

Key pERforMance Indicators in electronic paTient reported outcome measures – The KERMIT project

You are being invited to take part in a research project because you have been identified as a user of electronic patient reported outcome measures (ePROMS). It is important for you to understand why the research is being done and what it will involve before you agree to take part. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information. Please take your time to decide whether or not you wish to take part.

Please note that consent will be taken as given if you respond to the initial questionnaire.

Background

The use of patient reported outcomes measures (PROMs) has been shown to improve health outcomes, patient experience and survival in patients with cancer. It is likely that the use of PROMs in routine clinical care will increase in the coming years.

Key performance indicators (KPIs) are measures that assess the performance of a system to ensure reproducibility and reliability. The definition of what counts as a KPI is flexible and reflects what is considered to be important in an individual setting. In the context of cancer treatment, a KPI could reflect different domains such as patient experience and outcome, clinician experience and service impact.

In the NHS there is an increasing drive for clinical practice to be electronic. This has coincided with the development of several different electronic PROM platforms for patients with cancer. Several of these platforms are already in clinical use and have internal assessment; however there is currently no way to compare the performance of different ePROMs systems across a range of perceived important outcomes. This project seeks to define a framework of KPI's which can be used to support the assessment of ePROM implementation in routine care.

A Delphi consensus methodology will be used to define a battery of KPIs for use in future implementation projects. A structured literature review will identify potential performance indicators of relevance to applied PROMs including, for example, patient experience and outcomes, clinician engagement and health service impacts.

Your role

You have been identified as having expertise or experience of the use of electronic patient reported outcomes in cancer. Your participation is entirely voluntary.

As a participant, you will be asked to complete a series of questionnaires as part of the Delphi process. In the first questionnaire, you will be asked to give feedback on whether certain Key Performance Measure are useful in ePROMs implementation. There will also be opportunity for other suggestions and written responses.

Once the first questionnaire has been completed, your response will be analysed by the research team to give the group feedback. Participants in further rounds will be asked to revisit their answers in light of the group feedback.

You will be sent two reminder emails to complete each questionnaire. If we do not hear from you after these two reminders, we would assume that you do not want to participate any more and we will delete your email address.

You can withdraw from the project, by emailing the study team, at any time with no loss and do not have to give a reason. Your email address will be immediately deleted. If you decide to withdraw after you have submitted a response, we will keep your previous responses unless you email asking for them to be deleted as well within 2 weeks of the questionnaire hand-in deadline. Due to us creating group feedback from the responses, we will be unable to delete your individual responses after this time.

Consent will be taken as given if you respond to the initial questionnaire.

Personal information?

The Delphi process will take place online via the REDCap questionnaire system. You would be emailed a login to that system so no personal data will be required to use the online questionnaire. The online questionnaire will begin by asking you for basic demographic data which will be presented in any results as group demographics.

Email addresses will be kept during the study to enable distribution of the questionnaire and to enable the sending of reminder emails as discussed above. Email addresses will be deleted once the study has been concluded or if you ask for them to be removed. Basic demographic information including age bands, gender, country of residence, current job, educational qualification and time in a relevant field will be collected. No other personal data will be collected.

Email addresses will be stored separately attached only to your study ID in a secure file away from any other information of the study. Your responses will only be linked to your study ID. This will help maintain your confidentiality and personal data. We will anonymise the research data so that you will not be identifiable in any reports or publications. Consent is given by participating in the study and agreeing to be part of the study.

What will happen to the results of the research project?

The research project has been supported by the National Cancer Research Institute living with and beyond cancer methodology group. The results of this study will be shared with the group and disseminated within the National Cancer Research institute

The output will lead to the creation of a Key Performance Indicator Framework and guidelines for UK Cancer ePROMs Adopters. The results, framework and guidelines will be published in a peer reviewed publications and conferences

Who is organising/ funding the research?

This research has received no funding

Contact for further information

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