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Developing a Resource for Healthcare Professionals to Facilitate Family Centred Conversations

CUREC Approval Reference: R74959/RE001

General Information

The aim of this study is to develop a training resource for healthcare staff to help them support their patients with these family-centred conversations. Every day, adult patients are being told that they have a serious health condition such as heart disease, cancer or lung disease. Many of these patients will have important relationships with children (for example as a parent, grandparent, auntie or uncle) and need to decide what and how to share the news of their diagnosis with these children.

Studies have found that adult patients want help from their healthcare team to think about talking to children, but that this support is not always easy to access. Other studies have found that healthcare staff would like more training to better support their patients around talking with children. This is important because research has found that effective communication in families can promote families' psychological wellbeing when an adult is seriously ill.

We appreciate your interest in participating in this survey. You have been invited to participate as you are healthcare professional with experience of working with adult patients who have a serious illness. We are looking for healthcare professionals from a range of clinical disciplines who are working with adult patients (age 18 years and older) who have a serious illness in a UK NHS setting.

Please read through this information before agreeing to participate (if you wish to) by ticking the 'yes' box below.

You may ask any questions before deciding to take part by contacting the researcher (details below). The Principal Researcher is Dr Louise Dalton, who is attached to the Department of Psychiatry at the University of Oxford.

We would like you to answer 5 Likert-style questions about your usual practice when talking to patients. We would then like to you to look at the new resource we have developed. Once you have looked at this resource we will ask you the same 5 Likert-style questions and 3 further questions about your opinion of the film. This entire process should take 8-10 minutes. No background knowledge is required.

Your answers and data are anonymous. We will download the research data and store these on secure servers at the University of Oxford.

Do I have to take part?

No. Please note that participation is voluntary. If you do decide to take part, you may withdraw at any point for any reason before submitting your answers by pressing the 'Exit' button/ closing the browser.

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We have included a 'Prefer not to say' option for each set of questions should you prefer not to answer a particular question.

How will my data be used?

We will not collect any data that could directly identify you. Your IP address will not be stored. We will take all reasonable measures to ensure that data remain confidential. The responses you provide will be stored in a password-protected electronic file on University of Oxford secure servers and may be used in academic publications, conference presentations, reports for external organisations, websites, videos. Research data will be stored for 3 years after publication or public release of the work of the research.

Who will have access to my data?

The University of Oxford is the data controller with respect to your personal data and, as such, will determine how your personal data is used in the study. The University will process your personal data for the purpose of the research outlined above. Research is a task that we perform in the public interest. Further information about your rights with respect to your personal data is available from <https://compliance.admin.ox.ac.uk/individual-rights>.

Who has reviewed this study?

This project has been reviewed by, and received ethics clearance through, a subcommittee of the University of Oxford Central University Research Ethics Committee [Ref: R74959/RE001].

Who do I contact if I have a concern or I wish to complain?

If you have a concern about any aspect of this study, please speak to Dr Louise Dalton, louise.dalton@psych.ox.ac.uk, 01865 who will do their best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible.

Medical Sciences Interdivisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Headington, Oxford OX3 7GB.