Ethics resource.

What are ethics?

Ethics are what shape how we understand right and wrong. We apply ethics every day to make decisions about how to behave in the world. When we run activities with other people we must clearly understand, describe, and apply the ethical principles that will guide the work. This helps to protect everyone involved from potential harm and makes sure the work provides more benefits than it risks harms. When working with vulnerable populations who may be at increased risk for some harms, special consideration must be given to how ethical work is done with those communities (see *Vulnerable populations*, page 4). Avoiding harm should be a key consideration of any program, from how it's designed through to how it's evaluated.

> Even programs designed with the best of intentions have accidentally harmed the community.

In Australia there is a set of national guidelines on ethics that help us understand what values we need to apply to activities in practice, and which populations are considered vulnerable and need special consideration. These guidelines have informed this resource to assist Local Drug Action Teams in undertaking activities that follow ethical best-practice.[1]

Critical values

There are five critical values that must be applied at every stage of a program. How the values are applied in practice will differ between activities. Applying these values will often require serious and critical consideration, good judgement, and discussion between your team members and with the relevant community.

Merit: Being worthwhile. Deeming something as being 'worthwhile' is subjective, so defining what is worthwhile should be done collaboratively with the relevant community, as part of your community engagement. Consider the potential benefits of the activity. What do you think it will add to people's knowledge, wellbeing, and the skills or expertise of everyone involved? Has this type of activity been done before with a similar target population, and was it effective? Is it relevant to the community you're working with, and aims to address what they identify to be issues?

Beneficence: The benefits outweigh the risk of harm. This includes aiming to prevent potential harm to community members. Activity leaders are responsible for minimising the risk of harm or discomfort and communicating that risk clearly to community members in a way they can understand (see *Informed consent*, page 6).

Integrity: Being honest. Applying a commitment to strong moral principles in all work. Pursuing knowledge, understanding, and always sharing findings (even when unfavourable). Communicating honestly with your community members and other organisations to share your experiences and what you've learned.

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1. National Health and Medical Research Council (NHMRC) 2018. *National Statement on Ethical Conduct in Human Research* (2007). Updated 2018. The full guidelines can be found at NHMRC website: nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018

Justice: Being fair. This sense of fairness must apply to how you see the benefits from the activity being distributed, and to any burden placed on the community members. Special consideration must be given to unfair burden being placed on vulnerable groups (see *Vulnerable populations*, page 4). Examples of an unfair burden is asking for a significant amount of time, travel, energy, or out-of-pocket expense from your community members, without expecting the benefits of the program to outweigh those costs.

Respect: Recognising the intrinsic value of a human being. This includes respecting culture and heritage, beliefs, and worldview of community members. Special consideration must be given to respecting a person's right to make their own decisions (see *Informed consent*, page 6).

Key considerations

The key considerations to take into account when implementing any program activities are listed below. They need to be applied to each phase of your activity, from planning through to evaluation. While you are likely to be already taking many of these into account, it is critical that your team has a thorough discussion of exactly how these considerations are being accounted for.

As your activity progresses, your team will be monitoring how things are going as part of measuring your success. While doing so your team can also watch for any emergent unintended consequences and have a plan in place for making decisions around how that would be managed.

Harm

Avoiding harm

Harm can be experienced throughout all stages of implementing an activity. Avoiding harm should be considered as part of your overall risk management[2] process when planning an activity, setting the objectives, engaging and working with community members, and evaluating the activity. Some harms are easier to recognise than others. It is best practice to be aware of potential issues from the beginning of your activity. Some harms, such as psychological harms to community members may be the hardest to see but are just as important to plan for.

Some of the harms that need to be considered when developing projects include:[3]

- **Physical harms:** injury, illness, pain
- **Psychological harms:** feelings of worthlessness, distress or guilt
- **Devaluation of personal worth:** including being humiliated, manipulated or in other ways treated disrespectfully or unjustly
- **Social harms:** including social stigmatisation; damage to social networks or relationships with others; discrimination in access to benefits, services, employment or insurance
- **Economic harms:** including the imposition of direct or indirect costs to community members
- **Legal harms:** including discovery and prosecution of criminal conduct, in particular when dealing with issues around illicit drugs.

You should aim to thoroughly and critically explore the potential for harm as a key step in activity design. Conducting a risk assessment and creating a risk register that includes actions to take to manage each risk is a good starting point. Applying worst-case scenario thinking in the planning stages can help prevent harms before they happen and ensure that if any harm occurs there is a plan in place for how to minimise it.

