**Participant Information Sheet (PiS): Survey**

**Does using the FBMH (Faculty of Biology, Medicine and Health) Quality Mark improve Patient and Public Involvement and Engagement (PPIE) in research and teaching projects?**

You are being invited to participate in a research project looking at whether the use of a quality mark will improve Patient and Public Involvement and Engagement (PPIE) in research and teaching.

Before you decide whether to take part, it is important for you to understand why you are being asked to participate and what will be involved. Please take time to read the following information carefully before deciding whether to take part. You may want to discuss it with others if you wish.

Please ask if there is anything that is not clear or if you would like more information, contact details are provide at the end of this information sheet.

Thank you for taking the time to read this.

**About the research activity**

**Who will conduct the activity?**

Kay Gallacher, Public Contributor, Samantha Franklin, Social Responsibility Project Officer and Dr Hawys Williams, Social Responsibility and Public Engagement Manager from the Faculty of Biology, Medicine and Health, The University of Manchester will conduct the research activity.

We have been awarded a part-time [Open Research Fellowship](https://www.openresearch.manchester.ac.uk/projects/or-skills-training/fellowship-programme), funded by Research England to undertake this work, through The University of Manchester.

**What is its purpose?**

We want to find out if using a quality mark (available here: <https://www.staffnet.manchester.ac.uk/bmh/social-responsibility/ppie/ppie-quality-mark/>) improves Patient and Public Involvement and Engagement (PPIE) in research and teaching projects in practice.

We want to test if the benchmark criteria we have set are suitable, if applying the quality mark criteria improves the quality of PPIE and if this self-assessment tool is suitable and useable for a range of different types of research and teaching projects. We then intend to create a digital tool version of the quality mark.

Our initial project will focus predominately on PPIE in research projects, however we still welcome comments from you if your involvement/engagement is focussed on teaching.

You have been chosen as a potential participant as you are a member of staff, student, or member of the public and are either involved or have an interest in PPIE.

**Am I suitable to take part?**

All participants must be over 16 years of age and be able to provide informed consent. You must be involved or have an interest in PPIE by either having conducted/been involved in PPIE previously or about to get involved/conduct PPIE.

You must be a member of staff, student, or member of the public and can be of any gender and ethnicity. You can be affiliated with any organisation that conducts or supports PPIE e.g. NHS, NIHR, NCCPE, Universities etc. No specific medical condition is required.

Due to the nature of the project, all participants will be able to understand verbal and written English. Furthermore, due to the project being time and funding limited (12 months and staff/public contributor time) we will not be able to organise or fund translation services.

**Will the outcomes of the activity be published?**

We intend to share the results of our findings through a range of channels including social media outlets, webpages, newsletters/digest, blogs, presentations, written reports, publications, etc. We also intend to create a digital version of the quality mark.

As a participant, you can be kept informed of the outcome of the project by joining our distribution list. You will be able to opt in to receive this when you complete the survey, focus group, interview or workshop, and can opt out at any time.

**Who has reviewed the research project?**

The project has been reviewed and received ethical approval by The University of Manchester Proportionate Research Ethics Committee on 2nd February 2024 (Ref: 2024-18525-32907).

**Who is funding the research project?**

Our project is funded by an Open Research fellowship awarded by [The University of Manchester’s Office for Open Research](https://www.openresearch.manchester.ac.uk/projects/or-skills-training/fellowship-programme). The funding for the Office for Open Research was awarded to the University by Research England UK.

**My involvement**

**What would I be asked to do if I took part?**

You will be asked to complete a survey (on-line or hard copy), giving feedback on your thoughts of the quality mark concept, taking approximately 15 minutes.

You may also be invited to take part in one or more of the following:

* A focus group, made up of up to 10 people, a mix of staff, researchers, students, public contributors either in person or on-line lasting maximum of one and a half hours. You will be asked to give your thoughts on the quality mark and how it could be improved.
* One to one semi-structured interview, either in person or on-line lasting maximum of one hour, giving your views on the ease of use of the quality mark and how it could be improved.
* A workshop in person at the FBMH PPIE Celebration event, July 2024. Comprising of a mix of staff, students, researchers, public contributors, lasting approximately 1 hour, introducing the project, finding out ways to extend the use of the quality mark and how to best implement it nationally.
* A case study, writing about your project and your experience of using the quality mark

You are free to choose which parts of the study that you participate in. A separate participant information sheet will be provided for each activity.

This project is a low-risk study. Therefore, we envisage few risks for our participants. We expect that our participants will benefit from contributing to a live research project, helping to shape the creation of a new PPIE quality mark through critical feedback and be given the opportunity to reflect on the role of PPIE within their own organisational practices.

Any risks will be mitigated by the research team through the design and management of the research project (e.g. using a comprehensive data management plan to protect participant data collected as part of the research project).

**How long will the activity take and where will it take place?**

Timings as above. Interviews and focus groups will take place online via Zoom or in person at The University of Manchester (exact venue tbc). The workshop is for attendees of the PPIE Celebration event only and will take place at The University of Manchester (venue tbc).

