ETHICS, PRIVACY AND SAFETY IN PLACE-BASED WORK

Draft paper and tool
Introduction

This paper proposes a framework to inform the conduct of place-based work in relation to ethics, privacy and safety for the engagement of community members in design, research and evaluation activities and focuses on the collection of new information. This paper does not currently cover how to apply ethical, privacy and safety considerations to the use of existing information.

The paper provides a simple framework which lists what should be considered to meet ethical, privacy and safety expectations and explains:

- why ethics, privacy and safety are important to consider
- what ethics, privacy and safety mean in the context of engaging children, young people, families and other community members in the work
- when ethics, privacy and safety should be considered

Acknowledgement

The paper is a work in progress and has been drafted by Zazie Tolmer from Clear Horizon together with a place-based initiative. We are grateful for their generosity in sharing their learnings as practitioners in the Collective Impact space.

Contact

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See other tools and resources here.
1. **What should be considered in relation to ethics, privacy and safety?**

In this section, we provide guidance on the ethical, privacy and safety requirements to be considered throughout planning and conduct.

<table>
<thead>
<tr>
<th>Place-based pertinent activities</th>
<th>Ethics</th>
<th>Privacy</th>
<th>Safety</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The moral principles or values that govern the conduct of an activity</td>
<td>Protection of information recorded in any form, whether true or not, about an individual whose identity is apparent, or can reasonably be ascertained, from this information or opinion</td>
<td>The condition of being protected against physical, social, spiritual, financial, political, emotional, occupational, psychological, educational, or other types or consequences of failure, damage, error, accidents, harm or any other event that could be considered non-desirable.</td>
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</tbody>
</table>

### Specifically:
- **Recruitment to activities**
- **Participation in meetings, workshops, interviews and any other activity**
- **Information collection to better understand the problem/place, to design prototypes**
- **Monitoring and evaluation activities**
- **Closing the loop activities - Codification, communication and follow up**

#### Ethics:
- Participation is voluntary
- Provision of sufficient plain English information to enable informed consent to participation (signed consent forms)
- Separate contacts for accessing further information and making complaints are provided
- Participants acting in a non-professional capacity should be appropriately remunerated and be reimbursed for any travel or other costs associated with their participation (for example childcare)
- The information collected will be written up and provided to participants for approval before it is used
- Regular communications about the work, outputs and updates on progress are shared in a timely manner and accessible format with those involved in or engaged through the work

#### Privacy:
- Use of trusted intermediaries for first contact – personal information is only shared when informed consent has been given
- Participants personal information will not be kept with any notes or recordings from the activity – a coding system will be used
- The information collected will be stored electronically securely and separately to the contact list and personal information
- The information presented in reports and other communication will be de-identified, removing location names and other information that could identify the interviewee, their family or others mentioned

#### Safety:
- Trusted intermediary to establish whether potential participants are able to safely participate and to understand and organise mitigating actions
- Participants can exit at any time without needing to provide a reason.
- Activity is conducted in a private, safe and welcoming space and agreed to with participant and as much as possible the location and timing are convenient to participants
- Activity is led/facilitated by a professional experienced in working with people experiencing vulnerability
- Video, photographic, audio and written records are only done with the informed consent of the participants
- All interviewers/facilitators must have a national crime check and if required a working with children check
- Interviewees/participants/interviewers/facilitators have access to a debrief with an appropriate person if requested or required
2. Why are ethics, privacy and safety important considerations for the Place-based work?

Place-based work relies heavily on consulting, engaging, co-designing and collaborating with children, youth, family members (parents and others) and community members. As a result, this paper was developed to guide the consultation, engagement and collaboration activities to meet ethical standards, privacy obligations and to protect the safety of all participating individuals.

3. What are ethics, privacy and safety?

We have separated privacy and safety considerations from ethics (even though these are often considered as part of ethics) as there are legal obligations in relation to the privacy of personal information in Victoria\(^1\) and for the cohort of individuals the initiative is seeking to engage with, namely those who have experienced, are experiencing or are likely to experience vulnerability, safety is a very real and primary concern (for example survivors of family violence).

**ETHICS**

Ethics refers to the moral principles or values that govern the conduct of an activity. There are no legislative obligations that dictate what ethics are and what they apply to in direct engagement with individuals for research, evaluation and design purposes. In Australia we have Human Research Ethics Committees (HREC)\(^2\), they are responsible for developing guidelines on ethical conduct and assessing whether the methodologies of research and evaluation projects meet ethical guidelines. These HRECs are often specific to either an area of research such as medicine or a cohort of individuals such as Indigenous Australians (see annexes for further information on HRECs).