2. For more information about risk assessment, see: nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018#chapter_2_1__risk_and_benefit
3. NHMRC, 2007. *National Statement on Ethical Conduct in Human Research*. nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018#guidelines___section_1

In practice

The following examples are good starting points to ensure you are avoiding potential harms throughout your activity:

- Firstly, be open to the possibility that even the best laid plan can go awry. Be mindful that your planning process continuously pursues and faithfully works for the community's interest.

- Make sure only respectful and inclusive language is used at all stages of the project to avoid stigmatising or discriminating against any community members, or members of the broader community (see *Language*, page 5).

- Create safe environments in which people feel comfortable and respected. This can include a clear code-of-conduct and supporting policy that outlines how any issues that may arise will be managed.

- Make programs accessible by holding them in areas easy to reach by public transport and accessible by people with a movement disability or who use a wheelchair.

- Provide information about referral pathways and support available to community members throughout your activity. This may include lists with contact information for mental health support, counselling, local health contacts, legal support services, financial advice and support services, or any other services relevant to your specific community members.

- Clearly and honestly communicating the purpose and objective of your work, and any potential risks, to community members in a way that they can understand. This may require special consideration if you're working with a vulnerable population.

- Take data collection seriously, only collect data necessary to your purposes, and design a clear process for protecting participant identities and information (see *Data collection*, page 6).

If you do find any adverse effects resulting from your activity, discuss with your team how serious they are and if the activity can be changed, or if you should stop altogether.

Avoiding harms from discredited programs or approaches

Good intentions do not always lead to good results, and what's popular is not always what works. Research has demonstrated that some past program approaches, in Australia and internationally, have backfired and produced the opposite results than intended. For example, programs based on the 'Scared Straight' model which attempts to prevent youth re/offending by taking young people into jails to interact with people who are imprisoned, resulted in an increase in offending behaviours and recidivism in that community.[4]

You can search for evidence about program approaches that have and have not worked in similar communities to avoid repeating poor practice and increase the effectiveness of your activity.

In practice

When considering program design and approach ideas, start investigating for evidence through:

- Visiting the Community Hub to access LDAT toolkits and other resources at community.adf.org.au

- Desktop research through the Alcohol and Drug Foundation library;[5] evaluation reports, peer reviewed journals, the Cochrane collaboration,[6] and the National Institute for Health and Care Excellence[7]

- Talking to Alcohol and Drug Foundation Relationship Managers

- Getting in touch with universities, other research bodies, or peak organisations

- Contacting the Public Health Association of Australia.[8]

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4. Petrosino et al. 2003. *'Scared straight' and other juvenile awareness programs for preventing juvenile delinquency*. Cochrane Systematic Review. Cochrane Database of Systematic Reviews.
5. apac-tc.hosted.exlibrisgroup.com/primo-explore/search?vid=ADF&lang=en_US&sortby=rank
6. cochrane.org
7. nice.org.uk
8. phaa.net.au

Working with the community

Recognising the community as experts

Community members are the experts in their own community. Ethical work with communities means supporting those community members to identify and act on important relevant issues, while empowering them to create stronger and more connected communities.

Integrating community members into projects also helps to make sure those projects are relevant to the actual needs of that community, which is essential in ethical practice, and is what your activity should aim to do. This integration also results in the community adopting a sense of ownership or partnership of the activity.

In practice

- Don't assume that your team already knows what is the problem or the solution
- Involve diverse community voices as early as possible during the planning stages
- Consider the International Association for Public Participation (IAP2) Public Participation Spectrum[9]
- Take their perspectives, feedback and ideas seriously
- Be inclusive and encourage active contribution by treating the community members as equal and valuable team members
- Keep everyone informed by sharing information
- Always bring project learnings back to anyone who was involved in the activity at key stages as the activity progresses.

Vulnerable populations

Not all population groups are at equal risk of harms. Team members are responsible for considering ethics when planning to engage and work with people at increased risk of experiencing harm.

People may be at an increased risk of harm for many reasons, such as:

- Past and ongoing experience of trauma including; inter-generational trauma; racism; homophobia; transphobia; sexism; imprisonment or persecution; child abuse or neglect
- Risk of being stigmatised including; being drug dependent; having a condition or illness such as schizophrenia or HIV; being LGBTI, being a member of a 'minority' group, or a prisoner/ex-prisoner
- Economic and/or educational disadvantage
- Cognitive impairment
- Incomplete cognitive development during childhood or adolescence.

In practice

In addition to providing lists of general support services (see *Avoiding harm: In practice*, page 3) also provide population-specific services, such as youth services, Aboriginal people's health care services, migration services.

