and cope with the symptoms
5. Manage the physical, emotional and social Impact of the condition(s) on your life
6. Live a healthy Lifestyle

**Self-Management ...**
- Does not reduce the cost of care by reducing services
- Is not "SELF-TREATMENT"
- Will not discourage visits to the doctor
- Does not increase the risk of becoming unwell
- Will not threaten workers' role and expertise

**Benefits**
- Better clinical outcomes
- Improved health & QOL
- Reduced hospital admissions, unplanned GP visits, emergency visits
- Increased self-efficacy
- Increased satisfaction with service
- More efficient clinical practice
3. Principles, Foundations and Measures

3.1 Underpinning Principles

3.1.1 The diagram below sets out our vision of the Whānau Ora framework and shows the pivotal role of factors such as leadership (whānau, hapū and iwi), funding, government, whānau-centred services and whānau engagement in enhancing Whānau Ora. The reciprocal nature of the relationships between these factors and Whānau Ora is also shown, for example, access to strong leadership enhances Whānau Ora and Whānau Ora in turn enhances strong leadership.

3.1.2 The Taskforce has developed a set of seven principles underpinning Whānau Ora, which, in our view, should similarly underpin whānau-centred service delivery. The principles are shown in the diagram above: ngā kaupapa tuku iho; whānau opportunity; best whānau outcomes; coherent service delivery; whānau integrity; effective resourcing; and competent and innovative provision.
Appendix 25 - E-survey CHERRIES Part B: Response rate, prevention of multiple entries and analysis decisions

<table>
<thead>
<tr>
<th>Checklist for Reporting Results of Internet E-surveys (CHERRIES)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Response rate</strong></td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td><strong>Participation rate</strong></td>
</tr>
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<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td><strong>Completion rate</strong></td>
</tr>
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<tr>
<td></td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td><strong>Preventing multiple entries from same individual</strong></td>
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<td></td>
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<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td><strong>Analysis</strong></td>
</tr>
<tr>
<td></td>
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<td></td>
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<tr>
<td></td>
</tr>
</tbody>
</table>
Appendix 26 - E-survey Stanford Scales boxplots: Violation of normal distribution
Appendix 26 – E-survey Stanford Scales boxplots: Violation of normal distribution - continued
Appendix 27 - E-survey Stanford Scales bimodal graphs for MCCPHY and SEMDG
### Appendix 28 - Summary of international studies using Stanford Scales