It is very important to a) closely consider whether you need ethics approval before you start any engagement and b) regardless of whether you have ethics approval or not to conduct your engagement with individuals ethically.

Should you decide to apply for ethics approval you should be aware that:

- You will need a fully developed and detailed methodology.
- Application and approval take time and can delay your engagement significantly.
- Once you have ethics approval, you will not be able to change any part of your methodology without ethics approval for the changes you want to make.
- Some ethics HRECs are privately run and require payment.

**PRIVACY**

The Victorian Commissioner for Privacy and Data Protection (PDP) states that “privacy is a difficult concept to define, and no definition exists in any privacy legislation in Victoria. Daniel Solove, one of the foremost international experts on privacy, has conceptualised privacy into six general categories, one of them being ‘control over personal information’. Victoria’s legislative approach to privacy is centred on this category – allowing individuals control over information about them. This is commonly referred to as ‘information privacy’”\(^3\).

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\(^1\) Privacy and data protection Act 2014 and Health records Act 2001.


Personal information is defined in the (PDP Act) as ‘Information or an opinion (including information or an opinion forming part of a data base), that is recorded in any form and whether true or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion, but does not include information of a kind to which the Health Records Act 2001 applies’.

Examples of personal information include an individual’s name, address, telephone number, photograph, bank account details and fingerprints. There are ten principles referred to in the PDP Act which have been directly lifted from the Organisation for Economic Co-operation and Development’s (OECD) privacy guidelines, that guide the collection, handling etc. of personal data (see the annexes).

The key legislation in Victoria relating to information privacy include:

- Privacy and Data Protection Act 2014 (Vic)
- Health Records Act 2001 (Vic)
- Privacy Act 1988 (Commonwealth)
- The Charter of Human Rights and Responsibilities Act 2006 (Vic)

**SAFETY**

Safety is defined in Wikipedia as “the state of being “safe”, the condition of being protected against physical, social, spiritual, financial, political, emotional, occupational, psychological, educational, or other types or consequences of failure, damage, error, accidents, harm or any other event that could be considered non-desirable.” Safety is an important consideration when seeking to work collaboratively with individuals experiencing vulnerability.

4. **When should ethics, privacy and safety be considered?**

Considering ethics, privacy and safety should be undertaken during planning and throughout the delivery of the work. Ethics, privacy and safety should be considered for everyone involved in place-based work and in particular for individuals invited to participate in a non-professional capacity, as a community member, a community representative or a person with lived experience. This includes but is not limited to, any form of engagement such as recruiting individuals to become members of the leadership or design groups, collecting information from individuals for research or evaluation purposes, etc. Further consideration should be given for individuals that are part of at least one of the following groups (this list is not exhaustive):

- Child, mature minor or youth
- Aboriginal and Torres Strait Islander
- Experiencing vulnerability of some kind mental health, homeless, etc.
- Refugee
- Newly arrived migrant
- Non-English speaker

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4 Same as footnote 2
Annexes

Annex 1: Tools to help you to meet ethical, privacy and safety expectations

The following tools have been developed to assist you in understanding and conducting your work in a way that meets the initiative’s ethics, privacy and safety expectations.

1. The ethics, privacy and safety framework (this document - explains and provides resources and links to resources on good practice)
2. A checklist to help you think through the ethics, privacy and safety considerations
3. A template and guidance on writing information sheets in plain language
4. A template for consent forms to be signed by both the participant and person responsible for the activity.

(2) Checklist for ethics, privacy and safety

- Intermediary, or the person who can put you in touch with relevant individuals
  - Operating in a professional capacity - Yes/No
  - Trusted (professional relationship) by individuals we are trying to reach - Yes/No
  - Fully understands why you want to get in touch with individuals - Yes/No
  - Fully understands the ethics, privacy and safety guidelines - Yes/No
  - Has both the information sheet and consent form to share with individuals we are trying to reach - Yes/No
  - There are no benefits for the intermediary in reaching out to individuals - Yes/No

- Individual participating
  - They understand that there participation is voluntary - Yes/No
  - They have signed the consent form - Yes/No
  - They have contact details should they want further information on the activity or Yes/No
  - They have contact details should they want to make a complaint about any aspect of the activity - Yes/No
  - They are comfortable and feel safe about the location where the activity will take place - Yes/No
  - They are comfortable with the interviewer/facilitator - Yes/No
  - They have approved any notes from the activity for use as defined in the activity brief - Yes/No