Each population will require a different set of considerations, which may include:

- Working with young people
  - Consider if the young person has developed the capacity to understand what their participation means, especially any potential for long-term impacts
  - Requirement for parental informed consent
  - The child should also provide their agreement to participate, even though they cannot legally consent until they turn 18.
- People from diverse cultural backgrounds
  - Consider how to address potential language barriers, different worldviews and customs, and respect cultural norms
  - Some communities have experienced significant harms from their interactions with other population groups. Consider if your team is best-placed to do work in this community.
- Working with women who are pregnant
  - Consider the potential for pregnancy of community members, and how to use inclusive and appropriate language
  - Programs that focus on foetal alcohol spectrum disorder (FASD) need to consider the stigmatisation and blaming of mothers that can occur and be extremely sensitive in language and program design.

9. iap2.org.au/About-Us/About-IAP2-Australasia-/Spectrum

Working with people who use drugs

Working with people who use drugs

People who use drugs are considered a vulnerable population, who may be highly stigmatised, and engaging in criminal behaviour (such as purchasing illegal drugs). The kind of information that may be gathered about people who use drugs can be especially sensitive for these reasons, because problems with data privacy could result in significant legal or social harms.

But a person who uses drugs is still a member of the community whose opinions and perspective are as valuable as any other. And it's always important to engage with members of whatever target audience you're working with to ensure that your messaging and approach is credible and will resonate with that audience.

In practice

Consider the stigma and discrimination experienced by many people who use drugs at all stages of the program and discuss if any part of your program might be stigmatising. Even if you are running a prevention activity, some members may already be using drugs. Using inappropriate or stigmatising language such as 'drug-user' may make them feel like they do not deserve to be involved in the activity or result in discontinuation of their involvement. See the following *Language* section for guidance on appropriate and inclusive language you can use.

Language

Accessible language

The use of plain language is important when working with community members who may have a range of literacy and health literacy skills, and varying levels of knowledge about a given topic. Plain language means that your messages will be understood, and that your community members will be capable of informed consent, as they understand the purpose, requirements, and risk of their involvement.

As part of ethical work with the community, teams are obligated to inform community members about any potential risks of participating in the activity. This needs to be done in accessible language that can be easily and fully understood by your community members.

In practice

The use of plain language is essential within all stages of a project:[10]
- Avoid jargon, technical terms, and unnecessary acronyms
- Use active voice instead of passive voice, for example "The dog bit the man" (active) versus "The man was bitten by the dog" (passive)
- Keep sentences short
- Try to communicate only one idea per sentence
- Keep writing simple, to the point, and relevant.

Non-stigmatising language

Making poor language choices can contribute to the stigma of people who use drugs and alienate community members. Using person-first language that focuses on the individual, not their drug use, can help to destigmatise and remind others that people who use drugs are people.

In practice

There are a number of good practice guides on language relating to specific communities.
- People who use drugs: nuaa.org.au/info-for-health-professionals/language-matters
- Fetal alcohol spectrum disorder: Canadian FASD language guide: canfasd.ca/wp-content/uploads/sites/35/2018/01/LAEO-Language-Guide.pdf
- Aboriginal and Torres Strait Islander peoples: phaa.net.au/documents/item/2292

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10   For more information about plain language, see: https://guides.service.gov.au/content-guide/writing-style/

Consent

Informed consent

The purpose of informed consent is to ensure respect for each person's right to make fully-informed decisions of their own free will. To do so, a person must have clear information about their choices and what they mean, communicated in a way that they can fully understand. Community members must also be able to opt out of the activity without facing any consequences.

Informed consent requirements

1. The activity needs to be explained clearly and in full to the participant.
2. The participant needs to understand what they're being told – special care needs to be taken with some vulnerable populations, such as young people who are still developing cognitively, people who might not have a strong comprehension of English, and people at different levels of literacy. It is the responsibility of team members to make sure they communicate in a way that community members can understand.
3. Participation must be voluntary. Special care must be taken with people who are in unequal power relationships such as young people, adults who are imprisoned, or people who are dependent on carers for any reason such as intellectual or physical disability.

In practice
- Use plain language and honestly communicate all the potential benefits, risks, and participant requirements, as well as the purpose of the activity.
- Consider any limitations to communicating with your community members such as literacy, English language, or cognitive impairment.
- Consider any limitations on that community member's capacity to make a truly voluntary decision. Are they in a situation where carers, people in power or other influencers might be able to directly or indirectly force their participation?
- Ensure that all community members understand they are free to leave the activity at any time, and they understand there will be no consequences for leaving. An individual or organisation deciding to leave a certain activity should not affect their relationships with activity implementers or others still involved with the program.

