



A guide to ethics in not-for-profit research and evaluation

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Acronyms

ACID	Australian Council for International Development
AES	Australasian Evaluation Society
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
AIFS	Australian Institute of Family Studies
AMSRS	Australian Market and Social Research Society (now The Research Society)
ATSI	Aboriginal and Torres Strait Islander
CALD	Culturally and Linguistically Diverse
ERIC	Ethical Research Involving Children
HREC	Human Research Ethics Committee
ICIPR	Indigenous Cultural and Intellectual Property Rights
IP	Intellectual Property
IRB	Institutional Review Boards
NFP	Not-for-profit
NHMRC	National Health and Medical Research Council
NSW	New South Wales
STARTTS	NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors
UN	United Nations
UNICEF	United Nations Children's Fund

Introduction

Research and evaluation has increasingly been undertaken in the not-for-profit (NFP) sector in recent decades. This is mainly due to funding bodies, whether from government or other sources, adopting an 'evidence-based approach' and requiring programs and services to demonstrate outcomes, value and impact as a means of securing ongoing funding (Rogers et al 2017).

As NFP research and evaluation has evolved, practitioners working in the field have found themselves facing a number of challenges. One of these issues is ensuring that their research and evaluation processes are **ethical**.

While large organisations and institutions outside the NFP sector often have the necessary systems and resources to undertake a robust ethical process for their research and evaluation projects, many organisations in the NFP sector do not. This is especially true for small NFP organisations. In the absence of formal processes, NFP organisations are often responsible for their own ethical compliance without a high level of external or peer scrutiny and ultimately rely on their staff to accept responsibility and ensure ethical principles are maintained (Kelly 2017).

The 'ethical dilemmas' faced by researchers and evaluators in the NFP sector can be wide ranging. Consider the following scenarios below:

Large NFP organisations increasingly putting researchers and evaluators on staff with the ultimate goal of winning competitive tenders or grants over smaller, resource-poor NFP organisations in the sector.

NFP practitioners or organisations using intellectual property from another practitioner or organisation in the sector without acknowledging the source or getting permission, or using it as their own for organisational or professional gain.

NFP practitioners feeling pressured to alter research and evaluation findings to meet funding body objectives, or increasingly market-driven objectives in consumer-driven funding models.

Undertaking research and evaluation with diverse and often marginalised community groups (such as Aboriginal and Torres Strait [ATSI] communities, culturally and linguistically diverse [CALD] communities, children and young people) and being in a position of power to use the data provided for your organisation's purposes.

NFP organisations not having the appropriate policies, systems and structures to respond to existing and emerging research ethics issues, such as data privacy and security.

As a NFP researcher or evaluator, what would you do in these situations? It is often not clear cut and the support required to make the 'right and ethical' decisions is not always readily available within NFP organisations.

Therefore, the aim of this guide is to help NFP organisations and professionals understand what they need to consider to ensure that their research and evaluation processes are ethical. The guide covers a range of areas including:

- Key concepts in research and evaluation ethics
- Current ethical issues in NFP research and evaluation
- Working ethically with community groups

The guide also provides an 'ethics checklist' developed by WESTIR Limited to help NFP professionals put these value-based judgements into practice throughout their research and evaluation processes.

1. Key concepts in research ethics

1.1 Definitions and principles

There are a wide range of definitions available to describe 'ethics in research' and other related processes.

A quick search of 'research ethics' on reliable articles and websites on the Internet provides a range of definitions including:

"The application of moral rules and professional codes of conduct to the collection, analysis, reporting and publication of information about research subjects..."
(Encyclopedia.com)

"Research ethics provides guidelines for the responsible conduct of research. It educates and monitors those conducting research to ensure a high ethical standard"
(City University of Hong Kong)

"The most common way of defining ethics is the norms for conduct that distinguish between acceptable and unacceptable behaviour...One may also define ethics as a method, procedure or perspective for deciding how to act and for analysing complex problems and issues" (David B. Resnik, US National Institute of Environmental Health Sciences)

"Research ethics exist to ensure that the principles of justice, respect and avoiding doing harm are upheld, by using agreed standards... tends to revolve around the question of how to balance the interests of the individual with those of the community/society/family and the goals of research studies" (Virginia Morrow, University of Oxford)

The basic principles of research ethics are universal, although they are subject to subtle differences in how they are understood, interpreted and practiced from place to place. Below are some of the most common principles used in research ethics:

AVOIDING HARM: The researcher or evaluator has an obligation to protect the physical, social and psychological wellbeing and rights of participants. The possible risks or costs to participants need to be assessed, minimised and weighed up against the benefits of the study to individuals and wider society. If there are concerns that a participant will be harmed, there need to be strategies in place to reassess or discontinue your approach.

INFORMED CONSENT: Researchers or evaluators need to find effective ways of ensuring that the participants fully understand what the study is about and their requested involvement – including, but not limited to, its purpose and goals, all risks and benefits, and how data will be recorded, stored and used. This is usually communicated through an information sheet, but there may be other ways this is done to ensure that the participants consent voluntarily and are aware of their right to discontinue. It is important to note that consent is an ongoing process so participants can opt out any time they wish.

CONFIDENTIALITY, PRIVACY AND ANONYMITY: All participants have the right to remain anonymous and to have their rights of privacy and confidentiality respected. Confidentiality and privacy involves protecting the identity of those providing data and not sharing it beyond the study without permission. Anonymity goes beyond confidentiality and protects the participant from identification even from the researcher. Researchers or evaluators need to anticipate the ways in which confidentiality and privacy can be compromised and make every effort to protect the identities of participants.

NON-DISCRIMINATION AND LEGAL OBLIGATIONS: Discrimination against colleagues and participants on the basis of sex, age, race/ethnicity or other factors should be avoided and human dignity should be respected throughout the research or evaluation process. There is a duty on researchers and evaluators to think about the impact of their work when interacting with marginalised community groups, which will be discussed in a later section. Researchers and evaluators must also know and obey relevant legislation and policies, such as child protection, which will also be discussed in

BENEFICENCE AND RECIPROCITY: Researchers and evaluators should act for the benefit of others when weighing up the risks and harms of the process, with the welfare of others and broader society as the goal. The research or evaluation process should also be a reciprocal process between everyone involved, and include the following:

- No exploitation of participants and fair return should be made for any help.
- Giving participants the opportunity to alter content, withdraw statements or provide additional information so they have a say in how they are portrayed.
- The honest reporting of data and making sure data is not fabricated, falsified or misrepresented.
- Publishing findings or otherwise making it available to others, avoiding the deliberate suppression of results that were not expected.
- Authorship of findings should accurately reflect who contributed to the study, and intellectual property should be honoured.

(O'Leary 2010; Laws et al 2013; Wright & Wallis 2020)

1.2 Other important concepts in research ethics

As previously discussed, large institutions such as universities and hospitals have their own research ethics committees (also known as institutional review boards [IRBs]) to look at the overall quality and relevance of the research, as well as direct risks or harms to participants. This has been termed '**procedural ethics**'. While research ethics committees have heavily legislated obligations which are reviewed on an ongoing basis, it has still at times been criticised for being too focused on the process of obtaining approval rather than ongoing ethical conduct¹ (Haggerty 2004; Fujii 2012).

On the other end of the spectrum, there are many smaller organisations, including those in the NFP space, that do not have the formal processes for ethical compliance and rely on their staff ensuring ethical principles are maintained (Kelly 2017). This reliance on '**ethics in practice**' (that is, the everyday ethical issues that arise in the doing of research) can also have its pitfalls, but highlights that ethics is an ongoing responsibility throughout the research or evaluation process.

Striking a balance between 'procedural ethics' and 'ethics in practice' is difficult but can best be summed up with the following quote:

"Ethicality is a 'way of being' for a social science researcher [. . .] It is one of the most fundamental tools for engagement with participants and is not simply a process for gaining entry into a community. Ethical values, practices, and expectations are constantly being negotiated throughout the research process and the onus on being most ethically, all the time, falls squarely upon the shoulders of researchers" (Pidgeon 2019).

