Ethics process and plan

Ethics best practice when working with research participants

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Ethics plan

Complete the questions below and identify actions. Make your research meets ethical standards. For further information on our standards see Appendix 1. The questions have been divided into how your research project will run; planning, recruitment, activity, analysis and communication. The final section is on how to make the process safe for the participant and researcher.

Your sign off person should review and feedback on your plan. You should address their feedback and then get it approved. If there are highly sensitive issues that will need close monitoring and management then please discuss with Research Team Lead (Tress Carmichael) who will organise a peer review. *This decision will lie with your sign off person.

Project Name		User Centred Design Lead		Sign off (person)	
Project Dates		User Research Lead		Sign off (date)	
Project type				Does this need additional ethical review*	Yes☐ No ☐

Project Summary
Please describe here what the project is and the activities associated. This can be copied from the project brief. It is to give your reviewer of this plan the knowledge of the project.
E.g. usability testing of X site for X project with X number of rounds and X anticipated participants, OR Interviews of citizens for X project for X project partner with X number of rounds and X anticipated participants.

Project planning	Answer the questions below
1. Have you identified a gap in existing research, which demonstrates a need to undertake further primary	Yes ☐ No ☐

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research?	
2. When identifying participant groups, what steps will you take to make sure they are diverse and relevant to the area being researched?	*Explain here how the project will address inclusion of diverse perspectives*
3. If you are collecting personal data (PD), what legal basis for processing personal data will you use? (if you are not collecting PD go to question 5)	*Explain here your Legal basis; could be consent by individual or for legitimate interests. Use the interactive guidance tool by the ICO to help you. Please write the legal basis*

4.	If you are collecting personal information, have you completed a Data Protection Impact Assessment?	**Yes** ☐	**No** ☐
		Yes ☐	**No** ☐
	Has it been sent and reviewed by [the Data Protection and Information Asset (DPA) team](#)?		
	Has it been signed off by your Information Asset Owner?	**Yes** ☐	**No** ☐
		All 3 must be ticked yes before starting collecting personal data.	
Recruitment			
5.	Will you offer British Sign Language (BSL) support in the recruitment process? (Please provide information why if you answer no)	**Yes** ☐	**No** ☐
		Check that recruitment information provides a statement that a BSL interpreter can be provided if required. For example:	
		"We can provide BSL interpreters if required. Please give us 2 weeks' notice to ensure we can provide this service." (see appendix 1)	
6.	What steps will be taken to encourage participation from excluded or disengaged groups?	*Can you take any extra steps to identify and involve excluded or disengaged groups (socially disadvantaged areas, low literacy participants, etc.)*	

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7. What steps will be taken to ensure all participants can understand and give permission?	*Check any permission statement (if providing to participants) is at the national average reading age. Advice is available* <u>on mygov.scot resource</u>*s. Get it checked by a content designer or test it with participants before research begins or in pilots.* <u>SE Research Permission Statement</u>
8. Will your permissions guidance tell the participants: - The purpose of the project - Who will have access to the information collected - They can withdraw at any time - How information will be securely stored - How long information will be stored for - Confirm they have received a copy of their rights, what happened during the research and how to contact you (Please attach a copy once ready, and check it covers above)	**Yes** ☐ **No** ☐

9. Will any participants need extra assistance to understand and give permission? • BSL • Interpreter • Carer/helper (proxy) • Under 13 (please explain which group(s) and how you will support them)	**Yes** ☐ **No** ☐ *(if yes, please explain which group(s) and how you will support them)*
10. If your research will include children (under 16) how will you ensure they understand the purpose of research and what is expected from them? Is the consent opt-in?	**Opt-in** ☐ **Opt-out** ☐ *(Please use only opt-in) Please explain how you will ensure young people understand your research and expectations*
Research Activity	
11. When designing the research engagement and materials, what steps will you take to identify individual needs?	*Describe what steps you have taken here. For example, check questions have a low reading age, use the mygov.scot guide to readability, and have been checked by a context expert in the area.*
Analysis and Communication	

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12. When designing the research materials and analysis, what steps will you take to reduce bias? Will there be QA of outputs and reports by a senior researcher not involved in the project? Are you able to do a co-sensemaking session with participants to analyse the results?	*Identify relevant biases and suggest ways to mitigate. See [20 cognitive biases that screw up your decisions](). What measures are in place to ensure that the reporting and interpreting of findings protects against distortion and bias?* *(NB SE staff have undergone Unconscious Bias Training as part of their employment contract policies)*
13. How do you plan to share your findings and who will you share them with?	*What elements of the research are you going to discuss? What are the most effective and efficient ways of explaining this? What report format best meets the need of the customers/service providers/users? What accessibility measures are in place to ensure information is available to all?*
14. Do you need to over sample certain groups, or weight the data? (please explain if yes)	*Have you identified the different types of people that make up the target population, and worked out proportions needed for the sample to be representative? For further information on sampling please check ["what is sampling?"]() On explorable.com*
Participant/research safety	

