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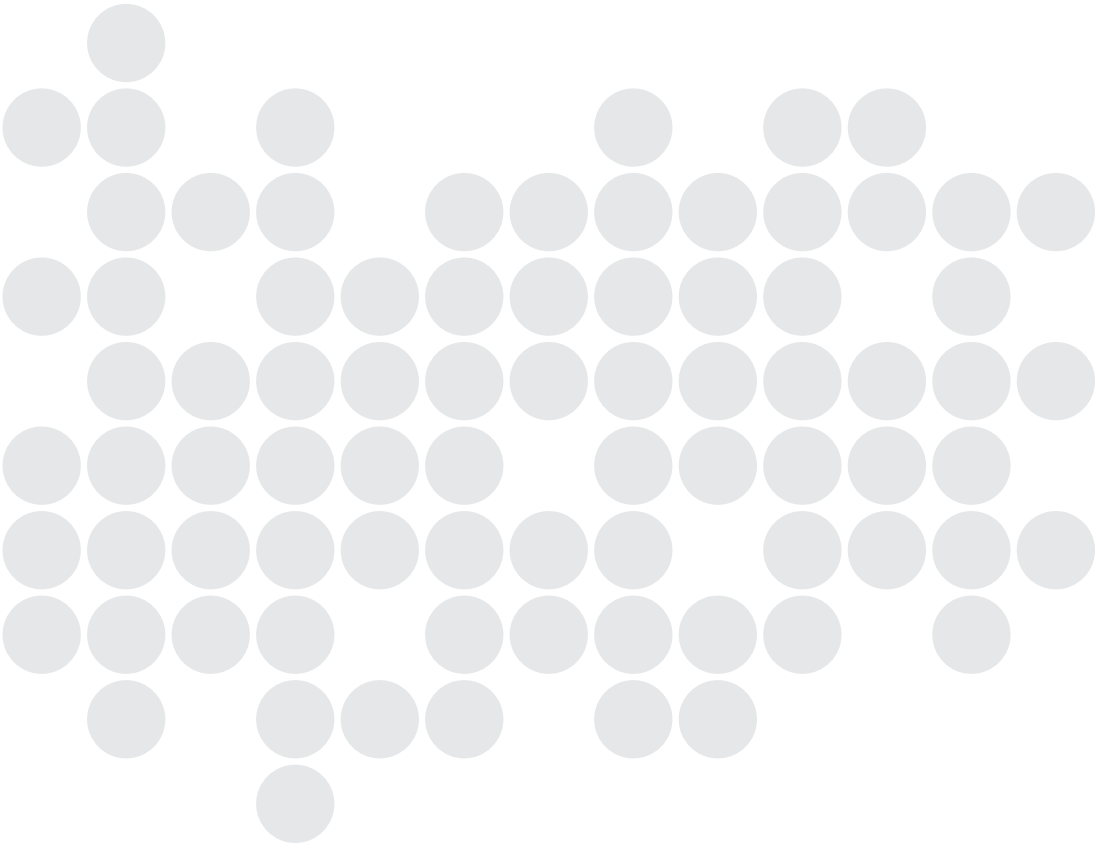
The Data Protection and Use Policy. A Policy for the respectful, trusted and transparent use of people's data and information in the social sector.

The Policy is based on *engagement findings* from the 'Your voice, your data, your say' engagement on social wellbeing and the protection and use of data.

Wellington, New Zealand

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The **Glossary** provides a full definition of key terms.



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Introduction

This Policy is about respectful, trusted and transparent use of people's data and information.

Why this Policy?

This Policy articulates what 'doing the right thing' looks like across the social sector in its collection and use of people's data and information. What personal data and information people share, who they share it with and how they share it matters. People share when they trust but when data collection and use go too far, trust can be lost. Building and maintaining trust is key.

When agencies are transparent and tell people what will happen to their information, what choices they have, and how they can easily access their information – all in a way they can understand – people are empowered.

This Policy was developed by the sector for the sector. The social sector comprises government agencies, non-governmental organisations (NGOs) and other providers of services to support New Zealanders' wellbeing across a range of areas including welfare, education, health, justice, child wellbeing, housing and disability support services.

This Policy refers to all such agencies and organisations as **agencies**¹.

Working with people who have the necessary understanding, capability and legitimate interest in the information, enables insights to be developed that lead to shared outcomes that improve the wellbeing of people and communities. This Policy recognises the value of working with people as equal partners and enabling a wider range of organisations to access, understand and apply insights for the benefit of their communities.

This Policy uses the word **insights** to mean non-personal information, including data and data sets, analysis, qualitative or quantitative information, statistics, research, reports or studies, that may support improved decision making.

About this Policy

This Policy describes values and behaviours that, when applied across the sector, will build trust and help to ensure that data practices are focused on the wellbeing of people and communities. These values and behaviours are represented as five **Principles** that have people and their wellbeing at the centre.

The focus is on relationships, rather than rules – a way of working that respects people, their information and their stories.

The Policy provides good practice guidance on how to uphold these Principles in four key areas. These **Guidelines** help organisations to understand and apply the Privacy Act in relation to these activities. However, this Policy goes beyond solely privacy matters to also think about ethical considerations when making decisions. Good practice requires that if, and when, agencies contemplate using people's information, it's done with the involvement, understanding, and support of the people impacted by those proposals.

The Guidelines will help agencies to:

- be clear about the vital importance of *purpose* to collecting and using people's personal information
- enable people to understand what's happening with their information and what choices they have
- make it easy for people to see and request correction of their information
- work together for better insights and outcomes.

¹ A full set of definitions used in this Policy can be found in the Glossary.

Development of this Policy

This Policy has been developed through extensive engagement with the social sector. The purpose of this engagement was to understand people's views of what is needed to establish and maintain respectful use of people's information, and to build trust and confidence between people and agencies throughout the sector, including funding agencies, NGOs and other providers, and the people who use their services.

To support and inform the engagement process, the Social Investment Agency (SIA) drew upon an extensive body of existing work in this regard, including reports from the Privacy Commissioner.

In providing their insights, the people who participated in the engagement drew upon their experiences. These included working in a wide range of contexts in the social sector, in navigating a complex landscape of law, regulation and policy, and in delivering positive outcomes to the people and communities who use their services. A full description of the engagement process, and the insights provided by the sector, can be found at sia.govt.nz/how-we-can-help/what-you-told-us. The Policy is based on these insights.

The Principles were created from the thoughts, ideas, experiences and viewpoints of a diverse range of people, who were clear about what they think 'doing the right thing' looks like. Some organisations, agencies and professionals already practice the essence of the Principles.

How this Policy will evolve

The Policy is expected to evolve over time in response to changing legislation, experiences gained through application of the Principles and Guidelines, and evolving guidance on data and information best practice. An accompanying **Toolkit** will provide practical resources to use when applying each Guideline. The Toolkit will also evolve over time, developed and enhanced by the sector.

Policy scope

Personal data and information, even once aggregated or de-identified so that no individual can be identified, will often be seen as an inseparable part of people, whānau, iwi and communities, their experiences and their lives. Some people during the engagement considered it to be taonga.

The Policy provides advice that relates to personal information and to non-personal information. The various parts of this Policy make it clear when advice applies to personal information, non-personal information, or to both.

This Policy uses the following definitions:

Non-personal information is information that does not identify people and that can't be used, even if combined with other information, to identify individual people.

Personal information is information about an identifiable individual, including information relating to a death that is maintained by the Registrar-General of Births, Deaths and Marriages.

Adaptability in using this Policy

The Policy will be applied in a wide range of quite different contexts to support the work of agencies in the social sector. The five Principles define a common set of values and behaviours that are applicable across the sector. People using social services can expect to experience respectful and transparent interactions and practices from agencies that adopt this Policy. Agencies will need to apply the four Guidelines in a way that makes sense for their agency, the type of work they do, the people they work for, and the range and sensitivity of information they hold about people.

How does this Policy relate to other laws and guidance?

The Principles, and the associated Guidelines, don't affect what can or must be done under laws relating to the collection, use or sharing of personal information (for example, the Privacy Act, the Oranga Tamariki Act, the Family Violence Act or the Social Security Act). But they take the position that at times there are good reasons to go further than meeting the bare requirements of the law in order to build trust.

The Principles and Guidelines are consistent with the Privacy Act. The Guidelines make it clear when they recommend good practice above and beyond the minimum legal requirements of the Act. Agencies are not legally bound by such good practice advice but are encouraged to follow it in accordance with the spirit and intent of the Principles.

This Policy exists alongside other guidance on the collection and use of personal information, such as *Principles for the safe and effective use of data and analytics*² prepared by the Office of the Privacy Commissioner and Stats NZ in 2018, but its Principles and Guidelines have been developed specifically with the social sector for the social sector.

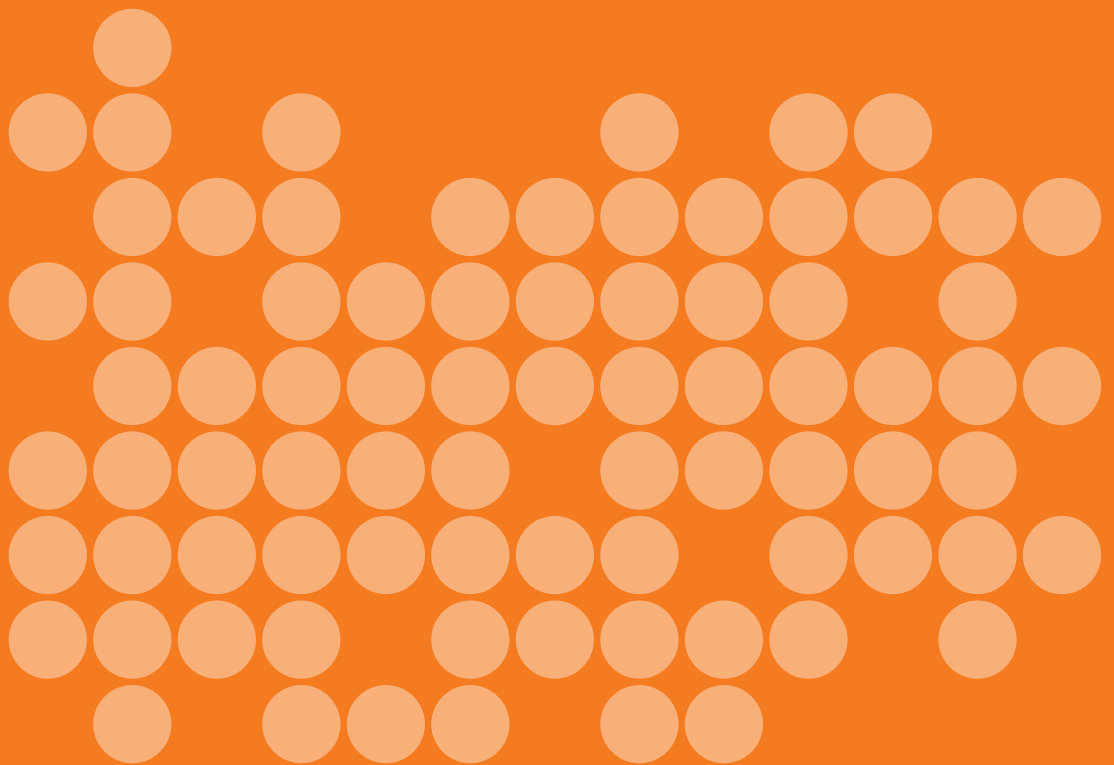
This Policy focuses on those topics that the sector identified as particularly important to inform people's understanding of what's appropriate and what's not. This Policy considers these topics with the particular structure of the social sector in mind, and the vitally important services it provides.

Related laws and guidance, along with other resources that support this Policy, are detailed in **References and Useful Links**.

2 stats.govt.nz/assets/Uploads/Data-leadership-fact-sheets/Principles-safe-and-effective-data-and-analytics-May-2018.pdf

Policy Principles

These Principles articulate values and behaviours to help ensure that data practices are focused on the wellbeing of people and communities



Overview of Principles

The five Principles articulate the values and behaviours that underpin the respectful and transparent use of data across the social sector.

The Principles guide the ways in which agencies working in the social sector should actively seek and include the views, choices and contributions of service users in their actions around data and information. Alignment with the Principles will enable agencies to design data and information practices that: empower service users; steward people's information and stories; and create insights that lead to wellbeing.

The five Principles work together and reinforce each other. When agencies³ consistently apply the Principles, the result is that:

- social sector agencies will share a common approach in how they work with people and their information
- agencies will work inclusively to develop and share valuable insights that result in the wellbeing of people and communities
- people who use social services will know what to expect and will have confidence in how agencies will use their personal information.

He tāngata p.12

Focus on improving people's lives – individuals, children and young people, whānau, iwi and communities.

Manaakitanga p.13

Respect and uphold the mana and dignity of the people, whānau, communities or groups who share their data and information.

Mana whakahaere p.14

Empower people by giving them choice and enabling their access to, and use of, their data and information.

Kaitiakitanga p.15

Act as a steward in a way that is understood and trusted by New Zealanders.

Mahitahitanga p.16

Work as equals to create and share valuable knowledge.

³ The Policy uses the term 'agency' to refer to government agencies, non-government organisations, and other providers of services.

Development of the Principles

The Policy engagement and design processes were developed to ensure that the final Policy genuinely incorporates the voices of many people and agencies involved in the social sector.

As the Policy developed it became clear that the Principles, Guidelines and related behaviours aligned with Te Ao Māori⁴ values. During the engagement and design process, and in collaboration with SIA's Chief Māori Advisor, conversations were held with various individuals and groups to determine how the Principles fitted with Te Ao Māori values and how each Principle could be best described in te reo Māori⁵.

Māori words, or kupu, are rich in meaning and can mean many things. In the context of the Principles in this Policy the meaning of the kupu chosen to describe each Principle are described below. These kupu have been tested with a range of Māori stakeholders.