As a NPF researcher or evaluator, below are some ethical issues that you will need to be aware of and consider in your day-day practice.

1.2.1 Power dynamics

Researchers and evaluators are in a position of power whether they recognise it, or not. They have the power to conduct and control the direction of their investigations, creating a power imbalance between the 'researcher' and the 'researched'. In many cases, researchers or evaluators also sit in a position of societal privilege, which is or can be insensitive to age, gender, race/ethnicity or social class. As a result, it can be difficult for the researcher or evaluator as an 'outside expert' to naturally immerse themselves into the communities they are studying and there needs to be a concerted effort to manage the power dynamics at hand (O'Leary 2010).

¹A similar concept called 'ethics creep' has been used to describe issues with the formal system for regulating the ethical conduct of scholarly research. Ethics creep is characterised by a dual process whereby the regulatory system is expanding outward to incorporate a host of new activities and institutions, while at the same time intensifying the regulation of activities deemed to fall within its ambit. One effect of the increasingly formalised research ethics structure is to rupture the relationship between following the rules and acting ethically. Such developments constrain scholarly research and, in so doing, structure what truths can be spoken and by whom (Haggerty 2004).

SOME TIPS FOR MANAGING POWER IMBALANCES

- 1. Acknowledge the position of power and privilege** that you may be sitting in as a researcher or evaluator. In many cases, you may be working in circumstances that privilege the biases and assumptions of Western views and there needs to be some thought in how the research or evaluation process can be made more sensitive to issues of age, gender, race/ethnicity or social class (O'Leary 2010).
- 2. Do not deliberately lie, trick or withhold information from participants.** This is always necessary, but is particularly critical if there is a risk of physical, social or psychological harm. You need to make a concerted effort to obtain **informed consent** in order for your research to be valid. In rare circumstances where information is withheld to maintain the integrity of the research, participants must be retrospectively informed in order for their consent to remain intact (European Commission 2018).
- 3. Find ways to build trust with your participants** to minimise any real or perceived power differential. There is no set of techniques that guarantee candour, but you must aim to create an environment for open and honest lines of communication. This may require assistance from members within the community that you are studying (O'Leary 2010).
- 4. You may want to consider participatory or co-design processes** to ensure that participants have a voice in shaping the research or evaluation, and they have ownership over the process as well (Curran & Taylor-Barnett 2019).
- 5. Your language** (both verbal and body) is important. Make sure that you are speaking the language of the 'researched' not the researcher (O'Leary 2010).

Managing power imbalances and dynamics with specific community groups will be explored in greater detail in the following sections.

1.2.2 Reflexivity and managing subjectivities

The ability for researchers or evaluators in the NFP sector to capture the 'truth' can be difficult. All researchers and evaluators come with their own beliefs, notions and biases and they are also studying people and communities that have their own agendas, are fallible and want to present themselves in certain ways.

Researchers and evaluators are challenged with the task of making sure their work meets the following standards:

- **It is credible:** That the study is of high quality and is believable.
- **It is authentic:** Authenticity has built on the concept of validity, which is the extent to which the results correctly measure what is supposed to be measured based on a

singular truth. The concept of authenticity looks at whether the conclusions are justified, credible and trustworthy even when the truth is dependent on multiple perspectives.

- **It is reliable or consistent:** that the same results of the study could be produced on repeated attempts.
- **It is verifiable:** that the results are deemed accurate, with others being able to see how the findings were generated.

This starts with the researchers and evaluators trying to manage their subjectivities (that is, their personal feelings and opinions devoid of external scrutiny). If these subjectivities are not managed, there is the risk that the research or evaluation will not accurately capture the reality of the situation. A common example of this is when a researcher or evaluator only listens to those who are the loudest or those in their own language, subsequently missing out on less dominant voices. Researchers or evaluators in the NFP sector may also have to manage the subjectivities of those around them (their leaders, managers, funders), which will be discussed further in a later section.

There are two main ways that researchers and evaluators can work towards managing their subjectivities. The first way is to ensure that the **methods used are rigorous, disciplined and have a level of standardisation**. The second is to practice **reflexivity**. Reflexivity is best described with the following explanation:

“Reflexive research means that the researcher should constantly take stock of their actions and their role in the research process and subject these to the same critical scrutiny as the rest of their “data”... As researchers, our social and political locations affect our research. Our research interests and the research questions we pose, as well as the questions we discard, reveal something about who we are. Our choice of research design, the research methodology, and the theoretical framework that informs our research are governed by our values and reciprocally, help to shape these values. Who we include and who we exclude as participants in our research are revealing. Moreover, our interpretations and analyses, and how we choose to present our findings, together with whom we make our findings available to, are all constitutive of reflexive research.

Reflexivity in research is thus a process of critical reflection both on the kind of knowledge produced from research and how that knowledge is generated. The goal of being reflexive in this sense has to do with improving the quality and validity of the research and recognising the limitations of the knowledge that is produced... It does not have an overtly ethical purpose or underpinning [however]...the reflexive researcher will be better placed to be aware of ethically important moments as they arise and will have a basis for responding in a way that is likely to be ethically appropriate, even with unforeseen situations” (Guillemin & Gillam 2004, p. 274-277).

SOME TIPS FOR MANAGING RESEARCHER SUBJECTIVITIES

- 1. Appreciate your own worldview and appreciate alternative perspectives.** Suspend your initial judgements until you seek out the 'full story'. This can involve incorporating as many voices and perspectives as possible, and checking your interpretations with community 'insiders'.
- 2. Strive for a rigorous research or evaluation process.** Ask yourself throughout the process: have subjectivities been managed and acknowledged? Are methods approached with consistency? Has the 'truth' been captured? Are arguments relevant and appropriate? Can the research be verified?
- 3. Honestly outline your study's limitations or shortcomings,** as well as the strategies employed to gather credible and trustworthy results.
- 4. Never fabricate, falsify, omit or misrepresent your results** in order to show 'significance'.
- 5. Practice reflexivity.** As a researcher or evaluator, critically reflect on the knowledge produced (data), plus how you have generated the knowledge (practice) and what is influencing the construction of this knowledge (internal/external factors). This will include acknowledging and scrutinising ethical dilemmas throughout the research process.

(Most content for this section has been derived from Guillemin & Gillam 2004 and O'Leary 2010).

1.2.3 Researcher competency and safety

In order to undertake studies that are ethical, it is important that researchers or evaluators be considered competent – that is, they should possess the knowledge, abilities, skills and experience appropriate to undertake the work at hand. They should fairly represent their competency, not practice beyond it and strive to keep abreast on current and emerging practices (AES 2013a; AES 2013b).

In addition to competency, organisations in the NFP sector must ensure that the safety of their staff while undertaking fieldwork is given explicit consideration during the research or evaluation process ((Laws et al 2013; Wright & Wallis 2020). Some tips to improve researcher competency and safety are outlined below.

SOME TIPS FOR IMPROVING RESEARCHER COMPETENCY AND SAFETY

1. Keep up with your professional development activities where possible. Do not over claim your professional abilities and ask for help from more experienced colleagues where necessary.

2. Assess the risks of your particular research or evaluation project, plan ahead and avoid danger as far as possible.

3. Consider implementing the following guidelines when physically going out to do fieldwork:

a) Make sure an appropriate colleague and a trusted friend or family member knows where you are, what you are doing each day and when you expect to return. Let them know when you return.

b) Where possible, consider working in pairs – this has other benefits in terms of quality of data collection and opportunities to learn.

c) Think about what you will need to take with you – a mobile phone for keeping in touch when plans change or you need help, carrying identity documentation to establish your identity as a researcher, dressing appropriately and avoiding carrying anything of value.

d) Keep up to date of any security issues in the area you are undertaking fieldwork in. If a security threat is encountered, it should be immediately reported through the appropriate channels in your organisation.