15. If your questions cover stressful or sensitive subjects, how will you reduce stress?	*What are you doing to keep the interview length to a minimum? Is there post-interview support?* *Are you informing the participant that they can stop at any time?*
16. Are interviewers properly trained and vetted?	**Yes** ☐ **No** ☐
17. Do you and other researchers have the appropriate level of disclosure (for the purpose of the project)?	**Yes** ☐ **No** ☐
18. What procedures are in place to ensure the safety of all researchers and participants? (Will there be home visits for the research)	*Contact participants in advance to explain the format and introduce yourself prior to meeting. For home visits, check who the participant is more comfortable with (2 female or 2 male or mixed researchers). Researchers should check in with a designated colleague before and after every home visit.*

19. What procedures will be in place to ensure participant confidentiality? How will this be this communicated to the participant? How will this information be kept and disposed of securely?	*Where will the information be kept securely? How will notes be disposed of? How will you make sure the information is disposed of in the correct amount of time? When do you tell the participant about this?*

Glossary

Bias – an opinion or view that affects the decisions and judgments that people make. By identifying these and considering how to reduce their effect will improve data capture, analysis and insights.

BSL – British Sign Language is a sign language spoken in the United Kingdom (UK), and is the first or preferred language of some deaf people in the UK.

Controller – (aka data controller) the organization who collects, stores, shares or alters personal information.

Data Protection Impact Assessment (DPIA) – under GDPR we need to complete this for all projects involving personal data. A single DPIA can address more than one project.

Diverse and minority groups – gender, disability, ethnicity, religion, sexual orientation, socio-economic status and age.

GDPR – General Data Protection Regulation is the general term we use for the UK Data Protection (2018) Act. This must be complied with when collecting personal data.

Participant groups – the individuals, colleagues or citizens involved in your research project.

Personal data - any data that relates to a living individual who can be identified from the data or from data the controller might come into possession of.

Primary Research – research involving data collection of personal information from research participants.

Robust insights – The insight(s) can be tested and remain effective when the situation is varied.

Background to ethics checklist

Overview

This is an overview of the ethics process for researchers in User Centred Design to ensure they meet ethical standards when designing and delivering research with participants. An ethical review is a way to consider the impact of your work on the participants involved and how to safely process the personal data you collect. It should provide a rigorous review that is proportionate to the potential risks.

Overview of ethics process:

When planning a project, you should perform an ethics review and create an ethics action plan for your project. You should engage with project stakeholders throughout. There are steps you should follow, including:

1. Read and understand the ethical principles for designing and delivering research which involves participants

2. Complete the ethics checklist within this document and develop actions to ensure ethical standards are followed throughout the project life. You might not know all the answers to the questions, but this document should be updated when you know the answers. It is a living document which should be updated and reviewed (see point 7).

3. Complete a Data Protection Impact Assessment (DPIA) report template for the project (if you are collecting personal information)

4. Submit an ethics plan for sign off, including the project plan and informed consent docs (to your relevant manager) and the DPIA report to the Information Asset Owner (Deputy Director) for your area

5. Ensure you complete a risk assessment. Risk assessments identify hazards, assess the risks and find ways to eliminate or reduce them. (This may have been done by others in your team)

6. Upload ethics plan and DPIA to your records management system, e.g. eRDM (see Information Asset Guide for further information)

7. Review ethics plan and make sure the ethics actions happen throughout the project's life

8. Discuss effective actions and suggest improvements at any wash-up meetings/ Improvement Reporting meeting when the project is completed.

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Principles for User Research

Introduction

The Scottish Government expects that its researchers follow five key ethical principles:

P1 Do research ethically and ensure findings are used and shared

- Existing data should be used where possible to avoid unnecessary replication of research
- Findings need to be robust and relevant
- Findings need to reflect the needs of government business
- Findings should be shared with public sector colleagues (where possible/allowed)
- Findings should help one or more of the following:
    - Improve a service
    - Inform legislation design
    - Inform consultation planning
    - Contribute to citizen and/or stakeholder engagement
    - Help citizens engage with government
    - Help ministers engage with citizens
- Consider the value of researching with seldom heard groups or people who have particular needs that could affect them taking part and the benefits that the research will bring

P2 Make sure participation is voluntary and use of data understood

Make sure you know the legal basis for processing personal data. Whichever reason you decide on, ensure you:

- Tell participants they are completely free to say they do not want to take part. They can stop at any point during the research. They do not have to tell us a reason why
- Tell participants if audio or visual recording is involved, how the information will be stored and when it will be deleted
- If you use consent, it should be tailored to the needs of the people involved
- If using social media as a research tool or for recruitment, make sure you confirm age, identity and ability of participants

P3 Increasing participation

- Consider excluded or disengaged groups and put steps in place to help participation, for example providing assistance with costs, like travel and child care
- The place you meet participants should be either a) in a place they have chosen or b) a place that is accessible. Think if the venue is suitable for people with different needs and no cause them any difficulty or discomfort getting to or being in. Are all areas accessible - not just the room where the research will take place