For more information, see:
healthdirect.gov.au/informed-consent

Data collection

Privacy and confidentiality

When any data is collected from community members a primary consideration is how to keep that data safe. This is critical to maintaining a relationship of trust between your team and the community members. It's especially important when dealing with vulnerable populations who may be at higher risk of experiencing harms from a breach of privacy, like people who use drugs, to consider how you can limit any data you collect to only what is essential for measuring the success of your activity.

In practice
- Don't collect personal or sensitive information if it's not critical to your activity or measuring your success. Sensitive information may be things like current or past drug use, mental or physical health concerns or illness, and information about past trauma or family history
- Inform community members on how their data will be stored – will personal information be stored separately from other data, will it be stored in locked cabinets/rooms, and in password-protected documents?
- Tell community members who will have access to their data, and the reasons why these people have access
- Get informed consent from community members before collecting data
- Have a clear plan for how you'll store and de-identify any data you collect
- During evaluation and sharing your outcomes, follow best-practice with de-identifying individuals and organisations.

Poor practice data collection

Surveys or questionnaires are a popular way of collecting data and can be useful. Well-designed questionnaires will result in the collection of relevant data and provide a good base for evaluation of your activities. Well-designed surveys or questionnaires:

- Utilise necessary and relevant data, and limit collecting data that you don't plan to use
- Reduce the chance of easily identifying a participant (especially in small communities)
- Reinforce only accurate assumptions/beliefs about the issue
- Avoid creating the perception there's a problem in the community
- Avoid re-traumatising, upsetting or offending vulnerable or sensitive individuals
- Avoid collecting unnecessary data that doesn't serve a purpose
- Limit biasing respondents to provide desired answers.

In practice

You should ask other people to review any surveys or questionnaires that you plan to distribute, and review with the following questions in mind:

- Are these questions relevant?
- How will I use this information? Is it necessary to ask?
- Could I frame this question differently to reduce potential bias?
- Could this question be misinterpreted?
- What are the potential answers to these questions?
- Have I used appropriate and inclusive language?

Legal requirements

Depending on the nature of your activity, you may require specific checks or clearances.

Some types of activities may require special ethics clearance. As a general rule, working with any vulnerable populations makes it more likely that you will require special ethics clearance. Teams will need to take the potential for special ethics clearance into account as part of their activity planning.

In practice

Some common requirements include:

- Working with Children Check
- Police Check
- Public liability insurance
- Professional indemnity insurance.

Considerations for individual stages of your activities

Many of the ethical considerations, such as avoiding harm and careful use of de-stigmatising language, are relevant to your activity from start to finish. But some issues are most relevant at specific project stages.

Confirm your local issue

Respecting your community members as experts in their own local area, and not starting your consultation believing you know the issue or the solution, is critical to working ethically at this stage. Consider the expertise of any vulnerable populations you may be working with, such as people who inject drugs, and how you can work with those community members in a safe and respectful way.

Determine your activity

Part of determining the details of your activity is critically examining any potential harms it could cause, including the risk of stigmatising some community members. Consider how to ensure your team only uses de-stigmatising language and messaging throughout your activity. Also consider what your activity's legal requirements are (e.g. Working with Children Check).

Set your objectives

Consider the benefits you expect your activity to deliver if you achieve your objectives, and who will experience those benefits. Discuss if the benefits will be experienced by the community in a way that is equitable. Make sure that the expected benefits from the activity outweigh the risk of harm to your community members.

Map your steps

The key ethical values should underwrite each of your steps. Consider at each stage if there is any potential to cause harm and how that can be managed.

Define your budget

If there are any costs to your community members, consider if there is space in your budget to cover or offset those costs.

Also consider the ethical accountability involved in receiving public funds, and the necessity to adhere to the terms of the contract signed for that funding.

Measure your success

Take great care with data collection, storage, privacy and confidentiality. Don't collect any data that you don't have a plan for using. Make sure that if you do collect data that might be sensitive, that individuals can't be specifically identified by that data. It's important to share the results of your activity, even if they don't seem favourable.

Next steps

Other resources to help your LDAT:

- [Identifying alcohol and other drug-related issues](#)
- [Community consultation](#)
- [Developing a Community Action Plan](#)
- [Evaluation resource](#)

References

National Health and Medical Research Council (NHMRC) 2018. *National Statement on Ethical Conduct in Human Research (2007)* – Updated 2018: nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018

New South Wales Users and AIDS Association (NUAA) 2018: *Language matters resource for health professionals:* nuaa.org.au/info-for-health-professionals/language-matters/