



Māori Partnership Board, Capital & Coast DHB

RESEARCH ADVISORY GROUP MĀORI (RAG-M)

26 February 2021

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Wellington

Tēnā koe

Re: RAG-M #809 – Implementing ADOC app in community-based rehabilitation services in New Zealand for adults with stroke: a participatory action research study

Your application is endorsed

Thank you for the response to the matters raised by RAG-M. RAG-M is satisfied with your response. We wish you all the very best with this study and look forward to receiving a copy of the summary report, upon completion.

Ngā mihi nui

Jack Rikihana
Chairperson

District Health Board Māori Review of Research

Application Form

Today's date: 3 December 2020

Expected start date of study: 4 January 2021

RAG-M Number: 809

Please ensure this form is sent as a word document (not pdf) NO hard copies are required.

Thank you

Study title: Implementing ADOC app in community-based rehabilitation services in New Zealand for adults with stroke: a participatory action research study	Documentation provided with this application: <input checked="" type="checkbox"/> all patient information and consent forms <input type="checkbox"/> documentation for collecting patient information <input checked="" type="checkbox"/> study protocol <input checked="" type="checkbox"/> ethics application form <input type="checkbox"/> fee payment form or receipt <input checked="" type="checkbox"/> other documentation, please describe: - Ngau Tahu previous cultural consultations (years 2016-2018-2020). - Serious adverse form - interview schedule - Patient information
Principal investigator: Carla Strubbia PhD student Department of Medicine, University of Otago Wellington	
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For guidance on completing this form and meeting the minimum requirements of Māori consultation, please refer to: *Simmonds S (2015) A Framework for Māori Review of Research in District Health Boards:*

[A Framework for Māori Review of Research](#)

Other documentation that may help with this application process: [CCDHB Tikanga Māori Guidelines](#)

1. Details of Research

1a) Please provide a brief outline of your research project:

One of the few technologies available in the market designed to support person-centred goal setting in rehabilitation is a Japanese iPad application called the "Aid for Decision-making in Occupation Choice" (ADOC). In 2018 an English version of the iPad application ADOC, called ADOC-E, was made available in the Apple store. Currently, the developer of the app, Dr. Kounosuke Tomori, and his team are creating another version of the app called ADOC-MP (ADOC for Māori and Pasifika). Findings from a qualitative study (manuscript in preparation) supports the idea that ADOC-E is acceptable in clinical practice in New Zealand and valued by both health professionals and patients. ADOC-E appears to facilitate shared

decision making and enhances patient centred practice. However, several barriers to the use of ADOC-E in clinical practice were also identified, such as the limited time available for health professionals to dedicate to the goal setting process due to their high clinical workload and the lack of specific guidelines on how to integrate ADOC-E into everyday clinical practice. Lack of confidence and knowledge on how to use ADOC-E appropriately also appeared to hamper its uptake.

We therefore plan to undertake a participatory action research project to explore the development and application of guidelines and process to better integrate the use of ADOC in clinical practice to facilitate person-centred goal setting in rehabilitation. Our method will follow four stages: Planning, Action, Evaluation, and Reflection. In the planning stage we will work with health professionals at CCDHB Community Rehabilitation Team, running focus groups to co-design new guidelines for the implementation of ADOC in clinical practice. During the action stage, we will support the Rehabilitation Team to access and use ADOC as part of their community stroke service over approximately a three-month period. In the evaluation stage, we will collect qualitative data on the views and experiences of health professionals using the app, which we will analysis and respond to in partnership with the health professionals during the reflection stage. We expect the study to take almost a year to complete, including the drafting of the manuscript.