He tāngata

The use of *he tāngata* comes from the whakataukī (Māori proverb)

“he aha te mea nui? Māku e kii atu, he tāngata, he tāngata, he tāngata”

which translates to

“What is the most important thing in the world? Well, let me tell you, it is people, it is people, it is people”

So, in this context, the use of *he tāngata* means that people – individuals, whānau and communities – are placed at the centre of everything we do and the goal of lifting them up, empowering them and improving their wellbeing is overriding in how we care for them and their information. It reminds us that when working with people's information, it should be done in their service.

Manaakitanga

Means the process of showing respect, generosity and care for the people who use social services, their whānau and communities. It also means to show respect and care for their information and stories. Mana is the essential life force within a person, place or object. In this context, caring for the people who share their information involves supporting, listening to and involving people in deciding what happens to their information. This results in empowering people and enhancing their mana.

⁴ Te Ao Māori denotes the Māori world view.

⁵ Te reo Māori is the Māori language.

Mana whakahaere

Means governance, authority, jurisdiction, management, mandate and power. Mana in this context refers to an individual's power or influence, and whakahaere refers to an individual's ability to influence or manage. To say that an individual has *mana whakahaere* over their data recognises the importance of their choice or say over where their data will go, who can access it, and what it can be used for.

Kaitiakitanga

Means to have guardianship and stewardship of the data and information entrusted by people who use social services. This is a trusted role that protects and keeps people's stories and information safe, respects what had been shared, understands its value and enables the sharing of that information when that is appropriate. The kaitiaki (or guardian) realises that they do not own this information but keep it in trust – making it easily accessible for the person whose information it is and growing the value of the information. Growth can mean using the information to create and share insights, or returning collective, non-personal data back to the people and community it came from for their use. This type of stewardship results in benefit and wellbeing for the individual, whānau and wider communities both now and intergenerationally – protecting information and delivering value into the future.

Mahitahitanga

This kupu expresses partnership, collaboration and cooperation. It refers to effectively engaging with one another and working together as equals in day to day activities. There is recognition that the value of the mahi (work) is enhanced when everyone contributes their knowledge, experience and wisdom. It is a commitment to one another and the process. When people are supported and cared for throughout the mahi, this provides and inspires valuable knowledge and insights that benefit everyone.

Manaakitanga

Respect and uphold the mana and dignity of the people, whānau, communities or groups who share their data and information.

Recognise and incorporate diverse cultural interests, perspectives and needs

- Be mindful of New Zealand's cultural diversity, and the different perspectives, needs and approaches that should influence how we work.
- Service users' and communities' views should be considered. What do they think about why and how their data and information is collected, used or shared?
- Different groups and people may value qualitative and quantitative information about themselves differently. It's important to recognise these different values when deciding what information to collect and to use when developing insights.
- Advisory groups, reference groups and other kinds of groups that have an interest in how data or information is used will benefit from having a diverse, informed, and representative membership to ensure quality practice and outcomes.

Include and involve service users whenever possible

- Service users can offer greater value than just their information and data.
- Their ideas and views are valuable and should be included when developing or testing proposals to collect and use data or information to improve wellbeing.

Incorporate the needs and priorities of people with a specific or particular interest in what is done with their data and information

- Some groups often have specific needs, priorities or interests in what information is collected, used and shared and why, as well as what happens with the results of any use.
- For Māori this means upholding their rights as Treaty partners and focusing on the collective and whānau outcomes of any work.
- For Pacific people this means considering the unique views and thoughts of their diverse communities.
- For children and young people, this means supporting their right to participate, hearing their voices as valuable, and communicating with them in the right way, at the right level.
- For disabled people this means considering accessibility issues, focusing on what works well, understanding their achievements and contribution, and making sure they are not 'invisible' in data and information.
- For service delivery organisations this means engaging people with the relevant cultural competence and experiences.
- Other people and groups are likely to have their own specific needs and priorities. It is important to be proactive in identifying and addressing those needs and priorities.

Kaitiakitanga

Act as a steward in a way that is understood and trusted by New Zealanders.

Recognise you are a kaitiaki, rather than an owner of data and information

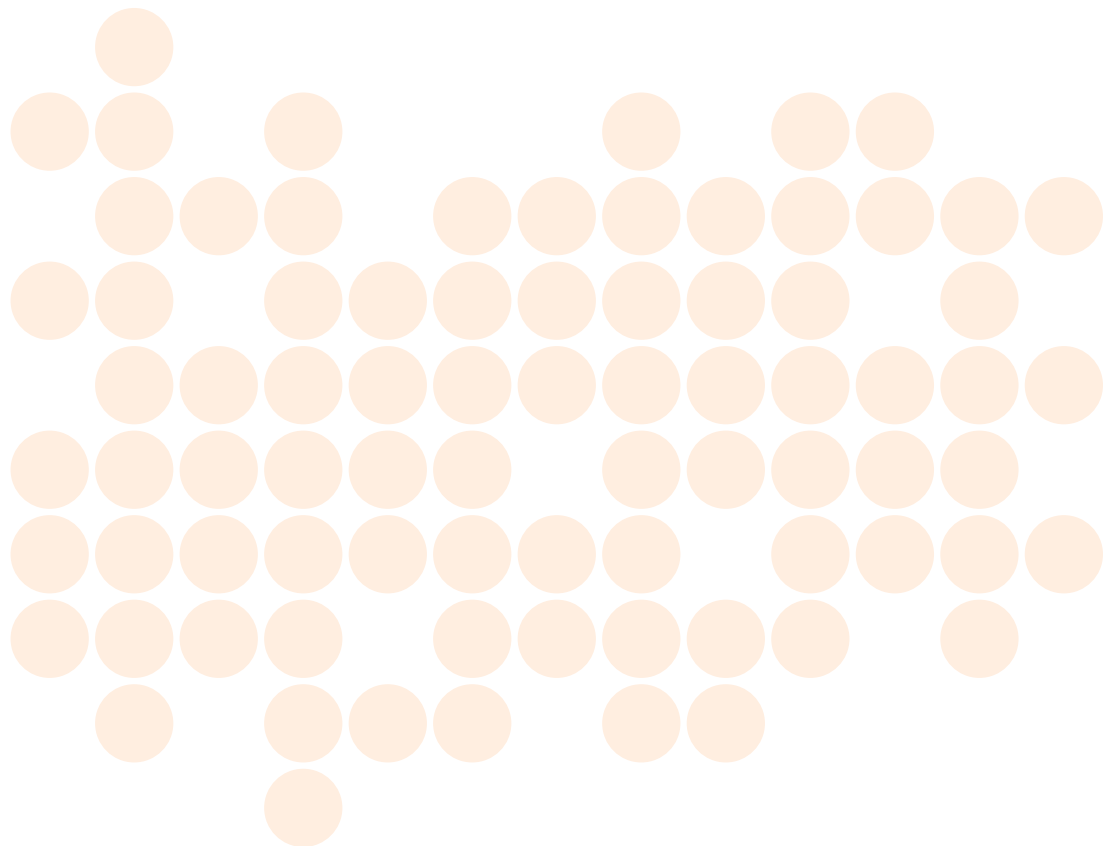
- Being a kaitiaki is about working in the service of, and being accountable to, New Zealanders around the collection, use and sharing of their data and information, and ensuring that it is valued and respected.
- Those who collect, use, share and store data and information are stewards and caretakers, not owners, of that data and information.
- A kaitiaki recognises the importance of people being able to access their information and helps them do that.

Be open and transparent; support people's interest or need to understand

- Building trust, being inclusive, respecting a wide range of views, and working in partnership all rely on open conversations about the collection, use and sharing of data and information and the reasons for doing these things.
- It's important to explain things in an accessible and easy to understand way, and in a manner that matches people's needs and interests. Different types, formats and levels of detail about data and information use will match different interests, levels of comprehension, context and needs of different groups.

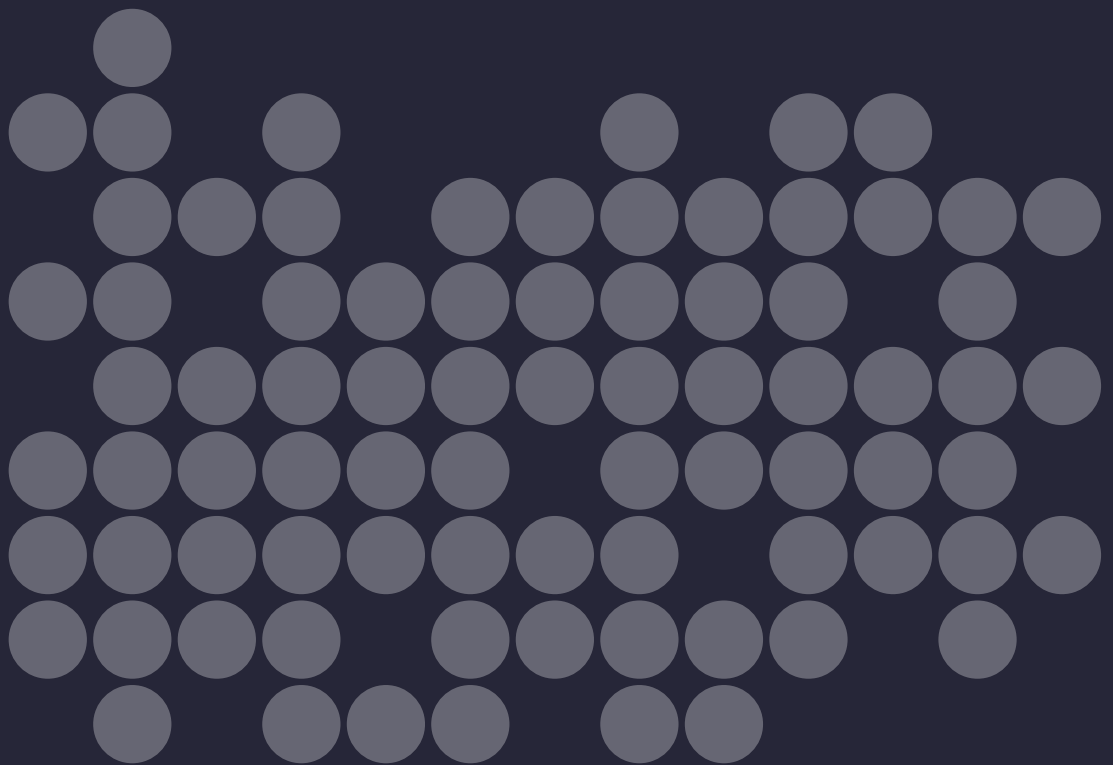
Keep data and information safe and secure and respect its value

- Use data management practices that are safe and secure, bearing in mind the nature of the information and data, and how it is being collected, used, shared, analysed and reported.
- Those who collect data and information (often frontline workers) need easy-to-use tools and processes for accurately and efficiently collecting, using and sharing information.
- Treat data as a valuable asset. Store and maintain it so that it is accessible and reliable, and only retain it for as long as it remains useful, relevant and necessary.
- Those who hold people's information are in a position to grow its value. They may do this by creating and sharing insights, or by returning collective, non-personal data back to the people and community it came from for their use. In all cases they must take care to comply with the law, protect people's privacy and maintain people's trust and confidence.



Policy Guidelines

**Guidance to implement the Policy Principles,
encompassing key topics and processes
identified as important by the sector**



Overview of Guidelines

The four **Guidelines** describe the elements and characteristics of key activities in accordance with the **Principles**. As part of providing this advice, the Guidelines also help agencies to understand and apply the Privacy Act in relation to these key activities.

The key activities covered by this Policy are those identified by the sector as the most important ones that would benefit from clear guidance.

The four Guidelines are on the right. You can read them in any order but the first one (**🔗 Purpose Matters**) has a key role. It responds to a key theme from the engagement phase summarised by the quote: *"it all starts with WHY"*. Understanding this topic has implications for the other Guidelines.

Purpose Matters p.20

The vital importance of purpose to collecting and using people's personal information

Transparency and Choice p.42

Enable people to understand what's happening with their information and what choices they have

Access to Information p.56

Make it easy for people to see and request correction of their information

Sharing Value p.68

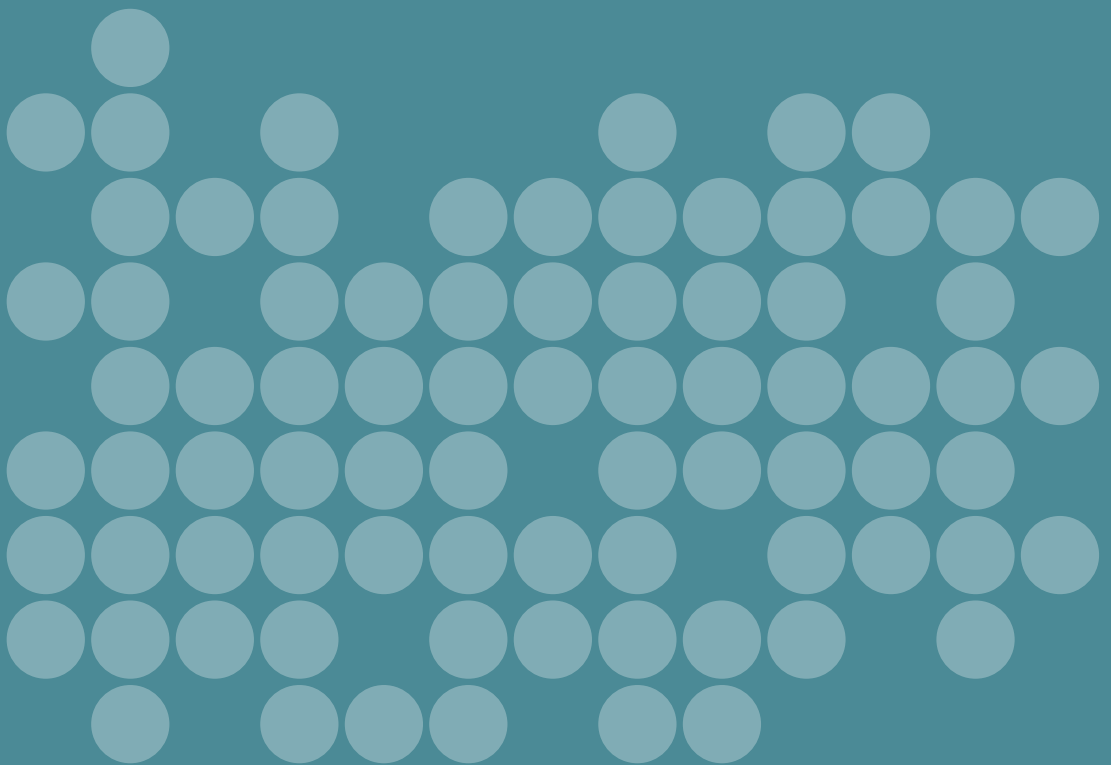
Work together for better insights and outcomes

Guideline

Purpose Matters

The vital importance of purpose to collecting and using people's personal information

Be clear about the purposes of collecting personal information, only collect what's needed, and consider how collection and use could affect people's wellbeing.



