Title: The Me-Amputee Study: Exploring meaningful outcomes of recovery following lower limb amputation and prosthetic rehabilitation: The patient’s perspective.

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Background: The difficulty in defining and measuring a successful outcome following lower limb amputation is discussed at length within the evidence base and current UK clinical practice. A review by Condie et al. (2006) found more than 25 different outcome measures used in amputee and prosthetic related studies and the NHS England service specification for prosthetic specialised services for people of all ages with limb loss lists a possible 15 measures. It is clear there is a lack of consensus around which outcome measures should be used.

In addition to this wide variety of measures, a growing body of evidence has sought to describe and document the experience of amputation and prosthetic use from a patient’s view point (e.g. Murray and Forshaw 2013). Little is currently understood about how patients define a successful recovery or outcome following amputation. This unique and critical viewpoint could offer interesting insights on the important factors that we as clinicians or researchers should be considering when we select outcome measures.

Method: This proposed study aims to use a qualitative methodology to undertake focus groups and interviews with patients with limb loss seeking to understand what patients feel are meaningful outcomes following lower limb prosthetic rehabilitation and how should they be measured.

Patients will be recruited from regional limb centres, social media and limb loss supporting organisations across the UK. 40 participants will be recruited and data will be analysed using thematic analysis.

The theme of patient involvement has also extended to the conduct of this study. People who have experienced limb loss have been involved in the development of this research from the outset. This has involved a group of patients working collaboratively with the researchers to: 1) formulate the questions asked in this project, 2) describe recruitment strategies that might be acceptable to patients with limb loss, 3) inform data collection methods and 4) develop dissemination strategies.

Potential implications: It is hoped that by understanding what recovery means to patients following amputation and prosthetic rehabilitation we can use this greater understanding of the patients experience to guide our rehabilitation and selection of outcome measures as well as reducing the measurement burden on patients.
This small study may also be able to inform a larger survey to explore the extent to which these beliefs are held by the wider amputee population. Identifying key measures will help to inform the amputee rehabilitation community of what outcomes are really important to patients and which existing measures may be able to capture this. We hope this will provide a unique patient led perspective for a consensus on the use of a core number of measures which is grounded in the experience of amputees.

References:
