User controlled research

User controlled research is research that is actively controlled, directed and managed by service users and their service user organisations. Service users decide on the issues and questions to be looked at, as well as the way the research is designed, planned and written up. The service users will run the research advisory or steering group and may also decide to carry out the research.

Some service users make no distinction between the term user controlled and user led, others feel that user led has a different, vaguer meaning. They see user led research as research which is meant to be led and shaped by service users but is not necessarily controlled by them. Control in user led research in this case will rest with some other group of non-service users who also have an interest in the research, such as the commissioners of the research, the researchers or people who provide services.

In an <u>INVOLVE report</u> exploring seven examples of user controlled research, service users highlighted several key reasons why for them, user-controlled research was important:

- a commitment to changing or improving the lives of their community of service users
- frustration with traditional research and services which exclude them
- frustration with mainstream research in failing to capture their needs or to research things they feel are important

View our video to find out more about user controlled research and some of the projects in the report

See also

Joint INVOLVE/National Institute for Health Research (NIHR)
School for Social Care Research webinar on user controlled
research