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Intent of this Guideline

This Guideline helps agencies who are considering the collection and use of people's personal information.

The first part of this Guideline explains important aspects of the law (particularly the Privacy Act) that are relevant to:

- purpose and collection of personal information;
- purpose and use of personal information; and
- purpose and sharing of personal information.

This Guideline then describes an approach to defining and assessing proposed purposes. The approach focuses on:

- being clear about the outcome(s) to be achieved;
- being clear about the method that will be used to achieve the outcome(s); and
- considering the context in which the information is being collected and used.

It also provides a range of checks and balances that can be worked through to help determine whether a proposed collection or use is lawful and appropriate, whether there's a need to obtain input from others, and when to seek such input.

The key concepts in this Guideline

Key concepts in this Guideline are that:

- social sector agencies must be clear about the purposes for which they collect personal information, whether that be directly from service users or from other agencies and organisations, and regardless of whether they are doing so under the general law or a specific statutory provision⁸ that authorises or requires the collection
- they can only collect personal information for lawful purposes connected with their functions or activities
- they can only collect personal information to the extent reasonably necessary for those lawful purposes, or as otherwise permitted by specific statutory provisions
- they should, when considering what's reasonably necessary, look at the intended outcomes together with the methods of processing and the context of use
- in some cases, the context may suggest that, even where a purpose of collection is lawful and it's reasonably necessary to collect personal information for that purpose, proceeding with the collection may be ethically questionable or otherwise undesirable
- social sector agencies can only use the personal information collected for the purposes for which it was collected, unless the law permits it to be used or disclosed for other purposes.

⁸ A 'specific statutory provision' is any legislative provision other than a provision of the Privacy Act that authorises, requires or otherwise regulates the collection, use or sharing of personal information, including provisions in particular Acts like the Social Security Act 2018, provisions in regulations under Acts, and Approved Information Sharing Agreements that are put in place under the Privacy Act.

When to use this Guideline

When collecting or using information that is or was about people

This Guideline should be used when a social sector agency is deciding whether to collect or use information, that is or was about people who use social services, for specific reasons.

From a privacy perspective, questions of ‘purpose’ most frequently arise in relation to the use of **personal information**. However, questions of purpose can also arise when personal information has been de-identified or anonymised. Full de-identification may result in a range of legal controls falling away (because, for example, the Privacy Act regulates what is done with personal information, not **non-personal information**), but ethical and other issues can still arise.

For these reasons, this Guideline is relevant to the collection and use of:

- personal information; and
- non-personal information that, prior to de-identification, was personal information.

Examples

- Personal information, in the form of information about identifiable individuals, may be removed from a dataset collected for one purpose but, if the dataset contains information that is culturally sensitive or otherwise specific to Māori, using it even in de-identified form for another purpose without involving Māori may not be appropriate.
- Personal information may be removed from the description of a serious offence against a child or another vulnerable member of society, resulting in there being no reasonable prospect of the child or other vulnerable person being identified, but that doesn’t necessarily mean it’s ethically appropriate to use the information for any other purpose, particularly if any form of publication is involved.

Relationship with the other Guidelines

Elements of this Guideline inform the three other Guidelines, as follows:

Transparency and Choice

Is about helping people understand why their information is needed and what their rights are. The purpose of collection is a key aspect of what collecting agencies need to tell people when collecting their personal information.

Access to Information

Is about helping people understand their rights of access, having control over their information where possible, and making it easy for them to exercise their rights. Understanding the purposes of collection, in the context of the intended outcomes and methods of processing, can influence how people are given access to their information and how they can request that inaccuracies be corrected.

Sharing Value

Is about working together to develop valuable insights from information collected from or about service users and sharing the value of those insights with others. The involvement of others in the design and implementation of intended collection and use processes may influence how the purposes of collection are formulated and communicated to people and how much information needs to be collected.

Glossary

A full set of definitions used in this Policy can be found in the **Glossary**.

Using the Policy Principles

Because this Guideline flows in part from the Policy Principles, it's useful to read it with those **Principles** in mind. They can help to identify considerations relevant to understanding and framing purposes for collecting and using information about people, even where these considerations may exceed minimum legal requirements.

Initial considerations include:

He tāngata

Are the purposes of collection and use clearly focused on positive outcomes (whether for individuals, groups or wider society) and is the information to be collected or used necessary to achieve those outcomes?

Manaakitanga

Is the collection or use of people's information for particular purposes sufficiently respectful of them or the cultures, communities or groups to which they belong? Does it support or detract from their wellbeing?

Mana whakahaere

To what extent, given the purposes of collecting personal information, can an agency allow people to opt out of providing their information?

Kaitiakitanga

How, as kaitiaki or stewards of people's information, can the purposes of collecting or using that information be framed in a manner that is easy to explain to people and that fosters their understanding and trust in what is being done with their information?

Mahitahitanga

To what extent can involving others help to formulate and double-check the appropriateness of proposed collections and uses of people's information?


Applying this Guideline

Be clear about purpose and collection

Clarity of purpose required regardless of the particular legal basis for collection

Social sector agencies must be clear about the purpose for which they collect personal information. Agencies must be clear about this, before collecting the information, because:

- where the Privacy Act's **information privacy principle 1 (IPP1)** (*Purpose of collection of personal information*) applies, they should not be collecting personal information unless the collection is for a lawful purpose connected with their functions or activities and, importantly, the collection is reasonably necessary⁹ for that purpose; and
- where they are collecting personal information under a specific statutory power that authorises or requires the collection, they need to be clear on the purpose of collection to ensure the statutory power covers the information they propose to collect and the reason for collecting it.

 Purpose will *always* be relevant. Assessing and articulating it properly is vital to both legal compliance and guarding against indiscriminate or excessive collection of people's information.

Clarity of purpose required regardless of whether collecting from individuals or from other agencies and organisations

Clarity of purpose is vital regardless of whether information is to be collected directly from service users or from other agencies and organisations. The reasons for that go beyond ensuring that a collection is lawful under either IPP1 or a specific statutory collection power:

- Where information is to be collected from individuals, clarity of purpose is vital to helping people understand why their information is being collected, as is usually required¹⁰ by the Privacy Act's IPP3 (*Collection of information from subject*). As the OPC has observed, "it is fundamental to people's right to privacy that, when providing information about themselves, individuals know why the information is being collected and what it is going to be used for".¹¹ This topic is discussed further in the [Transparency and Choice Guideline](#).
- Sometimes, providing people with details about the collection of their information, who will receive it, the reasons for doing so and other matters listed in IPP3, could undermine the reason for collection and justify not telling them. However, the relevant exception in IPP3 that would justify not telling them applies where telling them would "prejudice the purposes of the collection". If the purpose(s) of collection haven't been clearly articulated, it will be difficult to rely on this exception. Without clarity of purpose, it may also be difficult to rely on other exceptions in IPP3.

⁹ IPP1 uses the language of 'necessary for the purpose' rather than 'reasonably necessary'. However, it is generally accepted that an "agency does not need to show that it absolutely *must* collect the information in order to achieve its purpose". Rather, it needs to show "that it is reasonably necessary to collect it". See the Office of the Privacy Commissioner's website at [privacy.org.nz/the-privacy-act-and-codes/privacy-principles/purpose-for-collection-of-personal-information-principle-1](https://www.privacy.org.nz/the-privacy-act-and-codes/privacy-principles/purpose-for-collection-of-personal-information-principle-1)

¹⁰ Helping people understand why their information is being collected is required by the Privacy Act's IPP3 unless an exception in IPP3 applies or another law expressly overrides IPP3 (which is rare).

¹¹ Privacy Commissioner's "Inquiry into the Ministry of Social Development's Collection of Individual Client-Level Data from NGOs" (4 April 2017), paragraph 6.1.2.

- Except where an agency is authorised or required by a specific statutory provision to collect personal information from another agency, the information needs to be collected from the relevant individuals unless an exception in the Privacy Act’s IPP2 (*Source of personal information*) applies. One of those exceptions is that collection directly from the individuals concerned would “prejudice the purposes of the collection”. Again, if the purpose(s) of collection haven’t been clearly articulated, it will be difficult to rely on this exception. And again, without clarity of purpose, it may also be difficult to rely on other exceptions in IPP2.

If you’re collecting personal information from other agencies, they need to understand your purpose of collection

For illustrative purposes, the information below uses an example of a government agency (*Government Agency*) collecting personal information from a non-governmental organisation (*NGO*) that collects

it directly from service users. However, the guidance applies generally to any agency collecting information from another.

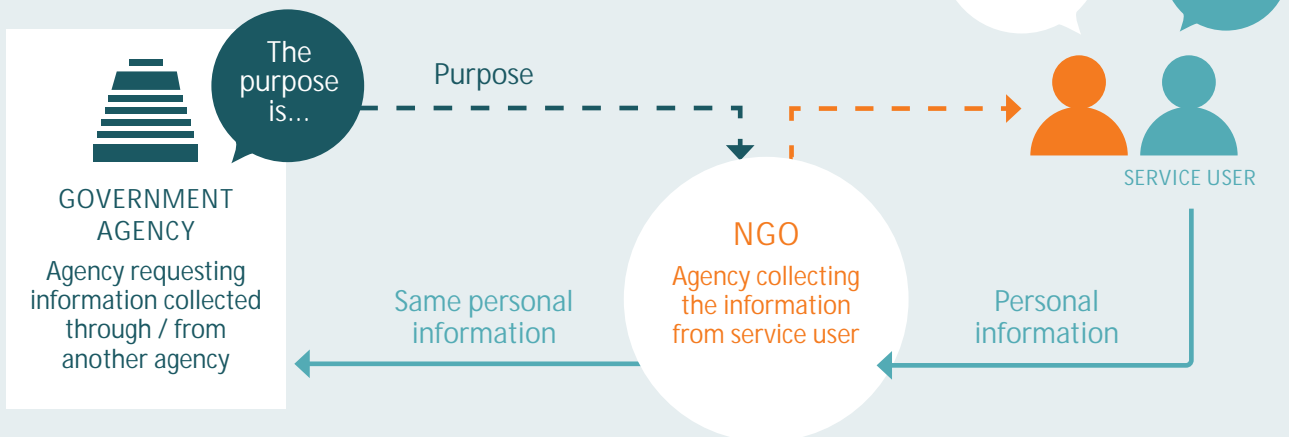
If *Government Agency* is collecting personal information from *NGO*, it’s important that:

- *Government Agency* has a clearly articulated and lawful purpose of collecting the information from *NGO*; and
- *Government Agency* fully informs *NGO* of *Government Agency*’s purpose of collection in a manner that is easy for *NGO* to understand and explain to its service users.¹²

Government Agency needs to tell *NGO* about *Government Agency*’s purpose, so *NGO* can include that purpose in *NGO*’s statement of purposes to service users.

Government Agency needs to tell NGO about Government Agency’s purpose, so NGO can include that purpose in NGO’s statement of purposes to service users.

NGO must be able to understand and explain the purpose (and other things) to service users.




¹² In some cases, NGO might not need to explain Government Agency’s purpose to service users, as an exception in the Privacy Act’s IPP3 might apply, but in most cases, NGO will need to do so.

Government Agency should also tell *NGO* whether *NGO's* provision of the information to *Government Agency* for the specified purpose(s) is mandatory (and, if so, under what particular statutory provision) or voluntary.

The Privacy Act does not specify all of these requirements (in terms of what *Government Agency* needs to tell *NGO*) but they are often vital. If *NGO* doesn't fully understand these matters, *NGO*:

- could struggle to assess whether it is *lawful* to provide the information to *Government Agency*, whether it *must* or only *may* provide the information to *Government Agency*, and – where provision is voluntary – whether it *should* provide the information to *Government Agency*; and
- might not be able to meet its own transparency obligations to service users under the Privacy Act's IPP3 (*Collection of information from subject*).

 *NGO* should not have to ask *Government Agency* for this information. If, for whatever reason, *Government Agency* does not provide it, or *NGO* wishes to ask further questions, it's important for *Government Agency* to provide the information that *NGO* reasonably requests, without *NGO* fearing the consequences of asking or being told it doesn't need to know.

If identifying information isn't required, don't ask for it

The Privacy Act's IPP1 says, in essence, don't collect personal information unless it's reasonably necessary for a lawful purpose connected with the agency's functions or activities. When IPP1 applies, if a collecting agency can achieve its purpose without collecting identifying information, then it shouldn't do so. If the Privacy Bill is enacted in the form reported back to Parliament by the Justice Committee in March 2019, then IPP1 in the new Act will also state: "If the lawful purpose for which personal information about an individual is collected does not require the collection of an individual's identifying information, the agency may not require the individual's identifying information."

