



Tools for Life: Data Sharing for Public Health

PARTICIPANT INFORMATION SHEET - DELIBERATION DAY

STUDY TITLE

Tools for Life: data sharing for public health. Stage 3: deliberation day

BRIEF SUMMARY

Members of the public, patients, and health professionals are being invited to take part in a deliberation day which aim to test tools developed to enable people to think about the benefits and risks of sharing their patient data for purposes beyond their direct care. There will also be discussion about what encourages or discourages people from sharing their patient data/medical records, and factors which influence peoples' decisions.

Please take time to read the following information carefully and discuss it with others if you wish. Before you decide it is important for you to understand why the study is being done and what it will involve. Please ask us if there is anything that is not clear, or if you would like more information.

PURPOSE AND BACKGROUND TO THE STUDY

Patient data is a valuable resource for research projects seeking to develop new treatments, and for planning to improve healthcare services. It is likely that there will be greater use of patient data in years to come because of improvements in technology and new methods of data analysis. This will make it easier to analyse large amounts of data, and link patient data with data from different organisations. However, little is known about what people think about sharing their patient data/medical records for these purposes; and why they may, or may not, choose to share their data, especially if this is for purposes beyond their direct care.

This study is being funded by the Wellcome Trust with the aim of empowering people to make informed decisions about whether they wish to share their patient data. Your views, experiences and opinions are valuable to us and will be used to understand this important public health topic, and to develop resources to enable people to think about the issues and make up their own mind in a more informed context.

WHY HAVE I BEEN CHOSEN?

You have been chosen because we want to hear the views of different people, patients, and health professionals.

DO I HAVE TO TAKE PART?

It is up to you to decide whether or not to take part. If you do decide to take part you can still withdraw from the study at any time without giving any reason and without any negative consequences. If you decide to withdraw from the study part way through the deliberation day, or if capacity to consent is lost during the study, all of the information collected prior to your withdrawal will be retained and analysed by the study team.

If you are not interested in taking part please disregard this information sheet.

WHAT WOULD TAKING PART INVOLVE?

If you do decide to take part you will be invited to contact the research team. You will then be asked to confirm eligibility, and provide contact details to the study team. We will also ask if you have any requirements or needs for the deliberation day. A member of the study team will then contact you about the date and time of the deliberation days which will be held online on the week beginning 24th May. The event website will be open to view animations and infographics at a time of your choosing (between 24th – 26th May). A live online workshop event will take place on 27th May (10am – 1pm).

The deliberation day will involve working in a small group with other people who have also volunteered. At the start of the event, a member of the study team will introduce you to everyone else in your group. Everyone attending will be encouraged to share their views and opinions about data sharing within this small group. There are no right or wrong answers, we are interested to hear everyone's views.

- You will be asked at the beginning, middle, and the end of the event whether or not you would share your patient data for research or to improve health services. This would be done via an easy to use electronic poll (a simple press button device to say 'yes', 'no', or 'undecided').
- We will share our research findings from interviews and a survey about the benefits and risks of data sharing. You will then have an opportunity to discuss the findings within your small group.
- You will watch short films about the benefits and risks of data sharing.

The Deliberation Day will be video-recorded and contents used for the study analysis, but your anonymity (identification) will be maintained at all times by the study team – we will ask everyone attending to respect the privacy of others when the Deliberation Day has ended. A researcher will also make notes on a flipchart.

There will be regular coffee breaks.

WHAT ARE THE POSSIBLE BENEFITS, DISADVANTAGES, AND RISKS OF TAKING PART?

Your views are valued and important to us. We think that you will find your involvement interesting. Whilst there are no immediate benefits for those individuals participating in the Deliberation Day, it is hoped the findings will provide an increased understanding of how to communicate the benefits and risks of data sharing. This will be useful to help us to develop resources to enable people to make informed choices about sharing data. We hope that the information will also be used to inform wider public debate about data sharing for public health.

