Research ethics and risk

June 2022



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About this guide

This guide sets out what to consider when assessing the risks and benefits of your research, including how to ensure your research is necessary, robust, proportionate, legitimate and appropriate.

Research ethics and risk

There are two main aspects of research ethics that you need to consider when planning research:

- Weighing up the benefits and risks for everyone involved in the research.
- Ensuring that the research is robust and appropriate.

Safeguarding people's interests

Whenever we conduct research with people, we must do it ethically, with the wellbeing of research participants being our top priority. We are also responsible for identifying and managing any risks to our own staff, volunteers and organisation.

These considerations are essential to the management of research ethics and should not be an afterthought, built into all stages of the research process.

Before beginning work, you will need to consider the benefits of undertaking the research against the risk. Here's a set of pointers to consider.

The benefits

- What are we intending to influence or change by undertaking this research? Will it make a big difference to people?
- What would happen if we didn't undertake this research? Would anyone else do it?
- Why are people's views essential for this research?
- Will undertaking and publishing this research have a positive impact on the reputation of your Healthwatch?

The risks

You'll need to consider several potential risks that can affect participants, those undertaking the research and the organisation itself.

Data security and protection

You will need to consider whether you need to gather personally identifiable and special category data and, if so, plan for correctly managing any data received. Refer to our <u>guidance on data protection</u> for more information. We also have a <u>template for phone scripts and an information sheet</u>..

Things to consider:

- Will people be identifiable if they take part? You can mitigate this risk by giving participants information about how you'll use their data and anonymise it in the final report. If the study is about a small defined group that could easily be identified or the issue is very sensitive even when anonymised, think about how you will anonymise it. You may need to check whether they wish to redact any parts of the information they have given you or whether you should redact it. The guidance on data protection has a section in it on how to anonymise data.
- Have participants been assured you'll always respect their confidentiality and privacy? You can do this by conducting interviews in private rooms, storing identifiable information in locked cabinets, encrypting any electronic data and shredding all hard copies with sensitive information as soon as possible. You must also ensure that only relevant staff have access to participants' data and that it will be as few people as possible. The guidance on data protection has a section in it on how to store data securely.
- Do participants fully understand the purpose of the research and how you'll use their information? Might they lack the capacity to understand fully? Do you allow them to ask to withdraw their data from the project?

The wellbeing of participants

Next, you will need to consider the participants' wellbeing and how you will ensure that they are treated with dignity and respect.

Things to consider:

- Is the time and location for carrying out interviews convenient for the participant? Can they reach the venue easily by public transport? Is the venue accessible for participants with access requirements, and are there appropriate parking facilities?
- When you interview participants, how can you make them feel that their views, values, lifestyle and beliefs are understood, respected and valued, even if they differ from yours?
- Is the subject of the study itself potentially risky because participants may have to reveal sensitive information?

For example, you are conducting research into sexual health service provision. Some of the questions you ask may make participants feel they have to reveal details of their sexual behaviour.

To avoid this, you need to reframe the questions, ensuring they are non-judgmental and are not leading. You reassure participants that you want them to be as comfortable as possible, and they do not have to answer all the questions if they do not want to. Your behaviour, as a researcher, suggests you are non-judgmental and caring as you explain that you are trying to help improve the services they use.

- Have the needs of people with learning disabilities been considered? For example, are they able to discuss issues in their own words rather than answering according to pre-defined responses in a questionnaire?
- Is there a likelihood that participants will become distressed during the research because the issue is difficult or sensitive? Can this be mitigated by a sensitive approach, including giving participants breaks and reminding them that it is OK to withdraw their consent?
- In the event of unintentional distress during an interview, do participants have access to a private space where they can feel at ease?
- Do you have a policy in place for when a participant tells you something you
 might need to escalate, for example, abuse? Does your general safeguarding
 policy cover this? See our guidance about <u>assessing risk and safeguarding</u>.
- Are the participants particularly vulnerable? Are they likely to feel pressured to participate? For example, is there a possibility that people might feel coerced by someone else to participate?

The risk to Healthwatch including the people undertaking the research

You'll then need to consider the risks for Healthwatch staff and volunteers undertaking the research and the organisation itself.

Things to consider:

- Have you prepared your staff and volunteers to undertake a piece of research? Do they have the necessary skills, or are you placing them in a situation they are physically and/or emotionally ill-prepared for? Have they received prior training and are well briefed on the research topic? Can they explain the purpose of the research, encourage respondents to co-operate, clarify questions and correct misunderstandings?
- Are staff and volunteers being put into potentially risky situations to undertake this research? Can these risks be mitigated by working in pairs and carefully choosing the venue for the research, for example, not travelling to the participant's home?
- If working with partner organisations, will there be a threat to the independence of Healthwatch by working with these partners? What arrangements can you make to ensure that our independence is not compromised? See our guidance on working with partners on research projects.