Be clear about purpose and use

Personal information only to be used for purpose of collection unless other uses permitted by law

Ordinarily, personal information should only be used for the purpose for which it was collected, unless another proposed use is permitted by:

- the exceptions in the Privacy Act's IPP10 (*Limits on use of personal information*); or
- a specific statutory provision.

As the OPC observes, the "effect of [IPP10] is to ensure agencies are accountable for their actions when collecting information by prohibiting them from 'repurposing' information".

This makes it important for collecting agencies to fully understand and carefully explain their purposes of collection at the outset. They need to ensure that their genuine proposed uses are covered, while always bearing in mind that they should not be collecting personal information if:

- it is not reasonably necessary for lawful purposes connected with their functions or activities; or
- the collection is under a specific statutory collection provision, and the collection exceeds the bounds of the provision.

It is generally acceptable for an agency to have and communicate more than one purpose for collecting personal information if, at the time of collection, the collecting agency genuinely proposes to use the information for more than one purpose. All stated purposes must be lawful purposes connected with the agency's functions or activities.

However, it is not acceptable to include vague ‘catch-all’ purposes in an attempt to capture remotely possible future uses, even if not reasonably contemplated at the time of collection. If an agency doesn’t genuinely contemplate using personal information for some distant or uncertain reason but is only adding it to its purpose statement to ‘hedge its bets’, then it’s difficult to say that the distant and uncertain reason is actually a genuine purpose of collection, regardless of whether an agency asserts that to be so. ‘Purpose creep’ like this needs to be avoided. Not only does it run the risk of the agency acting unlawfully, but collecting people’s information and then doing nothing of value with it can erode people’s trust and confidence in the collecting agency.

Clarity of original purpose also relevant to reliance on ‘directly related purpose’ exception under IPP10

Under IPP10, personal information can only be used for another purpose if an agency believes on reasonable grounds that one of the IPP10 exceptions applies. There are eight exceptions. One of them is that the purpose of using the information is directly related to the purpose for which the information was obtained. If an agency has not clearly defined the original purpose of collection, relying on this ‘directly related purpose’ exception¹³ could be difficult.

Clarity of other purposes also important

Where an agency wishes to use personal information for a purpose other than the original purpose(s) of collection, it remains important for the agency to be clear about and document the nature and scope of that other purpose. There are two reasons for this:

- to ensure that the other purpose is lawful, by checking it against either the Privacy Act’s IPP10 or, if a specific statutory provision authorises other uses, against that provision; and
- to have a record of the purposes for which personal information is being used and why each kind of use is permissible.

If the documented ‘other purpose’ is not lawful under either the Privacy Act’s IPP10 or a specific statutory provision, then the personal information should not be used for that other purpose.

Purpose still relevant when an alternative use appears to be authorised by a specific statutory provision

There are various contexts in the social sector in which specific statutory provisions authorise the use of personal information for purposes different to the original purpose of collection.¹⁴

Even in contexts like this, though, the purpose of a proposed alternative use needs to be clear before the specific statutory provision is relied on, to ensure the use is covered by the provision. If an agency doesn’t answer this question properly, and it turns out that the use wasn’t covered by the provision and that the alternative use would not have been permitted under IPP10, then the agency’s use of the information for the alternative purpose may (depending on the circumstances) amount to an “interference with privacy” under the Privacy Act.¹⁵

¹³ Sometimes people wonder whether a proposed use is ‘directly related’ to the purpose for which the information was obtained. The Office of the Privacy Commissioner has a useful summary on its website of what you need to consider: [privacy.org.nz/further-resources/knowledge-base/view/245?t=107250_150183](https://www.privacy.org.nz/further-resources/knowledge-base/view/245?t=107250_150183)

¹⁴ For example, under section 126 of the Public and Community Housing Management Act 1992, the Ministry of Social Development may use information obtained under a part of that Act, in its role as social housing agency, to perform its functions, duties, and powers under the Social Security Act 2018.

¹⁵ An “interference with privacy” occurs where, for example, there is a breach of an information privacy principle in the Act and that breach causes one or more individuals to suffer harm.

Be clear about purpose and sharing

Clarity of purpose relevant to the ability to share personal information

Clarity of purpose at the point of collecting personal information can also be relevant to whether an agency is able to share that information with others. This is because, under the Privacy Act's IPP11 (*Limits on disclosure of personal information*), an agency must not disclose the personal information unless the agency believes, on reasonable grounds, that one of the listed exceptions applies.

The first exception is that the disclosure is one of the purposes for which the information was obtained or is directly related to those purposes. To determine whether this exception applies, the agency must know what the original purposes of obtaining the information were.

If one of the purposes of collecting personal information is to share it with another agency for a particular reason, as often occurs in the social sector, the collecting agency needs to be clear about that upfront. If collecting the information directly from service users, usually the agency needs to explain this to them under IPP3 (*Collection of information from subject*) with a reasonable degree of specificity.¹⁶ This means explaining who the agency is and why the information is being shared with that agency.

If collecting the information from another agency or organisation, the agency should be clear with them about this too, again with a reasonable degree of specificity. This may influence whether that agency or organisation is willing to disclose the information and whether it may seek to impose controls on further distribution of the information (for example, under a memorandum of understanding or contract).

Purpose still relevant when disclosure appears to be authorised by a specific statutory provision

IPP11 can be overridden by specific statutory provisions that either authorise or require the disclosure of personal information to other agencies. There are many instances of this in the social sector. However, purpose remains relevant in this context as well. Usually such specific statutory provisions specify the purposes for which particular personal information can be shared. This means the agency needs to be clear about the purpose of disclosure before relying on a specific statutory disclosure provision, to ensure the proposed disclosure is covered by the provision.

If an agency doesn't answer this question properly, and it turns out that the disclosure wasn't covered by the provision, and that the disclosure would not have been permitted under IPP11 either, then the agency's disclosure of the information may amount to an interference with privacy.

¹⁶ This will be the case unless an exception in IPP3 applies.

Take this approach to assessing purpose and only collecting what's needed

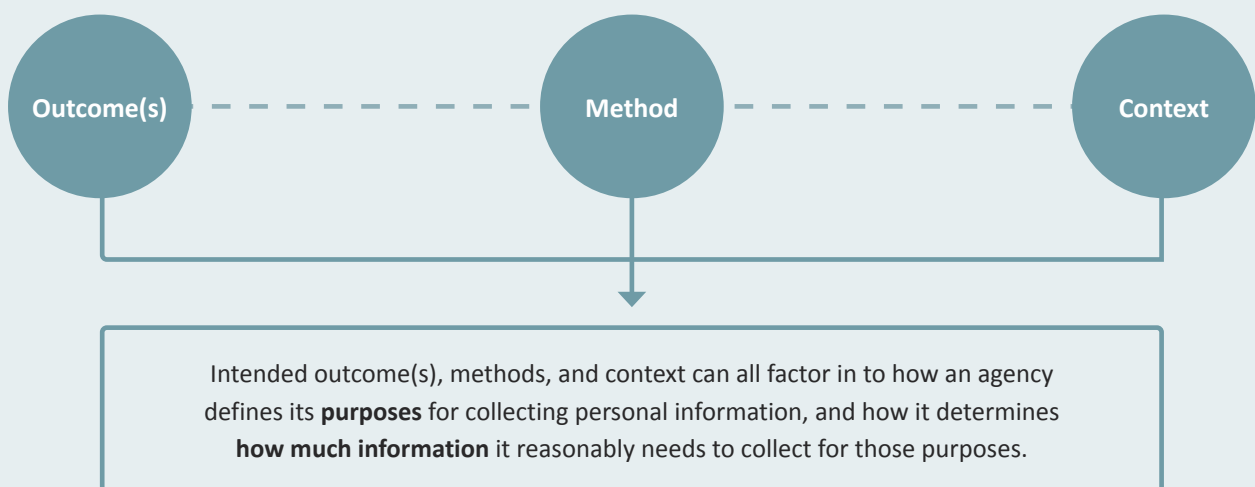
Overview

When assessing the purpose of collecting personal information and the kinds of information to be collected, agencies should:

- be clear about the outcome(s) to be achieved;
- be clear about the method that will be used to achieve the outcome(s); and
- consider the context in which the information is being collected and used.

Having clarity in these areas can help an agency to:

- formulate the purpose of collection
- assess whether that purpose is connected with the agency's functions or activities
- assess what particular personal information is needed to achieve the outcome
- determine whether the collection is ethically justifiable and aligns to respectful practice (even if it will tick all legal boxes).



Be clear about the outcome(s)

Well-defined and recorded outcomes are important

To have clarity of purpose it is necessary to understand *why* data or information is being collected, that is, the outcome or result of using it. This should be well-defined and easy for a range of people, including service users, to understand. It should be written down. The act of recording it:

- contributes to clarity of thought
- contributes to the information that needs to be communicated to service users (either directly, if the collecting agency is collecting the information directly from services users, or through another agency that is collecting the information from service users)
- provides the basis for the collecting agency to determine whether proposed uses or disclosures of the information in the future are for a purpose for which it was collected or a directly related purpose.

Without such clarity, an agency may not be able to determine whether it's necessary to collect the information the agency proposes to collect. In that event, the agency's collection may breach the Privacy Act's IPP1 or, where relevant, not fall within a specific statutory collection power the agency seeks to rely on.

Who do the outcomes serve?

When considering the outcome(s), it can be helpful to reflect upon whom the outcome(s) serve. That is, do the individuals from whom the information is collected benefit, or do other people or does wider society benefit? If the benefit is to other people or wider society, what will the people providing the information think about that? The Privacy Act or a specific statutory provision may allow it, but is using their information to benefit others ethically justifiable?

Avoid broad and ambiguous statements

Broad and ambiguous statements of purpose or outcomes need to be avoided. For example, if information is being collected for the purpose of analysis relevant to policy development or service delivery, either by itself or in conjunction with other data, it may be necessary to consider and articulate the potential uses of the results of that analysis. If the results will be used to provide more targeted services and better outcomes for people, then say that, with an appropriate degree of precision. If the results could lead to the taking of adverse action against people, say that too.

Consider telling people what their information will *not* be used for

IPP3 is concerned with telling people about the purposes for which their information *will* be used. That makes sense, especially when other uses are not permitted unless either an exception in IPP10 (*Limits on use of personal information*) applies or a separate statutory provision authorises another use. However, one cannot expect service users to understand this legal position.



It can sometimes be helpful, therefore, to explain to people that, while their information *will* be used for purposes A and B, it *will not* be used for purposes X or Y. For example, if your agency is collecting particularly sensitive information about people to provide them with immediate care, and there's no intention to allow any identifying information to be seen by researchers or other agencies, you could say that. Similarly, if the information you're collecting includes unique identifiers like a driver's licence number, IRD number or passport number, you might want to tell people that their number won't be used to match information you have about them with information another agency has about them. The desirability or otherwise of making statements like this will depend on the context.

This consideration can be particularly important where people may fear that their information will be used in a manner that could prejudice them. Taking this approach can help increase people's levels of comfort with what's happening with their information.

Be careful with evolving statements of purpose

When a policy, service or programme is in an evolving state, an agency's articulation of the purpose of a proposed collection may change or be refined before the information is collected. Where that is the case, the agency should be clear about which statement of purpose is the final one and, if the final statement is intended to replace earlier explanations that should be stated.

Having different explanations of the purpose of collection across different policy, service or programme documents can lead to confusion as to what the actual purpose of collection is or was. This could result in errors when explaining to people why the information is being collected and how it will be used. It could also result in a loss of trust on the part of service users. If there is cause for the purposes of collection to be investigated, different purpose statements over time could result in uncertainty and adverse findings.

Be clear about the method

Why the method is important

As well as having a clear understanding of the outcome, it's important to consider the method for achieving the outcome; both the end and the means are important. Knowing *how* the information will be processed to achieve the outcome can be relevant to determining whether the information being collected can or will contribute to the outcome and, therefore, whether all of it is required to achieve the outcome.

Example

An application form for a service might collect personal information comprising a person's name, date of birth, annual income, address, gender and ethnicity. However, a tool to process such applications, and designed to match the eligibility criteria for the service, may only need name, date of birth, address and annual income. The agency may have no plans to use the information relating to gender and ethnicity. In that kind of situation, collecting information on gender and ethnicity would be unnecessary and, in all likelihood, unlawful.

Consider whether there are different analytical techniques or processes

In some situations, there may be different analytical techniques or processes for achieving an outcome and, to achieve the outcome, the different techniques or processes may require more or less personal information, or even no personal information at all (because, for example, it can be de-identified before collection). If one technique requiring less personal information can easily be deployed over another that requires more personal information, respectful practice means choosing the former technique to minimise the amount of personal information collected.

If a collecting agency needs to know people are over 20 years of age, it might use a tool that asks for a person's date of birth or age but then determines from that whether the person is over 20 and only stores a "Yes over 20" response, instead of the date of birth or current age.



Collecting agencies that need help with this, can reach out to others with relevant experience or expertise. Depending on the context, it might be helpful to seek advice from other agencies such as Stats NZ, frontline NGOs, service user representatives, the Office of the Privacy Commissioner, or the Government Chief Privacy Officer.

