

## Final Priority Setting Workshops

### Frequently Asked Questions

#### **1. Do I have to do anything to prepare?**

Yes, we will ask you to read all the questions and rank them before the first workshop. If this feels difficult, we ask you, as a minimum, to select your top three, and lowest three priorities.

#### **2. What do I have to do at the workshops?**

Share your views! Contribute to the discussion, and listen carefully to others. There will be facilitators there to guide the discussion.

#### **3. Can I keep my video feed (camera) off?**

Yes of course, if you feel more comfortable that way.

#### **4. I would like to participate but want to stay anonymous. Can I participate with a pseudonym?**

Yes, we can arrange for you to use a pseudonym during the workshops, as long as you let us know in advance.

#### **5. What support will be available during and after the workshops?**

There will be a quiet room available to join should you find any topics or conversations distressing. This will be in the form of a separate Zoom call that can be joined at any time where a member of the team will be available to talk to you.

At the end of the workshops, we will provide contact phone numbers and websites for services where you can access support (nationally and locally).

#### **6. Will I have to share my personal experience?**

You only have to share what you feel comfortable sharing. The main thing is you are able to advocate for the research questions you consider to be priorities and why you consider them to be important, while listening to others views too.

## **7. Will the session be recorded?**

Sometimes we do like to record parts of the workshop. We'll ask for your permission to record parts in advance. If you prefer not to be recorded, or don't want your photo taken that's fine.

## **8. How are you making the sessions more accessible to people with ME/CFS?**

We will pre-record the information parts of each session so that people can watch them ahead of time.

Each of the workshops will be held on Zoom and include a rest break.

Participants may name a proxy to attend on their behalf if they can only attend part of the workshops and this enables accessibility.

If you have any other needs please email us at [questions@psp-me.co.uk](mailto:questions@psp-me.co.uk) and we will do our best to accommodate them.

## **9. Do I have to participate in all of the small group discussions?**

If at all possible, yes. It is important to have the continuity during the workshops. Let us know if you feel you need a proxy, someone to buddy you or advocate on your behalf for some of the small group discussions.

## **10. What confidentiality is there in terms of what is shared in the meeting and what will happen to the information afterwards?**

All participants will be required to follow [Chatham House Rules](#). This means that participants are free to use the information shared in the workshops, but must not reveal who said what. We will also ask people not to disclose the personal stories of others outside of the workshop, without explicit permission to do so.

Participants can choose whether or not they are named as attendees of the workshops.

We'll share the top ten questions afterwards, and explain more about how they were reached. We may share quotes from participants, but will ask them first.

## **11. What group agreement is there e.g. respect etc.?**

It is JLA policy to set ground rules around respect and confidentiality. This will be done at the start of the workshop and in each small working group. The facilitators are there to ensure everyone has their say. If at any time you feel uncomfortable about anything that is said or done, please alert your facilitator or one of the PSP team.