How do we value mental health?

As researchers at City University, London we would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?
We are researching a new way of involving service users, carers and staff in measuring something called ‘health utilities’.

Health utilities are used by policy makers and others to consider how people value the potential benefits and costs of a new treatment or intervention.

Most often, people with experience of mental health problems and their carers are not involved in this process. We think they should be and want to test whether this is possible.

In this study we want you to read some scenarios and then respond to some questions about those scenarios.

The scenarios you will read have been developed and written by mental health service users and carers working together with mental health researchers at City University London.

Why have I been invited?
You have been asked to take part in the study because you have visited the Rethink Mental Illness website and the hope is that the survey will be completed by a broad range of people. You may be a service user, a carer, a health care professional or someone who has a general interest in mental health.

Do I have to take part?
Taking part in the study is completely voluntary. If you decide that you do not want to take part in the research study you do not have to give a reason.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form.

What will happen if I take part?
We would like you to complete the electronic survey via an internet link on the Rethink Mental Illness website. It is estimated that this will take approximately 20-25 minutes to complete. We anticipate the research study will last for 6 months with the results being made available via the Rethink Mental Illness website by March 2016. The data collected will include some questions on your personal details and circumstances (sometimes this is referred to as socio-demographic data, such as age, gender, marital status etc.). Questions asked in the survey will also ask about your attitudes to living in hypothetical health states and your attitude to risk. We will NOT ask for your name or address.

What do I have to do?
As a participant taking part in this study, you will be asked to complete the electronic survey questionnaire, assessing your views and attitudes towards hypothetical health states and risk.
What are the possible disadvantages and risks of taking part?
Some of the questions and concepts may be complex. Participants will need to give questions some consideration and this will require a certain level of concentration. One of the central aims is to test the acceptability of asking scenario based questions in this format. Despite these questions being hypothetical in nature, some respondents may be distressed after reading them. Though we think this would be unlikely, if this were to happen, we would suggest you contact the Samaritans on http://www.samaritans.org/how-we-can-help-you/contact-us

The Samaritans telephone number is 08457 90 90 90.

Should you have any questions or queries please contact Dr Chris Flood; c.flood@city.ac.uk

What are the possible benefits of taking part?
We believe the potential benefits of you taking part in this research study as participants will be the opportunity to explore your own thinking around living in certain health states and how you would view risk.

Furthermore, published results of this study will become a source of knowledge and information for policy makers, mental health researchers and will have a national and international impact on commissioning decisions to aid better care for patients, families and carers.

What will happen when the research study stops?
We would like to keep any information or data we collect for 10 years and may use the data again in further studies relating to health utilities. After 10 years, data collected for this study will be destroyed in a secure way in accordance with City University’s policy on retaining data.

Will my taking part in the study be kept confidential?
The information you give us and that we collect about assessing your views and attitudes towards hypothetical health states and risk will be treated in confidence. We will do this in a number of ways:

- All information that is collected will be anonymous from the outset and will be seen and analysed only by researchers at City University London.
- Your involvement in the study and any personal data or questionnaire answers collected from you will not be shared or discussed with other University staff.
- Any personal data will be stored securely at City University London.

What will happen to results of the research study?
The study findings will be written up for publication and reported at relevant conferences. No research publication would identify you individually.

Participants will be able to view results of the study that will be made available via the Service User and Carer Group Advising on Research blog at https://blogs.city.ac.uk/sugar/

What will happen if I don’t want to carry on with the study?
If you do not wish to carry on with the study you may withdraw at any time.

What if there is a problem?
If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is:

Involving mental health service users and carers in measuring health utilities
You could also write to the Secretary at:
Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London
EC1V 0HB
Email: Anna.Ramberg.1@city.ac.uk

Who has reviewed the study?
This study has been approved by City University London School of Health Sciences
Research Ethics Committee

Further information and contact details
If you would like more information about this study you can contact one of the following:

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Thank you for taking the time to read this information sheet.