

Transforming Data for Trials Public Advisory Group

Interested in helping shape how health research is carried out? No experience required - just you, your time and your thoughts!

Expression of interest form: [Click Here](#)

Researchers across four universities (Oxford University, University College London, Cardiff University and Dundee University) are working with Health Data Research (HDR) UK to improve how medical research (in particular trials) uses patient data. This includes helping researchers have the information and skills to use patient data in a secure and ethical way. Including the voice of the public is essential in ensuring the trust held in researchers using patient data is upheld and maintained.

Researchers often work with members of the public who have experience of the health condition that the trial is aiming to help. But for this project, we're looking for anyone who has an interest in how patient records or data can be used in health trials. You may have taken part in other research as a public contributor or as a participant which is great! - But if you haven't, that's okay too and we can support you! You will have a named person you can contact with questions at any time.

What will be involved?

We are looking for 10 – 15 members of the public from across the UK to make up a 'public advisory group' for the project. The project runs until March 2028 however you do not need to commit to the whole duration of the project.

The first meeting will be in early 2024. We'll aim to meet as a group every six months, with the meetings lasting no more than two hours. Meetings will be arranged for a time that suits as many of the group as possible. All meetings will be online using Teams or a similar platform – we'll make sure to consider any special requirements and provide instructions and meeting links ahead of time. To participate, you will need an email address, and the ability to review documents and attend meetings online.

The first meeting will provide an introduction to the project including the planned work that we are hoping members can contribute to over the 4 years. Throughout the project, opportunities will be communicated by email. We will also give people the chance to get involved in different parts of the project during the meetings. You can choose which elements to contribute to, based on your interest and availability at the time.

What will I be asked to do?

To start with we will be asking for members to support the work Cardiff University are doing. Cardiff are developing online training videos on a range of topics related to how researchers use patient data (such as hospital or GP records) in trials [[See their study webpage here](#)]. These videos will be aimed at both researchers and members of the public. Members will help the team to decide what is important to include in different training topics, in particular from the public's viewpoint.

Some examples of topics that will be included:

- consenting to a trial that uses patient records,
- sharing trial data for further research (and why the public should be informed),

- why data should be of high quality for trials to use
- how to achieve privacy protection of patient records for trials

For most training topics, interested members will meet as a smaller group to discuss what to include from the public's viewpoint and then review a draft of the video script over email (or in a meeting if required). Some members may also wish to be involved in filming short clips for the videos, *but you wouldn't have to do this and we would ask permission for any filming*. Time commitments will vary depending on the topic but are flexible and will be agreed at the start of each training topic.

What will I be offered?

We can pay you for the time you give to our project (including attending meetings and reviewing documents) at the NIHR rate of £25 per hour. Individuals can request less, for example if they are in receipt of state benefits.

Who are you looking for?

We are looking for anyone with an interest in how patient records or data can be used in health trials. We are looking for a diverse range of experiences and points of view, from across all four nations of the UK. We are therefore asking that anyone (aged 18 and above) interested completes an expression of interest where they state their interest in this opportunity and how their experiences will contribute. Depending on how many individuals express an interest, we may arrange brief telephone or video calls to make sure we have as diverse a group as possible and to discuss any accessibility requirements.

What will happen next?

The deadline for expressing an interest is 20th Feb 4pm. Depending on how many individuals express an interest, we may arrange brief telephone or video calls to make sure we have as diverse a group as possible. We will email from ppie@ndph.ox.ac.uk to let you know.

Where can I get more information?

Any questions please email Sadman (Shad) Islam, Senior Public & Patient Involvement & Engagement Officer at Oxford Population Health, email address: ppie@ndph.ox.ac.uk or visit our workstream website <https://www.hdr.uk/research/research-data-infrastructure/transforming-data-for-trials/>

Expression of interest form URL:

<https://forms.office.com/e/YiKU1Wq6GM>