



## Which self-report measure? A Delphi study

### 1. Invitation to take part in the study

We would like to invite you to take part in a Delphi consensus study. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please read this information sheet carefully.

### 2. What is a Delphi study?

The Delphi technique seeks to obtain consensus on the opinions of experts (known as panel members) through a series of structured questionnaires or discussions. As part of the process, the responses from each round are fed back in summarised form to the participants who are then given an opportunity to respond again to the emerging data. The Delphi is therefore an iterative multistage process designed to combine opinion into group consensus.

### 3. What is the purpose of the study?

Research studies in oncology and palliative care settings use a range of self-report measures (or questionnaires) for emotional distress. A systematic review recently undertaken by this research group (Ziegler et al 2009 [in preparation]) identified a total of 50 different measures. The wide variation in measures currently being used is problematic - it limits our capacity to agree methods for running robust-multicentre trials and hinders direct comparison between study cohorts through meta-analysis.

The purpose of this study is to try and address this problem by;

- Developing consensus on a standardised measure appraisal framework
- Determining a short-list of measures for the longitudinal study of distress in cancer supportive and palliative care within the COMPASS collaborative and wider.

### 4. Who is organizing and funding the research?

This research is being run by a national research group; The Complex Assessment Trials and Implementation of services Collaborative (COMPASS). The Collaborative involves 12 UK universities and shares expertise in order to increase research capacity and to develop and test complex interventions in a range of settings from cancer diagnosis to survivorship, disease progression. The project steering committee consists of Dr Dan Stark, Professor Mike Bennett, Professor Irene Higginson, Professor Simon Gilbody, Professor Scott Murray, Dr Merry Womphrey, Dr Bridget Johnston and Dr Lucy Ziegler

## **5. Why have I been invited to take part?**

We are keen to gain service users views about how we should decide which self-report measures to use in our research studies. Specifically, we would like to ask your views about how important is it that a questionnaire is easy to understand and quick to complete; what format of questionnaire you find preferable and how important it is that all the questions are relevant to your circumstances.

## **6. What will I be asked to do if I take part?**

We are inviting you to take part in a focus group. This focus group will form part of the overall consensus study. The group discussion will last approximately 1 hour and will be facilitated by Lucy Ziegler, a research fellow from The University of Leeds.

## **7. Confidentiality**

The focus group will be recorded to enable comments to be transcribed and analysed. Your comments will be stored securely on approved computers within the hospital and university, for analysis by the research team. You will be given a study number by which your contribution can be identified. Direct quotes may be used in the future as part of the study report and in medical publications but these will be anonymised and not traceable back to you.

## **8. Data protection**

All information collected in the study will be strictly confidential, and your identity will never be divulged, you have the right to access this information according to the UK data protection laws.

## **9. What do I do now?**

Thank you for reading this information sheet and for considering taking part in this research. Please let us know whether or not you would like to take part by contacting us by email or phone.

Dr Lucy Ziegler (research fellow)

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