Ask whether, to achieve the outcome, it is reasonably necessary to collect personal information from every service user all of the time or whether allowing people to opt out is feasible

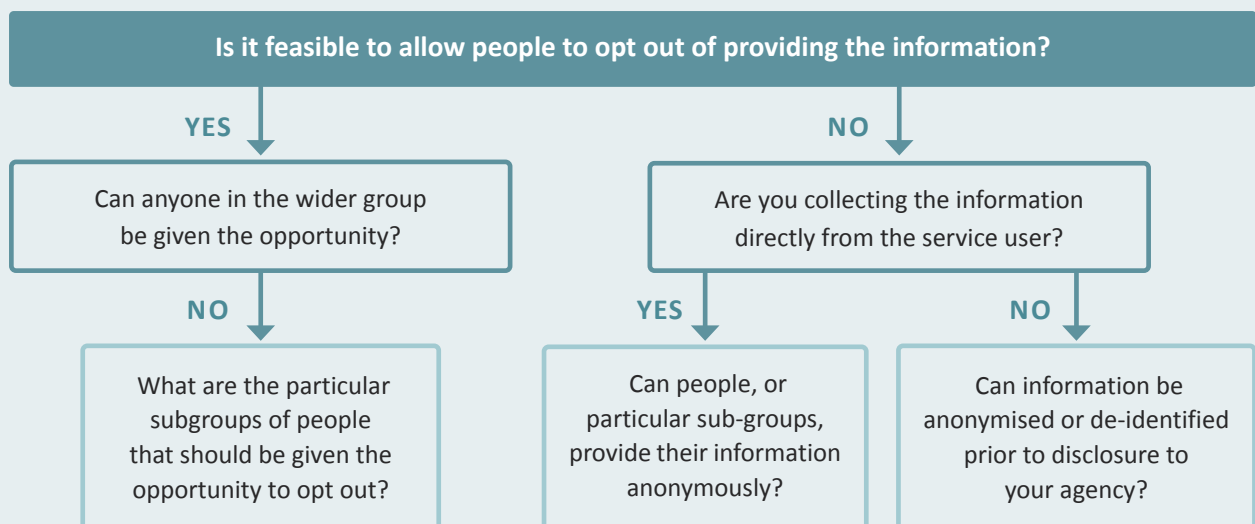
In some situations, an agency may propose to collect information from a wide group of people to achieve a stated purpose or outcome, despite the group having different subgroups or the group being comprised of people with different service needs, sensitivities or fears. At a macro level, it may be reasonable to conclude that it's reasonably necessary to collect personal information from members of the wide group of people to achieve the stated purpose. However, it doesn't necessarily follow that the information needs to be collected from every member of the group,

all the time, and regardless of individuals' different service needs, sensitivities or fears. Whether that is the case or not will depend on the context.

The key point is to consider whether the purpose can be achieved if only a proportion of people in the group provide the information requested. If the answer is yes, it may be helpful to assess whether allowing people to opt out of providing the information is feasible. If it is, the collecting agency can then consider whether anyone in the wider group should be given this ability or whether there are particular subgroups of people, for example, vulnerable people needing services for particularly sensitive issues, that should be given the opportunity to opt out.

If opt out isn't feasible, another option might be to allow people, or particular subgroups, to provide their information anonymously. Or, if the collecting agency (Agency A) is collecting information from another agency or organisation (Agency B) that collects personal information directly from individuals, it may be possible for Agency A's purposes to be achieved by collecting information from Agency B that has been anonymised or de-identified prior to disclosure to Agency A.

This decision process is illustrated below.



Similarly, if personal information is being collected to assist with something like policy development or analysis of a service, there may come a time at which it is no longer necessary to collect the same kinds of personal information from people, on the basis that the purpose has been achieved.

When IPP1 applies, these questions are directly relevant to whether the collecting agency is able to conclude that it's always reasonably necessary to collect the personal information from everyone, all of the time.



The wider and more diverse a group is, or the longer the period of information collection is likely to be, the more important this question may become.

If different kinds of personal information are being collected via a single channel or into a single repository, ask whether that poses any information access problems

Sometimes agencies collect different kinds of personal information for different purposes but through a single collection channel and into a single location. In other situations, an agency might use different collection channels but collate all the information into a single repository or output, such as a spreadsheet.

If there are different audiences or groups within the agency who have different access needs in relation to the different kinds of personal information, having it all compiled into a single location, repository or output could result in some staff having access to personal information they don't need to see and which, therefore, they should not see. This could also be contrary to the Privacy Act's IPP5 (*Storage and security of personal information*). Under IPP5, agencies need to ensure that personal information they hold is protected by reasonable security safeguards "against... access, use, modification, or disclosure, except with the authority of the agency that holds the information".

In this kind of situation, part of the method for achieving the outcomes, that is, the means for collecting and collating the information, may be inappropriate and need to be reconsidered. In the social sector this can be particularly important

because service users can get understandably worried about too many or the wrong people having access to their personal information.

Consider the context

The relevance of context

Context matters because it influences how people might feel about the collection or use of their personal information for particular purposes or how much information is collected, and that, in turn, may affect their wellbeing. It also affects the kinds of checks and balances an agency may decide to work through before collecting, using or sharing personal information for a particular purpose, especially if there's any risk that collecting, using or sharing personal information in the manner proposed could do, or be perceived to do, more harm than good.

Context can also be relevant to the collection, use or sharing of information that has been de-identified, in the sense that it won't be possible to identify specific individuals from the de-identified information. This is because de-identified information can still contain information that some individuals, groups or cultures may find sensitive.



It can be particularly important to remember that, whilst the Privacy Act is concerned with the privacy of individuals, we live in a society where broader groups have legitimate privacy interests. The Act's controls may fall away once personal information has been fully de-identified in the sense described above, but the remaining information could still be sensitive to, for example, whānau, hapū, iwi, other cultural groups, or other groups of society.

The next part of this Guideline provides guidance on potentially relevant contextual matters and describes some specific issues that may be particularly important in some situations.

Potentially relevant contextual matters

Contextual matters to consider in decision-making may include some or all of the following:

1. Which agency is collecting the information from service users?
2. What's the nature of the service or programme for which the information will be or was originally collected?
3. What's the nature of the information?
4. What are the circumstances of the people involved?
5. Is there potential for adverse consequences?
6. How could linking people's personal information with other data be perceived?
7. What should an agency tell people when their personal information is linked with other data?
8. If personal information is to be collected from other agencies, what is the potential impact on the unique trust relationships that those agencies may have in place with people?

1. Which agency is collecting the information from service users?

- Will your agency collect the information from service users? If not, which agency will, or did, collect it from them?
- If another agency will collect, or did collect, the information you want to use, will the service users be told or were they told that your agency would receive their information? If not (and assuming the original collecting agency is permitted to disclose it to your agency and that your agency is permitted to collect it), how might they feel about your agency having their information? Could your agency's use of their information be distressing to them or otherwise adversely affect their wellbeing?

2. What's the nature of the service or programme for which the information will be collected or was originally collected?

Generally speaking, the more sensitive, urgent or acute for people a service is, the more important it becomes to consider people's wellbeing and take that into account when considering the purposes for which their information will be collected (especially if those purposes entail disclosures to others) and how much will be collected. For example, if an agency is providing a support service to victims of serious crime, the nature of that service and what the victims have experienced are highly relevant to the purposes for which, and how much of, their personal information might be collected, used, and shared with others. This is the case regardless of what the law may permit.

3. What's the nature of the information?


- Is the information fairly routine or basic in nature or is it particularly sensitive? For example, is it about service users' mental health or their attendance in a programme? Consider that, in some situations, information that may sound fairly routine to the collecting agency may actually be quite sensitive for the people being asked to provide it.
- If information is collected in circumstances where those providing it don't need to establish their identity, is there a risk of receiving inaccurate information?
- Is there any potential for people to feel judged or discriminated against by an agency using their information in the manner proposed?
- Would the collection or use of the personal information affect people's trust and confidence in the agency collecting it or using it?

4. What are the circumstances of the people involved?


- Might the proposed use of service users' personal information be seen as unrepresentative or reinforcing of stereotypes?
- Is the information about children, people who are marginalised or stigmatised, or people at greater risk of harm, and whose information needs greater protection?
- If the information comes via a service or programme, do the people concerned self-refer or is their attendance compulsory? This may influence how much choice they have over the collection of their information and how they might feel about that or about it being used for other purposes, even if they're told about those other purposes when their information is collected.

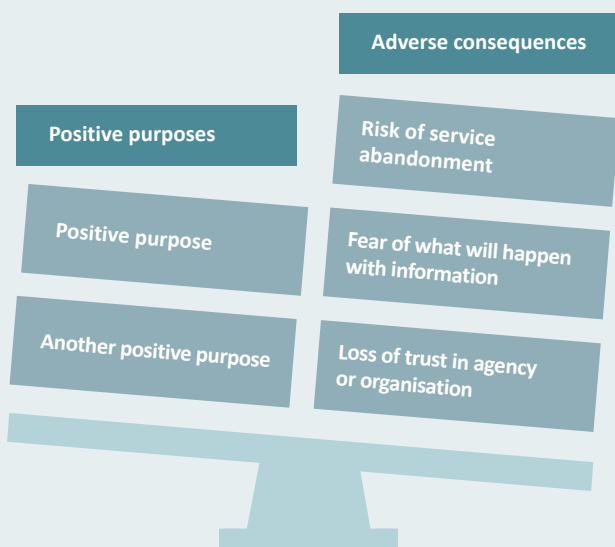
5. Is there potential for adverse consequences?

An agency's purpose for collecting personal information may be related to its functions or activities, well-intentioned, and understandable, and the collection of personal information to achieve that purpose may appear to be reasonably necessary. It may be consistent with government priorities and policy objectives and, from these perspectives, justifiable. From a legal perspective, it might tick all boxes under the Privacy Act's IPP1 (*Collection of personal information*).

Applying the  **He tāngata Principle**, though, means asking whether pursuit of the purpose and the collection of personal information for that purpose could have adverse consequences for people. This is an area on which the Privacy Act's information privacy principles are relatively silent. Indeed, there can be instances where a collection and use will not be contrary to any privacy principle but where the potential for adverse consequences, once understood, may prompt reconsideration.

In some situations, particularly where new policies, services or programmes are involved, it may be desirable to place an ethical lens over what's proposed. For example, it may be desirable to:

- take both the positive outcomes and the potential adverse consequences into account before proceeding, and to ask if pursuit of this purpose could do more harm than good, even if that's not the intention
- consider the importance of respecting people's dignity and treating them in a just manner, consistent with the  **He tāngata Principle**.



Sometimes, it can help to conceptualise what's proposed like this. This is a simple representation of what will often be a complex picture (in an actual situation, the positive purposes would be specifically described, and there could be additional or different adverse consequences) but it may help to put matters in perspective and prompt a collecting agency to ask whether it has only been thinking about one side of what lies in the balance.

Identifying the adverse consequences may also help an agency to take steps to avoid them while still enabling it to pursue one or more of its original purposes.

Example

If requiring information from people, or requiring service delivery organisations who collect information to pass it on to others, could result in people walking away from services they need for fear of what might happen to them or who might see their sensitive information, then that might result in more harm than good. Even when lawful, care may be needed to ensure that information collection practices do not deter people from seeking the help they need.

6. How could linking people's personal information with other data be perceived?

It is not uncommon for personal information to be collected with a view to linking it with other datasets to yield insights, whether as the sole purpose of collection or as one of the purposes of collection.

If a collecting agency is proposing to do this, it needs to be clear about the nature of the proposed linking and how resulting insights will or are likely to be used. This is important to avoid over-collection of personal information and to be able to explain to people how their personal information will be used.

While the law allows this kind of linking in certain situations (each situation needs to be assessed on its merits), it can be important for the collecting agency to ask itself, and sometimes service provider organisations and service users, what people would think about their information being linked up in this way.

This question remains important even when the resulting data will be de-identified or anonymised before further use as some people may still have concerns about information derived from their personal information being used in this way, particularly where the information is sensitive.

If the collecting agency elects to proceed with the collection for linking purposes, the next question needs to be considered.

7. What should an agency tell people about their personal information being linked with other data?

This topic naturally arises under the [Transparency and Choice Guideline](#), but it is mentioned here as well, given its relationship to the purpose of collection.

From an **ethical perspective** and bearing in mind the nature and range of information that circulates in the social sector, it is important to explain proposed data linking to service users, regardless of whether the law requires that.

This is not a straight-forward point because, under IPP3, one of the grounds for not having to explain the purposes of collection and other matters to people is where the agency believes that the information will be used for statistical or research purposes and won't be published in a form that could identify individuals. Where an agency's linking purposes fall squarely within this exception, the agency might conclude that it doesn't need to tell people about the linking and how the insights will be used.

However, there is nothing sufficiently unique about the collection of personal information for statistical or research purposes to justify not telling people that their personal information will be linked with other datasets to yield insights, even where a social sector agency can rely on the IPP3 exception.

8. If personal information is to be collected from other agencies, what is the potential impact on the unique trust relationships that those agencies may have in place with people?

People form trust relationships based on interactions they have with other people. Where information is being collected by frontline service delivery organisations, such as NGOs, those trust relationships may exist at the local level. They may have developed over time and they may be premised on particular approaches to, for example, information disclosure and consent, that the service delivery organisations have followed. In some cases, these approaches may have flowed from codes of ethics that certain kinds of service providers need to follow as a matter of professional obligation.

If an agency (Agency A) is proposing to collect personal information from frontline service delivery organisations, it can be important to take the existence of these trust relationships and approaches into account, and to ask what impact Agency A's collection from these organisations could have on them and their clients. It may be important to consult the organisations and, where appropriate, service users, at an early stage, before collection decisions are made.

Work through checks and balances when needed

When to work through some checks and balances

This Guideline emphasises the importance of getting the purpose(s) of collection right, only collecting what's reasonably necessary for those purpose(s) and taking care to avoid unintended adverse consequences. Given the significance of these matters, in some cases it can be helpful to subject an agency's initial thinking, around purpose and the necessity and appropriateness of collection, to one or more checks and balances. This is particularly so when an agency:

- is unsure about how it is articulating a purpose of collection, for example whether it's sufficiently precise and covers all genuine purposes or whether it could be over-reaching
- identifies a risk that others could be concerned about the collection, particularly if service delivery organisations or service users could be concerned
- is unsure whether a purpose of collection is sufficiently connected to the agency's functions or activities
- could be collecting more personal information than is necessary for the stated purpose(s)
- is embarking on a new service or programme that, for some people, may be controversial
- operates in a complex legislative environment (that is, in addition to the Privacy Act, an agency has powers or is subject to constraints in specific legislation that applies to that agency)
- is proposing to collect sensitive information or information that could be perceived to have no logical connection to the stated purpose(s) or where the type of information being collected (such as gender, marital status, ethnicity, religious belief, sexual orientation, or mental or other health information) could be used to discriminate against people
- is collecting the information or using it for a stated purpose in a manner that could adversely affect the trust and confidence people have in the agency, or run the risk of people in need not seeking the help that's available to them.