(Content derived for this section from Laws et al 2013)

1.2.4 Defining values in research and evaluation

When undertaking research and evaluation, it is imperative that there is an understanding of the values underpinning the work. Values are especially important for evaluation where they determine:

1. What programs or evaluation efforts are worth pursuing, credible and appropriate,
2. What kinds of criteria and methods are deemed to best capture what is 'valuable', and,
3. Whose perspectives and narratives are prioritised in the valuing process (Gullickson & Hannun 2019).

Values /'valju:/ noun

1. Principles or standards of behaviour; one's judgement of what is important in life.
2. The regard that something is held to deserve; the importance, worth, or usefulness of something.

There are a number of sources that researchers and evaluators can consult to clarify the values underpinning their investigations, making their reasoning process explicit and transparent (See Table 1). Engaging with relevant stakeholders can also assist in determining and applying values, ensuring that eventual findings are not dismissed as subjective or irrelevant and are reflective of the values of the wider group (Roorda & Gullickman 2019).

Table 1: Sources that can be consulted to determine 'values'

Sources that can be consulted to determine 'values'
<ul style="list-style-type: none">• Stated program goals and objectives (through logic models or theories of change)• Professional codes, standards and guidelines• Organisational strategic planning documents• Past performance and/or historical data• Pre-intervention baseline levels for target population• Expert opinion• Customs, practices or norms for programs or community groups• Legal requirements• Ethical or moral values (e.g. social justice, equity)• Cost or relative cost• Theoretical value models or frameworks

(Source: Berends 2007; Tulloch 2020)

SOME TIPS FOR DEFINING VALUES IN RESEARCH AND EVALUATION

1. If you are unclear on the values of your research or evaluation, **consult a range of sources** to determine the values that underpin your work. Professional resources are a good place to start (see next section), along with other examples in Table 1.
2. Consider **consulting with relevant stakeholders** of your research and evaluation project to confirm that the values are reflective of the wider group.

1.2.5 Ethical guidelines

There are a range of good practice guidelines that have been developed in Australia to support ethical research and evaluation conduct. The list below is not exhaustive, but researchers and evaluators in the NFP sector should familiarise themselves with their content:

- [National Health and Medical Research Council \(NHMRC\) National statement on ethical conduct in human research \(2007 – Updated 2018\)](#)
- [NHMRC Australian Code for the Responsible Code of Research \(2018\)](#)
- [NHMRC Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and Communities \(2018\)](#)
- [NHMRC Ethical considerations in quality assurance and evaluation \(2014\)](#)
- [AES Code of Ethics \(2013\)](#)
- [AES Guidelines for the Ethical Conduct of Evaluations \(2013\)](#)
- [Australian Council for International Development \(ACID\) Principles and Guidelines for ethical research and evaluation in development \(2017\)](#)
- [Australian Research Council Codes and Guidelines \(2015\)](#)
- [Australian Institute of Aboriginal and Torres Strait Islander Studies \(AIATSIS\) Guidelines for Ethical Research in Indigenous Studies \(2012\)](#)
- [BetterEvaluation.org Ethical Protocol for evaluation in Aboriginal and Torres Strait Islander settings \(2019\)](#)
- [The Research Society \(formerly the Australian Market and Social Research Society \(AMSRS\)\) Codes, Guidelines, Standards and Factsheets \(Various dates\)](#)
- [NSW Government Program Evaluation Guidelines and Toolkit \(2020\)](#)

SOME TIPS ON ETHICAL GUIDELINES

Navigating and applying multiple national ethical codes and guidelines to your daily practice can be daunting. As you review the resources above, select a maximum of five (5) action areas that can be realistically incorporated into your research and evaluation projects.

Your organisation or funding body may also have ethical procedures or requirements that it uses for research and evaluation projects. Make sure you familiarise yourself with these as well!

2. Current ethical issues in not-for-profit research and evaluation

There are a number of current and emerging issues that highlight the importance of ethical conduct when undertaking research and evaluation in the NFP sector. Not all can be covered in this section, but some of these issues are discussed in more detail below.

2.1 Data management

Keeping data safe, secure and private during the research or evaluation process has become more important than ever. The increase in cyberattacks and data breaches has shown that even the NFP sector is not immune to these issues. Researchers and evaluators in the NFP sector need to seriously consider how their data is managed – that is, how it is collected, stored, used and destroyed, as well as who is able to access the data and what needs to be kept private and confidential. Remember, all participants have the right to anonymity, unless they give explicit consent to be identified. Data management needs to therefore be considered at the beginning of the research and evaluation process to try and prevent data landing in the wrong hands (Justice Connect 2020).

SOME TIPS FOR DATA MANAGEMENT IN THE RESEARCH AND EVALUATION PROCESS

1. At the beginning of the research or evaluation process, develop a **data management plan** in relation to data generation, collection, access, use, analysis, disclosure, storage, retention, disposal, sharing and re-use of data and information, the risks associated with these activities and any strategies for minimising those risks. Some major issues the plan will need to address include: (a) physical, network, system security and any other technological security measures; (b) policies and procedures; (c) the conditions under which access to the data or information may be granted to others; (d) what information needs to be communicated to potential participants; and (e) the minimum period required to retain data or information.
2. You must comply with all **relevant legal and regulatory requirements** that pertain to the data or information collected, used or disclosed, such as the *Privacy Act 1988 (Cth)*, as well as the conditions of the consent provided by the participant.
3. You need to consider **how the data will be used by other people and in the future**. Participants should be informed of any sharing or re-use of their data in future research, preferably at the time of consent. If consent to future use was not obtained in the initial instance, it may be appropriate to seek additional consent for the sharing and re-use of this data.

(Source: NHMRC 2018)

2.2 Intellectual property and Indigenous cultural and intellectual property

Intellectual property (IP) has been described as the knowledge, creations or discoveries of you as the researcher, evaluator and/or the organisation you work for. IP can take on many forms, such as reports, publications, patents, confidential information or trademarks (Deakin University 2019).

Researchers and evaluators in the NFP sector may work with other colleagues within the sector to undertake their work, as well as colleagues in outside institutions such as government agencies or universities. While most of us would like to think that everyone's interests are taken into consideration, the sad fact is that some colleagues use these collaborations or partnerships to advance their own organisation's agenda or their professional careers at the expense of others (including participants). Once research or evaluation work is published, there have also been instances where individuals or organisations have used this work as their own without appropriate acknowledgement or permission. It is clear that a number of strategies need to be considered to protect your IP as a researcher or evaluator in the NFP sector.

SOME TIPS FOR MANAGING INTELLECTUAL PROPERTY (IP) IN THE RESEARCH AND EVALUATION PROCESS

1. When working with multiple colleagues, **decide on who will be acknowledged as authors** of the work at the beginning of the research and evaluation process (including lead author and subsequent co-authors). This conversation is often nowhere near as uncomfortable as it seems, and it will prevent any misunderstandings during the life of the collaboration or partnership. When reporting your research or evaluation results, the authorship should accurately reflect who contributed to the study.
2. **Respect the IP of those around you.** Any information related to IP and copyright arrangements needs to be provided to potential participants at the consent stage. Also remember to appropriately reference and cite the work of secondary sources. Do unto others as you would have them do to you!
3. The NHMRC *National statement on ethical conduct in human research* states that "When multiple researchers are collaborating... [they] should consider whether any intellectual property will be generated by the project and agree on the ownership of any intellectual property created. Agreements on such arrangements and ownership need not necessarily be in the form of a contractual document, but should facilitate a clear resolution of these issues" (3.1.44). Despite this guideline, it is still advised that **arrangements around intellectual properties be outlined in some written form**, whether it be in the research/evaluation brief or a contractual agreement.