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P4 Do no harm

The comfort, safety and feelings of both the people doing the research and those taking part should be considered in this document and in the risk assessment. Things to consider include:

- Will you need to provide post-interview support
- How will you ensure the safety of the researchers

Participants taking part might feel uncomfortable or unsafe if the research:

- Feels intrusive – ask yourself if there is a good reason to ask the questions
- Creates false hopes – people taking part often do so to help government improve people's lives. Be careful you don't create expectations of improvements, or the timescale, that is unrealistic
- Feels unnecessary – the questions have already been asked many times and we are not listening or using previous research
- Triggers emotions – how can you minimise the changes of this happening, and what will you do if someone does feel upset

P5 Keeping personal information safe and secure

We must make sure personal information is kept safe and secure and has appropriate legal safe guards. We need to be compliant with how we store protect and destroy the information.

- Personal data should be anonymised (or pseudonymised) and stored safely.
- Dispose of paper information by shredding or secured recycling.
- Be clear with how long you plan to keep any information. Make sure this is clear to the participant and you have appropriate process to manage the deletion.
- How long you keep information should be determined by the project team. Consider how long it will it take for you to analyse the data. Will you really ever come back to the personal information again to reuse it?

Further information can be found in the Ethics Guidance for Scottish Government Social Researchers and in the Data Protection guidance on Saltire.

Research with young people

There are also some additional things to consider if you are working with children:

P1 Getting consent from the young person or care giver / parent

As with all participants, we need to make sure we provide as much information as possible about what will happen. Extra considerations include:

- If the young person is 13 years old or over they can give their consent to take part. You will need to ensure that the information is understandable by the young person.

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- If the young person is under 13 you will need to get permission from the parent or care giver. We would also recommend getting it from the young person too. The young person should be allowed to say they do not want to take part.

P2 How and who do you reward?

If your project is giving an incentive for the research are you giving the reward to the young person only or to both the young person and the care giver / parent? What is the most suitable incentive for the child and is this going to be the same or different for the adult?

P3 Be realistic about dates and session times?

Think about how long your session will be and when you plan to hold the research.
- Will you able to keep the interest of the young person.
- Have you plans to change how you run the session if the young person isn't engaged.
- Have you considered when school terms are? Are you doing your research around the school day?

P4 Building a bond

Research can be daunting and can be especially so for younger aged participants.
- Should the care giver or parent be present? You will need to consider how their presence could affect your results, both for the good (young person more relaxed) and for the bad (may not talk as freely).
- You could suggest to bring a toy or something that would make the young person feel more relaxed. This can also be used as an ice breaker chat.

P5. Researcher training and Disclosure level

Research with younger people can require different skills than with adults. Your ethics plan should protect both the young person and the researcher.
- Do the researchers feel confident in talking with younger people and have experience of this?
- Do you have adequate level of Disclosure present during the research. A care giver or parents presence is sufficient. If there is no care giver present then someone present should have PVG membership
- Plan the research so that you are not alone with the young person.

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Including BSL users at events

Our aim
People whose first or preferred language is British Sign Language (BSL) will be provided with the information and support needed to participate on a fair and equal basis in the design of Scotland's digital public services and policies. We will learn how to do this as part of the national movement to create a shared Scottish Approach to Service Design.

How we will do this?
We will offer or provide BSL/English interpretation services at our events as required and advertise this on our invites. This will allow the BSL community to take part in our events and research. We will inform them by adding one of the BSL inclusion banners to electronic and hard copies of invites to take part.

We have a banners for:
An attendee requesting a BSL/English interpreter in A4 and A3.
A BSL/English interpreter being present at event in A4 and A3.

We will also make sure that any written information or instructions are of a standard that will be easily understood by native BSL users. BSL is a language distinct from English, with its own grammar, syntax and vocabulary. As such, you should not assume that BSL users have fluency in English when BSL is their first language. Information on readability is available on mygov.scot resources.

How do I contact a BSL/English interpreter?
We would encourage you to always book an interpreter who is a registered member of a professional body, such as SASLI, NRCPD, or RBSLI. This ensures the interpreter is qualified, regulated, has appropriate insurance and adheres to a code of ethics. Your participant may have a list of preferred interpreters or interpreting agencies they would like you to book. There is currently no procurement framework in place for face to face BSL/English interpreting, so you are able to engage the services of any freelance interpreter or BSL interpreting agency.

Resources?
As the event organiser, it is your duty to ensure your event is accessible, and so meeting the cost of interpreting provision is your responsibility.

For events other than short, 1-1, face to face meetings, it is likely you will need to book 2 interpreters to interpret between participants. When booking you should inform the interpreter of the nature of your event, the duration, and the expected number of participants to allow them to advise on the number of interpreters required.

Any other considerations?
You will need to make sure the venue can accommodate the BSL/English interpreter. If the interpreter is signing for multiple BSL users you need to consider where would they stand while signing etc. We have other documents available to help with considerations for venue use.

We also have access to information on best practice when working with participants who are BSL users, including advice on commissioning a BSL translation of an English document. Contact our BSL policy unit for this.

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