

BENEFITS & TIPS FOR RUNNING A LIVED EXPERIENCE GROUP FOR RESEARCH

From the Loneliness & Social Isolation in Mental Health Research Network **Co-Production Group**

What were the benefits for CoG members?

- Learning new skills from a broad range of people.
- Peer support.
- Enjoying collaborative thinking & exploration with CoG members and other partners.
- Gaining understanding of how research projects are run and how the peer review for funding calls operates.
- Access to resources (e.g. current research findings, skills gained through training) that could be shared with others.
- Personal validation (e.g. from being part of funded research).
- More confidence.
- Being able to initiate an idea and having the support to develop it with other members from start to launch (e.g. co-producing a dissemination booklet: <https://tinyurl.com/conversationsMHLoneliness>).
- Further opportunities to get involved in research.

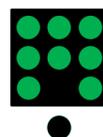
"The [personal] gain really was the success of the CoG and the formation of the Network...it makes me humbled and proud to have been able to be a small part of it all as an asset rather than being a liability to society, as I feel I have made a difference...The participation has encouraged me to be part of other [mental health research] Lived Experience Research projects."

"The experience of being in the CoG has already given me confidence and opened doors. I re-applied for a position that I had been rejected for 3 years earlier, and with the added experience got in this time. Without it I doubt I would have had the confidence to try a second time."

Read more about the Co-Production Group here:

<https://tinyurl.com/CoProductionGroup>

Contact us: Twitter @UCL_Loneliness



Loneliness &
Social Isolation
in Mental Health
Research Network

TIP 1: Regular meetings & updates

Meeting every month or so helps people to keep up-to-date and involved. Providing an agenda prior to meetings and taking minutes also helps with this. Enabling time for peer support is highly valued. Having a dedicated meeting space and opportunities to get to know each other is useful, especially when setting up the group. Doing this in consultation with members helps effective & meaningful involvement.

TIP 2: Inclusive & accessible ways of working

There needs to be awareness and sensitivity around people's lived experience and access needs, and the consequently different support they may require. It should be clear who the main contact is around this and for asking questions, especially about Patient & Public Involvement (PPI) payments. There should be a 'feedback loop' where members can submit queries and suggestions and receive timely feedback on any actions. Setting up a buddy system might help some people, and this could be particularly useful when new members join an existing group. Technical support may be needed (e.g. when all meetings switched online during the COVID-19 pandemic, some members struggled and would have benefitted from additional support).

TIP3: Valuing people, fair reward & impact

CoG members valued the respect shown within the group for each other's knowledge. They enjoyed collaborations with academics in which their contributions were valued, and power was shared. Receiving fair PPI payments for their contributions was important: these were clearly set out in our Terms of Reference and updated in line with best practice. Other forms of reward and recognition, such as training and conference opportunities, were also appreciated. Activities need to be offered and allocated fairly between members to ensure equity of opportunity. Asking for expressions of interest is a good way to facilitate and record this. Lived experience members also value knowing how their contributions have made a difference. Be clear about the purpose of the involvement and jointly plan to evaluate impact from the outset.

TIP 4: Making the most of members' networks

See members as assets: they bring their networks of different people and organisations that they are connected to. These links are helpful in raising the profile of your research, events and dissemination activities. For example, access to grassroots groups from black, Asian & minority ethnic and other minority communities could be facilitated via lived experience group members.

Thank you to all the LSIMHRN Co-Production Group (CoG) members who took part in the survey about their experiences of being the group from which these tips and potential benefits are drawn. This resource was created by Ellie Pearce in May 2022 with invaluable input from two CoG members.