4. Provide public reminders to readers to appropriately reference your research or evaluation work when they are using it. This may be in the form of general statements on your organisation’s website or placing a copyright disclaimer on your publications to encourage users to seek permission where necessary. At WESTIR Limited, publications have the following statement “*This work is Copyright. Apart from use permitted under the Copyright Act 1968, no part can be reproduced by any process without the written permission from the Executive Officer of WESTIR Ltd*”.

5. Some studies will go through a peer review process. Make sure to **publicly acknowledge the contribution of peer reviewers**, unless anonymity is requested.

6. If IP becomes an ongoing issue, consider advocating to your organisation to **adopt a policy or procedure that addresses IP** so it can be consistently dealt with over time.

(Sources: AES 2013b; NHMRC 2018; Wright & Wallis 2020)

It is also important to consider Indigenous Cultural and Intellectual Property Rights (ICIPR) when working with Aboriginal and Torres Strait Islander (ATSI) communities. ATSI communities and their knowledge, ideas, cultural expressions and materials have historically been exploited during the research or evaluation process, with little to no acknowledgement or benefit flowing back to these communities (Markewicz 2012).

ATSI communities have the right to assert and retain ownership of the cultural and intellectual property related to the information provided during studies and it is important these rights are respected. Protection of ICIPR is fragmented in current Australian legislation, however, the protection of the cultural and intellectual property of ATSI people is fundamentally connected to the right to self-determination (Ermine, Sinclair & Jeffery 2004). ICIPR is also closely linked to ‘data sovereignty’ where ATSI communities have the right to govern the collection, ownership and application of its own data through the existing laws and governance structures of their communities (Eades & Ferguson 2018).

SOME TIPS FOR MANAGING ICIPR IN THE RESEARCH AND EVALUATION PROCESS

The [NHMRC](#) and [AIATSIS](#) guides on ethical research with Indigenous communities provides some good advice on managing ICIPR during the research or evaluation process:

1. Research projects should be conducted in accordance with the principle of Indigenous peoples’ rights to maintain, control, protect and develop their cultural heritage, traditional knowledge, traditional cultural expressions and intellectual property.

2. Openly discuss co-ownership of intellectual property, including co-authorship of published and recorded works and performances, shared copyright, future management of the resources collected, and proper attribution and notices. There should be fair distribution of benefits to all parties involved.

3. Written agreements between researchers and Indigenous contributors should cover the management of ICIPR. Representation from the Indigenous community may also be necessary through this process to ensure the collective rights of the community are protected.

4. In any publication, seek permission before using information obtained from Indigenous peoples and acknowledge its usage. Be aware of copyright laws regarding moral rights and attribution and the various forms of protection for different research products, including performances and other elements of Indigenous cultural expressions. Where necessary, seek appropriate expert advice on intellectual property issues.

2.3 Influences on the research and evaluation agenda

Researchers and evaluators in the NFP sector have external and internal factors that influence the direction and focus of their work. A major influence on any research and evaluation work is who funds it – it is well established that there is unconscious, unintentional and recognised tendencies to produce study results favourable to the funding body (Krimsky 2012). Traditionally, the main influences of NFP research and evaluation have included:

- **Government/political influences:** government funders wanting research or evaluation to align with their priority areas and provide recommendations that are achievable within resource constraints.
- **Organisational influences:** NFP organisations, big and small, producing research that justifies the strategic directions of their organisation or is geared towards maintaining existing or attracting new funding sources.
- **Individual and peer network influences:** what the researcher/evaluator and their colleagues deem to be important based on experience, beliefs, culture and other factors.

In recent times, the shift towards competitive tendering, individualised funding and market based approaches has seen the rise of private service providers in the sector. The full impact of increasing privatisation in the community services sector is still to be fully known, including its influence on shaping the sector's research and evaluation narrative. Some potential impacts could include privileging voices that support economic profitability over social outcomes, decreased access and availability of data, and the ongoing use of research or evaluations by larger organisations to win funding over smaller organisations. The potential impact of these changes are profound and warrants ongoing investigation as time goes on.

SOME TIPS FOR MANAGING INFLUENCES ON THE RESEARCH AND EVALUATION AGENDA

Researchers and evaluators in the NFP sector often find it difficult to manage the influences on their work. While not the 'silver bullet', below are some strategies that may assist with this issue:

- 1. Practice transparency.** It is good practice to publicly disclose how your research was funded and any financial or other declarations of interests that you, your organisation or your funder may have. Participants should also be adequately informed of the funding arrangements of the research or evaluation during the consent process.
- 2. Always strive to present a well-rounded argument.** This includes acknowledging and discussing perspectives that you do not agree with, and outlining why you do not support with this approach. When making recommendations, it is also important that they are informed by the primary and secondary evidence you have collected so you can clearly justify and verify your position.
- 3. Be open to scrutiny and constructive criticism.** If your research or evaluation findings are questioned and you feel pressured to change them, make a decision as to whether they need to be reviewed again. If you stand by your original findings or recommendations, you may need to do some more work in better articulating the evidence collected.
- 4. Have inclusivity and social justice at the heart of your research or evaluation.** Make sure the perspectives and experiences of minority groups are identified and reported fairly. Also try to outline the ongoing advantages of a collaborative approach in an increasingly competitive environment.

2.4 Providing incentives for research and evaluation

There is ongoing debate as to whether incentives are ethically appropriate in research involving humans. Some view incentives as unethical as they are a form of undue influence on the participants' judgement, or are seen as a measure to coerce participation, leading to a less than representative sample of the studied population. Others see incentives within the lines of ethical research conduct as it reflects their appreciation of the participant's input into the study (Grant & Sugarman 2004). For the purposes of this discussion, an "incentive" is defined as anything which is likely to give benefit to a research participant which would not generally be available to others. It can include cash payments, gifts, vouchers or possible prizes drawn at random. It does not include the provision of items or the direct reimbursement of actual expenses incurred by participant in order to take part in the study (for example, food and travel expenses) (Sheffield Hallam University n.d.).

The use of incentives varies in the NFP sector, most often coming down to whether it can be afforded within the research or evaluation budget. There is no clear cut rule as to whether incentives should be used or not, but the *NHMRC National statement on ethical conduct in human research* provides some good guidance if faced with the situation (See Table 2).

Table 2: NHMRC advice when considering incentives and reimbursements

NHMRC advice when considering incentives and reimbursements
<ul style="list-style-type: none">• <i>No person should be subject to coercion or pressure in deciding whether to participate. Even where there is no overt coercion or pressure, consent might reflect deference to the researcher's perceived position of power, or to someone else's wishes. Here as always, a person should be included as a participant only if his or her consent is voluntary.</i>• <i>It is generally appropriate to reimburse the costs to participants of taking part in research, including costs such as travel, accommodation and parking. Sometimes participants may also be paid for time involved. However, payment that is disproportionate to the time involved, or any other inducement that is likely to encourage participants to take risks, is ethically unacceptable.</i>• <i>Decisions about payment or reimbursement in kind, whether to participants or their community, should take into account the customs and practices of the community in which the research is to be conducted.</i>• <i>Researchers should provide assurance that any proposed payment in money or kind, whether to institutions, researchers or participants, will not adversely influence the design, conduct, findings or publication of the research.</i>• <i>Researchers and reviewers should consider the degree to which any payment in money or incentives of any kind, whether to researchers, participants or others involved in recruitment, could result in pressure on individuals to consent to participate (see paragraphs 2.2.10, and 2.2.11). This is especially important with respect to research that involves more than a low risk of harm.</i>• <i>When those who are recruiting participants will receive some form of payment per recruited individual or other benefit, this must be disclosed to potential participants during the consent process.</i>

(Source: NHMRC 2018)

The Research Society (formerly AMSRS) has also created useful guidelines called '[Guideline on incentives for participation in market and social research](#)' (August 2017), with the main advice outlined in Table 3 below.