- Interviewer/facilitator
  - They are experienced in working with vulnerable individuals - Yes/No
  - They have a working with children check if required - Yes/No/N/A
  - They are across the activity and able to answer questions about it clearly - Yes/No
  - They are across the mitigation actions - Yes/No
  - They are sufficiently experienced to deliver the mitigating actions - Yes/No
  - Recording of any form is only taking place with the informed consent of participants - Yes/No
• Activity manager
  o All of the above is addressed - Yes/No
  o The activity has a detailed methodology which can be shared with relevant stakeholders - Yes/No
  o Regular communications are maintained with participants unless participants opt out of receiving communications - Yes/No
  o The personal information of participants is kept separate to any records of the participants participation - Yes/No
  o All records and personal information are stored securely on a - Yes/No
  o Unless approved by the participants, all data and quotes from participants are de-identified in any internal and external written (reports, stories, etc.) and spoken (presentations, discussions, etc.) outputs - Yes/No
  o All final outputs (design, report, etc.) are shared with participants unless they chose not to receive these - Yes/No
  o A suitable professional (not the activity manager) is made available to debrief with participants or deliverers if requested - Yes/No

(3) Participant Information and consent form (PICF)

The PICF needs a header with your logo and contact details, the name of the project, the principal Adviser and the date. The formal PICF required by HREC’s often has a shorter, clearer one page summary of the key points for stakeholders attached as a cover sheet. The main elements required by ethics committees are:

1. **Introduction:** One paragraph stating what the relevant project is about; who we are and who has contracted us; what this document is about and an invitation to participate. It is important to remind the participant to read the information carefully and ask any questions about it (to us or others), and reiterate that participation is voluntary.

2. **What is the purpose of this evaluation?** Paragraph explaining what the evaluation aims to do, when and why.

3. **What happens if I agree to participate?** Provide information as to the process once someone agrees to participate (i.e. you will be contacted by us, a time booked in, it will take 30-40 minutes (for example), it will be on the phone/ face-to-face, recorded with your permission, how their feedback will be used (to highlight themes alongside other feedback, used in summit – need to state that further approval will be sought if used in summit etc.).

4. **What are the possible benefits or risks?** Benefits are mostly about helping improve a service or project; risks are often about the personal/ emotional impact of talking about particular issues (i.e. family violence, homelessness) or involvement in projects. In addition, participants who are involved in process evaluations of projects that they were involved in implementing may experience discomfort discussing any issues or problems that arose during the implementation process, including fear about the consequences of disclosure for their professional relationships and employment. Where data collection processes could cause participants to experience discomfort or distress, referral for counselling or assistance services should be identified prior to data collection and offered to participants as necessary.

5. **What will happen to the information I provide?** This needs to be really clear. The information required by ethics committees is very complicated and detailed. The main focus needs to be on use of information, protection of confidentiality and privacy; including de-identification processes (i.e. coding, access to information, internal systems for using information), the destination of information provided (i.e. when sound recordings and transcripts are destroyed), who will be provided a copy of the report, and whether participants will have the opportunity to review the report before it is finalised.

6. **Who can I contact if I want more information?** Include details of the Principal Researcher/ Director of the project at xxx.
HOW THE PICF WORKS IN PRACTICE

The PICF (and even the interview schedule) can be sent to the potential participant via an email at first contact so they can make a decision about whether they would like to participate or not. If someone is contacted via telephone and asked to participate and they agree, the PICF (and interview schedule) should be sent to them.

At the time of the interview or focus group, hard copies of the PICF should be made available to all participants.

Regardless of the process, the researcher or evaluator should verbally talk all participants through the key points at the start of each interview, including:

- The project being evaluated
- Who we are and what we are doing
- Telling them what the consultation process involves
- What we would like to do with their input (i.e. pull out themes, maybe use in summit, maybe use quotes in report)
- Confirm that no reference will be made to individuals and all efforts to de-identify quotes will be made
- Offer them the chance to check over transcripts or quotes (depending on the project or circumstances)
- Ask if people have understood all of that and if they have any questions
- Ask permission to record (if appropriate)
- Advise them that if they have any questions or queries after the interview/ focus group, they can contact the project director or the client contact
- Explain that they can withdraw from the study at any time.

