

Ethical and Equitable Digital Design Matrix for Community Engaged Research

Melbourne Social Equity Institute

Introduction

Increasingly, community-engaged research projects use digital technology. They may use such technologies to recruit participants. They may develop digital technologies as an output of the project. This may be a way of disseminating the project findings, such as through hosting findings on a website.¹ Or, the purpose of the project may be to develop digital outputs to assist the community, such as a chatbot, app or other digital tools.² These uses of digital technology can bring advantages to the project team including through enabling higher levels of access, impact and longevity in the project outcomes. However, reliance on digital technologies may also carry the risk of unintended or unforeseen consequences, which may risk undermining the purposes of the project. For example, digital recruitment strategies may miss relevant participants with lived experience. Or, the digital output may not be accessible to the intended community of users; research participants may be denied a role in the ongoing governance of the digital outputs despite having co-created them, there may be insufficient resources for maintenance leaving an out-of-date orphaned tool. For these reasons, digital technologies should not be treated as an 'add on' element at the completion of the research or a mere technical aspect of the project. Questions around the ethical development, operation and governance of digital technologies developed through community research projects should be considered at the outset as part of the project design. These issues should be addressed as arising throughout the lifetime of the project, including after the project is completed and leading to the point where it is taken offline. Good planning in relation to digital technologies helps to ensure that they will genuinely contribute to the project goals and deliver benefits to the community.

The matrix

We have developed a matrix to support the ethical and equitable design elements of digital technologies used in community-engaged research. This matrix correlates the stages of the project with the elements of ethical design. This produces a series of questions relevant to design, operation and governance of the digital tool at each stage of the project.

¹ For collaborative ideas see <https://wwda.org.au/publication/our-site-final-report/>

² See for example the Burndawan project: <https://socialequity.unimelb.edu.au/projects/co-designing-technology-to-support-indigenous-people-experiencing-family-violence>

Legal considerations

In providing this ethical design matrix, we assume that the project is compliant with relevant legal obligations, particularly around privacy and data protection law, particularly where the project involves sensitive personal information.³ Trust and inclusion are supported by a project framework that is built in compliance with privacy law: because that means embracing principles of ‘privacy by design’, having processes in place to manage information securely and also protocols for data breaches.⁴

We also assume that the project team will obtain UoM ethics approval. Some of the issues we raise will also be covered in the ethics approval process. However, the matrix encompasses a broader range of considerations than this process.

Relevant people

In community-engaged research there are a number of relevant collaborators in addition to the university research team: the collaborating community organisation or group, individual participants in the project and users of any digital output. We take collaboration with the community group or organisation as given and focus on the important consultations with project participants and users.

The project stages

Typically, a community-engaged research project aiming to develop a digital output, such as a website for disseminating results or a digital tool to assist users drawn from the collaborating community, will involve the following stages:

- Planning
- Recruitment
- Data collection and analysis
- Developing the technology
- Sharing the results / operationalising the tool
- Maintenance

³ <https://www.oaic.gov.au/privacy/australian-privacy-principles/>

⁴ <https://www.esafety.gov.au/>

Ethical and equitable design principles

The goal of this matrix is to guide the design, operation and governance of digital outputs to ensure they meet the purposes of project and the collaborating community researchers and will benefit users of the technology. The matrix is intended to be used collaboratively with other ethical frameworks guiding community-engaged research.

We consider that the following principles are useful in this context:

- **Privacy** – This consideration embraces compliance with the legal regime but also notes privacy as a guiding research design principle.
- **Beneficial, safe and effective** – Digital outputs should enhance the well-being of the relevant community of participants and users. They should not contribute to increased risks or cause direct harm.
- **Equitable and inclusive** – Equity in a digital output means that it avoids unacceptable bias and is accessible to all relevant users. These goals should be promoted through inclusive design and governance processes.
- **Transparent** – Transparency looks to provide clarity in the design, operation and evaluation processes for digital outputs.
- **Accountable** – Accountability requires strategies to ensure digital outputs are used for appropriate purposes, and that outcomes can be reviewed. Moreover, participants and users should have a channel for continuing to provide feedback and participate in any ongoing development of the digital output.

Contact

The development of this resource was led by Prof. Jeannie Paterson (Melbourne Law School) and A/Prof Shanton Chang (Computing and Information Systems) with contributions from A/Prof. Ann Borda (Melbourne Medical School), Dr. Piers Gooding (Melbourne Law School / Melbourne Social Equity Institute), Dr. Yvette Maker (Melbourne Law School / Melbourne Social Equity Institute), Adam Lidders (Centre for Artificial Intelligence and Digital Ethics) and Charlene Edwards (Melbourne Social Equity Institute).

