

## Male genital oedema: tool for men to ‘tell it as it is’.

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This online overview presents a new self-report tool for men – **the Lower Limb and Genital Lymphoedema Questionnaire for Men (LLGLQ)**; for the full article see BLS News & Views 2018.

**Overview:** Men are generally considered to be reluctant to disclose symptoms of discomfort, dysfunction and distress regarding their genitalia, and disclosure may rely on more than simply building a trust relationship (Bullen et al 2010). Initial disclosure of sensitive issues may be better with written instruments than verbal questioning (Sampurno et al 2016). Further, interim findings of a current Tenovus Cancer Care (Wales) funded study would indicate that health professionals are likely to address sensitive issues earlier in the therapeutic relationship when using the cancer-related-lymphoedema version of the tool, LGUCQ (Noble-Jones et al 2014). This is perceived to have led to earlier identification of genital oedema-related problems, more specific, patient-led management, and enabled earlier teaching of dignity preserving self-management techniques. The study ends in April 2018 and will be fully reported later this year.

**Background:** In 2014 the Lymphoedema Genito-Urinary Cancer Questionnaire (LGUCQ) was developed by lymphoedema therapist/researcher, Dr Rhian Noble-Jones, in collaboration with patients (with and without lymphoedema), urology and oncology medics, lymphoedema therapists, academics and an experienced researcher. The participating men, ages ranging from 24 to 76.

The 2017-8 project has been following the incorporation of the questionnaire into the pathway of care in three health boards in Wales. Interviews with patients are exploring whether the use of the LGUCQ is acceptable and helpful to them in recognising and reporting the early signs of lymphoedema, and what support is needed when completing the questionnaire. In addition, interviews with the implementing health professionals ask what support they needed, whether the use of the tool reveals new information which enhances care, and how best to implement it in practice.

**Funding** for the development of the Glasgow LGUCQ study was provided by the [British Lymphology Society](#) (Research Fund Award) and the Lymphoedema Research Fund (London). Funding for the Wales project was received entirely from Tenovus Cancer Care.

During the Tenovus project the need for a generic, non-cancer-related genital oedema self-report tool emerged. This led to creation and testing of the **Lower Limb and Genital Lymphoedema Questionnaire for Men (LLGLQ)**. Rhian has enlisted the help of colleagues in other countries to assist in rolling out the tool to a larger population as service development. *Note that you may need*

*to register the tool with your Audit/R&D dept. to use it within your service. You can download the questionnaire as often as you like, we simply ask you to register your details the first time you download it so that we get an idea of how widely it is used.*

Dr Rhian Noble-Jones, would like feedback on the generic version of the tool (LLGLQ) when you have used. Would you be happy to discuss your experience? In short,

- **Did it help the men ‘tell it as it is’?**
- **Will you ‘tell it as it is’?** Did it reveal more information or greater understanding than previous assessments of this patient group? Did you use it for review as well as initial assessment?

## References

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Patient/client (name, address, contact details).

### Lower Limb and Genital Lymphoedema Questionnaire for Men (LLGLQ)

Self-completion questionnaire for men who have lower limb oedema and may also have genital area oedema / Lymphoedema.

