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Faculty of Biology, Medicine and Health’s Template Information Sheet for Public Contributors involved in

Patient and Public Involvement and Engagement (PPIE)

Adapted from The University of Manchester’s Participant Information Sheet for medical studies.

This is a template Public Contributor Information Sheet**.** It is recommended that you use the same headings for your sheet(s), adding sections and changing order as appropriate for your PPIE activity.

This information sheet should be used alongside the Public Contributor appointment letter: <http://documents.manchester.ac.uk/display.aspx?DocID=46393> and the ‘Being a Public Contributor guide’: <http://documents.manchester.ac.uk/display.aspx?DocID=41420>

If using a hard copy version of the Information Sheet, please ensure you include the full URL of any links you add or a hard copy of the documents are printed and attached to the information sheet.

**Important note:** the information described in this template should be adapted, where necessary, including when Public Contributors are children, adults with learning difficulties or non-English speakers.

We have provided guidance notes in **red** for you to consider, please ensure you replace these with your own text or delete sections if not appropriate to your project (e.g. DBS checks). In all of the example text provided below you **must change the wording in red** to reflect the details of your PPIE activity. **You should also delete this guidance section before sending**.

**Inset Title of PPIE activity Information Sheet**

You are being invited to be involved in [**insert PPIE activity and include** **why you are wanting them to be involved e.g. to advise**].

Before you decide, it is important for you to understand why you are being asked to be involved and what will be involved. 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 the information sheet.

**About the activity**

**Who will conduct the activity?**

Insert the name, Division/School affiliation, The University of Manchester and name any other collaborating institutions.

**What is its purpose?**

Provide a brief and simple explanation of what you are hoping to achieve with your PPIE activity

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

Provide details of anticipated outcomes and if public contributors will be informed of the outcome or whether they will be published e.g. journals, student thesis, social media.

**Disclosure and Barring Service (DBS) Check (If this section is not relevant please delete)**

Provide a statement declaring that you who may have access to children or vulnerable adults has undergone an appropriate level of DBS check (as determined by their School and obtained either via The University of Manchester or another external organisation).

**My involvement**

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

Describe what you would like the public contributor’s role to be during the activity as well as what they will be expected to do and, specifically, where/when this will occur (location and venue). This should be laid out in order, as a ‘journey’ and also include details of any possible risks/benefits to them.

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

Provide details of the duration of the activity (e.g. 3x ½ hour interviews; 1x 30 minute questionnaire etc) including how long in total they will be involved (from consent to final visit). It may be helpful to include a flow chart or diagram here.

If the public contributor will require any form of support (such as from family members, friends or carers) during the course of their involvement this should be laid out in detail.

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

Provide a clear statement of payment arrangements for compensation for the Public Contributor’s time and inconvenience and any out-of-pocket expenses, if applicable. For further details see the Faculty’s fees and payments guidance for PPIE: <http://documents.manchester.ac.uk/display.aspx?DocID=40790>

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

It is up to you to decide whether or not to take part. Give details here about how the public contributor should inform you whether they want to take part or not.

If you do decide to take part you will be given this information sheet to keep and will be asked to sign a volunteer appointment form **[template Public Contributor appointment form:** <http://documents.manchester.ac.uk/display.aspx?DocID=46393>**]**. You can leave this involvement opportunity 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. [delete this section if not applicable]

If you decide not to take part you do not need to do anything further.

For audio/video recordings you must explicitly state whether Public Contributors are free to decline the recording or whether it is essential to their participation. You must also state that they should be comfortable with the recording process at all times and they are free to stop at any time.

For a template PPIE distress protocol visit: <http://documents.manchester.ac.uk/display.aspx?DocID=46877>

**Data Protection and Confidentiality**

**Information about you.**

In order to volunteer we will need to collect information that could identify you, called “personal identifiable information”. Specifically we will need to collect:

List the personal information you will be collecting in bullet point format.

For [audio/video recordings](http://documents.manchester.ac.uk/DocuInfo.aspx?DocID=38446%20) you must state: (delete if not applicable)

* what the recordings/photographs will consist of (e.g. voice only, facial features, full body, surrounding environment, other individuals, etc) and how they are obtained (e.g. during a focus group discussion, asking participants to take images or recordings of their lives, etc)

We will only ever collect information that is appropriate and necessary.

**The legal part**

Data protection law requires us to have a valid legal reason to process and use personal data about you, known as a ‘legal basis’. For PPIE activities, the specific reason is that it is “a public interest task” and “necessary for the pursuit of the legitimate interests of the University (i.e. PPIE)”.

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?**

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.