Everyone who participates in the Deliberation Day will be offered a £40 Amazon voucher after the Deliberation Day to compensate them for their time and effort and to thank them for their help with the study.

We do not expect that there will be any disadvantages or risks for you in taking part in this study. However, please be assured that if you raise any problems the study team will respond to all issues and views sensitively, as well as confidentially.

WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

All the information collected about you during the course of the study will be kept strictly confidential and will only be accessible to members of the study team. All identifiable data (names and contact details) will be stored confidentially and securely in an access restricted folder on the secure University of Sheffield filestore. Data collected during the Deliberation Day will not be reported, discussed or made available in such a way that will enable you to be identified. Any names, locations, or any other things that could potentially identify you, will be replaced with pseudonyms or broad descriptions. Your name will not be associated with any reports or publications

WHAT IS THE LEGAL BASIS FOR PROCESSING MY PERSONAL DATA?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general/>.

WHAT WILL HAPPEN TO THE DATA COLLECTED, AND THE RESULTS OF THE STUDY?

Members of the study team will use your identifiable data (names and contact details) as needed, to contact you about the study. With your consent Deliberation Days will be video-recorded and then transcribed verbatim. Transcriptions will be anonymised and not include any identifiable information. These data will be kept in an access restricted folder on the secure University of Sheffield filestore, only accessible to members of the study team. We will also collect flip charts used on the day.

Identifiable data will be kept until the completion of the study. With your permission we will use your contact you to invite you to take part in a later Deliberation day. There will be no expectation that you will take part in this event.

Anonymised data will be stored for 5 years on the University of Sheffield's repository ORDA. It will be destroyed after this time.

The findings from the Deliberation Day will be used to further develop tools to help people to think about the issues involved in data sharing, so that people can make an informed choice about whether they wish to share their data.

The results of the study will be written up in a report, as well as in specialist research journals and presented at conferences where the information will be of interest to healthcare professionals, researchers and policy makers throughout the UK and also internationally. Direct quotes from the

Deliberation Days will be used in reports and publications; however, the quotes will be anonymised to ensure that you cannot be identified. At no point will your name be associated with any report, publication or presentation.

Due to the nature of this research it is likely that other researchers may find the data collected to be useful in answering future research questions. Therefore anonymised data may be shared and used in future research.

WHO IS ORGANISING AND FUNDING THE STUDY?

The study is organised by the Information School, The University of Sheffield. The study is funded the Wellcome Trust.

WHO IS THE DATA CONTROLLER?

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

WHO HAS ETHICALLY REVIEWED THE PROJECT?

This project has been given a favourable ethical approval the University of Sheffield ethics committee and by the London, Brighton & Sussex NHS Research Ethics Committee (REC Number:20/LO/0649).

WHAT IF SOMETHING GOES WRONG AND I WISH TO COMPLAIN ABOUT THE RESEARCH?

If something goes wrong please contact Jonathan Foster (Chief Investigator) email: j.j.foster@sheffield.ac.uk, telephone: 0114 222 2665 to discuss any problems. We will take your complaint seriously and do our best to address it immediately.

If you feel your complaint has not been handled to your satisfaction, you can contact Dr Paul Riley, Research Ethics Coordinator, Information School, University of Sheffield (email: ischool_ethics@sheffield.ac.uk, 0114 222 2647) who will then escalate the complaint through the appropriate channels.

If your complaint relates to how your personal data has been handled, you can contact Anne Cutler, The University of Sheffield Data Protection Officer (email: dataprotection@sheffield.ac.uk, 0114 222 1117).

Further information about how to raise a complaint can be found in the University's Privacy Notice: <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>. If you feel your complaint has not been handled to your satisfaction, you can contact the Information Commissioner's Office (ICO): <https://ico.org.uk>.

CONTACT FOR FURTHER INFORMATION

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Thank you very much for taking part in the study.