



**WAVERLEY**  
**care** Positive about HIV, Hep C  
& Sexual Health in Scotland

## Principles of Ethical Research

This document sets out several overarching principles that we believe constitute ethical research. We expect potential research collaborators to demonstrate that they understand these principles and have embedded them with their research. These principles have been developed in consultation with people with lived experience of our work, as well as researchers working across the third, academic and public sectors.

### Participant involvement

We believe that the people and communities who will be recruited as research participants should be involved in the development and design of research projects. For example, in a project exploring the sexual health needs of gay and bisexual men, we would expect to see that the researcher had talked to gay and bisexual men, community groups and community leaders .

We believe that participants should be involved and informed throughout the process. Where time and capacity allows, we believe researchers should take steps to confirm or 'validate' their findings with participants before publication. Published findings should be shared with participants in a format that is accessible and understandable to them.

We support peer-led approaches where peers are genuinely and meaningfully involved in research and paid or reimbursed in another way.

### Need

We believe research should only be carried out where there is clear evidence of need. Research involves asking people to disclose – often sensitive – information about their lives, which they should be asked to do without a valid justification. We recognise that some communities are 'over-consulted' by researchers and so will not support projects where there is a duplication of existing research.



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While we recognise that there can be a value in research with a purely academic or theoretical focus, as an organisation with limited capacity and resources we will usually only support research where there is a clear practical value.

Likewise, while we recognise students often need to conduct empirical research in order to fulfil the requirements of their degree, we will only support projects that have a clear practical value and do not duplicate existing work.

## Accountability

We believe researchers should ensure that they are accountable to their participants and stakeholders. This means being clear about why the research is taking place, what the expected impact of the research is, and the timescales associated with the research. It also means ensuring that participants and stakeholders know who is funding and managing the research, as well as who they can complain to about the research.

Researchers should keep in contact with participants and stakeholders, to update them on the research throughout the process. The frequency with which this should take place will depend on the individual project.

Researchers should ensure that participants and stakeholders are informed of the research findings, in an accessible and tailored format.

## Mutual benefit

We believe that research should be mutually beneficial to both researchers and participants. While we recognise the positive impact of research in driving change in policy and practice, this is often a long-term process and is unlikely to immediately benefit participants. We therefore expect participants to directly benefit in some way from the research process. Ideally, this should involve reimbursing participants and, as a minimum, we would expect participants to receive at least £9.50 per hour of their time. This amount is based on the current Real Living Wage rate. Preferably, this should be provided in cash, as we do not believe it is the position of researchers to judge or regulate how participants spend money.



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If it is not possible to provide financial reimbursement, researchers should provide reimbursement in-kind, for example, providing participants with practical assistance to access services or to meet other needs.

## Confidentiality and anonymity

We believe that researchers should maintain the highest standards of confidentiality. This means thinking carefully about how information is recorded, transported, and stored. Personal data should be collected and stored in accordance with GDPR.

Confidentiality should only be broken if a participant discloses that they, or another person, are at immediate or significant risk of harm. If safe and appropriate to do so, the researcher should tell the participant that they intend to break confidentiality and their reason for doing this.

Unless the participant or another person is at immediate or significant risk of harm, we do not believe researchers should disclose illegal activity, if told about this in the course of carrying out research. An exception to this would be cases where there is a legal obligation to report specific types of illegal activity, such as terrorism and money laundering. Further guidance on such cases is available here: <https://ethics.grad.ucl.ac.uk/forms/Research-Involving-illegal-activities.pdf>

Researchers should rigorously anonymise research outputs. This goes beyond removing names and other identifying details, but also considering whether quotes or extracts are included verbatim. Within small communities, a description of a particular experience or viewpoint could be sufficient to identify someone. It is important to us that researchers carefully consider how they will protect anonymity.