**Faculty of Health Science**

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**Participant Information Sheet**

**Study title: Exploring the views of local health and care commissioners about commonly used quality of life measures**

You are invited to take part in a research study to help us understand the views of local health and care commissioners about quality of life measures, in the context of local integrated commissioning decisions. The following will help to explain the nature of the research and what it would involve for you. My contact details are on the last page, if you would like more information regarding any aspect of the study.

**What is the background to the study?**

Quality of life questionnaires are used to measure the outcomes of health and care interventions. They ask questions about aspects of an individual’s health or wellbeing that may affect their quality of life. These questionnaires can be used to capture changes in quality of life outcomes over time, such as before and after individuals receive an intervention. In England and Wales the National Institute for Health and Care Excellence (NICE) use this quality of life information to help make decisions about which health and care services will be publicly funded and provided through the NHS and local authorities. To help make these decisions NICE compare interventions in terms of costs and quality of life outcomes and calculate which option produces the greatest gains in quality of life outcomes per pound spent. Therefore, the question of which aspects of quality of life should be measured is critical for decision making.

**What is the purpose of the study?**

At the University of Bristol we are conducting research to help us understand the views of local health and care commissioners about what is needed in quality of life measures and about the relevance and relative importance of some commonly used measures, in the context of integrated local commissioning. Whilst these quality of life measures are primarily used in decision making by NICE, the perspective of local commissioners is important because there should be alignment between the outcome measures used by NICE and the objectives of those commissioning services. Local commissioners also often have a ‘birds-eye’ view of services that cross the health and care sector and so are able to provide a unique and valuable perspective about the relevance of different quality of life measures for the whole system. The research is being carried out as part of a PhD and it will add to the growing body of knowledge about the quality of life measures used in health and care decision making.

**Why have I been invited to participate?**

You have been invited to take part in this research study because you are employed by an Integrated Care Board or a Local Authority and your role involves planning and commissioning local health and/or care services.

**Do I have to take part?**

No. taking part is entirely voluntary. There is no obligation to participate. We will describe the study and go through this information sheet with you before you participate and answer any questions you might have. If you agree to take part, we will then ask you to sign a consent form.

**What will happen to me if I take part and what will I have to do?**

If you choose to take part in the study you will participate in an individual interview which will last roughly one hour and no longer than an hour and a half. You will be offered the option to be interviewed either online via a video call or face to face at a location that suits you. During the interview you will be asked to discuss your views in relation to quality of life from your perspective as a commissioner. You will be asked to look at some measures which are commonly used to assess people’s quality of life and you will be asked some questions which involve allocating tokens between different combinations of these measures according to what you consider to be important. This is not a test and there are no right or wrong answers; we are interested in your views. Face to face interviews will be audio recorded. Online interviews will be both audio and video recorded using the ‘record and transcribe’ function. However, as soon as the transcript has been checked, the audio recording will be separated from the video recording, and the video recording will be destroyed and only the audio recording retained. The audio recordings, along with all the other information you provide, will be kept strictly confidential as detailed below (please see the section below titled ‘Will my participation in this study be kept confidential?’)

**What are the possible disadvantages and risks involved in taking part in the study?**

We are asking you to commit some time which we realise is scarce**.** Whilst we do not foresee any specific risks occurring from your participation, if at any stage during an individual interview you are distressed or uncomfortable about topics being asked you can ask the researcher to move on, to pause the interview or to stop the interview completely.

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

Although there may be no direct benefits to you personally, some people like the opportunity to discuss their own experiences and views. By taking part in this research you will be contributing to our understanding of what is needed from quality of life measures in the context of local commissioning decisions. We hope this will contribute to achieving more alignment between the outcome measures used at a national level by NICE, and the objectives of those commissioning health and care services at a local level.

**Am I free to withdraw from the research?**

You are free to withdraw from the interview and the research, without the need to give a reason. You can do this at any time up to the point at which your interview has been transcribed in full by the researcher (which will usually be one week after the interview) by sending an email to louise.proud@bristol.ac.uk or telephoning 07858286918. If you withdraw from the research during or after the interview we will ask you if you want your contribution to be included. If you would like us to not include your contribution we will destroy all the data you have provided and we will not report anything you have provided when we write-up the research and when we publish the findings. There will be no consequences for you if you withdraw.

**Will my participation in this study be kept confidential?**

Yes. All information which is collected about you during the course of the research will be kept strictly confidential. A unique identity code (a study participant number) will be allocated to any information you provide. This allows any identifying data such as your name, organisation and contact details to be stored separately to all other data collected from you. Any information collected from you will be labelled using this study participant number only, so that you cannot be recognised. Interviews will be recorded on an encrypted digital recording device and/or an encrypted laptop. Recordings, and any other information collected during the interview, will be transferred onto a computer as soon as possible after each interview and stored in a password protected file on a secured network. Audio-recordings will be transcribed by the researcher aided by transcription software. In those stored transcripts, you will be referred to only by your study participant number and any other words that could identify you will be removed. All the information you provide will be stored in password protected files and folders on a password protected secured network which is maintained by the University of Bristol. Only the lead researcher, and a small number of colleagues working on this study, will have access to any of these files. The data collected may be analysed with colleagues at the University of Bristol and the University of Exeter who have expertise on quality of life measures research that will be informative to the project. Upon completion of the PhD and any associated publications, all nonessential data will be wiped. Interview recordings, transcripts, demographic data and consent forms will be kept for ten years, after which they will be deleted, and all copies destroyed in accordance with the University of Bristol’s secure erasure of data policy.

**What will happen to the results of the research project?**

The results of this project will form part of the researcher’s PhD thesis. Data from this research will be published in academic journals and presented at academic conferences. This will include anonymised quotes from the interviews. All results that are made public will be anonymised by removing any words that could identify you. The name of the organisation that you work for will not be used. You will not be identifiable in any publications.

**Who is organising and funding the research?**

This work is supported by grant [MR/N0137941/1] for the GW4 BIOMED MRC DTP, awarded to the Universities of Bath, Bristol, Cardiff and Exeter from the Medical Research Council (MRC)/UKRI and by the Wellcome Trust [205384/Z/16/Z].

**Who has reviewed the study?**

The study has been approved by the University of Bristol Faculty Research Ethics Committee, Health Sciences.

**What is the complaints procedure?**

If you feel you need to complain or raise concerns about any aspect of this research please contact the Faculty of Health Science Research Ethics Committee, via the Research Governance Team, research-governance@bristol.ac.uk.

**What now?**

You are free to take your time to consider whether you would like to participate. If you are interested in taking part in this study, please either scan the QR code below, or go to <https://forms.office.com/r/XjNAei2dYa> to register your interest. We will then contact you with further information regarding participation. Alternatively you can register your interest in the study, or ask any questions about participating in the study, by contacting Louise Proud at:



**email:** **louise.proud@bristol.ac.uk** **mobile: 07858286918**

Thank you for taking the time to read this.