

Attitudes to ePRO PPI survey

Within health care and clinical trials, questionnaires can be used to collect information from patients on the impact that treatments and health conditions may be having upon their quality of life. This data is called patient reported outcomes (PRO). This can include general information such as mobility and tiredness, as well as more disease or treatment specific questions such as those about bowel movements or sexual function.

Traditionally, these questionnaires are provided to patients on paper for them to complete either during clinic or at home. If these are used as part of a clinical trial, they will then be posted to the research team running the clinical trial for the information to be added to a database.

More recently patients have been offered the opportunity to complete these questionnaires electronically such as via a website or a mobile phone app. Some studies have shown that there can be different factors which can limit an individual's willingness to complete these questionnaires electronically.

The Institute of Cancer Research Clinical Trials and Statistics Unit would like to introduce electronic questionnaires to the participants of the clinical trials it conducts. To be sure that this will be successful and user friendly we would like to gather your opinions about the electronic collection of health questionnaire responses and what may be barriers for trial participants wishing to complete questionnaires electronically.

Your response will be anonymous unless you choose to provide us with your personal details at the end of the survey.

Individual Details

We are collecting these details in order to understand what groups of participants have filled out the survey so that we can be sure that we are getting a variety of groups of people responding and make sure our results are not biased.

Age

- <20
- 21-30
- 31-40
- 41-50
- 51-60
- 61-70
- 71-80
- 81-90
- >90

Gender

- Male
- Female
- Other

Ethnicity

Please choose one option that best describes your ethnic group or background

White

- English/Welsh/Scottish/Northern Irish/British

- Irish
- Gypsy or Irish Traveller
- Any other White background, please describe

Mixed/Multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed/Multiple ethnic background, please describe

Asian/Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background, please describe

Black/ African/Caribbean/Black British

- African
- Caribbean
- Any other Black/African/Caribbean background, please describe

Other ethnic group

- Arab
- Any other ethnic group, please describe

Household Income

Approximately what is your household's current total gross/pre-tax salary or income (including pension)?

- Less than £18,000
- £18,001-£25,000
- £25,001-£35,000
- £35,001-£40,000
- £40,001-£50,000
- >£50,000
- Prefer not to say

Education

Which of the following best describes your highest level of education completed?

- Less than compulsory education (left school prior to age 16)
- Compulsory school education (up to the age of 16)

<ul style="list-style-type: none"><input type="checkbox"/> Apprenticeship<input type="checkbox"/> Further education (6th form college or equivalent)<input type="checkbox"/> Higher education (undergraduate degree)<input type="checkbox"/> Higher education (post graduate degree)<input type="checkbox"/> Professional qualification (e.g. accountancy/nursing)<input type="checkbox"/> Other, please specify
<p>Which of the following best describes you? (please select the most relevant option)</p> <ul style="list-style-type: none"><input type="checkbox"/> Previous or current participant within a clinical trial<input type="checkbox"/> Patient currently receiving cancer treatment (but not participating within a clinical trial)<input type="checkbox"/> Patient who has previously received treatment for cancer (but did not participate within a clinical trial)<input type="checkbox"/> Healthcare professional/researcher<input type="checkbox"/> Other member of the public
<p>Please let us know where you heard about this survey:</p>
<p style="text-align: center;"><u>Your use and experience of technology</u></p>
<p>Are you comfortable using any of the following? (please tick all that apply)</p> <ul style="list-style-type: none"><input type="checkbox"/> Smart phone<input type="checkbox"/> Tablet computer<input type="checkbox"/> Laptop or desktop computer<input type="checkbox"/> None of the above
<p>Do you currently have an email address?</p> <ul style="list-style-type: none"><input type="checkbox"/> Yes<input type="checkbox"/> No
<p>Do you have access to internet at home or via your mobile?</p> <ul style="list-style-type: none"><input type="checkbox"/> Yes<input type="checkbox"/> No
<p>Have you ever filled in an online survey?</p> <ul style="list-style-type: none"><input type="checkbox"/> Yes<input type="checkbox"/> No
<p>Have you ever used an online reporting tool in relation to your health?</p> <ul style="list-style-type: none"><input type="checkbox"/> Yes

<input type="checkbox"/> No										
How would you answer a health questionnaire?										
<p>Would you prefer to answer a health questionnaire on paper or online (via a website or mobile phone application)?</p> <input type="checkbox"/> Paper <input type="checkbox"/> Online										
<p>If your preference would be paper: Would you be willing to complete a health questionnaire online if requested?</p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A										
<p>If you were answering a healthcare questionnaire online would it be more comfortable using a website or a mobile phone application?</p> <input type="checkbox"/> Website <input type="checkbox"/> Mobile phone application <input type="checkbox"/> No preference										
<p>If you were to complete the health questionnaires electronically would you be happy to receive emails, or notifications on your phone, to let you know you have questionnaires available to complete?</p> <input type="checkbox"/> Yes <input type="checkbox"/> No										
<p>Please select the most appropriate response for each statement below</p> <p>I am worried about potential breaches in the privacy of my data when completing a health questionnaire <i>online</i></p> <table border="1" style="width: 100%; text-align: center; border-collapse: collapse;"> <tr> <td style="padding: 5px;">Strongly disagree</td> <td style="padding: 5px;">Disagree</td> <td style="padding: 5px;">Neither agree or disagree</td> <td style="padding: 5px;">Agree</td> <td style="padding: 5px;">Strongly agree</td> </tr> </table> <p>I am worried about potential breaches in the privacy of my data when completing a health questionnaire <i>on paper and sending it in the post</i></p> <table border="1" style="width: 100%; text-align: center; border-collapse: collapse;"> <tr> <td style="padding: 5px;">Strongly disagree</td> <td style="padding: 5px;">Disagree</td> <td style="padding: 5px;">Neither agree or disagree</td> <td style="padding: 5px;">Agree</td> <td style="padding: 5px;">Strongly agree</td> </tr> </table> <p>I am worried about potential breaches in the privacy of my data when completing a health questionnaire <i>in a clinic</i></p>	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree						
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Do you have any other thoughts about introducing electronic patient questionnaires into a clinical trial?				
<u>Focus Group</u>				
Would you be interested in taking part in a focus group to comment on the design and ease of use of an electronic patient reporting system?				
<input type="checkbox"/> Yes <input type="checkbox"/> No				
If yes please give your name and contact details below,				
Name				
Address				
Telephone number				
Email address				