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## Participant Information Sheet – Patient

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**Study title:** Experiences of the use of an iPad application (ADOC-E) for shared decision making around goal setting in rehabilitation: a qualitative descriptive study

**Locality:** ABI Rehabilitation, Hutt Valley DHB and Auckland DHB

**Ethics committee ref.:** Northern B HDEC ref n. 20/NTB/40

**Sponsor:** University of Otago, Wellington

**Lead investigator:** Carla Strubbia, PhD candidate, Department of Medicine, University of Otago

**Contact phone number:** 020 4160 4900

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You are invited to take part in a study on the experience of the use of an iPad application called ADOC-E for shared decision making around goal setting in rehabilitation. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time. This study is being conducted as part of a PhD by the University of Otago, Wellington campus.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 6 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

### WHAT IS THE PURPOSE OF THE STUDY?

We have made an English-language version of a Japanese iPad app called the "Aid for Decision-making in Occupation Choice" (ADOC). We made ADOC-E to help health professionals talk to patients about their goals and what they want from therapy. This will help patients participate more in decisions about the direction of their rehabilitation, making therapy more meaningful for them.

In this study, we want to examine the impact of ADOC-E on the rehabilitation process, patient and therapist experiences, and on patient health outcomes.

This study has been approved by the Northern B Health and Disability Ethics Committees (HDECs), ref number xx, on the xx/xx/xx.

## WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

You can participate in this study if:

- You are an adult over 18 years of age
- You a patient at this rehabilitation service because of any type of injury or illness (e.g. stroke, traumatic brain injury, spinal cord injury, or a fractured)
- You are able to make your own decision about joining this study and able to sign the consent form
- You are able to communicate with us about your experiences

We wish to recruit 6 to 12 patients to this study. We also will be recruiting health professionals to participate in this study.

We would like you to try ADOC-E out with your therapist to discuss your goals for your therapy. You do not need any experience with computers or iPads. Your therapist will explain everything to you and will assist you at any time. ADOC-E uses pictures and words to help you talk about everyday activities that are important to you. ADOC-E will help you and your therapist to pick up to 5 important and meaningful activities to focus on in rehabilitation. You will be asked to use ADOC-E only one time. After that, we want to meet you to ask you few questions about your views on ADOC-E. I will come to meet you while you are still hospitalized at the rehabilitation service. We will meet in a quiet and safe room where you will feel comfortable. The interview will be performed within 4 weeks or shortly before your discharge from the rehabilitation service. We would like to know how useful you found ADOC-E and also what you liked or didn't like about it. We want to audio-record our discussion with you so we can make sure we do not miss anything important that you say.

This meeting may take up 30-60 minutes. We can stop and start your involvement in the study, even meet with you on different days, to fit in with your energy levels and other activities. Remember that you can decide to leave the study at any time you choose.

We wish to audio-record our discussion with you. We will ask few questions about your thoughts on using the app. We will ask what you liked or didn't like about it, and if you think it changed your involvement in the rehabilitation process. We will be interested in your views on ways we could make the app better. We will use this information and any other comments you make, to understand whether ADOC-E should be part of the clinical practice or not. We will also send the information to the developer of the app that he will use to improve ADOC-E, which will make the application more useful in therapy in the future.

We would like to also collect a little bit of information about you, so we can say what types of people participated in our study. This will included information about your gender, age, ethnicity and primary health concern. We would also like to gather information from a simple cognitive test (Montreal Cognitive Assessment). We will gather all this information from your clinical records.



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## HOW LONG WILL THE STUDY RUN FOR?

The study will run from March-April 2020 to September 2020.

## WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

We are not aware of any risk to you as a result of your participation in this study.

## WHO PAYS FOR THE STUDY?

This is not a funded study. The study does not cost any money. ADOC-E will be given for free as an iPad application to the health professionals by the developer, Dr Kounosuke Tomori. The researchers involved in the study are working on it as part of their work.