Suggested checks and balances

If any of the circumstances listed earlier exist, the collecting agency (or, where relevant, an agency disclosing the information to a collecting agency) may wish to do one or more of the following:

- check with a line manager, and get that person's opinion
- ask the agency's privacy officer for help
- seek input from a privacy consultant
- seek legal advice from a lawyer or firm with a solid understanding of privacy law
- undertake a privacy impact assessment or, if available to your agency, apply a framework like the Ministry of Social Development's Privacy, Human Rights and Ethics framework (PHRaE)¹⁷
- seek advice from an appropriate review group or panel if ethical questions arise, for example, the Data Ethics Advisory Group¹⁸
- raise with the agency's executive management team any risks or uncertainties about the proposed purpose(s) of collection and the information to be collected
- seek input from other agencies, including, where relevant, service delivery organisations who have a relationship with service users
- consult relevant Māori groups if the collection or use could have a distinct impact on Māori, or raise concerns for Māori.
- seek information from service users or service user representatives
- consider whether to establish or seek advice from a review board, external reference group, ethics committee or client reference group
- consult the OPC.

¹⁷ msd.govt.nz/documents/about-msd-and-our-work/work-programmes/initiatives/phrae/phrae-on-a-page.pdf

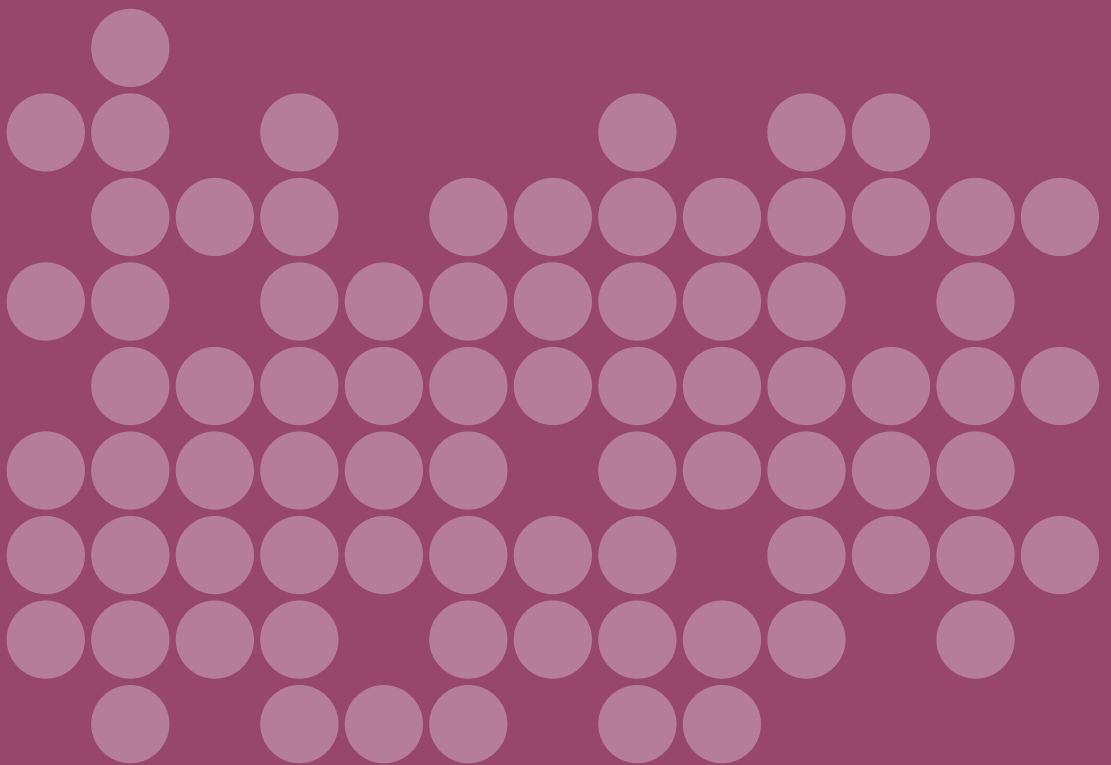
¹⁸ data.govt.nz/about/government-chief-data-steward-gcgs/data-ethics-advisory-group

Guideline

Transparency and Choice

Enable people to understand what's happening with their information and what choices they have

When collecting information from people, help them understand why it's being collected, how that might help them or people in similar circumstances, and what rights they have to access and request changes. Provide them with choices whenever possible.



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About this Guideline

Why a Guideline on Transparency and Choice?

People who use social services want a good understanding of why their information is needed. When they're unclear about it, this can cause anxiety, especially if their current situation is already a difficult one.

This Guideline recognises a range of factors.

- Service users who are in crisis may not, when seeking support, have a clear wish or be able to fully understand what is happening with their information, but will often express an interest at a later date.
- Service providers and service users emphasise the importance of people knowing what information is held about them, having a say about how it's used and who gets to see it, and having confidence that information held about them is accurate.
- Frontline professionals emphasise that how you explain your uses of people's information or gain their consent to using it, directly influences building relationships of trust.
- Service users sometimes express concern that their information will be used against them or their whānau without their knowledge, for example by being disclosed to other agencies who may judge them or make a decision that negatively impacts them.
- Service users are aware of the potential value of their information to enable better outcomes for people in similar circumstances and want to be confident their information will be valued, protected, respected, and used in accordance with that potential.
- The context of the individual is important in ensuring understanding and choice. For example, age, cultural, language and literacy must be considered, and any other circumstance of the individual that is relevant to respecting mana and enabling understanding of their choices.
- Māori providers and other Māori/iwi groups want te ao Māori considered when Māori communities are a key focus.
- Pacific peoples are looking for clear and simple explanations for people about why their personal information is being collected and how it will be used, and greater accountability to families and communities on how their data is used.
- Disabled people also highlight the need for clear information about what information is being collected, for what purpose and a greater understanding of people's situations when asking for identification information (for example, some disabled people do not have a driver's licence).

The language of choice

This Guideline uses the language of 'choice' rather than 'consent'. 'Consent' is given when a person voluntarily agrees to something based on a good understanding of the consequences. The language of 'consent' is often used in the sector, but without common agreement about what it means (it can have specific definitions in fields such as medicine, research and law) and often in circumstances where people who want to access a social service won't receive the help they need if they don't provide the information requested. For this reason, this Policy uses a plainer word – 'choice' – and focuses (in part) on the processes that help give people choices and enable them to act on those choices. This language also reflects the fact that, for the most part, the Privacy Act is not consent-based privacy legislation.

Intent of this Guideline

This Guideline helps agencies¹⁹ facilitate service users' understanding of and, where feasible, having choices about, when and how their information is collected and used. Having this understanding and choice improves people's trust in agencies collecting and using their information. The steps described in this Guideline also help to ensure that information is accurate and relevant for its intended purpose.

Service delivery organisations collecting personal information, and service users themselves, stress that the approach must be one of openness and honesty. Clear guidance in this area helps service delivery organisations that collect and use people's information to:

- find ways, where feasible, to identify and give people choices as to what information is collected and how it's used, while still enabling the purpose of collection to be achieved
- avoid using the language of consent that may suggest that people have choices in situations where, for all practical purposes, sometimes they don't, or their only real choice is to not use a service that they need
- be transparent and ensure understanding about what information is collected, why, and how it may be used
- explain what happens to information if and when it is used beyond frontline assessment or service delivery.

The key concept in this Guideline

This Guideline describes an approach that focuses on transparency and openness as the foundation of improved trust. It describes collaborative responsibilities for agencies to ensure that service users are able to understand in a way that makes sense to them and their context, including opportunities to further develop that understanding over time. The Guideline also outlines how this might be done in a manner that respects people's mana.

¹⁹ This Policy uses the term 'agency' to refer to government agencies, non-government organisations (NGOs), and other providers of services.

When to use this Guideline

When deciding how to inform people about the collection and use of their information and giving them choice

Use this Guideline when deciding how to help service users understand why their information is needed, how it will be used, and what rights and choices they have.

This Guideline applies to agencies (including NGOs and other service delivery organisations) collecting information directly from service users, as well as to agencies collecting through other agencies and organisations.

This Guideline is mostly about people's understanding and rights in relation to their **personal information**. However, people often think of information they have supplied, or that is *about* them, as personal, even when it has been de-identified or anonymised and is being used in a **non-personal** form. For this reason, this Guideline recommends actions relating to the use of this type of information as well. The relevant sections of the Guideline make it clear when those additional recommended actions are not required by the Privacy Act.

Relationship with the other Guidelines

Elements of this Guideline inform the three other Guidelines as follows:

Purpose Matters

Explains how the concept of 'purpose' is fundamental to making good and lawful decisions that underpin understanding and trust. It describes considerations that help agencies to formulate purposes of collection and check them against potential adverse consequences that might suggest a given collection, while lawful, is not desirable. It also identifies circumstances where a purpose of collection may be able to be approached in a way that gives service users a choice as to whether to provide personal information and, if so, how much.

Access to Information

Describes ways to enable people to understand and exercise their rights to access and request correction of their personal information.

Sharing Value

Sets an expectation that when information is collected to improve outcomes, service users can be given examples of where and how this will occur or has occurred.

Glossary

A full set of definitions used in this Policy can be found in the [Glossary](#).

Using the Policy Principles

Because this Guideline flows directly from the Policy Principles, it's useful to read it with those **Principles** in mind. They can help to identify considerations relevant to providing people with choices where possible and helping them to understand what happens with their information.

Initial considerations include:

He tāngata

Will service users understand that providing their information is either useful or necessary to help them, or may help people in similar circumstances?

Manaakitanga

What actions can be taken to uphold people's mana by involving them in defining useful steps to take to improve understanding of their choices?

Mana whakahaere

How can people be empowered to make decisions by knowing what their choices are and the value of those choices?

Kaitiakitanga

As kaitiaki or stewards of people's personal information, how can you keep track of, and communicate, the range of uses of the information in your care, and the improved outcomes enabled by it?

Mahitahitanga

How can agencies work together, for example funders and service providers, to improve transparency and provide clear information about, and support for, choices for all those involved?

Applying this Guideline

Help people to understand what information they're being asked to provide, and why

What service users need to be made aware of

Under the Privacy Act's information privacy principle 2 (IPP2) (*Source of personal information*), agencies that collect personal information need to collect it directly from the individuals concerned, unless an IPP2 exception applies. Collecting information directly from people is a primary means by which agencies can ensure that they are being transparent with people about their collection of information, given the immediacy of the relationship with them and agencies' obligations in information privacy principle 3 (IPP3) (*Collection of information from subject*).

IPP3 sets out what an agency needs to make people aware of when collecting personal information from them.



This Guideline proposes that 'ensuring service users are aware' should mean helping them to reach a reasonable understanding in a way that makes sense to them, at the time(s) that work for them.

The focus of IPP3's transparency requirements is on ensuring people are aware of what information will be collected from them, why it's needed (the 'purpose' of collection), and what choice they have over its collection. Ideally, this level of understanding should be achieved before the information is collected, but this may not always be possible (or 'practicable', as IPP3 puts it). Where it's not, the agency needs to make people aware 'as soon as practicable' after collecting

their information. What is practicable will depend on the situation, including the circumstances of the service user and the nature of the service that person needs.

The specific matters that people need to be made aware of are these:

- the fact that information is being collected, what information is being collected, and why (the purpose for which their information is needed);
- who will receive (or be able to see) their information (this important topic is discussed on the following page);
- where the collection is authorised or required by law, what that law is, and if people can choose whether or not to provide the information;
- what the consequences might be if someone doesn't provide the information requested; and
- people's rights of access to, and to request correction of, their information (see the [Access to Information Guideline](#) for more information on these rights).

There are some limited circumstances in which an agency that's collecting personal information from people doesn't need to make them aware of these matters. An agency doesn't need to do so if it has already done so in relation to the same kind of personal information in the recent past. The agency also doesn't need to do so if it believes on reasonable grounds that:

- a person consents to not receiving the information referred to in IPP3 (what is being collected, why, who will receive it, et cetera);²⁰
- not providing that information would not prejudice the interests of the individual concerned;
- not providing that information is necessary (in the case of a public sector agency) to uphold or enforce the law, protect the tax base, or assist court or tribunal proceedings;
- providing that information would prejudice the purposes of collection;

20 This exception is an oddity and does not appear in IPP3 in the Privacy Bill that will replace the current Privacy Act.

- providing that information would not be reasonably practical in the particular case; or
- the personal information collected from the individual concerned will not be used in a form in which the individual is identified or will be used for statistical or research purposes and will not be published in a form that could reasonably be expected to identify the individual.

Reliance on these grounds is the exception rather than the norm. The default is to provide people with the information required by IPP3. It's also important to note that many of these exceptions must be considered on a case-by-case basis and do not justify non-compliance with IPP3 for a broad group of service users.

