### AIHW Ethics Committee: Guidance for applicants regarding community expectations

#### The requirement

In Section 2 of the Ethics Online System (EthOS) application form, researchers are required to address the following question:

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| **2.17 Describe how consideration of community expectations has been reflected in the development of this proposal.** |

This question seeks to elicit information for the Committee to assist it, in reviewing ethics applications, to consider matters related to community expectations and trust arising from its responsibilities to:

* Conduct Privacy Impact Assessments (PIAs) required under the *Privacy (Australian Government Agencies) Privacy Code.* Guidance on PIAs is provided by the Office of the Australian Privacy Commissioner’s (OAIC’s) *Guide to Undertaking Privacy Impact Assessments* (2020) which states that, in addition to addressing compliance with the legislated Australian Privacy Principles in the *Privacy Act 1988*, a PIA should always consider privacy risks such as those that may arise if personal information is not used consistent with community expectations towards privacy.
* Meet the requirements of the National Health and Medical Research Council’s (NHMRC’s) *National Statement on Ethical Conduct in Human Research* (2018) which similarly provides guiding principles on ways of demonstrating respect for the expectations of individuals in the context of consent and secondary use of data or information.

#### Consideration of community expectations

Your response to this question should outline the community(ies) of interest and/or stakeholders you have identified that will be most affected by this research, how you have ascertained their expectations and a summary of the outcomes.

Where relevant, please provide reasons why consultation was not undertaken.

Community expectations should be considered in the context of the data to be used and the perceived benefits of the research.

There are no established criteria for satisfying the community expectation requirement, however, relevant guidance from the OAIC and NHMRC is extracted below.

##### *Community expectations and PIAs*

The OAIC’s [*Guide to undertaking privacy impact assessments*](https://www.oaic.gov.au/privacy/guidance-and-advice/guide-to-undertaking-privacy-impact-assessments/)(2020), provides the following guidance on the importance of addressing community expectations in PIAs, the extent to which consultation might be undertaken, and consultation models. This may assist you in completing the question, as well as the privacy-specific questions in Section 3 of the application form.

* *‘A PIA is much more than a simple compliance check. It should ‘tell the full story’ of a project from a privacy perspective, going beyond compliance to also consider the broader privacy implications and risks, including whether the planned uses of personal information in the project will be acceptable to the community.’* (p. 3)
* *‘Potential benefits of undertaking a PIA include … building community awareness and acceptance of the project through public consultation.’* (p. 4)
* *‘A PIA should always consider community attitudes to and expectations of privacy.* *Affected individuals are likely to be key stakeholders, so public consultation is important, particularly where a substantial amount of personal information is being handled or where sensitive information is involved.’* (p. 11)
* ‘*Privacy impact analysis investigates … how the use of personal information in the project aligns with community expectations.’* (p. 18)
* *‘How consistent is the project with community values about privacy? (You are likely to need to undertake some form of consultation in order to assess this, but could also look at community responses to similar projects, or research into community attitudes about privacy).’* (p. 19)
* *‘… even if the project appears to be compliant with privacy legislation, there may still be other privacy risks that need to be addressed, such as community expectations.’*
(p. 19)
* *Key elements for inclusion in a PIA report include… description of any privacy risks that cannot be mitigated, the likely community response to these risks, and whether these risks are outweighed by the public benefit that will be delivered by the project.’* (p. 30)

In describing any consultation undertaken, the following extracts from the OAIC’s Guide may be helpful:

* *It may not be necessary to consult with all the identified stakeholders, depending on the scale and likely privacy impacts of the project, but some form of consultation should occur as part of the PIA.* (p. 12)
* *For consultation to be effective, stakeholders will need to be sufficiently informed about the project, be provided with the opportunity to provide their perspectives and raise any concerns, and have confidence that their perspectives will be taken into account in the design of the project. Many consultation models are available, including telephone or online surveys, focus groups and workshops, seeking public submissions, and stakeholder interviews.* (p. 13)
* *Different models will be appropriate for different stakeholder groups and different stages of the project, and careful consideration should be given to which consultation model/s will be appropriate in the circumstances.* (p.13)
* *It is important that some form of targeted consultation is undertaken, even if widespread public consultation is not possible (for example, if a private organisation is concerned about sharing commercially sensitive information widely), such as with groups representing relevant sectors of the population, or advocacy groups with expertise in privacy.* (p. 13)

##### *Consent and secondary use of information for research*

In relation to secondary use of information, the [*National Statement on Ethical Conduct in Human Research*](https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018)(2018) states:

* *‘It is usually impractical to obtain consent from individuals for secondary use of administrative data or information. In these circumstances, respect for participants can be demonstrated in other ways, including, but not limited to, community consultation, ensuring that the research results are translated into improvements in services and practices, acknowledging the source of the data or information in publications and/or publishing the research results in a location and language suitable for the general community. In particular, using data or information without consent may undermine public trust in the confidentiality of their information.’* (p. 36)
* *‘Privacy concerns arise when the proposed access to or use of the data or information does not match the expectations of the individuals from whom this data or information was obtained or to whom it relates.’* (p. 36)

Chapter 2.3 of the National Statement – qualifying or waiving conditions for consent – states:

* *‘2.3.10 Before deciding to waive the requirement for consent (other than in the case of research aiming to expose illegal activity), an HREC or other review body must be satisfied that:*

*d) there is no known or likely reason for thinking that participants would not have consented if they had been asked.’* (p. 21)

##### *Consideration of community expectations –non-exhaustive list of examples*

* Consultation with key stakeholders or client group representatives, for example via working groups or advisory groups
* public engagement such as broad public consultations
* use of focus groups
* engagement with expert groups
* information from engagement events for similar projects
* government initiatives
* public polls
* literature reviews. [[1]](#footnote-1)

Where the research involves follow-up of an original cohort or a re-use of the original cohort for a new research question, consideration of community expectations could take into account any engagement with/expectations of, the original cohort.

The above examples may also be relevant in the context of responding to Sections 3.7 and 3.11 (consent arrangements) in the application form to the Committee.

1. <https://uksa.statisticsauthority.gov.uk/wp-content/uploads/2019/05/2019_Self-assessment_guidance_V2.1.pdf>, p. 15 [↑](#footnote-ref-1)