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# Plain Language Statement

Faculty of Arts

## *Project: Keeping Pain in Check: Can a checklist help identify pain in people with intellectual disability?*

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## Introduction

Thank you for your interest in participating in this research project. The following few pages will provide you with further information about the project, so that you can decide if you would like to take part in this research.

Please take the time to read this information carefully. You may ask questions about anything you don't understand or want to know more about by contacting Tessa at tzirnsak@scopeaust.org.au or Stella at skoritsas@scopeaust.org.au.

Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.

## What is this research about?

This study is about identifying pain in adults with intellectual disability and limited communication. We are interested to learn whether using a Pain Checklist can help disability support workers to identify pain in adults with intellectual disability and limited communication. The Pain Checklist focusses on non-verbal signs of pain, such as vocalisations and emotional reactions. It lists several non-verbal characteristics and asks the respondent to indicate whether these are present.

## Who can participate in the study?

To participate in the study, you must be:

- A Disability Support Worker
- An adult
- Reside and work in Australia
- Work with someone who has an intellectual disability and limited communication

For the purpose of the research, limited communication is defined as communicating in a way that is not easily understood by most people. It excludes people who use speech to communicate and those who can make themselves understood using alternative and augmentative communication.

## What will I be asked to do?

Participation in the research will take up to 1 hour and involves completing a brief online course, a survey, and the Pain Checklist (two times).

The Pain Checklist needs to be completed about an adult with intellectual disability and limited communication who you work with. This person must:

- Be an adult
- Have an intellectual disability
- Have limited communication (see above for definition).

To complete the Pain Checklist, it is important that you know the person with intellectual disability well. For this reason, we ask that you select a person who you have worked with for at least 6 months.

You will not be asked to identify the person with disability. Instead, you'll develop a code for the person. We will provide instructions on how to create a code. We will use this code to remind you who you have provided information about, if you forget.

Your participation is entirely online, unless you want us to send you the Pain Checklists to complete in hardcopy. If you want hard copies, please contact Tessa on 03 9843 4488 or email tzirnsak@scopeaust.org.au.

More detail about participation is provided below:

| Step 1 | Step 2 | Step 3 | Step 4 |
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| Complete a brief online course about pain in people with intellectual disability. Completion takes ~20 minutes. | Once you complete the course, you will be invited to complete an online survey. The survey will take up to 10 minutes. It asks for some information about you and the person with intellectual disability, and for feedback about the course. | After you complete the survey, you will be given access to a copy of the Pain Checklist through your online log in. This Checklist should be completed when the person with intellectual disability is **content**. Content means when the person is peaceful or at ease. It will take you about 10 minutes to complete this Checklist. | You will be given access to another copy of the Pain Checklist. This Checklist should be completed when you think that the **person is experiencing any type or intensity of pain**. You will also be asked some questions about the suspected reason for pain, what you did to address the pain, if it worked, and what you thought about the Pain Checklist. |

Please note that **Step 4 should only be completed once the person with ID has been attended to**, that is, you have done everything you can do, in accordance with your organization's policies and procedures and the person's health care plan (if applicable) to manage the person's pain. **If medical attention is required, this must be sought before you complete the checklist** or participate in that part of the research.

The survey and Checklists can be completed online. You can use your smart phone, tablet or other electronic device to do this.

## Why do I need to provide my name and contact details?

If you want to participate, you will need to provide an email address so that you are given a login to access the course. Having a login allows the website to remember how far into the research project you have progressed so that you can automatically pick up from where you left off rather than start at the beginning (if you can't finish the course in one sitting).

Providing your name and contact details also means that we can send you reminders to complete the research. We will only ever send you up to three reminders, then we will stop contacting you.

We also need your name and contact details so that we can link the first Pain Checklist with the second Pain Checklist. We will not disclose your personal information to anyone. No information that would reveal who participated will be included in the presentation of results.

Demographic data that is collected will be used in the write up to report on the general characteristics of the participants in this study. This is so that we, and anyone else interested in the research can understand if the participants in this study are representative of the broader population of disability support workers and people with intellectual disability. It would be quite difficult for us to publish any data from this study without being able to give a sense of who our participants were in general terms. This information will only be reported in the context of the whole group of participants, and so you won't be identifiable from this.