COMMON ETHICAL ISSUES AND PRECAUTIONS TO BE AWARE OF

Despite all best efforts, ethical issues and ‘incidents’ can arise in the course of a research or evaluation project. If an ethics incident occurs (e.g. government department provides data that is not de-identified as was outlined in the ethics approval submission) this must be immediately reported to the project director and relevant HREC (if appropriate). If an HREC has not been used, the client should immediately be contacted to talk through ways of rectifying the situation; if required, action may be needed to address any issues that result from the ‘incident’.

Some examples of ethics issues include:

Participant not clear on the consequences of their involvement – Inform participants as clearly as possible, allow them time to understand what they are getting themselves involved in and seek consent. Obtain written consent and/or record participants verbal consent (including asking them to indicate whether they have read the PICF, understood the PICF from the reading and/or explanation of the evaluator, and have had the chance to ask the evaluator any questions they have about the process, including whether those questions were answered to their satisfaction). These questions can be built into the start of your interview guide.

Participant experiences discomfort or distress. If at any time during a data collection process a participant experiences discomfort or distress the process should immediately be suspended and the participant should be asked if they would like to terminate their involvement in the study and if there is anything the evaluator can do to help them to feel better (e.g. call a friend, colleague or other support
person). If available, the evaluator should also give them the name of and/or a referral to an appropriate support service (identified prior to initiating the data collection process). If the participant chooses to continue with data collection but continues to experience distress, the evaluator should wind down and end the data collection process as quickly as possible. In addition to participants verbally signalling their experience of discomfort or distress, the evaluator should watch for physical signs such as the participant becoming tearful or crying, becoming angry or shouting, tensing of facial muscles or hands, fidgeting or moving around restlessly, ‘zoning out’ or finding concentration difficult.

Quotes or stories used contrary to the participant’s desire – if a quote or story is used and a participant subsequently withdraws permission or is upset that it has been published, the quote or story should be removed from the publication as soon as possible (unless, for example, a report has already been approved and published). It is important from the outset to ensure that PICFs are clear; ensure that clear consent is provided for the actual process or product where their input is being used (e.g. presentation at a summit) and that the participant has had the PICF communicated to them in an accessible way.

Reporting: using a quote that is contentious or identifies an individual – if it is deemed important to use a contentious quote, it should be double checked with the interviewee (i.e. member checked) for final approval. The use of quotes should be done strategically, sparingly and with a clear understanding of what that quote contributes to the evaluation narrative.

(4) Participant consent form template

| I have read or have had the information in this form read to me in a language that I understand. |
| I understand the purposes, procedures and risks of this research project as described in this information sheet and/or by a member of the evaluation team. |
| I have had an opportunity to ask questions and I am satisfied with the answers I have received. |
| I freely agree to participate in this research project, as described. |
| I understand that I will be given a signed copy of this document to keep if I want. |

Participant’s name (printed): ___________________________________________________

Signature: ________________________    Date: ________________________

Declaration by researcher

| I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation. |

Researcher’s name (printed): ___________________________________________________

Signature: ________________________    Date: ________________________
## Annex 2: Useful resources for ethics, privacy and safety

<table>
<thead>
<tr>
<th>Author</th>
<th>Date</th>
<th>Resource name</th>
<th>Resource key points</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>IDEO (private design company)</td>
<td>2015</td>
<td>The little book of design research ethics</td>
<td>Developed for practitioners (designers). Uses three principles (respect, responsibility and honesty) and provides guidelines or recommended actions embodying those principles. Does not cover legal expectations. The guidelines work through the design steps: Planning and preparation; Gathering Information; Using and sharing. It has useful reflections and reflection questions throughout.</td>
<td>Highly relevant to design</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Good quality – built from 25 years of design practice</td>
</tr>
<tr>
<td>Austral-asian Evaluation Society</td>
<td>July 2013</td>
<td>Guidelines for the ethical conduct of evaluation</td>
<td>Includes key principles and guidelines (practical) organised into three sections Commissioning and preparing for an evaluation, conducting an evaluation and reporting the results of an evaluation.</td>
<td>Relevant – Evaluation specific</td>
</tr>
<tr>
<td>AIATSIS</td>
<td>2012</td>
<td>Guidelines for Ethical Research in Australian Indigenous Studies</td>
<td>Goes through 14 principles under 6 categories (rights, respect and recognition; negotiation, consultation, agreement and mutual understanding; participation, collaboration and partnership; benefits, outcomes and giving back; managing research – use. Storage and access; and reporting and compliance) and how to apply these in research projects with Indigenous people and communities.</td>
<td>Relevant to research Good quality Accessible to researchers mostly</td>
</tr>
<tr>
<td>Source</td>
<td>Date</td>
<td>Resource</td>
<td>Description</td>
<td>Relevance</td>
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<tr>
<td>------------------------</td>
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<td>--------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td>TACSI</td>
<td>Not dated</td>
<td>Draft Risk Assessment and Mitigation options</td>
<td>A really useful example of the risks and how these are managed. It was developed for the Crisis supported Accommodation Discovery project – Insights into the client experience.</td>
<td>Highly relevant to design and research</td>
</tr>
</tbody>
</table>
Annex 3: Human Research Ethics Committees