You will receive a 20\$ koha to thank you for your time and collaboration.

## WHAT IF SOMETHING GOES WRONG?

If you were injured in this study, you would be eligible to apply for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery.

If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

## WHAT ARE MY RIGHTS?

It is important you to know that you are welcome to withdraw from the study at any stage, without needing to say why and without this affecting your medical care. Your involvement or non-involvement in this study has no impact on any healthcare service you are getting or might get in the future. We will not collect any information that could be used to identify you personally. We will keep your name and contact details separately from the study data. We will only use your name and contact details to report back to you on the outcomes from the study, if you wish so.

All study data will be anonymous and your personal information will be kept confidential. When reporting on the completed research, we will not identify any individual people either directly or indirectly. Only the researchers involved in this study will be access to the raw study data. We keep all of our data on a password protected computer during the study.



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## WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

After the study, we destroy all the audio-recordings of the data and just keep the written study data (which will be anonymous data) locked in a filing cabinet in a private University office room. We are required to keep this study data for 10 years before destroying it.

If you wish, within ten months from the end of the study, we will send you by post mail or e-mail a summary of the results from the study.

## WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

*Name, position:* Carla Strubbia, PhD candidate, University of Otago  
*Telephone number:* 020 4160 4900  
*Email:* [carla.strubbia@postgrad.otago.ac.nz](mailto:carla.strubbia@postgrad.otago.ac.nz)

*Name, position:* William Levack, Dean and Professor, University of Otago  
*Telephone number:* 04 918 6279  
*Email:* [william.levack@otago.ac.nz](mailto:william.levack@otago.ac.nz)

*Name, position:* Rebecca Grainger, Associate Professor, University of Otago  
*Telephone number:* 04 385 6783  
*Email:* [rebecca.grainger@otago.ac.nz](mailto:rebecca.grainger@otago.ac.nz)

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050  
Fax: 0800 2 SUPPORT (0800 2787 7678)  
Email: [advocacy@advocacy.org.nz](mailto:advocacy@advocacy.org.nz)  
Website: <https://www.advocacy.org.nz/>

For Maori Health support contact:

*Name, position:* Bernadette Jones, Research fellow, University of Otago  
*Telephone number:* 04 918 6845  
*Email:* [bernadette.jones@otago.ac.nz](mailto:bernadette.jones@otago.ac.nz)

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS  
Email: [hdecs@moh.govt.nz](mailto:hdecs@moh.govt.nz)



## Participants Consent Form - Patient

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**Lead investigator:** Carla Strubbia, PhD candidate, Department of Medicine, University of Otago

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### Please tick to indicate you consent to the following:

I have read and understood the Participant Information Sheet. Yes  No

I have been given sufficient time to think about whether or not to participate in this study. Yes  No

I have had the opportunity to talk with my Doctor, whanau/family, friend or other people of my choice to help me ask any questions and understand the study. Yes  No

I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet. Yes  No

I consent to the research staff collecting and processing my information, including information about my health. Yes  No

I know that my participation in the study is entirely voluntary (my choice), and that I am free to withdraw from the study at any time without having to give a reason and without this affecting my medical care. Yes  No

I understand that my participation in this study is confidential and that no material, which could identify me personally, will appear in any spoken or written report of the study at any stage. Yes  No



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I understand the nature and size of the risks of discomfort or harm which are explained in the Information sheet. Yes  No

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I know that all personal identifying information will be removed from the paper records and electronic files, and that these will be stored in a locked room on a University secure storage, and kept for at least ten years. Yes  No

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I understand I will be given a voucher for participating in this study. Yes  No

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I know who to contact if I have any questions about the study in general. Yes  No

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I understand my responsibilities as a study participant. Yes  No

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I wish to receive a summary of the results from the study. Yes  No

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**Declaration by participant:**

I hereby agree to participate in the study.

Participant's name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Declaration by member of research team:**

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I have explained the study and believe the participant understand the study and has given informed consent to participate.

Researcher's name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_