**Will I be paid for taking part?**

No, as this is a research project, you will not be paid for taking part, however, we will provide reasonable travel expenses where required (e.g. for public contributors attending focus groups in person). Travel expenses payments will be provided by the Social Responsibility and Public Engagement Team funded by the Open Research fellowship detailed above.

**What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether you want to take part. If you decide not to take part, you do not need to do anything further.

If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. You can leave this research project at any time without giving a reason and without detriment to yourself. However, if you have provided data that has been anonymised it will not be possible to remove your data from the project once this has happened as we will not be able to identify it. This does not affect your data protection rights.

We will audio and/or video record the interviews and focus groups. You will be free to decline the recording and/or stop the recording at any time if you are not comfortable with it. The reason for audio/video recordings is that it will enable the research team to analyse the research findings more easily. Any outputs will be fully anonymised, and the recordings will be deleted at the end of the project.

**Data Protection and Confidentiality**

**What information will you collect about me?**

For you to participate in this project, we will need to collect information that could identify you, called “personal identifiable information”. Specifically, we will need to collect:

* Your name
* Contact details
* Job title (where relevant)
* Record of consent
* A recording of your voice and face (Zoom conversation)

We will only ever collect information that is appropriate and necessary. We will only use face and voice recordings to help us to transcribe the project outputs. Recordings will not be shared with anyone else outside the project team.

**Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with UK data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

We may also use your personal information in the following situation, which is likely to be rare: “Where we need to protect your vital interests (or someone else’s interests)”

If we require your consent for any additional uses of your personal information, including your image and more sensitive personal information (e.g. ‘Special Category Data’) we will obtain it.

**What are my rights in relation to the information you will collect about me?**

You have several rights under data protection law regarding your personal information. For example, you can request a copy of the information we hold about you, including audio recordings or photographs.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice for Research](https://documents.manchester.ac.uk/display.aspx?DocID=37095).

By law you have rights in relation to the personal information we hold about you. These include the right to:

* See the information/receive a copy;
* Correct inaccurate information;
* Have any information deleted;
* Limit or raise concerns to our processing of the information;
* Move your information (‘portability’);

The above would be granted unless it is legally prohibited and/or would put you or another person at serious risk of harm.

**Will my involvement be confidential, and my personal identifiable information be protected?**

Your personal information will be always kept confidential. In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential, and used only in the way you have been told it will be used.

All researchers are trained with this in mind, and your data will be looked after in the following way:

* The study team will store your identifying information (name and contact details) securely and separately from your study data.
* Your data will be marked with an ID number and not your name. The key for linking your ID number to your identity will be accessible only to the research team. Once all the data has been analysed, we will destroy the key, anonymising your data.
* Your consent form (including your name and signature) will be retained separately for 5 years after the end of the study.
* We are also required to keep your data past the research project end date as we would like to extend the range of the quality mark to also focus other areas of the involving the public e.g. participatory research, PPIE in teaching etc. and may need to refer to your comments.
* We will also ask for your permission to keep your contact details on file and contact you about future studies that you might be interested in. If you provide consent for this, your details will be safely stored on University servers in a digital folder only accessible to the study team and used only for the purposes described above.
* We will also ask for your permission to keep your contact details on file and contact you about the outcome of the project. If you provide consent for this, your details will be safely stored on the University’s servers in a digital folder only accessible to the study team and used only for the purposes described above. You can opt out of these communications at any time.

**Recordings**

The recordings will be transcribed by a member of the research team and will be recorded in Zoom. Your personal data will be processed by Zoom. This may mean that your personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the United Kingdom to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the Data Protection Act 2018 and the UK General Data Protection Regulation are in place.

The recordings will be removed from the above third-party platform and stored on The University of Manchester’s managed file storage as soon as possible following the completion of data collection. Recordings will then be deleted at the end of the project.

In accordance with The University of Manchester’s Research Privacy notice and with your consent, we would like to be able to share your anonymised data with other University of Manchester researchers who are doing studies like ours.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this project to make sure it is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the project will have a strict duty of confidentiality to you.

**What if I have a complaint?**

If you have a complaint that you wish to direct to members of the research team, please contact **Hawys Williams (**[**hawys.williams@manchester.ac.uk**](mailto:hawys.williams@manchester.ac.uk)**) or Samantha Franklin (**[**samantha.franklin@manchester.ac.uk**](mailto:samantha.franklin@manchester.ac.uk)**) Tel: 0161 306 6797**

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researcher in the first instance, then please contact:

**The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing:** [**research.complaints@manchester.ac.uk**](mailto:research.complaints@manchester.ac.uk) **or by telephoning 0161 306 8089.**

If you wish to contact us about your data protection rights, please email [dataprotection@manchester.ac.uk](mailto:dataprotection@manchester.ac.uk) or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner’s Office](https://ico.org.uk/make-a-complaint/) about complaints relating to your personal identifiable information Tel 0303 123 1113

**Contact Details**

If you have any queries about the information provided or you are interested in taking part, then please contact: **Name: Sam Franklin and/or Hawys Williams, (**[**samantha.franklin@manchester.ac.uk**](mailto:samantha.franklin@manchester.ac.uk)**;** [**hawys.williams@manchester.ac.uk**](mailto:hawys.williams@manchester.ac.uk)**)**