Table 3: Advice from The Research Society on incentives

Advice from The Research Society (formerly AMSRS) on incentives
<ul style="list-style-type: none"> • <i>The incentive must comply with any relevant legislation. For example, if the incentive being offered is alcohol, the researcher must first check that all participants are aged 18 years or over. If the incentive involves any element of chance (for example, participants' names will be selected at random for a prize draw), then it is deemed to be a trade promotion lottery and there are regulatory requirements that must be followed in each state/territory.</i> • <i>If working for a client, the client's products or services, or vouchers for them, must not be used as an incentive or prize in a prize draw as this provides a selling opportunity for the client from the research project. There are exceptions (such as a member of an ongoing panel where rewards and incentives are agreed upon), however, incentives should be proportionate and clearly represented as a gift for participation and not as a form of inducement or bribe.</i> • <i>The incentive must not lead to any perceived harm or adverse consequences to the participant. If participants are offered a choice of incentive, then all incentive options should be of equal value, to avoid any adverse effect to the participant by their choice.</i> • <i>The offer of an incentive is not appropriate for some types of participant, for ethical or legal reasons. For example, some business or government representatives may have regulations forbidding the receipt of gifts.</i> • <i>The participant must not be misled in any way when being offered the incentive. Researchers should fully inform participants about the incentives associated with a research project, including the exact nature of the incentive, when they will receive the incentive, who will give out the incentive (the researcher, the client or a third party) or whether any conditions are attached to receiving the incentive.</i> • <i>A participant's anonymity must not be compromised as a result of receiving the incentive. For example, if they have to provide personal details in order to obtain the incentive, these should be held securely by the researcher and not used for any other purpose.</i>

(Source: AMSRS 2017)

SOME TIPS WHEN CONSIDERING INCENTIVES

There is no clear cut rule as to whether incentives should be used in NFP research and evaluation (although reimbursements are generally considered acceptable). If you are considering using incentives, it is recommended that you consider the advice outlined above.

It is also important to understand the characteristics of the community or population you are studying as in some circumstances, it may exacerbate existing vulnerabilities or create harm. For example, if you are doing a study that involves problem gamblers, it is probably not a good idea to offer the incentives, such as a prize draw, that encourage further gambling!



2.5 The rise of online research in times of crisis

The rapid rise of technological developments in recent decades have made it possible for aspects of research and evaluation to be undertaken online. Global crises, notably the COVID-19 pandemic of 2020, has led to more online data collection tools being embraced by professionals in the research and evaluation space. Some of the main tools being used include online surveys, over-the-phone interviews, video conferencing applications and social media groups (See Deborah Lupton's '[Doing Fieldwork in a Pandemic](#)' for more tools and methods). The ethical ramifications of online research continue to emerge and will need to be frequently discussed in order for researchers and evaluators to continue working ethically.

SOME TIPS FOR ONLINE RESEARCH IN TIMES OF CRISIS

1. Consider the **work health and safety of your peers**. Doing research and evaluation remotely has its limitations but it may be the safest option depending on the environment and circumstances you are working in.
2. Consider the **impact of the digital divide** when undertaking online research or evaluation. Doing your investigations online may open you up to some sections of the population (for example, regular social media users), but also exclude you from others (for example, disadvantaged groups with limited internet access). Be honest about these limitations and how this impacts your research or evaluation design.
3. **Revisit and revise your documentation** so that you are transparent about your online work and how it will be undertaken. This may include research or evaluation plans/frameworks, program logics or theories of change, terms of reference, contractual agreements, and information and consent forms (see point 4 below).
4. When doing fieldwork remotely, you will need to factor this into the **consent process**. For example, participants will need to consent to being video recorded if undertaking interviews via video calls and, should be given information on how their data will be used stored and protected. You may also need to consider online platforms, such as www.smallpdf.com, to facilitate the collection of electronic signatures when verbal consent is insufficient.
5. **Check the security settings of the digital platforms** before undertaking fieldwork to ensure data security and privacy is maintained. In addition, when undertaking video calls, it is recommended that researchers or evaluators use a generic background to shield details of their personal spaces from participants.

2.6 Research ethics governance

As previously mentioned, research and evaluation projects conducted through large institutions (such as universities and government agencies) are commonly subject to an official ethics approval process. On the most basic level, this often involves the submission of an ethics approval form that is scrutinised by a Human Research Ethics Committee (HREC) (also known as Institutional Review Boards [IRBs]). HRECs look at the overall quality and relevance of the research, as well as direct risks to respondents (Laws et al 2013; NHMRC 2018; Wright & Wallis 2020).

Researchers and evaluators in the NFP sector may not go through the same level of ethical scrutiny undertaken at large institutions in other sectors. There are a range of reasons for this, including the fact that many organisations (particularly small operations) do not have the policies, systems and structures to undertake comprehensive ethical review. The absence of these governance structures need to be seriously considered by NFP organisations as it cannot be assumed that the research or evaluation that they undertake, particularly with vulnerable community members, is “low risk”.

SOME TIPS FOR RESEARCH ETHICS GOVERNANCE

If you are NFP researcher or evaluator working in an organisation with limited ethics approval and review processes, you may want to reflect on and advocate for the following:

- 1. Consider how ethical issues are currently addressed and whether it needs to change.** It may be sufficient to incorporate ethical considerations into initial research or evaluation briefs, or a more comprehensive process may be required to assess and manage risks such as the checklist available at the end of this guide (See Section 4).
- 2. Consider the current structures of ethical review and approval and whether it needs to change.** If you do not have anyone in your organisation who is responsible for ethical review and approval, you may need to consider appointing a particular person within the organisation, setting up an independent board or committee, or establishing a relationship with a university to undertake this work.
- 3. Make sure your organisation has the mechanisms in place to deal with actual or potential ethical breaches.** This includes policies and procedures to receive complaints or concerns about ethical conduct and how they will be investigated and resolved fairly. There should also be measures in place to identify and manage actual and potential conflicts of interest throughout the research or evaluation process.

3. Working ethically with community groups

The following sections explore how NFP researchers and evaluators can work ethically with some of the many groups present in their communities. Each community has unique characteristics and challenges that need to be respectfully navigated through the research and evaluation process.

“There are a wide range of vulnerable groups – children, women, disabled people, LGBTQI people, victims of violence among others – and each demands careful consideration regarding the unique set of potential risks your research may raise. Thinking systematically through strategies for minimising such vulnerabilities is critical from the outset... you have a responsibility to familiarise yourself with the particular vulnerabilities of the research group in question, both in general terms and with regard to the community you will engage. Obviously, the risks of different research projects vary widely in nature and intensity – each needs to be assessed specifically” (Laws et al 2013, p. 166).

3.1 Aboriginal and Torres Strait Islander (ATSI) communities

As briefly outlined in Section 2.2, Aboriginal and Torres Strait Islander (ATSI) communities in the past have been regularly exploited through the research and evaluation process. Researchers and evaluators, many of non-Aboriginal origin, have been known to enter a community with a pre-determined agenda, extract data and knowledge with little regard for Aboriginal culture, and then leave with little to no acknowledgement or benefit flowing back to these communities (Scougall 2006; Price, McCoy & Mafi 2012). The need to redistribute power and voice back to these marginalised communities has been clear through approaches that prioritise self-determination and reinforce human rights outlined in the *UN Declaration on the Rights of Indigenous People* (Putt 2013; Rogers et al 2017).

There are a number of current ethical guidelines for researchers and evaluators working with ATSI communities. An overview of the guideline principles are found in Table 4. It is recommended that researchers and evaluators in the NFP sector consider how the action areas sitting under these principles can be applied and tailored to their respective studies.