1b) What type of research or trial design best describes your study? (tick any that apply)

- | | |
|---|--|
| <input type="checkbox"/> an observational study | <input type="checkbox"/> a minimal risk observational study |
| <input checked="" type="checkbox"/> an interventional study | <input type="checkbox"/> audit or related activities |
| <input type="checkbox"/> student-led research | <input type="checkbox"/> a multi-national study initiated outside NZ |
| <input type="checkbox"/> a clinical trial | <input type="checkbox"/> other, please detail |

For definitions, please refer to: Standard Operating Procedures for Health and Disability Ethics Committees, version 1.0 2012 <http://ethics.health.govt.nz/operating-procedures>

1c) Which option best represents the current status of the study's ethical approval?

- | | |
|---|---|
| <input type="checkbox"/> received ethics | <input checked="" type="checkbox"/> applied for ethics |
| <input type="checkbox"/> not yet applied for ethics | <input type="checkbox"/> not applicable, please explain: <i>type or paste text here</i> |

Please include copies of all ethics documentation with this application form

1d) What is the expected level of involvement for Māori in your research project as participants?

- | | |
|---|---|
| <input type="checkbox"/> (1) no expected involvement | <input type="checkbox"/> (2) possible involvement |
| <input checked="" type="checkbox"/> (3) probable involvement | <input type="checkbox"/> (4) definite involvement |
| <input type="checkbox"/> (5) significant involvement (or exclusively Māori) | |

Please provide details:

The participants for this study will be team leaders and health professionals working in the community-based rehabilitation service for adults after stroke at Capital and Coast DHB, in the Wellington region: Wellington Regional Hospital in Newtown, Kenepuru Hospital in Porirua, and Kapiti Health Centre in Paraparaumu. Currently there are about ten staff members per locality involved in the stroke rehabilitation service that could potentially be part of this study. Not all staff will necessarily need to be involved fully in the co-design process and the teams involved may choose to establish a small working group to lead this work. We expect to have a minimum of fifteen participants, five per locality. However, among those thirty health professionals working in the community rehabilitation after stroke's team, one is of Māori ethnicity,

who will potentially be a participant, upon of course his/her voluntary decision to take part of this study and sign the consent form.

Note that if you have indicated levels 3-5, you may be requested to meet with the Research Advisory Group-Māori, and provide further detail of engagement with Māori. We will make contact with you if this is required. Please refer to Simmonds S (2015) [A Framework for Māori Review of Research in District Health Boards](#), table 1 to help identify levels of Māori involvement in a research project.

1e) Please describe what is required of participants in the study.

Participants will be provided with the ADOC app installed in their work iPad and with a short training in the use of ADOC-E and ADOC-MP. They will also be provided with a short training workshop on person-centred practice, shared decision making and collaborative goal setting in rehabilitation. Finally, they will receive information from our prior studies on ADOC-E and ADOC-MP, what value they may add, and what limits their application to clinical practice.

During their routine clinical practice, we want health professionals to use ADOC for collaborative goal setting with their patients. We will suggest that health professionals offer both ADOC-E and ADOC-MP to all patients, allowing patients to choose which version of ADOC they wish to use during their goal setting regardless of ethnicity. ADOC-E and ADOC-MP have different images and text because different communities were involved in their design, but both versions follow the same method of use.

The ADOC app has pictures of people doing activity of everyday living, including personal care activity, physical activities, work activities and leisure activities. There are 94 illustrations matched with text, which briefly explains the intended activity.

During shared decision-making health professional participants will choose a maximum of 20 activities that they consider important to set as goal for their patient. Then, health professionals will discuss together with their patient to choose up to 5 urgent and most meaningful activities to focus on in the rehabilitation programme.

We will ask the participants (health professionals and team leaders) to meet us on several occasions in the form of focus groups and individual interviews. We will meet the first in a focus group, before the implementation of ADOC in clinical practice. We will listen to their views regarding the strength, weaknesses, and challenges of their current approach to goal setting. After the first focus group, all participants will be asked to provide feedback in drafting guidelines that will help us to better implement and facilitate the use of ADOC in the workplace. After the guideline have been finalized, health professionals' participants will be asked to use ADOC, ADOC-E or ADOC-MP, with their patients to discuss goals for the therapy, for a period of approximately three months (as described above). After this period, we will organize focus groups or individual interviews with team leaders and health professionals to talk about their overall experience with the app and with the research in general.

