Use of peer-led research design model in HIV policy research

Results and Learning
This way of working has resulted in better quality research outputs and has shown to be a robust method in a range of contexts. Aspects which have worked particularly well include:

- Full involvement in the design of data collection tools and question writing has helped to ensure all surveys, workshops and interviews are relevant and worded appropriately for the target audience.

- The consistent use of data collection tools has been ensured through running practice sessions and reviewing the pilot stage transcripts together as a group. This in addition to pairing less experienced members of the team with those with more experience for workshop facilitation.

- I was worried about facilitating the workshop as I had never done this with a group of school children before. But the training support and running really built my confidence.

(Youn Peer Researcher in the RSE workshops)

- Peer researchers were able to quickly build rapport and understanding with participants, leading to rich and insightful data being collected.

- A data summit is held at the end of the analysis phase, where the peer research team looks over all the data and analysis findings, to review what most resonated with their experience of the research. This process allowed the findings to be interpreted and policy recommendations set in a way relevant to the people involved.

- I did feel that with the meetings held that my ideas, thoughts and comments were all taken on board, and I felt as though my input was valued by the (project manager) and the team.

(Peer research for Uncharted Territory)

- Peer researchers reported benefits of the model included the opportunity to build research skills and use their experiences of the research topic in a professional context.

- 'I really wanted to be a peer researcher so I could gain research experience, but most of all I wanted to ensure our lived experience and expertise was embedded in all the stages of the research.'

(Jane, Peer Researcher for Invisible No Longer)

- 'I valued the experience very much, and feel that it is an important piece of research to guide future policy within the sector and ultimately government.'

(Peer research for Uncharted Territory)

Method
The peer-led research model of working was piloted by Terrence Higgins Trust in the policy research project ‘Uncharted Territory - a report into the first generation growing older with HIV’. For this project twelve volunteer peer researchers were recruited to the project team. Inclusion criteria for peer researchers matched that of the research participants, all must be living with HIV, aged 50 or older and living in the UK.

Following the success of this pilot this way of working is now being integrated into all aspects of Terrence Higgins Trust’s policy research work and has now been replicated in two further projects. These were the Invisible No Longer project which focused on women living with and at risk of HIV, and most recently, young peer researchers were part of the research team who engaged young people on their opinions on how Relationships and Sex Education (RSE) should best be delivered in schools. This work informed our response to the government consultation on the draft RSE guidance.

Although the inclusion criteria for who can be a peer researcher, as well as some of the ways of working varies between projects, a set process for conducting peer-led research has been established. When recruiting new peer researchers prior research experience is not essential, although transferable skills are desirable. Research skills training and a supervision framework is provided. The peer researchers are involved throughout the research process from design to dissemination.

Conclusion
The model has successfully shown to be a robust approach to research within the HIV policy context. This way of working has been reproduced for a range of research topics and although some details have to be adjusted, the model itself is applicable in a range of contexts. The research has also been given greater recognition and credence across the sector due to the meaningful involvement of the community.