Additional matters people should be made aware of

Whilst the Privacy Act doesn't require this, it is also good practice to explain:

- how people's privacy will be protected, in terms of safe storage and security of their information and the access controls that will be placed on it in a manner that is consistent with the agency's obligations under IPP5 (*Storage and security of personal information*)
- how the information will be used to help them or people in similar situations to them (if this is not already part of the communicated purposes of collection) and, where possible, examples of this happening
- if the collected personal information will be matched or linked with other data relating to the same individuals, particularly data sourced from other agencies, the fact that matching or linking will occur, why it is being done and what it could mean for those individuals

- if relevant, how particular information may be used in a form that doesn't identify them. People often think of their information as being *about them* even if it doesn't identify them and like to know how the information they provide will be used even when identifiers are removed or masked.²¹

The importance of clarity as to who will see service users' personal information

In the social sector, the question of who will be able to see the often sensitive personal information collected from service users is an important one, particularly where a collecting agency is large and has multiple different functions, and where personal information may be shared with other agencies.

The Privacy Act's IPP3 refers only to making people aware of the "intended recipients of the information". This phrase does not distinguish between recipients within the agency collecting the information and recipients in the form of, for example, other agencies. In addition, and as the website of the Office of the Privacy Commissioner (OPC) puts it, it doesn't require the collecting agency "to list every possible person it might pass personal information to - it will be enough to give a general idea of who is likely to see the information and why they might see it."²²

At the same time, it is also clear from that material that the OPC considers it can be appropriate not only to inform people of any other agencies with whom the information may be shared, but also the kinds of people within the collecting agency who will see their personal information. This Guideline takes the same approach. It's an important point because this part of IPP3 is often read as relating only to sharing personal information with other agencies. This can result in little or nothing being said, in privacy statements for example, about the limited audiences within the collecting agency who will be able to see people's personal information and that, in turn, can generate worry and concern on the part of service users.

21 Under the Privacy Act's IPP3(4)(f)(i), an agency doesn't need to tell people about a collection of personal information, its purpose and the other matters listed in IPP3 if the agency believes on reasonable grounds that the information will not be used in a form in which the individual concerned is identified. It may still, however, be good practice for the agency to tell them.

22 See privacy.org.nz/the-privacy-act-and-codes/privacy-principles/collection-of-information-from-subject-principle-3



In general, the larger and more multi-faceted a collecting agency is, the more important it becomes to give service users comfort by explaining who within the agency will and won't have access to their personal information. What can be said in any given situation will depend on the context and who within the agency may need to see the information. What's important is not leaving people with the impression that anyone inside the agency's four walls will be able to see it, especially when they don't have a genuine need to see it.

Help frontline staff to understand so they can fulfil their responsibilities and help service users to understand

For a range of reasons, sometimes those collecting personal information directly from people do not know all the reasons why it's being collected, as the decisions as to what to collect may have been made by others in their agency or in parallel with another agency or by another agency. In other words, there can be a knowledge gap between those deciding to collect, and those who actually do the collecting.

Anyone involved in designing information collections or communicating them to others, for example in contracting documents, needs to help ensure that people all the way along the chain, including those dealing directly with service users, have a good understanding of the 'what and why' as outlined in this Guideline. Failure to do so may undermine people's responsibilities, which often flow from legal duties that agencies have to service users. If those dealing directly with service users don't have a good understanding of why information is being collected, they may not be able to prepare their privacy statements, explain matters proactively or answer questions that service users put to them.²³

At the same time, those involved with collecting personal information from service users and, where relevant, those being asked to share it with other agencies, need to feel able to ask 'why', safely and confidently, and without fear of negative consequences. People involved in the 'chain' of collecting, using and sharing information have a right to be given a good answer, and it should be assumed that at some point a service user will ask the same question.

Remember that ensuring that service users are aware can help an agency meet its accuracy obligation

Agencies have a responsibility under the Privacy Act's IPP8 (*Accuracy, etc, of personal information to be checked before use*) to take reasonable steps, before using personal information, to ensure in relation to the purpose of use that the information is accurate, up to date, complete, relevant, and not misleading.

Helping service users to have a good understanding of what's being collected and the purpose(s) of collection, while providing them proactively with means to access and request correction of their information (or to correct it themselves), can help agencies meet their own obligations under IPP8, in that service users may be more likely to request corrections of their personal information (or, if possible, update it themselves) if they think it's inaccurate or incomplete.

²³ This topic is discussed further in the Purpose Matters Guideline (under the heading 'If you're collecting personal information from other agencies, they need to understand your purpose of collection').

Match the approach to the context

Approaches to transparency and choice can take many forms. Keep the outcome in mind (providing good and safe opportunities for service users to understand and to ask questions) but think broadly about the approach.

Consider a range of methods that might work for the service users you work with

It can be helpful to consider a range of methods for explaining matters to your service users. These might include:

- one to one conversations
- brochures, fact sheets or FAQs to take home
- posters in offices
- website information at different levels of detail
- information on forms they are asked to sign, and copies they can take away
- presentations to groups of people.

The most effective approach will often be to talk people through these topics in person so that they can ask questions. Whilst a range of different approaches can work it's important to ensure that the outcome of ensuring understanding is achieved, by checking with people from time to time, and by respecting cultural and language considerations.

Provide multiple opportunities if that's what people need

Service users will sometimes be stressed or in crisis when they initially look for support. They may not yet be interested, willing, or ready to think about what may happen with their personal information. For that reason, it may be necessary to offer a number of opportunities to re-visit the topic, and to respond appropriately to their level of interest in understanding. Service users in this kind of situation could include victims of crime, or children or young people whose authority over or willingness to make decisions about themselves changes as they become older.

Example

In some situations, service users might be informed face-to-face of key matters relating to the collection and use of their personal information, but also be given a one-page information sheet to take away and/or be told that they can always check the agency's privacy statement on its website for further information about the handling of their information and who to contact if they have any questions.

Be as specific as you can

Be as specific and clear as possible with explanations so people have the best chance of understanding what information is being collected from them, how their information will be used and who will be able to see it.

Here are some example comparisons of good versus not-so-good practice:

Better explanation	Insufficient explanation
"We will share your information with agencies X, Y and Z for these reasons..."	"We will share information with relevant agencies".
"Your information might be used without your name, address or anything else that identifies you to help us apply for more funding".	"Information is used for service improvement".
"This information about you will be linked with other information about you that we hold, to help us research [XYZ], but anything that identifies you will be removed before anyone uses it for research".	"Information will be used for research purposes".
"People directly involved in providing services to you and our internal researchers will be able to use your information, but other people, for example contract managers, will not be able to see it".	"We will share your information with people who need to see it".

... Examples of things to think about

- Will service users be surprised by anything if they come to understand or hear about it later?
- What are the communication needs of your particular service users? What timing, language, format, visuals, flowcharts, pictures or other things could be helpful?
- Is this a one-off encounter or a long-term engagement when there may be further opportunities to discuss the information being collected and what may happen with it?
- What kind of information is being collected, what will it be used for and how might that impact what service users need to understand, either now or over time?
- Who should people contact if they have questions? Do they know how to do that?
- Does it make sense to provide detailed information, or can more general explanations be used, given the variety of purposes and information collected? Think carefully about the balance, as generalisations can raise further questions and risk being inappropriate, and assumptions about how service users perceive the sensitivity of their information may not be accurate. Note also that, through the likes of layered privacy statements, both general and detailed information can be given.
- If another agency is collecting information on your behalf, what support does it need? The collecting agency should be given the information it needs and feel able to freely ask all the questions that service users may ask it.
- Who can help to develop or test forms, explanations and other communication material?
- If service users are concerned about something, or would like to complain, how can they do that, and are they aware of their ability to do so? For example, will you provide details of who they can contact, by email or phone? Will you provide an online contact form? Will you invite them to come and talk with you if they wish?

Make sure there is a safe and responsive environment

It's particularly important in the social sector for people to be able to obtain a good understanding of what's being done with their personal information in a safe and responsive environment. To enable people to reach a good understanding it's helpful to consider how to ensure people feel safe to list and ask questions, and what kind of information will work best for them.

... Examples of things to think about

- How will you ensure that people feel safe and confident to ask questions, either when information is first collected, or at regular intervals?
- Appreciate that people read, hear, learn and understand in different ways. Be prepared to offer choices about how they want to understand things. Information, processes and communication material should be adapted to meet the needs of different service users, given for example their kaupapa Māori contexts, age, spoken languages, and other factors that might suggest necessary alternatives.
- How can you check people's level of understanding and interest? Thinking about their personal information won't always be their first priority, but it will matter at some stage. Find ways to check that the required level of understanding is being achieved. For some groups of service users, this might be achieved through ad hoc sampling.
- Consider if timing matters. As noted earlier in this Guideline, the Privacy Act requires that service users are told of the matters listed in IPP3 (*about the collection and use of their personal information*) at the time of collection, or if that's not practical (for example they are in crisis or there is an emergency) as soon as possible after that. In some situations, it may be appropriate to explain a minimum amount straight away and then follow up with the person, with more detailed information, later.


Offer choices when you can

Whether people have real choices as to whether or not to provide personal information depends on the context. People may have:

- **no choice:** such as being required by a specific statutory provision to provide personal information when requested by an agency from which you've already applied for a particular benefit or service;
- **limited choice:** accepting that providing some level of personal information is an essential part of using the service in question, such as using a mental health counselling service (so the only choice is whether to accept the service or not); or
- **some choices:** such as choosing to enrol in a drug and alcohol support programme where a person will have choices about what experiences they do or don't share, and with whom.

Even when it's not feasible for an agency to offer a person a choice as to whether to provide their information (for example, because the information is required to provide a requested service), it may still be possible to offer choices about:

- **how** the information is captured (for example, by a member of the agency's staff writing down what a person says versus giving someone a paper or online form to fill out); or
- **who** is able see or use the information (for example, by enabling people to record their wishes about limiting access and respecting those wishes).

 It is important that people who need to access a social service to improve their wellbeing or that of their whānau, understand how their information will be collected and managed and the benefits of providing it. When their only practical choice is to provide their information or refuse a service, having this understanding may help them to provide their information with confidence, rather than refuse a service that could help them.

People within agencies who are involved in deciding what personal information may need to be collected for specific purposes should endeavour to identify any choices that are consistent with and won't defeat those purposes (see [Purpose Matters Guideline](#)). This may include:

- identifying and putting processes in place for situations where it is acceptable to provide no, or limited, personal information, for example, cultural considerations or people with disabilities or people experiencing high levels of stress may warrant such an approach, including practical considerations such as alternatives to confirming identity when individuals don't have a driving licence
- enabling people to agree to some purposes for which their personal information can be used, but not others
- enabling people to provide summary information if detailed information is particularly sensitive
- enabling people to provide information anonymously if, for example, the purposes of collection can accommodate this.

For further discussion of the question of offering choices to certain groups of service users, see the section of the [Purpose Matters Guideline](#) headed '*Ask whether, to achieve the outcome, it is reasonably necessary to collect personal information from every service user all of the time or whether allowing people to opt out is feasible*'.

Examples of things to think about

- Is it possible to offer people choices for certain kinds of collection without defeating the purposes of collection?
- If you were asked, could you provide a clear explanation as to why offering people a choice as to the collection of their personal information is not feasible?
- Do you need any help to make decisions on these issues and, if so, who can help? Can subject matter experts or service provider or client representatives help?

Collect in a lawful and fair manner

This Guideline's focus is on transparency and choice. It may be helpful to note, though, that when it comes to the actual collection of personal information, the Privacy Act's information privacy principle 4 (IPP4) requires agencies to collect the information by means that are lawful, fair and that do not intrude to an unreasonable extent upon the personal affairs of the individuals concerned.

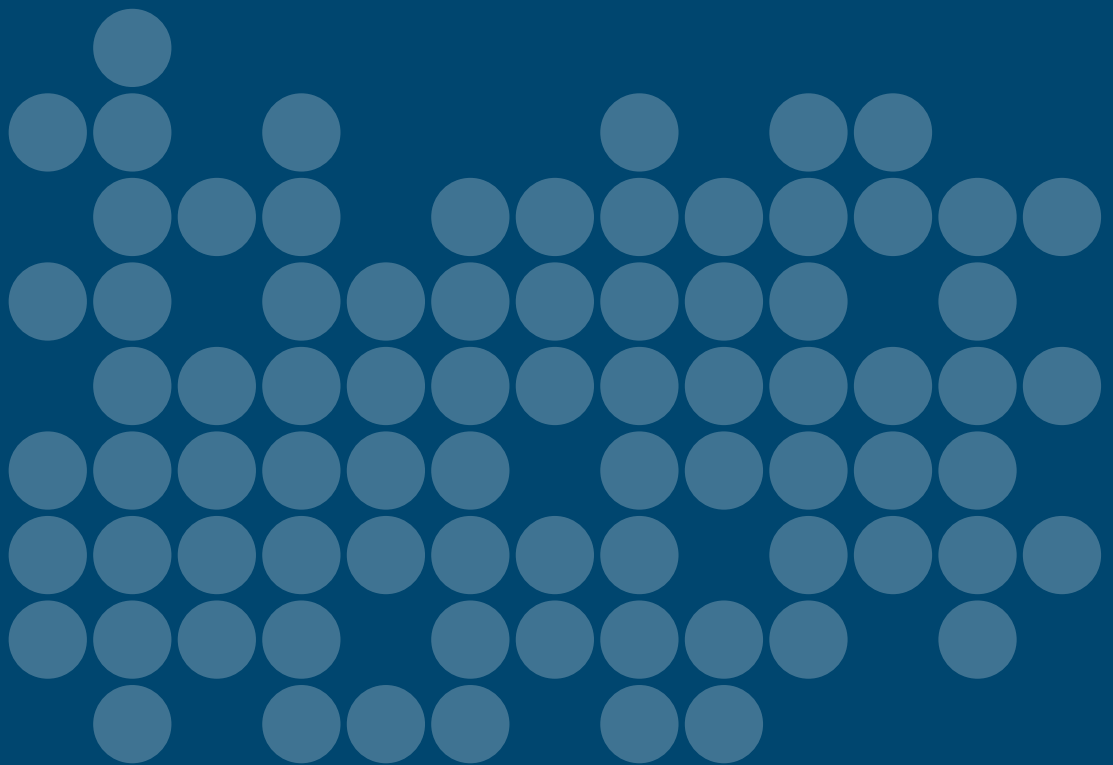
If the Privacy Bill is enacted in the form reported back to Parliament by the Justice Committee in March 2019, IPP4 will also state: "When collecting personal information from children and young persons, an agency must take into account their vulnerability".

