

# Data Protection and Use Policy

# Transparency and Choice Guideline — a summary



Data Protection

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Respectful • Trusted • Transparen

Transparency and empowerment are a key part of building trust between New Zealanders, service providers and government agencies. When it comes to collecting or using people's data and information, being transparent and offering choices are part of the **Manaakitanga Principle** — upholding the mana and dignity of people who share their information, and understanding their needs and interests.

There may be situations where people cannot be told why their data or information is collected, how it's used, or cannot be given choices. However, offer as many choices as possible based on a clearly defined purpose (see **Purpose Matters** Guideline).

Any decision not to offer choice needs careful consideration. It can have negative effects on people's trust, or their willingness to use services that they want and need.

Collaboration between agencies is important, and those who decide what to collect or use will benefit from the ideas of those who engage with service users and collect their data.

Having different perspectives about what choices could be offered can help to support ethical decisions and approaches that are respectful of people who may share their information — hearing their ideas about transparency and choice is vital.

### **Transparency and Choice has many benefits**

Enhances mana

- If people do not know what is collected about them or how it's used, they can feel powerless, frustrated or anxious. This can make them feel unsafe about engaging with a service.
- Being transparent and giving choices empowers people to take an active role in what's happening in their lives. It upholds the Mana Whakahaere Principle.

Ethical and legal

- when it comes to personal information many laws that apply require levels of transparency and choice (for example, the Privacy Act 2020, the Education Act 1989 or the Oranga Tamariki Act 1989).

  Beyond the law, agencies are likely to be bound by
- Beyond the law, agencies are likely to be bound by ethical codes of practice that require as much transparency and empowerment of people as possible.

Accurate information

- Being transparent dispels myths and misunderstanding.
- It can help service users and whānau understand the importance of accurate information and increase their willingness to share.
- It helps anyone who has to collect information for someone else be clear and accurate about what they are doing.

## Help people understand about collection and use of their information

Help them understand why it's being collected, how that helps them or people in similar situations, and their right to access their information and ask for changes. Provide them with choices where possible. If the purpose for collecting or using it is clear, then most of this has already been thought about (see the **Purpose Matters Guideline**).

## Be transparent about 4 key things

This Guideline identifies transparency on collection, choice, use, and access and correction as good practice. For each topic, the things required under the Privacy Act 2020 (when the information does or can identify someone), are marked with (P) below. The advice is also relevant when information is from or about people, but does not and cannot identify them. This is because people may still see the information or its uses as sensitive to them or their community.

#### Collection

- What data or information will be collected in a way that does or could identify people (is personal) (P) and what will be collected in a way that cannot identify them (is non-personal).
- What people must provide and what is voluntary. (P)
- What the consequences are for people who do not provide their data or information. (P)
- What laws allow the collection of people's information. (P)

#### Use

- For each separate purpose, what information will be used and why (P), and how does this benefit the person the information belongs to, or others in similar situations.
- Who will be able to see or receive someone's information, or parts of it in your agency and any other. (P)
- If people's information will be shared with another agency what will be shared, and why.
- What laws or agreements allow this use. (P)
- What someone's information will not be used for and who won't see it.
- If people's information will be linked or matched with other data or information about them in your agency or another.
- How people's information will be kept secure.

#### Choice

- What choices people have about who sees or uses their data or information.
- If they do not have a choice, why that is so.
- How they can be involved in decisions around the use of their data or information.

#### Access and correction

- What people's rights are to access their personal information and ask for corrections to be made to it (P), and how to use those rights.
- What will happen if a person's information cannot be changed in response to a request for correction, and their right to ask that their request to change information is included in the original, unchanged information. (P)

Saying information will be used for 'research or statistical purposes' is not transparent. People should be able to understand how their information is used, and how it will help people in similar situations, even if it's used in a form that does not and cannot identify them.



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Whenever possible, offer choices around the collection or use of data or information from or Choice is not be a one-off thing — situations change. So keep checking back in with service about people (even if it cannot or will not identify them). Choice might be about what's provided, how it's provided, or how it's recorded or shared and who gets to see or use it. People can have various levels of choice (outlined below).

users. Work with others to understand what choices make sense for the purpose and are the most respectful of the service users. There will be situations where service users cannot be given any kind of choice, but test the thinking carefully and tell people why choice is not possible — this is the Manaakitanga Principle.

### Some choice

- Service users need to provide some information that identifies them (personal) to receive a service but it's minimal.
- They can choose whether information, identifiable or not, is shared or used for any reason other than providing the service.

### **Limited choice**

- A large amount of information that identifies them (personal) is needed to provide the service.
- Service users may be able to choose how some of this is used.
- Service users cannot choose how information that cannot or will not identify them is used.

### No choice

- The law requires that all the information is provided.
- The purpose means that all the information has been thoroughly checked and it's reasonable and necessary to not give choices.
- It may be unsafe or get in the way of the law to provide choices.

### Examples

To attend a group parenting course service users provide contact details, basic details about how many children they look after and their ages. Any other information they share during the course is up to them.

No identifiable or personal details are used for anything or provided to another agency without the involvement and agreement of the service user.

Service users do not have a choice about the service provider giving the funder information that cannot identify anyone. For example, how many people attended the course, their relationship status and how many children they collectively care for.

### **Examples**

To access intensive drug treatment a service user will need to discuss things like drug use, motivations, life experiences, mental wellbeing, and so on. There's an element of choice about how much of their story they share, but without talking about these things it will be harder for the provider to help them.

Service users can choose if the detail of their story is shared with others, but they do not have a choice about some identifiable information being shared with the Ministry of Health for funding, policy development or service design (National Health Index number, employment status, if they have engaged with other services or not).

### **Examples**

Information sharing related to serious child protection issues. The service user is not told what is shared with Oranga Tamariki or when it's shared. This is because the provider is concerned it will put the child more at risk.

Requirement to share financial, household and contact information to receive a benefit. Without providing this information the person's eligibility cannot be assessed.

A service user may be under a court sentence (like probation) and have no choice about their detailed information, for example, from a parenting or alcohol and drug course being shared with the courts.

## **A**Keep in mind

- If service users do not have a choice about what to provide, who sees it or how it's used, it's important that they know why, unless telling them would cause a serious risk to someone's safety, health or would get in the way of upholding the law.
- If you, your team or your agency do not directly collect the data and information you use, you still have a role in transparency. If you ask another agency to collect people's information for you, make sure they know everything they need to so they can be transparent with service users on your behalf.
- Aim for a 'no surprises' approach service users should not be surprised about the information that's held about them or how it's used.

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