

Participant information – quality standard for rare disease online survey

General Information

The aim of this project is to develop a set of quality statements for what good care looks like in rare diseases.

We appreciate your interest in participating in this survey.

You may ask any questions before deciding to take part by contacting the quality standard project group – please email anna@principleconsulting.org.uk.

As part of this survey, you will be asked to rank a set of statements about rare disease care, based on how important they are to you. This should take about 20 minutes. No background knowledge is required.

The data from the survey will help us to develop a set of quality statements for rare disease, based on the statements and themes which are most important to the community.

We will also ask for non-identifying information about you, such as your role in the rare disease community, the disease group which is most relevant to you, and the UK nation which is most relevant to you, as well as some questions for equality and diversity monitoring. The purpose of these questions is to ensure that the output from the survey reflects the diverse range of experiences across the rare disease community.

Finally, we will also provide the option to share your email address, so that we can contact you with a link to take part in the next survey round. This is optional, and your if you choose to share your email address, it will be stored separately from your survey responses – they will not be associated. The email addresses will be deleted once we have shared the link to the next survey round via email, or after 24 months, whichever is sooner.

Please note that you may only participate in this survey if you are 18 years of age or over.

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.

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?

The data we will collect that could identify you will be email addresses – sharing your email address is optional. If you choose to share your email address, it will be stored separately from your survey responses – they will not be associated. Email addresses will be deleted once we have shared the link to the next survey round via email, or after 24 months, whichever is sooner.

Your IP address will not be stored. We will take all reasonable measures to ensure that data remain

confidential.

Who will have access to my data?

The rare disease quality standard project group is the data controller with respect to your personal data and, as such, will determine how your personal data is used in the research, and will process your personal data for the purpose of the project outlined above.

Who has reviewed this research?

This research has been reviewed by, and received ethics clearance through King's College London.

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

If you have a concern about any aspect of this research, please contact the quality standard project group, by contacting anna@principleconsulting.org.uk, and we will do our best to answer your query.