To find out more about your different rights or the way we use your personal information to ensure we follow the law, please visit our PPIE Privacy Notice: <http://documents.manchester.ac.uk/display.aspx?DocID=43063>.

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

Your personal information will be kept confidential at all times. The University as Data Controller, [If UoM is not the sole Data Controller this will need to be revised and the other data controller added] will remain responsible for keeping your information safe. We would not share information with other people or organisations about you or pass on your contact details without your permission. All staff members are trained in data protection, and your data will be looked after in the following way:

**Important note:** The University requires identifiable data to be anonymised as soon as the objectives of the project allow. The standard retention period for data once anonymised is 5 years unless funders or regulators have specified longer retention requirements.

To find out how long the data you have collected can be stored please visit the University records retention schedule: <https://www.staffnet.manchester.ac.uk/igo/records-information-management/retention-schedule/>

Provide details of:

* + the measures you will take to ensure confidentiality
  + If and when you will be anonymising the data and whether it will be fully anonymised or [pseudonymised](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/what-is-personal-data/what-is-personal-data/).

For each description below you should be clear whether the data will be identifiable or anonymous.

* + Where data will be held (e.g. University shared drive)
  + when/how it will be transferred (if applicable)
  + How long data will be stored – see records retention schedule above
  + If data is transferred outside the EU or to any cloud services, what will happen to the data at the end of the study
  + If you will be sharing the data with any other organisation
  + If you will be keeping data or contact details for use in future PPIE activities

**Example:** Only the Social Responsibility and Public Engagement (SRPE) team at The University of Manchester will have access to your personal information, but they will anonymise it as soon as possible. Your name and any other identifying information will be removed and replaced with a random ID number. Only the SRPE team will have access to the key that links this ID number to your personal information. Your consent form and contact details will be retained for X years (describe where, why and how).

**Potential disclosures:**

If the nature of the project means that individuals outside of the PPIE team may need to be provided with details about the public contributors involvement in the study, this should be stated and included in the **consent form. Examples include:**

If, during the project, we have concerns about your safety or the safety of others, we will inform your GP/care team/family member.

If, during the project, you disclose information about misconduct/poor practice, we have a professional obligation to report this and will therefore need to inform your employer/professional body.

If, during the project, you disclose information about any current or future illegal activities, we have a legal obligation to report this and will therefore need to inform the relevant authorities.

Individuals from the University, the site where the project is taking place and regulatory authorities may need to review the information for auditing and monitoring purposes or in the event of an incident.

**For audio/video recordings or photographs you must state the following:**

* If the recordings will be used to create transcripts, state who will be performing the transcribing, for example a member of the PPIE team, another UoM employee or a third party who is a UoM approved supplier. If they are another UoM employee, ensure they are reminded of the guidelines regarding confidentiality and ask them to sign a copy of the Confidentiality Agreement). <<link to be inserted for Confidentiality Agreement>> If they are a third party they must be a UoM approved supplier as this ensures a confidentiality agreement is in place between their organisation and UoM.
* whether the personal identifiable information will be removed in the final transcript or not
* when and how the recordings/photographs will be destroyed or digitally altered to remove personal information (for example, by Pixellation / voice masking software).
* who will have access to the recordings/photographs (if different to the rest of the personal information).
* **REMINDER**: you are **not permitted** to use personal devices (e.g. iPhones, iPads, tablets, other personal, portable devices) to capture audio/video recordings or photographs. Any devices used must be encrypted by UoM and be exclusively for research use.

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?**

You must include a way for the public contributors to contact someone if they have any complaints. If they wish to direct their complaint to someone within the PPIE team, they should be directed to yourself/**your supervisor if you are a student**/PI. If they wish to direct their complaint to someone independent of the PPIE team, this should be the RGEI Officer as listed below:

**Contact details for complaints**

If you have a complaint that you wish to direct to members of the local team, please contact: **PROVIDE CONTACT DETAILS IN LARGE BOLD PRINT.**

**Name:**

**Email:**

**Telephone number:**

If you wish to make a formal complaint related to activity or if you are not satisfied with the response you have gained in the first instance then please contact:

The Social Responsibility and Public Engagement Team, Faculty of Biology, Medicine and Health, Simon Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: [srbmh@manchester.ac.uk](mailto:srbmh@manchester.ac.uk) or by telephoning 0161 306 6797

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 about complaints relating to your personal identifiable information <https://ico.org.uk/make-a-complaint/> Telephone: 0303 123 1113

**Contact Details**

If you have any queries about the information provided or you are interested in taking part then please contact **PROVIDE CONTACT DETAILS IN LARGE BOLD PRINT.**

**Name:**

**Email:**

**Telephone number:**