We want to audio-record our focus groups and interviews. The first focus groups might take between 1 and 3 hours of each participant's time, depending on their availability. We will meet the participants inside the rehabilitation facility during working hours in a designated, quiet and safe room where they will feel at ease. We will be interested in their ideas about how to better implement ADOC in their clinical practice.

We will use all information and comments, to understand how ADOC should be used in clinical practice in New Zealand. We will also send the information to the developer of the app that will use to improve ADOC, which will make the application more useful in therapy in the future.

We would like to collect a little bit of information about health professionals and team leaders' participants. This will include information about gender, age and profession. We will not collect any information that could be used to identify them personally. Participants will have to read the information sheet and sign the consent form before taking part in the study. We will make very clear that participants can decide to withdraw from the study at any time without having to say why.

All participants will not receive any remuneration for participating in this study, but they would be able to keep the app in for future use.

1f) What is the expected level of involvement for Māori in your research project as researchers, research assistants or advisors?

Please provide details:

We have involved Bernadette Jones, Senior Research Fellow at the Department of Medicine UOW, as our Māori advisor from the development stage of this project and her name will appear in the information sheet should any participant need to contact her for questions. Bernadette will be involved throughout this project as a secondary supervisor.

2. WHAKAPAPA. Research should involve the development and maintenance of respectful relationships and clear, appropriate communication

2a) Please detail how participants are recruited for this study, and strategies to ensure appropriate recruitment of Māori:

We will recruit team leaders and allied health professionals. The health professional participants in the study will include nurses, social workers, physiotherapists, occupational therapists and speech language therapists, typical members of a stroke rehabilitation unit.

Participants will be able to participate in the study if they are registered allied health professionals, employed by CCDHB and working in the community-based stroke unit rehabilitation service.

2b) Please provide the following details for each of your patient information and consent forms:

Supplementary material	Flesch reading score	Number of words	Number of pages
Information sheet	51.5	1774	5
Supplementary material	Flesch reading score	Number of words	Number of pages
Consent form	43.6	427	1

2c) What steps have you taken to ensure your patient information and consent forms are appropriate for Māori?

All members of our team have expertise in health literacy research and have had considerable input into the writing of these documents, so they convey messages using plain, understandable English language

for lay people who have a range of literacy levels. We also involved Bernadette Jones as our Māori advisor and to give us feedback based on the study protocol. We based this on the universal process for health literacy as developed by Health Literacy NZ and recommendations from the MoH health literacy research with Māori.(see MoH website, Health Literacy research and resources).

2d) Does this study involve the collection of tissue samples?

No. Continue to question 2g.

Yes. Please provide all details of the nature and amount of samples, storage and transport, overseas transport and method of disposal:

2e) Please confirm that separate consent forms are supplied for storage of samples for future unspecified use

Yes Not applicable (not part of this study)

2f) Please confirm that separate consent forms are supplied for use of samples for genetic analysis

Yes Not applicable (not part of this study)

Please include copies of all patient information and consent forms with this application

2g) Please detail how study results will be disseminated to study participants and whānau

If the study participants wish, we plan to provide them and their whānau with written summaries of the result, within ten months from the end of data collection.

2h) We would appreciate receiving a summary of the study upon completion. Does the study dissemination plan include sending a summary report to the RAG-M group?

Yes

No Please explain

Please provide the date of completion for the study: December 2021

2i) Please confirm that the dissemination plan for the study includes a locality report to be provided to the Māori DHB reviewing team:

The locality report will detail the numbers of Māori recruited and any specific issues or concerns recruiting or maintaining Māori in the study. This may be submitted following the completion of local involvement in the study.

