

# PRESENT: Patient Reported Experience Survey Engineering of Natural Text study

**Information sheet for NHS patients and carers:**

 **Design of our dashboard**

**Ethics number**: 15/NS/0104

This leaflet tells you why our research is being done and what you can expect if you take part. Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to tick a consent box in the initial survey pages. You can ask the study manager, Daria Tkacz, if you have any questions. You can phone her on 023 8059 7962 or email at D.M.Tkacz@soton.ac.uk.

The leaflet covers:

1. What this research study is about – what it’s trying to achieve?
2. Why do we need to involve people like yourself? What are the potential benefits? Are there any risks in getting involved? Are there any expenses?
3. Your safeguards: Will my participation be confidential? What will happen if things go wrong? What if I need to complain?
4. If you are still interested – what happens next?

Please keep this information sheet and you can also save a copy of the survey and its consent pages in case you forget the details later, and as a record of your participation. You will be asked if you want to print the survey at the end of the survey, if you take part.

# What is the study about?

Patients are often asked about their experiences in surveys so that healthcare teams can find out where there are problems and try to improve health services. Most questions in these surveys involve choosing one option from several choices or answering yes or no, or grading an experience by likelihood or severity. These answers are easy to analyse and they have been successfully used to improve services.

However such surveys often include comment boxes where patients are invited to provide details of some aspect of their experience, or bring something to the attention of the researcher, *in their own words.*

These responses are harder to analyse. One of the most successful patient experience surveys, for example, for cancer, called CPES, has over 70,000 comment boxes filled in each year by patients. To analyse these, they must be read by someone and then made sense of – usually by grouping them into different topics or themes and summarising these. This can take months to do.

So we are developing a new automated way of analysing the freetext comment boxes in patient surveys using sophisticated computer technology that still allows us to retain the richness of information from the original freetext.

We are also developing a website page called a ‘dashboard’ that will be able to show the results of our analysis in a practical form that facilitates immediate service improvement. Like car dashboards, our dashboard will give a visual overview of complex data. We will use visuals to summarise themes from our novel analysis, and relevant data that NHS Trusts routinely collect. Each visual can be clicked on for more detail, including original freetext comments.

Patient involvement is fundamental to both of the key aspects of the research and patients and carers have helped us with the first stages of our study already, This included large focus groups, where similar tasks were carried out to those in the survey we are now asking you to do. These tasks will help us design our special ‘dashboard’ in the ways that you will find most useful. We have decided to extend the focus groups with surveys to get more feedback from people like yourselves.

# Why am I being asked to fill in a survey?

We have designed three special surveys:

1. to ask potential users to choose the features of the dashboard – an interactive website
2. To ask users to name the themes we are grouping the freetext comments into, so the names have meaning for users I(a consensus exercise – ie we will choose the names that people tend to agree on)
3. To ask users to choose the pictures that are used as icons for the themes

We are inviting you to fill in one or more of these surveys.

Ultimately we want our special website to present freetext comment box analyses in a way that can be easily understood by patients, carers and healthcare professionals, and that will be useful to each of these.

## What will answering the survey involve?

Each survey comprises between 10-28 questions and we expect each will take you about 20 minutes to complete. You can leave a survey part way through and come back to it later.

# Do I have to fill this in?

No. It is entirely up to you whether or not you take part. If you take part you will be asked to tick a box at the start of the survey saying that you have consented to do it and for us to use your answers in our study. We do not ask you for your name on the survey. We will ask for some information about you such as your age but this will be to help us understand who has filled in the survey so that we can make sure we have not missed important groups of people. We do not ask any information in the survey that enables us to identify you individually and we recommend you avoid giving this information.

Once you press the submit button the survey will be sent to us. This means that while you are filling it in you can change your mind at any time and just avoid pressing submit (or posting the survey to us if you are filling in a paper copy) and we will never know you even tried to take part.

Once you submit your survey we will be unable to destroy your answers as we will have no way of working out which survey responses were yours, unless you also provide your email address in the text box we give for this.

Your responses will be included in our reports and presentations and educational and research materials, but only in aggregated form. What this means is that we will combine all the responses into a summary and will not report them as individual responses. So you could never be identified from the data we publish.

If you choose not to take part, or withdraw from the study at any time after saying you will take part, this will not affect your legal rights. Whether you take part in the study or not there will be no adverse effect to your care.

