# **Distress protocol - Patient and public involvement and engagement (PPIE) (Adapted from the** [University’s distress protocol template](http://documents.manchester.ac.uk/display.aspx?DocID=36477)**)**

**Important Note: This distress protocol is an example specifically related to direct contact with public contributors. If your PPIE will involve speaking to public contributors over the phone, via an online medium or utilising online or postal questionnaires you will need to change the measures below. In addition, this document is for example purposes only and the content must be adjusted according to the specific constraints and risks for your PPIE.**

**Introduction**

The University of Manchester conducts Patient and Public Involvement and Engagement (PPIE) to the highest possible standards to maximise benefit to our research, teaching and wider contribution to society. When involving and/or engaging members of the public (commonly referred to as Public Contributors) in your research and/or teaching or through public engagement events the University has a duty of care to provide a safe, supportive environment for everyone.

Whilst it is unlikely that involvement/engagement will result in a distressing situation, it is important to consider any required strategies to put in place prior to the activity. Examples could be discussing sensitive subjects, including an individual’s lived experience.

## **Roles and Responsibilities**

If you involve and/or engage public contributors in your research and/or teaching or organise public engagement events it is your responsibility to ensure that the Public Contributors are fully informed and are working in a safe environment during their involvement and/or engagement.

## **Before your involvement and/or engagement project/event**

**Risk assessments/ethical approval:**

Before you involve or engage public contributors it is recommended that you complete a risk assessment for your project or activity. A template PPIE risk assessment can be accessed here: <http://documents.manchester.ac.uk/display.aspx?DocID=46876>. This will help ascertain and mitigate against any identified risks.

Ethical approval may also be required if you are discussing sensitive or potentially distressing content. PPIE has now been added to the University’s ethics decision tool, for further information visit the University’s research ethics page: <https://www.staffnet.manchester.ac.uk/rbe/ethics-integrity/ethics/>

**Information sheet:**

You may need to create an information sheet or an email with details of who the public contributor should contact if they experience distress which should be provided prior to the commencement of their involvement and/or engagement. You must also circulate these details again to the public contributor at the end of their involvement and/or engagement**.** A template information sheet can be accessed here: <http://documents.manchester.ac.uk/display.aspx?DocID=46875>.

## **During your involvement and/or engagement project/event**

Before the involvement or engagement starts explain the process for if the Public Contributor would like to take a break e.g. an additional meeting room has been booked, please feel free to leave the room at any time etc. Explain that it can be common for people to feel this way and that it is absolutely fine if anyone needs to leave the group for a few minutes to take some time

Should a public contributor report or show signs of distress or feel uncomfortable (e.g. getting upset) during their involvement and/or engagement, the following actions will need be taken by the staff contact:

## **Step 1**

* Suggest that they take a break, have a drink of water, go to a separate room etc.
* Ask them how they are feeling, listen with empathy and offer support. If the Public Contributor says they don’t want to discuss something or don’t want to take a break then they must be respected. Do not try to get more information on that subject or delay the break.

## **Step 2**

* If they would like to continue, explain that they can take a break from their involvement and/or engagement at any time. Staff contact to offer continued support and/or signpost them to further support external to the University.
* If the public contributor would like to stop or appears highly distressed please follow the actions in **Step 3**

## **Step 3 (choose one of the middle steps, most applicable to your project/event)**

* Stop the involvement and/or engagementand for:
	+ **Mild distress:** Encourage the public contributor to speak to **XXX** **(insert appropriate individual in your team)** for support OR offer to do so for the public contributor.
	+ **Moderate distress:** Immediately inform or offer to call a family member of friend andask them to come and collect the public contributor or contact the Public Contributor’s emergency contact.Stay with the public contributor until they arrive.
	+ **High distress:** Staff contact to phone the police/ambulance/mental healthservices/University security (contact number on back of staff card) for assistance but remain with the public contributor until they arrive.

In all instances please seek support from your supervisor/line manager.

## **Follow-up actions (adjust as needed based on PPIE requirements)**

* Offer to follow them up with a phone call the following day.
* Offer them the opportunity to withdraw from their involvement and/or engagement and for their data to be deleted if appropriate.
* Recommend the public contributors contacts external support services if they continue to feel distressed (see below link for useful contacts)
* Consider whether any members of staff (including yourself) require any emotional support and make the necessary arrangements (see below).

## **Where to go for advice and guidance:**

**Staff:**

University distress policies and debrief sheets: <https://www.staffnet.manchester.ac.uk/rbe/ethics-integrity/ethics/app-prep/>

A list of University support services for staff and students: <http://documents.manchester.ac.uk/display.aspx?DocID=46245>

**Public contributors:**

A list of external support services/contacts for public contributors: <http://documents.manchester.ac.uk/display.aspx?DocID=46244>

**For further information regarding PPIE:**

To find out more about PPIE across the Faculty visit the Faculty’s Social Responsibility and Public Engagement Team website

<https://www.bmh.manchester.ac.uk/connect/social-responsibility/public-patients/>

or

contact the Faculty of Biology Medicine and Health’s Social Responsibility and Public Engagement Team on srbmh@manchester.ac.uk.

For more documents, guidance and information regarding PPIE, visit the Faculty’s PPIE Toolkit resource at <https://www.staffnet.manchester.ac.uk/bmh/social-responsibility/public-and-patient-engagement/ppie-toolkit/>.