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 **Participation Information Form**

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Phantom Limb Pain Management and Physiotherapy: Exploring Beliefs and Experiences of Physiotherapists and Persons with Amputations

**Principal Investigator:** Garrett Saxton (student physiotherapist)

**Project Supervisor:** Gill Phillips

**Invitation**

You are invited to take part in our research study. Before you decide whether you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Please ask if anything is unclear. If you would like more information, a contact number and address are at the end of this information sheet. It is important that all your questions are answered before you decide whether to participate in the research study.

**What is the purpose of the study**

The purpose of this study is to explore the attitudes and beliefs of both physiotherapists and individuals with amputations towards the physiotherapy management of phantom limb pain.

**Am I a suitable participant for the study?**

We are seeking volunteers who have an amputation, have experienced phantom limb pain in recent memory, and have been treated by a physiotherapist. You will need to be available to partake in a telephone interview lasting no longer than 20 minutes.

**Do I have to take part?**

No. It is your decision whether to take part. If you decide to take part you will be given this participant information form to keep. You will be required to sign a consent form if you decide to take part in the study. You are free to withdraw from the study at any time although your data may be kept as it is valuable to the study. You do not have to give your reasons for withdrawal. You will have the opportunity to review the transcribed interview before it is taken to publication. The transcribed interview can either be emailed or posted to you. This is to ensure your attitudes, beliefs, and views are correctly represented. At this point you may withdraw but the data collected will be kept for study purposes.

**What will happen if I agree to take part?**

You will be asked to contact Garrett Saxton to arrange an interview at a mutually convenient time. Please thoroughly read and sign the consent form. Before the interview begins, you will have an opportunity to ask questions and seek clarification. The study purpose and procedures will be explained again and you will again be asked for your consent. You will be asked to send your consent form to the researcher.

**What are the possible benefits of taking part in the study?**

The study will not help you directly. The findings will help us understand the attitudes and beliefs of both physiotherapists and individuals with amputations towards current phantom limb pain management. The findings may help influence future phantom limb pain research and guidelines.

You can have access to your data at the end of the study although we are unable to make any health inferences from them as the data is solely used for research rather than diagnostic purposes. If we observe any unusual findings we will ask you if we can inform your GP. This is standard practice when conducting this type of research.

**What are the possible risks of taking part in the study?**

The experiment has been risk assessed and ethically approved by Leeds Beckett University and these documents are available on request. This study was categorised as low risk. It is possible that the interview may bring back painful or frightening memories. It is advised that a close family member or friend is with you during the interview. If you wish, the researchers can put you in touch with a Limbless Association support group in your area.

**What if there is a problem?**

If you have a concern about any aspect of this study you should ask to speak with Garrett Saxton or Gill Phillips. They will do their best to answer your question. If you wish to complain formally about any aspect of the study, including the conduct of the investigator, you can do this through the Independent Contact Person identified at the end of this sheet. If something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone’s negligence then you may have grounds for a legal action for compensation but you may have to pay your legal costs. The normal University complaints mechanisms will still be available to you.

**What do I have to do before I take part in the study interview?**

You must have access to a telephone. There are no other requirements, so you can continue with your normal diet and daily activities.

**What will happen to the results of the study?**

It is expected that the study findings will be presented at a scientific conference and written up for a scientific journal.

**Will taking part in this study be kept confidential?**

All information collected about you will be coded for anonymity and kept strictly confidential other than to those of us who are involved directly with the study. The study is not designed to collect information about your attitudes or behaviours that are deemed ‘sensitive’. We are duty bound to disclose any information that you provide that relates to criminal activity so we encourage you not to engage the investigators in conversation about such matters. Any data gathered that leaves Leeds Beckett University will be coded to maintain your anonymity. You are free to leave the study at any time and without giving a reason. If you do wish to withdraw before study completion, unless you object, we will keep records relating to you as this is valuable to the study. The information will be kept confidential always and held securely on paper and electronically at Leeds Beckett University under the provision of the 1998 Data Protection Act.

**Complaints and Independent Contact**

If you have any complaints, concerns or would like to chat about any aspect of the research with someone independent to the research you should contact:

Mrs Sheila Casey (Quality Assurance & Governance Officer).

HSS Faculty Office, Faculty of Health and Social Sciences, Leeds Beckett University, Calverley Street,

Leeds, LS1 3HE

Tel: 0113 81 24312 or email s.a.casey@leedsbeckett.ac.uk

**or**

Dr Alison Caswell (Health and Safety Officer), Faculty of Health and Social Sciences, Leeds Beckett University, Leeds, LS1 3HE

Tel: 0113 2832600 or e-mail: a.caswell@leedsbeckett.ac.uk

**Contact for further information**

If you require further advice about this study you may contact

Garrett Saxton

MSc Physiotherapy (Pre-registration) Student

Leeds Beckett University

Email: g.saxton9862@student.leedsbeckett.ac.uk

Gill Phillips

Principal Lecturer

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Tel: +44 (0)113 8123362

Email: g.phillips@leedsbeckett.ac.uk

**What do I do next?**

If you decide that you would like to take part in the study then please inform Garrett Saxton as the principal investigator who will arrange a mutually convenient time for an interview. You may keep this information sheet and the consent form. You can have more time to think this over if you are at all unsure.

Thank you for taking the time to consider participating in this study