You may choose to ask for independent information or advice about your rights as a research participant or about being involved in this particular research study by contacting the local Research and Development Department (please see the end of this sheet for contact details).

# Are there any risks involved?

We do not anticipate that there will be any risks to any participants. Although illnesses such as cancer can be distressing, we will not be asking about peoples’ personal experience in the surveys. We will be talking about dashboard design, service improvement and how people talk about disease and healthcare in general. However if you feel anxious or uncertain about your own illness situation as a result of reading this information sheet or taking part in this study, please do not hesitate to contact the Macmillan Cancer Supportline if you have cancer on 0808 808 0000, Monday to Friday, 9am – 8pm.

# Will my participation be confidential?

We have a strict process in place to ensure no-one has access to your data during the study except for the research team. All the information we have about you will be securely stored at the University of Southampton on a password-protected computer.

Each survey will have a Participant ID number. We will always use this code number or a false name and never your name, when storing and analysing and referring to your data. Once the study has ended we are required to store data in a special secure archive at the University of Southampton for 10 years, but this is always anonymised data and there is a secure process in place to restrict access to the data.

We will maintain anonymity – we do not require you to give us your name to take part, and so for many of you we will never know it, and if you have included your email in the survey we will delete it at the end of the study in May 2017.

# What happens once I have taken part?

The data from the surveys will be used to help us finalise our dashboard design, to make sure it is useful and sensitive to the needs of patients and carers as well as healthcare professionals.

Research data will be destroyed after 10 years in line with University of Southampton secure procedures. If you have given us your contact details they will be destroyed at end of the project in May 2017 or within three months of the end of the project.

# Will I be informed about the findings of the study?

Many of you will not have provided your contact details, but even if you have, we will not contact you directly about this. We suggest you check our project website [www.present.org.uk](http://www.present.org.uk), which we will keep updated. The website will also have details about a series of events at the end of the study to which all participants will be invited, and at which our findings will be shared.

One important outcome of our project will be our special website or dashboard. You will be able to access this and explore our analysis. We would welcome feedback from you about what you think of it, as we can alter it even after the study has ended. There will be a special feedback form on the website itself. The website url will be <http://dashboard.present.org.uk/> We hope that this dashboard will be used within the NHS to help them improve services. We also hope that we will continue to analyse data from the National Cancer Patient Experience Survey and to update our dashboard each year with the new survey findings.

# Will there be any benefit to me?

We will make our first dashboard analysis available on the worldwide web. You or people you know may find this useful and informative.

If you wish, you may be acknowledged by name for your help in designing this, on our University of Southampton study website or the website you help to develop, itself. However this would mean people might make assumptions about which bits of data are yours.

We also hope that our approach can be transferred to other surveys. The benefits to health services are therefore potentially huge and so you may benefit indirectly from the study at a later date, through improved healthcare.

# Who has reviewed this study?

This study has been reviewed by patients as well as independent experts in this area of research. It has also been considered by a Research Ethics Committee – an independent group of people which works to protect your interests.

# Who is organising and funding the research?

The research is funded by the National Institute for Health Research under its Health Services and Delivery Research programme. Dr Carol Rivas at the University of Southampton is leading the study with a team of experienced researchers and healthcare experts from around the country.

None of the research team is able to deal with individual aspects about your condition or its treatment and many of them are not medically trained. If you have concerns about your personal illness or personal care please speak to your GP or another healthcare professional involved in your treatment.

# What happens if something goes wrong or I wish to complain?

If you have a concern or a complaint about this study you should contact the Research Governance Office (Address: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ; Tel: +44 (0)23 8059 5058; Email: rgoinfo@soton.ac.uk).   If you remain unhappy and wish to complain formally the Research Governance Office can provide you with details of the University of Southampton Complaints Procedure.

# Where can I get more information?

Please contact the project’s principal investigator, Dr Carol Rivas, if you have any questions, on 023 8059 8532. You can also look at our website [www.present.org.uk](http://www.present.org.uk), which we will keep updated with new information, including reports and articles about our study and its findings when they are published.

For general enquiries about research participation, please contact the Research Governance Office (Address: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ; Tel: +44 (0)23 8059 5058; Email: rgoinfo@soton.ac.uk).

# I am still interested, what is the next step?

Your next step is to look at the survey. If you need a paper copy or have lost your paper copy please contact us on 023 8059 7962 or via email at D.M.Tkacz@soton.ac.uk.

Thank you for taking the time to read this information.