<table>
<thead>
<tr>
<th>ID</th>
<th>Author, Year</th>
<th>Aim/Method</th>
<th>Country</th>
<th>Setting</th>
<th>Participants</th>
<th>Demographics</th>
<th>Diseases</th>
<th>Scales Used</th>
<th>Tests Run</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Lorig, Ritter, Laurent &amp; Plant (2006)</td>
<td>Aim: determine efficacy of Internet based CDSMP. Randomised to intervention or usual care control.</td>
<td>USA/Internet</td>
<td>Internet based CDSMP</td>
<td>I = 354; C = 426</td>
<td>Age range 22-84 Female – I: 71.2%, C: 71.6%; Non-Hispanic white – I: 87.3%; C: 88.7%</td>
<td>Heart, lung, arthritis or type 2 Diabetes</td>
<td>SHD SRH MCPHY ?SEMCD</td>
<td>t-tests regression ANCOVA</td>
</tr>
<tr>
<td>B</td>
<td>Jernigan &amp; Lorig (2011)</td>
<td>Aim: feasibility of Stanford Internet Diabetes programme. Pilot study - Stanford Internet Diabetes Self-management workshop (IDSMW).</td>
<td>USA</td>
<td>Internet based DSMW</td>
<td>Total 54; AI/AN=27 Non AI/NA=27</td>
<td>Age range 27-68 Female – American Indian and Alaskan Natives 87.1%; non AI/AN 85.9%</td>
<td>Diabetes</td>
<td>SHD SRH MCPHY DASRA ?SE scale</td>
<td>Descriptive t-tests</td>
</tr>
<tr>
<td>C</td>
<td>Lorig et al., (2008)</td>
<td>Aim: evaluation of online self-management programme. Prospective longitudinal study. Advertised online, general population with chronic condition</td>
<td>UK</td>
<td>Internet Expert Patient Programme offered online</td>
<td>593</td>
<td>Age range 18-74 Female – 77.9%; White – 94.2%</td>
<td>Diabetes 1&amp;2, heart, lung, arthritis, mental health, ME, MS, back and other</td>
<td>SHD SRH MCPHY SEMCD</td>
<td>Paired t-tests</td>
</tr>
<tr>
<td>D</td>
<td>Lorig et al., (2002)</td>
<td>Aim: determine if Internet can be used to improve health status/healthcare utilisation for back pain. RCT.</td>
<td>USA</td>
<td>Email group</td>
<td>Baseline = I: 296; C: 284</td>
<td>Mean age T: 46; C: 45 Male = T: 62%; C: 61% Ethnicity not reported</td>
<td>Back pain</td>
<td>SHD SEMCD</td>
<td>t-tests ANCOVA regression</td>
</tr>
<tr>
<td>E</td>
<td>Chan et al., (2011)</td>
<td>Aim: evaluate locally adapted CDSMP. Longitudinal quasi-experimental study.</td>
<td>Hong Kong</td>
<td>Primary care, community</td>
<td>I = 302; C = 298</td>
<td>Mean age – I: 72.57 (8.57); C: 76.05 (7.94) Female – I: 76.82%; C: 82.89% Chinese</td>
<td>Arthritis, heart, diabetes, stroke, lung, cancer, other</td>
<td>SRH SHD MCCPHY DASRA SEGIAD</td>
<td>Chi-square Mann Whitney t-tests ANCOVA</td>
</tr>
<tr>
<td>F</td>
<td>Chan, Siu, Poon &amp; Chan (2005)</td>
<td>Aim: evaluate effects of CDSMP: Quasi experimental, multi-baseline study.</td>
<td>Hong Kong</td>
<td>Community</td>
<td>Two cohorts of 23 with one drop out</td>
<td>n = 22 Age range 25-65 (most 35-54) Female – 77.3%; Male – 22.7% Chinese</td>
<td>Heart, renal, rheumatoid arthritis and ankylosing spondylitis</td>
<td>MCCPHY SEGIAD SEOHUFFF SECPHY SEMDG SEDC SESRA</td>
<td>ANOVA Friedman Paired t-tests Wickxon</td>
</tr>
</tbody>
</table>
### Appendix 27 - Summary of international studies using Stanford Scales - continued

<table>
<thead>
<tr>
<th>ID</th>
<th>Author, Year</th>
<th>Method</th>
<th>Country</th>
<th>Setting</th>
<th>Participants</th>
<th>Demographics</th>
<th>Diseases</th>
<th>Scales</th>
<th>Tests Run</th>
</tr>
</thead>
<tbody>
<tr>
<td>G</td>
<td>Dongbo et al., (2003)</td>
<td>Aim: evaluate effectiveness of Shanghai CDSMP. RCT; five urban communities</td>
<td>Shanghai, China</td>
<td>Community</td>
<td>I = 430 C = 349</td>
<td>Age range - I: 29.2-89.8; C: 22.1-88.9 Female – I: 73.3%; C: 69.1% Chinese</td>
<td>Heart, arthritis, lung, diabetes, cancer, other</td>
<td>SRH, SHD MCPHY DASRA SEMDG</td>
<td>Mann Whitney U</td>
</tr>
<tr>
<td>I</td>
<td>Gitlin et al., (2008)</td>
<td>Aim: Pre/post evaluation of adaptation of CDSMP for African American participants</td>
<td>USA</td>
<td>Senior centre with 7000 members</td>
<td>519</td>
<td>Age range – 56.3-94.1 Female – 80% African American</td>
<td>Diabetes, heart, asthma, COPD, arthritis, cancer</td>
<td>SRH, SHD MCPHY DASRA SEMCD</td>
<td>Chi-square Wilcoxon rank &amp; paired Cluster analysis</td>
</tr>
<tr>
<td>J</td>
<td>Griffiths et al., (2005)</td>
<td>Aim: determine effectiveness of adaptation of lay-led self-management program. RCT</td>
<td>UK</td>
<td>East London community</td>
<td>I = 238 C = 238</td>
<td>Age Mean – I: 48.9; C: 48 Female – I: 56%; C: 58% Bangladeshi ethnicity</td>
<td>Diabetes, asthma, arthritis, heart</td>
<td>MCPHY STATA linear multiple, proportional odds ordered logistic and poisson regressions</td>
<td></td>
</tr>
<tr>
<td>K</td>
<td>Lorig et al., (1999)</td>
<td>Aim: evaluate effectiveness of self-management programme in heterogeneous group. RCT across a four county area</td>
<td>USA</td>
<td>Multiple community sites</td>
<td>I = 561 C = 391</td>
<td>Age range – I: 40-90; C: 40-89 Female – I: 65%; T: 64% White – I: 91.4%; C: 88.8%</td>
<td>Heart, lung, arthritis, stroke</td>
<td>SRH, SHD MCPHY DASRA</td>
<td>Covariance and 2 way analysis of variance</td>
</tr>
</tbody>
</table>
### Appendix 27 - Summary of international studies using Stanford Scales - continued

