



Genital Oedema (GO) Education Need Survey

(including the terms genital edema/lymphoedema/lymphedema)

Overall project Title: genital oedema education needs of health professionals.

This survey is part of a project to identify the education needs of health professionals who may manage people who have genital oedema (see also other terms above). Anecdotally health professionals report that it is common for patients to be reluctant to report genital oedema. A previous study by this research team found that there was a perception that many health professionals lacked confidence in their knowledge to address it but that self-report tools may help (Noble-Jones et al 2018). This project seeks to identify that need to ultimately improve the care of this patient group.

The aim of the project is to produce needs-led recommendations for the content and method of delivery of education for health professionals caring for people with genital oedema.

What will I have to do?

We would like to invite you to take part in this **online survey which takes approximately 15 minutes to complete**. If you prefer, you may complete it in a paper version on request to the researcher named below. If you are completing the questionnaire on-line questions you do not need to answer will be blocked out; the paper copy clearly states which questions you should answer.

If you would **also** be interested in participating in an **online focus group discussion** at a later date please separately email rhian.noble-jones@wales.nhs.uk for details. You can participate in the survey without being involved in the focus group, but if you want to be part of the focus group we would like you to have first completed the survey.

Why me?

You have been invited as you are a person who may treat/manage patients with this condition. It is important for you to understand why we are doing this and what it would involve for you.

Is the questionnaire confidential?

Personal information will not be asked on the questionnaire other than in which country you live/work, whether you are a health professional and whether you are male/female/identify otherwise. All your answers to the questionnaire will be fed into Survey Monkey, an



electronic secure software site, details of their security measures are available at

<https://www.surveymonkey.com/mp/legal/security/>

Only the Coordinating Principle Researcher, Dr Rhian Noble-Jones and the research team have access to the survey data. A report of the analysed and anonymised results of the survey will be available to the organisations helping to distribute this survey link in your country (Australian Lymphology Association, the Australasian College of Phlebology) and to the organisations responsible for this project: Lymphoedema Network Wales and the International Lymphoedema Framework, the sponsors Swansea Bay University Health Board and the funders Tenovus Cancer Care (Wales). Details of all of these organisations can be found by searching online.

Do I have to take part?

You are completely free to choose whether you take part in the survey or not, and can stop at any time through the questionnaire. Once you have completed and submitted the survey the data cannot be withdrawn as it will be anonymous. If you are interested in the subsequent focus group discussion you will need to email separately to register your interest which does not commit you to participate.

What is understood as genital oedema in this project?

For the purposes of this study **genital oedema** is swelling of the scrotum and/or penis, or vulva, which would be considered a chronic oedema* and has been subject to medical differential diagnosis for underlying acute pathology.

*ILF identifies chronic oedema is an umbrella term that includes both primary and secondary lymphoedema and other chronic swelling. Chronic oedema is defined as '**oedema which has been present for more than 3 months and involves one or more of the following areas: limbs, hands/feet, upper body (breast/chest wall, shoulder, back), lower body (buttocks, abdomen), genital (scrotum, penis, vulva), head, neck or face**'.

Further questions?

If you have any questions please contact Dr Rhian Noble-Jones, tel: (+44)7964-908718, or rhian.noble-jones@wales.nhs.uk

Noble-Jones, R., Thomas, M. J. and Bose, P. (2018) The Lymphoedema Genitourinary Cancer Questionnaire in urology follow-up clinics. International Journal of Urological Nursing, (doi:10.1111/ijun.12174)