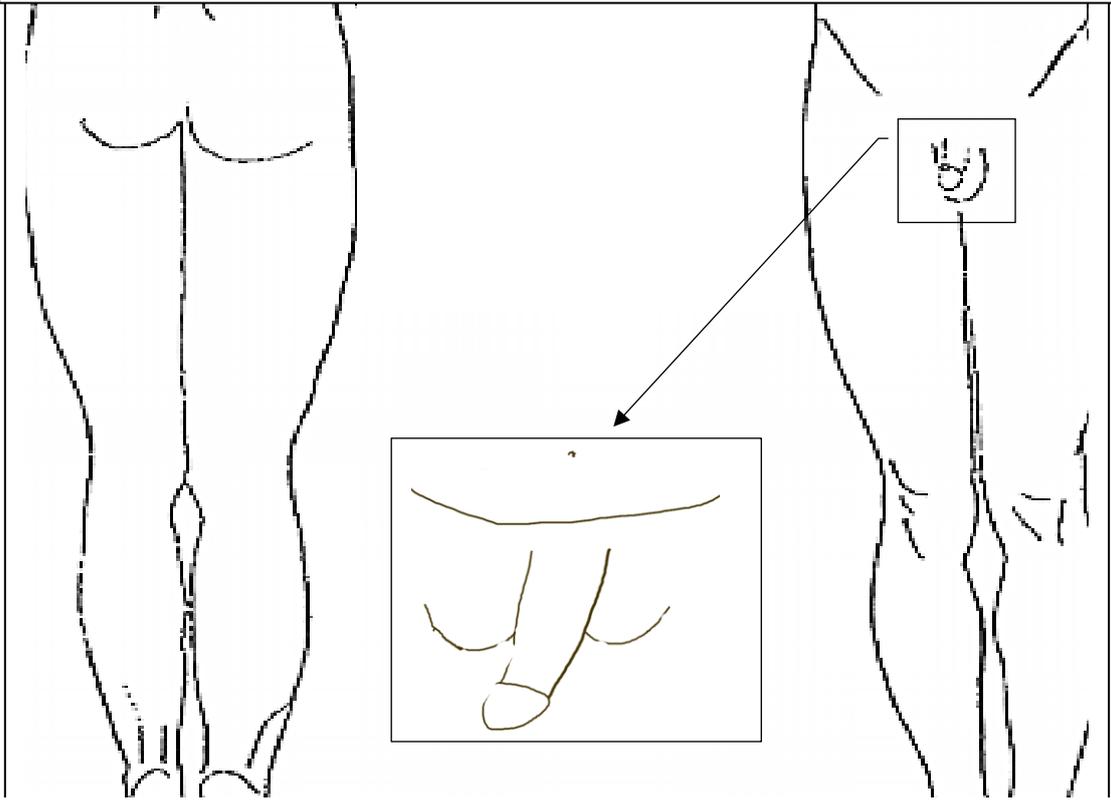
Today's date: \_\_\_\_\_

Swelling in the legs / genitals can be quite normal for a few weeks after some treatments or with some chronic conditions. Sometimes these can be difficult to describe but this questionnaire may help. Please complete the questions below to help us give you the appropriate advice and care.

Changes in your lower body since your cancer treatment		Not at all (or not relevant) <b>0</b>	A little bit <b>1</b>	Quite a bit <b>2</b>	Very much <b>3</b>
	<i>(for example)</i>		✓		
I have swelling:	in my leg(s)				
	in my genitals				
<b>If you feel you have <u>no</u> swelling at all you do not need to complete the rest of this questionnaire.</b>					
The swelling is noticeably more by the end of the day					
The swelling is affecting:	which clothes/shoes I can wear				
	my sitting				
	getting in/out of bed				
	my walking				
	urination				
	my sexual function				
The skin around the swollen area:	feels tight				
	has changed colour				
	feels different				
	feels wet/cold				
The swelling gives me discomfort:	in my leg(s)				
	in my genitals				
I need to take painkillers for the discomfort					
During the last year have you needed antibiotics for infections (cellulitis) in your leg(s) or genitals?				Yes	No
If yes, how many times has this happened?					

Patient/client (name, address, contact details).

If you have swelling of your legs or genitals please show in this picture where it is, by shading like this: 



On average this week how severe has the swelling been?			
0 = No swelling	1 = a little bit	2 = quite a bit	3 = very swollen

Is there anything else you would like to tell us about how this is affecting you physically or emotionally?

	Yes	No
Have you been offered any advice or treatment for lymphoedema (swelling)?		
Would you like any information or advice?		
<b>For completion by doctor/therapist/nurse:</b>		
Referred to Lymphoedema service for assessment? (date)		