For queries, or to provide feedback, on this document, please contact:

Jeannie Paterson jeanniep@unimelb.edu.au

Shanton Chang shanton.chang@unimelb.edu.au

The matrix

The matrix has ethical principles in the vertical axis and the temporal dimensions of the project in the horizontal axis. The questions are intended as prompts. Not every question must be addressed or will even be relevant.

| | Planning | Recruitment | Data collection and Analysis | Developing the digital output | Operationalising the digital output | Digital governance and maintenance |
|--------------------------------|---|---|---|---|--|--|
| Privacy | <p>What processes are in place to ensure data is collected, processed and stored according to privacy and data protection requirements?</p> <p>Further information on legal requirements around these issues is available here.</p> | | | | | |
| Beneficial, effective and safe | <p>What are the purposes of any project digital outputs?</p> <p>Who is it intended to benefit?</p> <p>What harms are possible, through intended or unintended but foreseeable use?</p> | | | <p>How will the project's digital output achieve its intended purposes?</p> <p>Have you considered other ways of developing the output?</p> | <p>How will the impact of the digital output be evaluated?</p> <p>How will participants and their communities benefit from the roll out of the digital output?</p> | <p>What governance processes are in place to ensure the continued efficacy and safety of the project's digital output?</p> <p>Have you considered the sustainability of the digital output, including around the hosting platform?⁵</p> |
| Equitable and inclusive | <p>How do you know that any digital output developed is needed by</p> | <p>Where research participants have been recruited to guide the design of a project</p> | <p>If using an online platform for data</p> | <p>Are participants' experiences genuinely</p> | <p>Are community co-researchers involved in decisions about the</p> | <p>What processes are in place to ensure that the digital outputs remain</p> |

⁵ For example see the Cth government's guidelines for developing digital tools: <https://www.dta.gov.au/help-and-advice/digital-service-standard/digital-service-standard-criteria>

| | | | | | | |
|--|---|---|--|---|--|---|
| | <p>the intended community or user group?</p> <p>Have you consulted with potential users, paying attention to the needs of those who may experience the most disadvantage?</p> <p>How will you facilitate community engagement across the project lifecycle? Do you have the budget to fairly remunerate community researchers and participants for their participation?⁶</p> <p>Have you clarified the respective roles of community researchers, research participants and users?</p> <p>Which groups are being excluded and why?</p> | <p>digital output, are these participants reflective of the intended users?</p> <p>What supports might people need to participate? (E.g. translators, accessibility supports for people with disabilities, childcare bursaries)?</p> <p>With online recruitment, have platforms used by diverse groups been utilised? This may include platforms in other languages.</p> <p>If recruitment is only undertaken online, who might be left out of the data collection?</p> | <p>collection, consider the following:</p> <ul style="list-style-type: none"> • are the target participants familiar with this platform? • is that platform accessible to target participants? Consider bandwidth, mobility, accessibility (e.g. for vision impairment). <p>In any data collection process:</p> <ul style="list-style-type: none"> • are the questions asked in a form that is clear to the target participants, including second/third language English speakers? • are the questions asked in a manner that is accessible to people with disabilities? (E.g. people with cognitive disabilities) | <p>part of the design process?</p> <p>Are there processes in place to reduce the risk of bias and discrimination in any technological outputs?</p> <p>Are community co-researchers involved in decisions about the content, look and features of digital outputs?</p> | <p>deployment of the digital outputs?</p> <p>How will the digital outputs from the project be made accessible to community co-researchers, research participants and intended users?⁷</p> | <p>accessible to participants and users?</p> <p>What processes are in place to review the digital tool to ensure it continues to operate fairly without bias?</p> <p>How do community co-researchers retain ownership or control over ongoing maintenance and development of the digital outputs?</p> |
|--|---|---|--|---|--|---|

⁶ The MSEI has developed guidelines for equitable remuneration for research participants https://socialequity.unimelb.edu.au/_data/assets/pdf_file/0010/3427345/remuneration-guidelines.pdf

⁷ See also inclusive digital design guidelines from the Cth government <https://guides.service.gov.au/content-guide/accessibility-inclusivity/>

| | | | | | | |
|-------------|--|--|---|---|--|---|
| | | | Are participants compensated for their time – both in terms of remuneration but also recognition of their contributions? | | | |
| Transparent | | Is clear, accessible information about the project, the data collected and the outputs available to all participants? The UoM ethics approval process provides guidelines on this information that must be provided. | Can participants obtain clear explanations about data collection when needed? What happens if participants are excluded? | What steps have been taken to ensure that information about the design and development stages are available to participants. | Are the objectives and processes of the digital tool clearly explained? If there is an outcome from analysis that might adversely impact the participants or their communities – will they be informed? | Are there clear governance structures for the ongoing operation of the digital output? Can participants clarify any part of the process post-participation? |
| Accountable | | | Can participants access their information for review or editing? Can participants be confident that their data will be digitally secure? | Are community co-researchers, participants and users involved in the decisions that are made about the development of the digital output? How will the participants contributions be acknowledged? | Does the digital output respond to the objectives of co-researchers and the identified needs of users? How has this been tested? What opportunities have been provided for input from participants and intended users? | How is co-governance with community partners maintained and enabled? What processes are there for participants and users to participate in ongoing evaluation of the project digital outputs? What safeguards are in place to allow ongoing feedback on the operation of the digital outputs? |