<table>
<thead>
<tr>
<th>ID</th>
<th>Author, Year</th>
<th>Method</th>
<th>Country</th>
<th>Setting</th>
<th>Participants</th>
<th>Demographics</th>
<th>Diseases</th>
<th>Scales</th>
<th>Tests Run</th>
</tr>
</thead>
<tbody>
<tr>
<td>L</td>
<td>Lorig, Ritter &amp; Jacquez (2005)</td>
<td>Aim: evaluation of CDSMP and Spanish version in different settings. Quasi experimental.</td>
<td>Texas New Mexico and Chihuahua Mexico</td>
<td>Community</td>
<td>Spanish = 261, English = 104</td>
<td>- Spanish (n=322) mean age 61.3, English (n=123) mean age 62.1</td>
<td>Diabetes</td>
<td>SRH, SHD, MCPHY, SEMCD</td>
<td>Paired t-tests, regressions</td>
</tr>
<tr>
<td>M</td>
<td>Lorig et al., (2001)</td>
<td>Aim: assess 1 and 2 yr outcomes for CDSMP. Longitudinal follow up to RCT</td>
<td>USA</td>
<td>Community</td>
<td>Completers at 1 year: 683, 2 years: 533</td>
<td>- Age 1 yr 65.3 (10.6), Male 1 yr 34.6%, Non-Hispanic white 1 yr 90.8%</td>
<td>Heart, lung, stroke, arthritis</td>
<td>SRH, SHD, DASRA, SEMCD</td>
<td>t-tests, matched paired t-tests, multiple regressions</td>
</tr>
<tr>
<td>N</td>
<td>Rose et al., (2008)</td>
<td>Aim: One group pre/post evaluating CDSMP</td>
<td>USA</td>
<td>Community</td>
<td>Completers of baseline and 10 week data n=68</td>
<td>N=153; age range 47-96, Female – 81.7%, African American – 86%</td>
<td>Heart, arthritis, diabetes, asthma, cancer</td>
<td>SRH, SHD, MCPHY, DASRA, SEMCD</td>
<td>Descriptive t-tests</td>
</tr>
<tr>
<td>O</td>
<td>Siu, Chan, Poon, Chui &amp; Chan (2007)</td>
<td>Aim: evaluation of CDSMP Quasi-experimental randomised to CDSMP or Tai chi</td>
<td>Hong Kong</td>
<td>Community</td>
<td>148</td>
<td>Age more than half 45-55 yrs old, Female – 75% Chinese</td>
<td>Chronic diseases</td>
<td>MCPHY, SEMDG</td>
<td>t-test, X² test, One way ANOVA, Repeated measure ANOVA, ANCOVA</td>
</tr>
<tr>
<td>Q</td>
<td>Tomioka, Braun, Compton, &amp; Tanoue (2012)</td>
<td>Aim: evaluating adaptation of CDSMP for Asian and Pacific Island communities. Three groups pre/post</td>
<td>Hawaii Asian Pacific Is</td>
<td>Community settings</td>
<td>424</td>
<td>N=675; age range 25-95, Female – 85.6%, Caucasian 17.8%, Japanese 16.7%, Filipino 23.7%, Native Hawaiian 39.1%, Pacific Is 2.7%</td>
<td>Diabetes, heart, lung, arthritis, osteoporosis</td>
<td>SRH, SHD, MCPHY, DASRA, ?SE scale</td>
<td>Descriptive t-tests</td>
</tr>
</tbody>
</table>
Appendix 29 - Reference list for international studies using Stanford Scales

D  Lorig, K., Laurent, D., Deyo, R., Marnell, M., Minor, M., & Ritter, P. (2002). Can a back pain e-mail discussion group improve health status and lower health care costs? *Archives of Internal Medicine, 162*, 792-796.