3. TIKA. Researchers should have the appropriate skills and experience required to design research that contributes to equity and to Māori health development

3a) Will ethnicity data be collected and stored using the standard ethnicity question as recommended by the Ministry of Health?

Yes

No Please explain

Please include copies of all documentation for collection of patient details with this application. Refer to ethnicity data protocols: <http://www.health.govt.nz/publication/ethnicity-data-protocols-health-and-disability-sector>

For international studies, please add ethnicity question in the format recommended by the Ministry of Health to the standardised data collection form for the study.

3b) Will the study undertake an analysis of results by ethnicity?

Yes, please describe

No, please explain

3c) The proportion of Māori participants in the study should reflect the proportion of Māori in the community with the health condition of interest. Please detail the following:

- Total number of study participants in this locality: 15
- Total number of Māori participants expected: 1
- Proportion of Māori participants expected: 6.7%

3d) Please explain your calculations for 3c above, and provide the source of any data used:

Currently there are about ten staff members per locality involved in the stroke rehabilitation service, that could potentially be part of this study. Not all staff will necessarily need to be involved fully in the co-design process and the teams involved may elect to establish a small working group to lead this work. We expect to have a minimum of fifteen participants, five per each locality. However, among those thirty health professionals working in the community rehabilitation after stroke's team, one is of Māori ethnicity, who will probably be a participant, upon of course his/her voluntary decision to take part of this study and sign the consent form.

Useful sources of data for these calculations include stats NZ population data and projections (www.stats.govt.nz), Health Needs Assessments for DHBs or Māori Health Profiles 2015 (www.health.govt.nz), Māori health plans and strategies for each DHB (available on DHB website)

3e) Researchers are strongly encouraged to attend the CCDHB Tikanga Māori- Research specific education offered monthly at Wellington Hospital. Please contact ragm@ccdhb.org.nz for further information. Please provide the details of all researchers and their attendance at training:

Researcher name	Research role	Training attended	Attendance date
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William Levack	Co-researcher & Supervisor	CCDHB Tikanga & Research Training	2012
Rebecca Grainger	Co-researcher & Supervisor	CCDHB Tikanga & Research Training	2014 2016
Bernadette Jones	Māori advisor & Supervisor	CCDHB Tikanga & Research Training	2020

3f) Please provide the details of previous or current involvement by your research team in other research projects of importance to Māori:

One of key functions of ADOC is to support partnership and participation of patients and their whānau in goal setting to support clinical decision making in rehabilitation. The app therefore directly related to a Tiriti-based approach to rehabilitation. One of the team members, William Levack, is currently involved in a qualitative study to explore Māori patients experience in the use of a prototype of the app ADOC-MP (ADOC for Māori and Pasifika). ADOC-E and ADOC-MP have different images, content, and text because different communities were involved in their design. The Māori/Pacific version includes option related to Te Ao Māori (e.g. goals around Māori-specific activities such as participation in marae life; playing Kī o Rahi; gathering kai moana, and rongōa).

The Māori/Pacific version also incorporate Te Reo and all the images in the app (over 100) were drawn by a Māori design company, Maui Studios. Both apps are prototypes. We are fully expecting to continue to develop both apps based on the findings from our research in this area. Ultimately, we would like to see ADOC being used to support a decolonisation of rehabilitation processes in our hospital services.

Bernadette Jones has led several Kaupapa Māori research projects over the past 15 years in partnership with Māori communities.

4. MANAAKITANGA. Research should be conducted with respect for all persons involved and respect for their culture

Please confirm the following:

4a) Have contact details for Māori Health services that support patients and whānau / cultural support been provided on your patient information and consent form?

Yes No, please explain:

4b) Has provision been made for the participant's whānau to be involved as support during the study?

Yes No, please explain:

4c) Has provision been made for participants to undertake the study in te reo Māori if desired?