- Will undertaking and publishing the research harm the reputation of your Healthwatch? How will research findings be monitored and quality assured to minimise this risk?
- Will researching this topic affect your staff and/or volunteers undertaking the research? This might be the case if the topic is very distressing or traumatic, for example, female genital mutilation or domestic abuse. You must provide an opportunity for them to debrief with their line manager or supervisor afterwards.

For example, a local Healthwatch is planning to undertake research into bereavement services for families of those who have taken their own life.

The Research Officer involved in this project is worried about talking to families and listening to potentially distressing issues. They attend a training course on how to deal with distress and support people in distress before conducting any interviews with families. They also attended 1:1 meetings with their manager throughout the project and after for further support.

Ensuring our approach is necessary, robust, proportionate, legitimate and appropriate

Necessary

Research is necessary when we do not already know enough about the topic. You can consider the following to make sure your work is essential:

- Will your research be a tool to build on existing knowledge?
- Will it help better understand certain issues and increase public awareness?
- Can it be used to find, gauge and seize opportunities, such as securing funding or influencing important stakeholders?
- Is this research going to help raise the profile of Healthwatch?

2. Robust

Whenever you undertake any research, it is essential that you can describe your study to answer the following questions:

- What is the purpose and significance of this research?
- How will it be conducted?
- Have the right research methods been chosen for the topic? Are they
 appropriate for the issue you are researching? Do they offer the most
 reasonably efficient way of answering the research questions? What are the
 pros and cons of using these methods? Are they appropriate for the targeted
 groups? Will the research collect the right amount of information? Your
 research shouldn't collect data you can't use.
- Is there any bias, such as having a self-selected sample when the research topic is sensitive, or the researcher is making subjective interpretations of participants' responses? See our guidance <u>about managing bias in research</u> for more information.
- Are there any potential risks for those involved? How will they be mitigated?
- What type of data will the research generate, and how will you analyse it?
- How will the information from the research be managed?
- Would external organisations be able to understand the events and decisions taken during the progress of the research?

3. Proportionate

It is essential to consider what constitutes a proportionate way to carry out research. To do so, you can think about:

- What is the context of this research?
- Is there any external evidence, and are there any gaps in knowledge?
- Will your research address the gaps in evidence?
- Is there a balance between the needs of research and available resources?
- · How many participants do you need to derive reliable conclusions?
- Can you demonstrate the effectiveness and impact of your work?

4. Legitimate

The research you undertake must conform to the law, accepted social values and cultural sensitivities. It is equally important to choose respondents to maximise equality and diversity through your work. You can think about the following:

Will the research be able to gather a wide range of perspectives?

- Do the chosen participants add something new to your understanding of the topic?
- Will the results of the research equally benefit people of all groups?

See our guidance about ensuring a representative sample for more information.

5. Appropriate

It is vital to consider who you need to target for each research project and ensure that your methodology is appropriate. Here are some things to think about:

- Are the research methods you plan to use appropriate for the target group(s) you are targeting?
- Do you need to reach out to groups you don't usually engage with for this research project? What's the best way of engaging them?
- What practical measures do you need to put in place to ensure that particular groups can participate?

For example:

Do you need interpreters/translations for non-English speakers?

Do you need easy-read questionnaires for people with a learning disability or literacy problems? Or do you need "I want to speak please" cards to allow people with dementia or learning disabilities the opportunity to speak up and be heard in focus groups?

Will people with mobility issues be able to access your research venue?

Do you need paper questionnaires for people who can't access surveys online?

See our guidance on engaging with <u>seldom heard groups in Healthwatch</u> <u>research</u> and <u>how to co-produce with seldom heard groups</u>.

When risks outweigh the benefits

If you have considered all the above questions and think the risk outweighs the benefits, you may want to reconsider your planned research or use a different or more appropriate method(s).

You should also consider that risk could escalate during a project. Therefore, it is vital to have regular check-in points during the entire research process so that any potential risk is identified early on and is mitigated by changing how things are being done. An excellent way to do this is to incorporate such review points and milestones during project planning.

healthwatch

Healthwatch England
National Customer Service Centre
Citygate
Gallowgate
Newcastle upon Tyne
NEI 4PA

www.healthwatch.co.uk t: 03000 683 000 e: enquiries@healthwatch.co.uk

@HealthwatchE

f Facebook.com/HealthwatchE