Table 4: Principles of current ethical guidelines when working in Aboriginal settings

<p>AIATSIS <u>Guidelines for Ethical Research in Australian Indigenous Studies (2012)</u></p>	<p>NHMRC <u>Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders (2018)</u></p>	<p>Better Evaluation <u>Good evaluation practice in Aboriginal and Torres Strait Islander settings: Putting ethical principles into practice — a protocol to support ethical evaluation practice in Aboriginal and Torres Strait Islander settings (2019)</u></p>
<p>The Guidelines comprise of 14 principles grouped under the broad categories of:</p> <ul style="list-style-type: none"> • 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. 	<p>The Guidelines are underpinned by 6 core values:</p> <ul style="list-style-type: none"> • Spirit and integrity • Cultural continuity • Equity • Reciprocity • Respect • Responsibility <p>Other related principles discussed include:</p> <ul style="list-style-type: none"> • Consent • Research agreements • Cultural and intellectual property • Cultural competency 	<ul style="list-style-type: none"> • Prioritise self-determination, community agency and self-governance • Communicate transparently, build trust and obtain individual and community consent • Strengths-based recognition of cultures, acknowledging communities and individuals • Share benefits and apply two-way learning • Formalise accountability processes on ethical practice • Facilitate control and data sovereignty

Non-Aboriginal evaluators and researchers working with Aboriginal communities have to be mindful of their position as ‘outsiders’ and the tensions this poses. As stated by Scougall (2006):

“The expectations placed on an evaluator [or researcher] working in an Indigenous context are often great. The ideal is someone: in close relationship with the community; employing culturally sensitive methods; fostering broad community involvement; transferring evaluation [or research] skills; and contributing to a process of empowerment and positive change. The hard reality is that evaluators [or researchers] are most often outsiders with limited resources and precious little time to spend in the field. By ‘outside’ I mean someone not of the people, culture and place. They are typically short on contextual understandings and need to work across many project sites... Furthermore, outsiders often struggle to ‘hear’ correctly and to elicit meaningful information from Indigenous people due to cultural barriers and poor rapport... These are major impediments that give rise to very real tensions... (p. 49).

There are a number of strategies that non-Aboriginal evaluators and researchers can implement when working with Aboriginal communities to navigate these tensions (See Table 5).

Table 5: Strategies for non-Aboriginal evaluators and researchers when working with Aboriginal communities

Strategies for non-Aboriginal evaluators and researchers when working with Aboriginal communities
<ul style="list-style-type: none"> • Attend cultural awareness training before undertaking the research or evaluation. • Use local ‘sponsors’ (for example, Aboriginal service staff, prominent community members or elders) to build trust and rapport with participants. • Where possible, seek permission from the community and ask them to be a part of the design of the research or evaluation process. Make sure that data ownership and intellectual property is explicitly outlined and agreed upon in agreements or contracts. • Provide a culturally safe space for participants (for example, local Aboriginal service). • Where resources allow, engage, collaborate and adequately compensate local Aboriginal researchers or evaluators as they provide important insight into local culture, knowledge and culturally appropriate methodologies. • Make an effort to ‘report back’ to solidify a sense of community ownership over the process and show a genuine desire for the work to be used in informing community outcomes.

(Source: Lawton, Hamilton & Jackson 2020)

ADDITIONAL RESOURCES

There are also a range of general resources available that are helpful when doing research and evaluation with Aboriginal communities:

- [Aboriginal Participatory Action Research: An Indigenous Research Methodology Strengthening Decolonisation and Social and Emotional Wellbeing \(2020\)](#)
- [Undertaking Research and Evaluation in Aboriginal Public Sector Contexts: A 'How To' Guide \(2018\)](#)
- [Evaluating the outcomes of programs for Indigenous families and communities \(2017\)](#)

3.2 Culturally and linguistically diverse (CALD) communities

With Australia being a proud multicultural nation, research and evaluation in the NFP sector will often involve communities that are culturally and linguistically diverse (CALD). These communities in and of themselves are highly diverse, comprising of immigrants, refugees, asylum seekers and those born in Australia. When undertaking research or evaluation with CALD communities, there are a range of social, political, historical and cultural factors that need to be taken into consideration. Some of those are outlined in Table 6.

Table 6: Factors that need to be taken into account when working with CALD communities

Factors that need to be taken into account when working with CALD communities
<ul style="list-style-type: none">• Cultural norms, attitudes, power relations and customs• Within-group cultural variation• Language(s)• Dominant religious practices• Family structures (patriarchal//matriarchal)• Demographic trends (historical/current)• Immigration history• Experience with political regimes, war, trauma and conflict (and its effects)• Stereotyping and racism• Conflicts with other ethnic groups

(Source: Fisher & Ragdale 2005; STARTTS 2012)

Research or evaluation undertaken with CALD communities needs to be done in a culturally sensitive and respectful way. This can be done by considering the following:

- **Informed consent:** Differing cultures have differing views on and approaches to informed consent. While individual consent may be obtained during your research or evaluation, you may also need to go through a formal or informal process of gaining acknowledgement, support and consent from other influential members of the particular CALD community you are working with. In saying that, some participants from small or closed communities may want to only deal with outsiders and remain

anonymous – in this case, their confidentiality should always be maintained throughout the process (Morrow 2009).

- **Managing language barriers:** Where language barriers are an issue and the resources are available, you may need to use interpreters or professional bilingual workers to communicate with the community you are studying.

You will have to invest some time to explain the purpose of your investigation to the interpreter, and explaining any concepts that do not translate easily. You may also want to use some common communication techniques to make all parties comfortable – this includes using everyday language over jargon and technical terms, politely checking if people who look confused have grasped concepts, and utilising visual tools. Spending time with the interpreter immediately after interviews (or other technique used) will also help clear up any questions or misunderstandings.

If interpreters or bilingual workers are limited, you may need to restrict your investigation to English speaking members or a specific language group within the community. Be transparent and honest about these limitations, as you need to prevent any harm associated with misinterpreting or misrepresenting the views of the community as a whole (Laws et al 2013).

- **Involvement of local co-researchers or leaders:** Where possible, the involvement of local co-researchers or leaders may help in providing relevant cultural values and insight. For example, they may be able to identify hostilities between cultural and language groups that may make certain research methods, such as focus groups unappealing. Collaborating with local co-researchers or leaders may also help in identifying situations where you as the researcher or evaluator may be ill-equipped to undertake research without additional professional support or training (such as refugees and asylum seekers who have experienced trauma) (ACFID 2017).

ADDITIONAL RESOURCES:

The NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS) has a resource called '[Community development evaluation manual: A guide to planning and evaluating community development work with refugee communities](#)' which discusses the ethical considerations that need to be taken into account when working with communities, particularly those who have gone through trauma.

3.3 Children and young people

Children and young people² are increasingly playing a role in research and evaluation that affects them. They have traditionally been viewed as weak, immature and unable to make their own decisions and, therefore, have often been sidelined in favour of the perspectives provided by carers, parents and other adults (Evans-Locke & Hsu 2020). This has changed in recent times, with many arguing that the child or young person's voice and lived experience should be at the centre of any research or evaluation process about them (Kelly 2017; Purdue, Peterson & Deng 2018).

There are many benefits with an approach that centres the child or young person's voice. These benefits include encouraging informed decision making, reducing power imbalances in an adult centred world, and providing an opportunity for children and young people to participate in a way that is consistent with their self agency and human rights conventions (notably, the *United Nations [UN] Convention on the Rights of the Child*) (Bell 2008; Carson 2020). Some have also embraced 'co-research' or 'youth-led' approaches as it is seen as another way to develop young people into future leaders and agents of change (Purdue, Peterson & Deng 2018).

There are a range of issues that need to be considered if researchers and evaluators want to ethically include children and young people in their work. This includes, but is not limited to:

- **Informed consent and capacity to consent:** Informed consent must be obtained from stakeholders at the beginning of the project. At a minimum, guidelines suggest that consent be obtained from the child or young person, and at least one parent or guardian if they are under the age of consent (which is usually 16 years old in Australia – some funding bodies may have differing age ranges) (Morrow 2009; NHMRC 2018). Consent must be presented clearly and transparently to all participants at their comprehension level so they are fully aware and comfortable with the research process, and their ability to opt out if they so choose (Kingston 2016; Kelly 2017).