The role of HRECs is to formally review human research and evaluation proposals against the requirements of the National Statement on Ethical Conduct in Human Research (the National Statement⁶), approve those that are perceived to be compliant, and provide additional guidance aimed at improving those that aren't⁶. As such, HREC’s provide an added level of insurance that all proposed research and evaluation practice is ethically acceptable and complies with endorsed standards and guidelines.

You may not be mandated to submit proposals to HREC review. However, HREC review may be specified by a partner organisation. Alternatively, you may decide that the ethical complexities of a specific project mean that HREC review and guidance would be beneficial. If HREC review is required, you will need to allow sufficient time to complete all relevant forms, submit them by HREC meeting dates, and await and respond to HREC feedback as appropriate. Generally, funds will also need to be put aside to cover HREC costs.

For more information on HREC review processes, consult the HREC specified by the partner organisation. A full list of all currently accredited HRECs is available on the National Health and Medical Research Council⁷ website and on the Australian Indigenous Health Info Net website can be found a list of HRECs that focus on Aboriginal and Torres Strait individuals⁸.

Annex 4: Key privacy legislation for Victoria

The key legislation in Victoria relating to information privacy include:

- Privacy and data protection Act 2014 (Vic) – governs the collection and handling of personal information (excluding health information) in the Victorian Public sector and provides for the establishment of a protective data security regime. It also ensures the security of law enforcement data.
- Health records Act 2001 (Vic) – Health information includes information or opinion on physical, mental or psychological health, a disability, individual’s wishes about the future provision of health services to him/her, health services provided/to be provided to an individual. (see http://www.health.vic.gov.au/hsc/ for more information)
- Privacy Act 1988 (Commonwealth) regulates personal information held by federal and Norfolk Island government agencies as well as large Australian private sector organisations, including those operating in Victoria.
- The Charter of human rights and responsibilities Act 2006 (Vic) sets out the basic rights, freedoms and responsibilities of all people in Victoria (see http://www.humanrightscommission.vic.gov.au for more information)

Annex 5: OECD privacy principles

These are taken from the OECD’s privacy framework p.14 -

1. **Collection limitation** – There should be limits to the collection of personal data and any such data should be obtained by lawful and fair means, and where appropriate, with the knowledge or consent of the data subject.

2. **Data quality** – Personal data should be relevant to the purposes for which they are to be used and, to the extent necessary for those purposes, should be accurate, complete and kept up to date.

3. **Purpose specification** – The purpose for which personal data are collected should be specified not later than at the time of data collection and the subsequent use limited to the fulfilment of those purposes or such others as are not incompatible with those purposes and as are specified on each occasion of change of purpose.

4. **Use limitation** – personal data should not be disclosed, made available or otherwise used for purposes other than those specified in accordance with principle 3 except:
   a. With consent of the data subject
   b. By the authority of law

5. **Security Safeguards** – Personal data should be protected by reasonable security safeguards against such risks as loss or unauthorised access, destruction, use, modification or disclosure of data.

6. **Openness** – There should be a general policy of openness about developments, practices and policies with respect to personal data. Means should be readily available of establishing the existence and nature of personal data, and the main purposes of their use, as well as the identity and usual residence of the data controller.

7. **Individual participation** – Individuals should have the right to;
   a. Obtain from a data controller, or otherwise, confirmation of whether or not the data controller has data relating to them
   b. Have communicated to them, data relating to them:
      i. Within a reasonable time
      ii. At a charge, if any, that is not excessive
      iii. In a form that is readily intelligible to them
   c. Given reasons if a request made under subparagraph (7a) and (b) is denied, and to be able to challenge such denial
   d. Challenge data relating to them and, if the challenge is successful to have the data erased, rectified, completed or amended.

8. **Accountability** – A data controller should be accountable with measures which give effect to the principles stated above.