### When will you delete my name and contact details?

Once we begin data analysis, your name will be replaced with a code. At this point, your name and contact details will be permanently deleted from the data that you have provided.

### What are the possible benefits?

It is hoped that you will learn about pain in people with intellectual disability. Completing the Checklist will help us determine whether they might be used to assist other disability support workers and service providers identify pain in people with intellectual disability and limited communication. If it does, it may lead to improvements in managing pain in this group.

### What are the possible risks?

The risks associated with participation in this study are limited. There is some risk that thinking about pain or trying to manage the pain that the person with intellectual disability that you work with might experience may be upsetting. If you become distressed as a result of being in the research you should contact your general practitioner or Lifeline 13 11 14. You may also be able to access the employee assistance program at your workplace.

You **must** address the person's pain (if applicable) before you complete the Pain Checklist. Please refer to the person's Health care plan or seek assistance from your colleagues and supervisor if you are unclear about what to do.

### Do I have to take part?

Participation in the research is voluntary. Your decision about whether to participate will have no effect on your employment, your relationship with Scope, or the researchers.

If you consent now, but change your mind later, you can withdraw from the study by informing one of the researchers or not responding to the reminders you receive. Once we begin data analysis, all identifying information (e.g., your name and contact details) will be deleted from the dataset. This means that if you withdraw, we can only delete your data before we start data analysis.

### Will I hear about the results of this project?

A summary of the results will be made available through our website. If you would like to receive a copy of the results, please email Tessa tzirnsak@scopeaust.org.au.

### What will happen to information about me?

All the data and consent forms will be stored on a secure online server at Scope that is password protected. Only the researchers will have access to the data.

Any data that is received in hard copy will be stored in a locked filing cabinet at Scope that can only be accessed by the researchers. After 10 years from the last report from the data, the hard copies will be destroyed.

The results will be reported in papers (such as journal papers, reports) and conference presentations. Only group results will be reported. No information that would reveal who participated will be included in the presentation of results.

All data will be securely destroyed ten years after publication of the results. Consent forms will be destroyed at this point too.

We would like to use the data you give us for future related research. Related research means research that is on a similar topic. You can tell us that you don't want us to use your data for future related research by checking a box on the consent form.

### Will I find out about the results of the study?

A summary of the results will be made available through our website. If you would like to receive a copy of the results, please email Tessa tzirnsak@scopeaust.org.au.

### Who is funding this project?

This research is being funded through a Perpetual Impact Grant.

### Where can I get further information?

If you would like more information about the project, please contact the researchers;

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| **Prof. Keith McVilly**<br>Responsible researcher<br>Academic<br>Social and Political Sciences<br>University of Melbourne<br><br>E: keith.mcvilly@unimelb.edu.au | **Dr Stella Koritsas**<br>Honorary Fellow<br>Faculty of Arts<br>University of Melbourne<br><br>Manager Strategic Research<br>Scope (Aust) Ltd<br><br>T: 03 9843 2065 \| M: 0488 541 443<br>E: stella.koritsas@unimelb.edu.au |

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| **Assc. Prof. Rachael MacDonald**<br>Program Leader, Disability<br>Swinburne University of Technology<br><br>E: rachaelmcdonald@swinburne.edu.au | **Dr. Nick Hagiliassis**<br>Honorary Fellow<br>Faculty of Arts<br>University of Melbourne<br><br>Senior Clinician-Psychologist<br>Scope (Aust) LTD<br><br>T: (03) 8311 4013<br>E: nick.hagiliassis@unimelb.edu.au<br>nhagiliassis@scopeaust.org.au |
| **Tessa-May Zirnsak**<br>Research Assistant<br>Scope (Aust) Ltd<br><br>T: 03 9843 4488<br>E: tzirnsak@scopeaust.org.edu.au | |

## Who can I contact if I have any concerns about the project?

This research project has been approved by the Human Research Ethics Committee of The University of Melbourne. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Manager, Human Research Ethics, Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 3 8344 2073 or Email: HumanEthics-complaints@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence please provide the name of the research team or the name or ethics ID number of the research project.