Researchers and evaluators must also consider the capacity of young participants to consent when designing and undertaking their projects. The *National Statement on Ethical Conduct in Human Research* suggests that some children are vulnerable to immaturity while others are not and that this vulnerability cannot be defined by age ranges but is different for each child. Researchers and evaluators must, therefore, be responsive to children's developmental stages by exercising reason, reflexivity and thoughtfulness (Kelly 2017; NHMRC 2018).

- **Embracing creative mixed method approaches:** When working with children and young people, you may need to be flexible with your research techniques to ensure it is participatory and best captures their view of the world. Traditional methods such as interviews and observation can be suitable, but other creative tools can also be considered. For young children, this can include drawing and painting, photography

²For the purposes of this section, children are defined as any individual between 0-11 years old and young people are defined as anyone between 12-24 years old.

(by the children), group work and role play. For young people of an older age, other effective techniques include dotmocracy (participants are asked to rank ideas using stickers), story boards, video or social media journaling and guided walks (Kingston 2016; Purdue, Peterson & Deng 2018).

- **Creating comfortable spaces:** During the research or evaluation process, it is important that the children and young people are provided a safe and comfortable space where they can express themselves, including feelings of dissent. This may be in places such as their school or play centre. For children who are being asked about previous traumatic experiences, there may be a need to delay investigation for a specific time period (for example, 12 months after the trauma) to minimise further trauma occurring (Carson 2020).

Researchers and evaluators may also ask professionals (such as teachers, social workers or youth workers) to help them establish a connection with young participants in an effort to establish rapport and trust. Finally, conducting research or evaluation with children and young people is best done in full view of others. Such transparency is critical for the safety of the child and the researcher (Laws et al 2013).

Despite the increasing empowerment of children and young people in research and evaluation, there is still a legal and moral obligation as adults to prevent any harm to children done by the research, or act on any risk of harm they become aware of:

- When it comes to child protection, **researchers and evaluators have a clear statutory duty to report or disclose any abuse or risk of abuse** according to any regulations or guidelines authorised by the law. The limits to confidentiality in the interests of the child or young person's safety must be clearly explained to participants in the consent process.
- The researcher or evaluator must also be able to assist young participants in accessing appropriate help or support that they are comfortable with, and recognise their own professional boundaries by not providing counselling themselves.
- In organisations where child and young people are regularly involved in research or evaluation, they should have policies in place to address safeguarding issues with consistency.

It should also be noted that, in their positions of power, there is a risk that a researcher or evaluator could take advantage of their position to abuse children. As part of their organisational policies, NFPs should ensure that they **carry out police and working with children checks on all staff** that are directly working with children and young people during the research and evaluation process (Morrow & Richards 1996; Laws et al 2013).

ADDITIONAL RESOURCES:

[Chapter 4.2](#) of the *National Statement on Ethical Conduct in Human Research* provides specific ethical guidance when it comes to research involving children and young people.

The Ethical Research Involving Children (ERIC) project is an ongoing collaboration with Southern Cross University and UNICEF's Office of Research. Their [website](#) provides a range of resources for the research community to understand, plan and conduct ethical research involving children and young people in a range of contexts.

The Australian Institute of Family Studies (AIFS) has also published guidance around ethical conduct involving children and young people. This includes articles '[Demystifying Ethical Review](#)', '[Ethical considerations for evaluation research](#)', '[Collecting data from parents and children](#)', and '[Ethical considerations in research and evaluation with children and young people](#)'.

3.4 Communities living with impairment

This section explores undertaking ethical research or evaluation with individuals who suffer from an impairment or disability that is of the following nature – cognitive, intellectual, psychiatric, neurologic or sensory. While these conditions are inherently different, they raise similar ethical issues and, therefore, a broad discussion on what needs to be considered is presented below. It is recommended that specific guidelines be sought when working with specific conditions.

There are a range of challenges that have been attributed to doing research or evaluation with those living with an impairment. Much like other minority groups, those with impairments have historically been treated as voiceless and passive participants who cannot make their own decisions freely. While there may be issues, persons who have cognitive, intellectual or mental impairment are not automatically incompetent in making decisions or providing consent. There is a need to find ways that makes research and evaluation accessible and inclusive, empowering those with an impairment to have a voice in processes that affect their lives (Lidz 2006; Mietola, Miettinen & Vehmas 2017).

The NHMRC *National Statement on Ethical Conduct in Human Research* dedicates a whole chapter for people with a cognitive impairment, an intellectual disability, or a mental illness ([Chapter 4.5](#)). The guidelines state that research design should take into account any factors that may affect the participant's capacity to receive information and provide consent (such as nature of the condition, fluctuations in the condition, medication or treatment) and find ways to minimise any distress or discomfort created by the process. Consent to participation should be sought from the participant living with impairment if they have the capacity to consent. If the impairment is temporary or episodic, an attempt should be made to seek consent outside of these periods. Where a participant is not able to provide consent, the

person's guardian or any person authorised by the law can provide consent, although the researcher should still explain to the participant what the investigation is about and what it involves. If the participant recovers the capacity to consent during the course of the investigation, they should be offered the opportunity to continue or withdraw their participation.

There are other ethical issues that should be considered when working with people living with impairment. This includes, but is not limited to:

- **Take the time to understand the best way to respectfully communicate with those living with an impairment.** For example, those with a hearing impairment may need speakers to be turned up more loudly and interviewers should prevent covering their mouths. For those with more profound deafness, they may be able to effectively communicate through lip reading and signs, or use a complex sign language that requires an interpreter. Those with a visual impairment will need written materials accessible in another format, such as large print, reading it out loud or as an audio recording. There are a range of technological tools that can assist with communicating to people with sensory impairments and these should be explored before the research or evaluation process is commenced (Laws et al 2013).
- **Put measures in place to prevent unnecessary re-traumatisation and distress.** There may be a range of mechanisms to consider, including ensuring anonymity, allowing a supportive friend or carer to be present during interviews (subject to participant consent), and/or providing participants with a range of support service options they can access after their participation (Laws et al 2013).
- **Undertake further training** as the researcher or evaluator to ensure that you can adequately gauge informed consent and the risk-benefit relationship of their work. This may include disability awareness training or mental health first aid training. (Roberts 2006; National Disability Authority Ireland 2009; Helmchen 2011).

ADDITIONAL RESOURCES

The [National Disability Authority Ireland Ethical Guidance for Research with People with Disabilities](#) provides a comprehensive guide on how to undertake ethical research with those living with disability.

3.5 Victims and survivors of abuse and violence

When undertaking research or evaluation, there is a chance that you will be working with participants who have currently or previously experienced abuse or violence (for example, child sexual abuse or domestic and family violence). This section focuses on working with adult participants of abuse or violence, as opposed to underage participants where researchers or evaluators have specific child protection obligations to disclose abuse or violence when detected (See Section 3.3).

There has been much debate as to whether it is ethical or not to ask about abuse and violence during the research or evaluation process. Some researchers and evaluators are reluctant to ask about abuse or violence as they believe this may deter participants from being involved or may retraumatise them when reflecting on these experiences (Becker-Blease & Freyd 2006). There is increasing evidence to suggest this is not always the case, with many victims/survivors choosing to tell their stories (some which have been hidden for many years) as part of their healing process. Studies have also shown that disclosing abuse or violent experiences during research is no more stressful than other everyday experiences and less stressful than specific sensory triggers related to the trauma (Ellsberg & Heise 2002; Becker-Blease & Freyd 2006). Overall, the risks of asking about abuse and violence need to be weighed up with the risks of not asking. There is always a cost to not asking, as researchers and evaluators can lose information to prevent victimisation and help survivors, can underestimate the role of abuse when compared to other factors, and can add to the trauma of victims/survivors if they feel they are being ignored or silenced (Becker-Blease & Freyd 2007).

