



## Participant Information Sheet

<b>Study title:</b>	<b>Painful shoulders: Together building a patient webpage</b>	
<b>Principal investigator:</b>	<b>Gisela Sole School of Physiotherapy Associate Professor</b>	<b>Contact phone number: 03-4797936</b>

### Introduction

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

### What is the aim of this research project?

This project will explore ideas and suggestions of patients living with shoulder pain and physiotherapists for a web-based resource. We will explore what information patients and physiotherapists consider to be important for such a website, and how it should be presented. At the end of the project, we hope to make the website available to physiotherapists and other health professionals in New Zealand. The physiotherapists will then share it with relevant patients and their whānau. Based on suggestions from this study, we may also make the website directly available to individuals with shoulder pain, for example via a Google search.

### Who is funding this project?

This project is funded by an Activation Grant of the Health Research Council.

### Who are we seeking to participate in the project?

We are seeking up to 12 men and women (aged 25 to 70 years) who have had shoulder pain for at least 3 months over the past years, AND have sought physiotherapy for that pain. You may also have had shoulder surgery. Your shoulder pain may have recovered at the time of this project, or may still be present.

We are also seeking 4 New Zealand-registered physiotherapists with at least 3 years clinical experience in the field of musculoskeletal practice.

We are specifically seeking participants of different ethnicities, including Māori, Pasifika, Pākehā, Indian, Asian and/or Latin American, Middle Eastern or African volunteers.

### **If you participate, what will you be asked to do?**

First, you will be sent a link to an online questionnaire to ask you for brief information about yourself (contact details, age, presence or past shoulder pain, ethnicity; physiotherapists' year of entry level qualification, experience in musculoskeletal care). If you meet the inclusion criteria, Gisela Sole will then invite you to meet with her via Zoom or in person (in Dunedin). That meeting will be half an hour at most. Gisela will describe the study in more detail to you, including the time commitments. She will ask you about why you want to take part in this project, and whether you will be available for meetings. That will also be opportunity for you to ask her any questions you have about the study.

If you agree to participate, we will ask you to attend up to 5 meeting over a period of 4 months (February to June 2021). You would be able to attend the meetings in person at the School of Physiotherapy (Dunedin) or via Zoom.

We will be using a process called 'Participatory Action Research' (PAR) whereby team members from the community team up with researchers. You would meet members of the PAR group at the first meeting. The research members will show the rest of the team the resources they had designed previously, and sample webpages. The group will then decide together what the next step should be. That may relate to what content or type of information about shoulder pain would be useful for patients, and how it should be presented. You will be involved in that decision making. During the second and third meetings, the team would work towards a template or framework for the webpage. Science communication team members and the web-provider will then join the group and use the team's framework to draft the website and its resources. During the fourth and fifth meetings, they will provide suggestions and drafts. The webpage will then be finalised.

We will offer you a koha/gift voucher of \$25 for every meeting that you can attend.

### **Is there any risk of discomfort or harm from participation?**

We do not anticipate there to be any risk of discomfort or harm from taking part in this project.

### **What data or information will be collected, and how will they be used?**

Your personal information will be kept in locked storage for 10 years at the School of Physiotherapy in password-protected electronic files. Only the named researchers will be able to access that information. Any personal information (such as contact details) will be destroyed at the completion of the project even though data derived from the research will, in most cases, be kept for much longer or possibly indefinitely. Anonymity of all participants will be preserved by removing names and identifying features from the data. The international researcher (Dr Craig Wassinger) will not have access to the raw data.

The PAR meetings will be recorded and the researchers will make summaries of the discussions. While your name will be mentioned (and recorded) during the meetings, written summary notes will not contain your name in order to protect your privacy. During the meeting, participants may share their experience of their shoulder pain and of other health conditions with the group. You may also feel

comfortable to share your experiences with them. All participants will be asked to sign that they will keep all personal information confidential.

The research team will be writing the project and the results of the PAR meetings up as a publication in a peer-reviewed journal article. All personal data will be de-identified.

All PAR members (physiotherapists and patients) will be asked whether they would like to be acknowledged by name in the article. Similarly, we will ask you whether you would like to be acknowledged by name on the final website. We will discuss this with you when the draft website and the draft journal article is completed. If you agree to be acknowledged, we will ask you to give us permission to do that in writing before the website is made publically available, and before the manuscript is submitted to a journal.

### **What about anonymity and confidentiality?**

While your name will be mentioned (and recorded) during the meetings, written summary notes will not contain your name in order to protect your privacy. During the meeting, participants may share their experience of their shoulder pain and of other health conditions with the group. You may also feel comfortable to share your experiences with them. All participants will be asked to sign that they will keep all personal information of team members confidential. Your name will be included on the website only if you have given us written permission to acknowledge you. Any resources created for the website will be anonymous unless you give express written consent for use of identifiable material.

### **If you agree to participate, can you withdraw later?**

You may withdraw from participation in the project at any time and without any disadvantage to yourself.

### **Any questions?**

If you have any questions now or in the future, please feel free to contact either:

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<b>Co-researchers</b>	
Prof Nancy Longnecker Centre for Science Communication	Dr Tracey Pons, Registered Physiotherapy Pain Specialist Christchurch
A/Prof Nicola Swain Department of Medical Psychology	Rosey Acker Physiotherapist, School of Physiotherapy
Dr Ally Calder Lecturer, School of Physiotherapy Christchurch	A/Prof Craig Wassinger Department of Physical Therapy, East Tennessee State University, USA

*This study has been approved by the University of Otago Human Ethics Committee (Health), Ref H20/128. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.*