Yes No, please explain: This is a student project and is unfunded, and there is no other funding available to employ fluent Te Reo speaking researchers. However, our team will use basic te reo kupu wherever possible as directed by our Māori participants.

4d) Has provision been made for appropriate tikanga Māori protocols to be carried out when required?

Yes No, please explain: We are happy to be guided by any Māori participants who may wish to follow tikanga Māori protocols such as being accompanied by their whānau in the interviews or starting the research with a karakia.

4e) Please describe how measures to ensure privacy and confidentiality are provided for participants and whānau:

We will anonymise data in the focus group and individual interview transcriptions by removing names of people, places, or any other identifying data before analysis or reporting. Any typist who transcribes the focus groups, but who is not otherwise involved in the study, will sign a confidentiality agreement before starting this work. All information collected will be anonymised and stored on a data base where access is restricted to our research team only.

4f) Does your research team have a support agreement with a Māori health group or an equivalent provider?

Yes No. Please provide details: We are a University of Otago Wellington based research group and as such are part of a MOU with CCDHB and have a close relationship with Whānau Care Services regarding referral of participants. All Māori participants and their whānau will be given contact details for Whānau Care Services if needed.

5. MANA. Research relationships should be reciprocal and equitable and acknowledge the rights, roles and responsibilities of all involved.

5a) Describe the process for obtaining consent from participants (and whānau):

The study to participants will receive the information sheet by the primary investigator, who will give them as much time as they need to consider their participation and to discuss it with whānau or friends. They will also be encouraged to ask any questions they need to the research staff.

5b) Describe how this research project can contribute to improving health literacy for Māori participants and whānau:

ADOC has the potential to facilitate the communication around goal setting between health professionals and patients. Consequently, the therapy will be more person-centred focused, which will improve patient's satisfaction, experience and quality of life. With ADOC health professionals and institutions will be able to communicate more effectively with their patients of both Māori and non-Māori ethnicity. ADOC will also help patients to make more informed decisions about their therapy goals and take appropriate actions to protect and promote their health. All these aspects are part of the process to improve health literacy.

Useful reference: <http://www.hqsc.govt.nz/publications-and-resources/publication/2046/>

5c) Describe how this research project can contribute to Māori research capacity development:

Over the last past years, our aim was to develop qualitative research studies about the use and implementation of the app ADOC in the New Zealand health system and our research team together or individually managed to publish few articles. Moreover, our aim is also to ensure health equity and to create important contribute to improve Māori health. For this reason, we spent more than one year in working toward the development of ADOC-MP. Currently, we are also collecting qualitative data of Māori patient's experience in the use of the app ADOC-MP. Hopefully, we will able to publish all these studies and contribute to Māori research capacity.

5d) Describe any contribution of koha (gift) to participants, or reimbursement of costs for study participation:

Participants will not receive any remuneration, but to thank them for their time and involvement, we will donate the latest version of ADOC for use on their work iPad.

5e) Describe any other provisions you have made in your study to ensure the cultural preferences of Māori have been considered:

All Māori participants will be given the opportunity to follow their preferred cultural preferences. Tikanga will be respected through all stages of this study. All our researchers follow the Health Research Council of NZ Te Ara Tika Guidelines for Māori research ethics, We ascribe to the philosophy of Hirini Moko Mead and endeavour to ensure that "Process, procedures and consultation need to be correct so that in the end everyone who is connected to the research project is enriched, empowered and enlightened and glad to have been a part of it." (Hirini Moko Mead 2003. Tikanga Maori. Living by Maori Values. Huia Publishers, Wellington, Aotearoa.)

Thank you for taking the time to complete this form. Please save as a word document and email with all other required documentation to: ragm@ccdhb.org.nz

Kia ora.

Office use only	Date	Comment
Date received:		
Date acknowledged:		
Proposal sent to review:		
Next committee date:		
Due date for feedback:		
Provisional endorsement:		
Response received:		
Final endorsement:		