If there is a strong case to ask participants about their abuse and violence history, it is recommended that advice in Table 7 (on the next page) be followed. A [trauma-informed approach](#) should be adopted to ensure that participant's experiences are treated in a sensitive and effective way, and to minimise any [vicarious trauma](#) experienced by the researcher or evaluator.

Table 7: Ethical recommendations for abuse and violence research

Ethical recommendations for abuse and violence research
<ul style="list-style-type: none">• Consent and study design should include a number of actions aimed at reducing any possible distress caused to the participants. This include providing access to resources and professional support services to help them disclose or manage abuse or violence during or after their participation.• Some victims/survivors of abuse or violence have serious mental health or substance abuse problems that may affect their ability to assess the risks of research – these additional ethical considerations need to be addressed (See Section 3.4 for further advice).• Understand any legal obligations you may have in disclosing abuse or violence – sometimes only the disclosure of child abuse is required, while in other locations, there may be laws that require the reporting of suspected cases of violence.• Don't use unnecessary inflammatory language that can cause further harm and anxiety.• Don't overemphasise the vulnerability of survivors/victims of abuse and violence, but make sure they feel believed when they disclose their story. Also make sure that they are able to disclose their story in a safe and comfortable space that does not trigger past traumas.• Study designs need to be methodologically sound (and limitations openly acknowledged) so that it does not under-report or minimise the experience of abuse or violence.• Protecting confidentiality (through mechanisms such as anonymous consent and de-identification) is essential to ensure both participant's safety and data quality.• In some circumstances, collaborating and partnering with victim/survivor organisations may be beneficial in building trust with participants.• Findings need to be properly interpreted and presented to advance policy and intervention development.• All research team members should receive specialised training to ensure a trauma-informed approach and ongoing debriefing sessions to manage their own exposure to trauma.

(Source: Ellsberg & Heise 2002; Becker-Blease & Freyd 2006; Becker-Blease & Freyd 2007)

ADDITIONAL RESOURCES:

The NSW Office of Children's Guardian has released a guide called '[Engaging sensitively with survivors of abuse](#)'. While this publication is not for research or evaluation, it presents useful and detailed advice on how to engage with survivors/victims of abuse using a trauma-informed approach.

4. Putting it into practice: NFP Ethics Checklist

Based on the issues discussed in this guide, an 'ethics checklist' has been developed for NFP professionals to use throughout their research and evaluation processes.

Many NFP organisations, particularly small operations, do not have sophisticated structures in place to consider the ethical dimensions of their research or evaluation. In the absence of these structures, this checklist aims to support NFP professionals in ensuring that ethical issues are strongly considered and acted upon throughout the research and evaluation process.

A note to the user: It should be noted that this checklist is not a 'one size fits all' tool – it can be tailored to your unique situation and can be added to over time. There also may be aspects of the checklist that do not apply or are not possible due to lack of resourcing. It is first and foremost a tool to make it easier for you to embed ethics into your practice but could also be used as a tool to advocate for necessary changes within your organisation.

Table 8: NFP Ethics Checklist

ACTION AREA/QUESTION	YES	NO	N/A	SPECIFIC ACTIONS/NOTES
Before and during research/evaluation				
Have you reviewed public ethical codes, guidelines or standards that may apply to your research/evaluation (internal or external)?				
Have the risks and costs been weighed with the benefits of the research/evaluation?				
Have you adequately obtained informed consent from your participants? (e.g. information sheets, consent forms)				
Do you have a plan in place to ensure your participant's confidentiality, privacy and anonymity is protected?				
If you want to re-use or share the study's data in the future, have you obtained participant consent for this?				
Are the methods that you are using rigorous (credible, reliable, authentic and verifiable)?				
Are you and your colleagues practicing reflexivity (i.e. critically reflecting on your subjectivities and how they can be managed)?				
Have you determined the values underpinning your research/evaluation (from stakeholders or other sources?)				
Is there an argument to undertake participatory or co-design processes with the community you are studying?				
Are you adequately qualified to undertake the research evaluation?				
Do you need more professional development/training?				
Do you have a plan to keep you and your colleagues safe while doing fieldwork (i.e. physical and psychological safety)?				
Do you have a data management plan that is compliant with relevant legislation and participant consent?				

ACTION AREA/QUESTION	YES	NO	N/A	SPECIFIC ACTIONS/NOTES
Has intellectual property and ownership been adequately outlined in your research/evaluation briefs and/or agreements?				
Are you using incentives as part of your research/evaluation? Do you have measures in place so it does not coerce or harm participants or adversely impact the research/evaluation design?				
Do you have a plan when undertaking research/evaluation online? (e.g. digital consent, safety of digital platforms)				
At the end of the research/evaluation				
Have you given participants the opportunity to alter content, withdraw statements or add additional information to their contribution?				
Have you strived for a well-rounded 'evidence-based' argument throughout your research/evaluation?				
Have you made sure the research findings are honestly reported with no fabrication, falsification, misrepresentation or suppression?				
Have you honestly outlined your study's limitations and shortcomings in the presentation of results?				
Have you appropriately referenced and cited the work of primary and secondary sources?				
Have you disclosed how your research/evaluation is funded and any other interests you, your organisation or your funder may have?				
Has your research/evaluation gone through a peer review phase (with internal and/or external reviewers)?				
Have all authors, contributors and peer reviewers been appropriately acknowledged in the final reporting?				

ACTION AREA/QUESTION	YES	NO	N/A	SPECIFIC ACTIONS/NOTES
Have you placed appropriate reminders (e.g. copyright disclaimers, general statements) on your publications to ensure your work is used properly by third parties?				
Working ethically with communities				
Are you working with any of the following communities (please tick all that apply):				
• Aboriginal communities				
• CALD communities				
• Children and young people				
• Communities living with impairment				
• Victims of abuse and/or violence				
• Other (Please specify in 'specific actions/notes' column')				
At a minimum, have you considered the following for the community(s) you are studying:				
Have you reviewed and applied any public ethical guidelines specifically related to the community?				
Do you have a clear plan or policy to report child abuse (or risk of abuse) or any other abuse/violence that requires mandatory reporting?				
Have researchers/evaluators undergone necessary checks when working with vulnerable community members? (e.g. working with children check, police checks)				
During the consent process, have you provided information where participants can access professional support to address any distressing issues brought up by the research/evaluation?				
Have you fairly negotiated data ownership and intellectual property with the community being studied?				
Do you understand the social, cultural, historical and political factors impacting on the community?				

ACTION AREA/QUESTION	YES	NO	N/A	SPECIFIC ACTIONS/NOTES
Have you undertaken any necessary training before the research/evaluation? (e.g. cultural awareness, disability awareness, mental health first aid)				
Have you chosen methodologies and data collection techniques that are suitable for the studied community?				
Have you organised the research/evaluation to be undertaken in a safe and comfortable space?				
Do you need to seek permission from community members/groups to undertake the research/evaluation?				
Have you developed a relationship with relevant community members (professional and non-professional) to build trust and rapport with participants?				
Have you addressed any communication issues that may impact the research/evaluation? (e.g. language or illiteracy issues, visual impairments)				
Have you built the capacity of local community representatives to undertake future research/evaluation?				
Have you reported back to the community in an accessible way and allowed time for reflection and feedback?				
Research ethics governance				
Has the ethics of your research/evaluation been reviewed by the appropriate person(s) or committee(s) within and/or outside your organisation?				
Is your research/evaluation consistent with relevant policies/procedures within your organisation? (e.g. codes of conduct, complaints handling, conflict of interest)				
Are there any ways your organisation can improve their ethical review process? (If so, please specify in 'specific actions/notes' column')				

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