Guideline

Access to Information

Make it easy for people to see and request correction of their information

Help people to understand what personal information is held about them, to access it, to request correction of it and, where possible, to correct it themselves.



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About this Guideline

Why a Guideline on Access to Information?

People who use social services may not understand what rights they have to see the personal information that has been collected about them or is about them, to ask for that information to be corrected, or to express a preference as to how they'd like to access their information. Understanding these rights is important. If people are unsure about what is recorded about them, or whether it is accurate or up-to-date, that can affect their trust or confidence in how it's used. That uncertainty may deter them from providing the information in the first place, or from opting to receive a service they need. Conversely, the more proactive an agency²⁴ is and the easier it makes the process, the more empowered service users will be. Their confidence that correct information will be used for the purpose for which it was collected will also be greater.

This Guideline recognises a range of factors.

- For many people, their information is an important part of their story and who they are. Because of this, they want to feel confident that their information is respected and treated with care. This includes enabling them to understand what information is held about them and why, and that such information is relevant and appropriate for the purpose for which it was collected.
- Even where people broadly understand their rights, they may not understand how to exercise them or there may be a lack of practical opportunity to exercise them.
- When people are in a crisis or vulnerable situation, they may not initially be concerned about how they can access and request correction of their information. However, it is usually still important at the appropriate time to proactively ensure that they understand and are able to exercise their rights to access and request corrections to their personal information.

- The difficulty individuals face in accessing their information can result in their having to repeatedly re-live experiences they would rather not. Sometimes re-telling their story can be harmful for them. If they can obtain a copy of their story as already relayed to one agency, and provide that to another, it can save them from having to re-live aspects of a traumatic experience.
- People sometimes assume that government agencies can share, access and exchange information about them without constraint. Enabling people to more readily understand what is actually known about them, and by which agencies, can reduce the sense of disempowerment that this assumption causes.

Intent of this Guideline

This Guideline recommends a proactive and pragmatic approach to ensuring that people understand and can exercise the options they have to access their information, request corrections to it, or in some cases change it themselves. This helps to address trust and confidence problems that can arise when people feel that they have no practical or easy way to understand or control what's happening with their information.

It is recommended that agencies implement the practices described in this Guideline proactively and regularly, with a view to promoting the rights people have and enabling people to understand and exercise those rights at a time that works for them.

The key concepts in this Guideline

Taking regular, proactive and practical steps to engage with people about what information is held about them, and to enable them to access it and ensure its accuracy, helps to build trust and confidence by:

- reducing people's concerns and frustrations; and
- supporting them with a sense of empowerment.

It can also help to ensure that agencies act on accurate information and that the services people receive are the most appropriate ones for their situation.

²⁴ This Policy uses the term 'agency' to refer to government agencies, non-government organisations (NGOs), and other providers of services.

When to use this Guideline

When defining processes that ensure people's information can be easily accessed

This Guideline is for people involved in:

- collecting, storing or recording **personal information** collected from or about service users
- identifying or designing methods and practices to ensure that information is readily available if and when service users ask about it
- managing or designing services that service users regularly use, including a range of channels such as digital and face-to-face channels, during which they may voice an interest in their information.

The practices described in this Guideline may sometimes be carried out by people outside of the areas of responsibility identified above. In these situations, the responsibility to enable and apply those practices may sit with people in a range of different roles, who will need to know about and understand this Guideline.

Relationship with the other Guidelines

Elements of this Guideline inform the three other Guidelines, as follows:

Purpose Matters

Explains why it's important to be clear about the purpose for which information is collected, and how to do that. Understanding this Guideline is relevant because service users can only ensure that information is accurate and relevant to the purpose of collection, if they are given a reasonable understanding of what information is held about them, and why it is held.

Transparency and Choice

Describes what a service user should be enabled to understand, and what rights and choices they should be informed about at the point that information is collected from them, including the rights discussed here in this Guideline.

Sharing Value

Describes the importance of collaborating with people who have a rich knowledge of the information and the people it represents, so the best outcomes can be achieved. Understanding this Guideline is relevant because it sets an expectation that when information is collected to improve outcomes for service users, they can be given examples of where and how this has occurred, when they express any interest in what is happening with their information.

Glossary

A full set of definitions used in this Policy can be found in the **Glossary**.

Using the Policy Principles

Because this Guideline flows directly from the Policy Principles, it's useful to read it with those **Principles** in mind. These can help to identify natural considerations for enabling people to access their information.

Initial considerations include:

He tāngata

How can service users understand the link between the information stored about them, and the ways in which it is intended to be used?

Manaakitanga

How can people's mana be acknowledged and upheld by how they are engaged in relation to what information is recorded about them, how it is recorded, and how they can access it?

Mana whakahaere

How can people be empowered by ensuring that their needs and wishes about accessing their information are understood, captured and addressed?

Kaitiakitanga

How can kaitiaki or stewards of the information contribute to service users' understanding of how information about them is held, and enable easy access to their information?

Mahitahitanga

How can agencies work together to practically enable service users' rights of access and be responsive to their requests for access and correction?

Applying this Guideline

Help people to understand their rights

Why it's important to remind people about their rights

The Transparency and Choice Guideline

describes what service users should be told when their information is collected, including their rights in relation to information held about them.

These rights can be summarised as:

- the right to understand what personal information is collected and stored
- the right to access that information
- the right to request correction of that information, bearing in mind the purposes for which it may be used.

However, in the social sector, there are a number of factors that can affect people's understanding of these rights, or their motivation to exercise them.

For example:

- people won't always be thinking about the information being collected or held about them when they initially seek help – they may be stressed in some manner, and more focused on getting the help they need
- over time, more information about them may be gathered or created without their knowledge, such as information lawfully obtained from other agencies or information that is recorded about them when they are not present (for example, case notes)
- service users often engage with several agencies on related topics. Over time they may become uncertain about which agencies hold what personal information, what the personal information covers, and what those agencies are doing with their information.

These factors can contribute to eventual concerns about where their often sensitive information is held, whether any of it is out of date or could be misunderstood and, therefore, whether it may not be helpful in terms of the services they need.

In addition, sometimes people become concerned about the way in which their sensitive information is recorded, as the act of recording a person's story can involve interpretation and sometimes adverse judgement, stigmatising, generalisation or stereotyping. Having such concerns while also not knowing how to access or request correction of one's personal information can impact negatively on a person's sense of wellbeing.

For these reasons it's important to proactively remind people of their rights from time to time. This gives people an opportunity to think about their information, and exercise their rights if and when they would like to. Ensuring that they know what they can do, and that they can readily take action whenever they wish, helps to alleviate a sense of disempowerment that they may have in relation to their information.

While there are grounds for saying no to an access request, the default is to say yes

There are situations where an agency can say no to a person requesting access to his or her personal information. The grounds for saying no are contained in Part 4 of the Privacy Act. They recognise that other interests may be harmed if a person's access to his or her personal information is allowed. The grounds most relevant in the social sector concern situations where disclosure would:

- be likely to endanger the safety of any individual
- interfere with the privacy of others
- breach confidentiality or legal or professional privilege²⁵

²⁵ Legal professional privilege is a term applied to the protection of confidential communications between a lawyer and a client. If legal advice is protected by legal professional privilege, it may be protected from disclosure under the Official Information Act 1982 and the Privacy Act 1993, and will not be required to be produced for inspection during discovery in legal proceedings. There are two categories of legal professional privilege: (1) "solicitor/client privilege" which applies to communications between a lawyer and a client, where the lawyer is acting in his or her professional capacity, the communication is intended to be confidential, and the communication is for the purpose of obtaining legal advice; (2) "litigation privilege" which applies to communications or information compiled for the dominant purpose of preparing for a proceeding or an apprehended proceeding.

- be likely to prejudice the physical or mental health of an individual (if the agency is satisfied of this after, where practicable, consulting the individual's medical practitioner)
- in the case of an individual under 16 years of age, be contrary to that individual's interests
- be likely to prejudice the safe custody or rehabilitation of people convicted of an offence or detained in custody
- be likely to prejudice the maintenance of the law, including the prevention, investigation, and detection of offences, and the right to a fair trial.

An agency may also refuse a person's request to access their information if the information can't be found or doesn't appear to exist, or if it is not readily retrievable.

While these grounds do exist, they need to be considered on a case-by-case basis and do not justify a general denial of the right to access one's personal information. To the contrary, the default approach is to grant access to one's personal information when requested unless one of the grounds applies. For this reason, the existence of these grounds does not affect the importance of reminding people about their rights.

! It is important when recording information about a person to ensure that it is accurate, clear and well written, both as a matter of respect and because the person is able to request access to and view what has been written about them. It is especially important that when subjective comments are included these are carefully weighed, respectful and professional. Agencies cannot say no to a person's request for personal information merely because the information was poorly written or expressed with insufficient care.

... Examples of things to think about when helping people to understand and exercise their rights

- Will service users be asked how they want to be involved in managing their information?
- What needs to happen to enable service users to ask about their information from time to time and to feel comfortable and safe in doing that?
- How much support might they need to understand or exercise their rights?
- What steps can be taken to confirm that a person is aware of their rights?
- Do you have a process in place to deal with requests from an individual's representative?²⁶
- How can operational practices emphasise telling service users upfront what is recorded and how they can access it? This may be in general terms, or specific to the person in question.
- What limits should there be on access in this particular context, and how can service users be told about them upfront?
- If there are limits, why do those limits exist, and are they lawful?
- Is there anything that can reasonably be done to reduce or remove such limits safely to enable access to the information?

26 Under the Privacy Act, people are only able to request access to personal information about themselves. There are two main exceptions to this: first, if an individual has authorised someone else to act as that person's agent or representative, that other person can make requests on behalf of the individual; second, if a child is too young to act on his or her own behalf or if a child has consented, a parent or guardian can request access to information for the child. As to the first situation, and as noted on the Office of the Privacy Commissioner's website, "[w]hen an access request is being made by a representative acting for an individual, the agency should ensure that the representative has the written authority of the individual to obtain the information. This can be done in a letter or email." See further section 45 of the Privacy Act, and "Can I request someone else's information?" at privacy.org.nz/further-resources/knowledge-base/view/83

Help people to ask for their information

Given the range of agencies that service users encounter or engage with who may hold various elements of their information, they may feel overwhelmed at the challenge of exercising their right to ask for their information or feel intimidated by the process. Sometimes people are simply too shy to ask. Language, culture, and disability (for example literacy) may also be barriers to individuals feeling comfortable about asking to see their information. These challenges can result in service users being left with general concerns about where their information is, and the range of agencies that have access to it.

It's important to note that the Privacy Act requires agencies to "provide reasonable assistance" to people who wish to request access to their personal information or request correction of their personal information.

Practical and proactive ways to help

- Offer the information about rights without being asked for it, in a safe and comfortable way that supports the ability of the service user to absorb and understand the information being provided.
- Check with service users on a regular basis to see whether they would like to update their information, or if anything in their circumstances has changed.
- Help people to use the *AboutMe*²⁷ tool offered on the Privacy Commissioner's website.
- Offer to act as the person's agent or representative (where the person wants to request their personal information from another agency), and making appropriate requests on their behalf.
- Offer pre-prepared general summaries of which agencies will hold what kinds of information. This can help by alleviating concerns about agencies knowing things that they are unlikely to know on any general basis, and/or focusing the conversation on the agency or agencies the person is most interested in. Offering these summaries may be done directly by your own agency, or through others that provide services to service users that you may hold information about.

²⁷ The *AboutMe* tool is an easy way to ask for personal information from any organisation, business or government agency in New Zealand [privacy.org.nz/aboutme](https://www.privacy.org.nz/aboutme)

Make it easy to access and request corrections to information

As service users become familiar with their rights and wish to exercise them, people working in a range of different contexts can contribute to making this easy for them to do.

When dealing directly with a service user in a face-to-face situation

There will be two situations to consider:

- situations where your agency holds information about service users for your agency's purposes, or as a consequence of another agency's purpose (for example, maybe you collected the information on their behalf); and
- situations where the information a service user wishes to see is held by another agency.

Examples of the kinds of actions that may help to make it easy include the following:

Information held by your agency	Information held by other agencies
Consider sharing your screen, show people what's recorded about them, ask them to identify any inaccuracies or voice any concerns they may have about that information.	If a person makes a request to your agency for his or her information but you believe the information is held by another agency, the Privacy Act requires your agency to transfer the request to the other agency, promptly and within 10 working days, and inform the person you've done so.
Provide screen prints, or other pre-prepared reports that your ICT system may offer, or alternatively allow them to take a photo if they have a phone camera. Ask them to highlight any areas they might wish to be changed.	Offer to help them fill out the Privacy Commissioner's <i>AboutMe</i> form or connect them to the other agency to help them ask directly.
Email a photo of the screen to them, taking care to double-check email addresses, and ensure that the service user wishes to have this information by email.	Fill out the <i>AboutMe</i> form on their behalf, and act as their representative, for example, if they share an email address with a spouse or partner and would rather the information be kept private.
Provide photocopies.	If you have established relationships at an operational level with the agencies in question, contact them by phone and ask on behalf of the service user, or with the service user present.
Supply the information in an accessible format, adapting this for the needs of differently abled people, for example, children, people with low literacy levels, sight-disabled people and those with English as a second language. What timing, language, format, visuals, flowcharts, pictures or other things could be helpful? Talk through the information, if that helps with a person's comprehension. Use a support person who can speak in the person's first language and translate if possible.	Consider establishing a protocol ahead of time with other agencies about access that will make it easier and more convenient for agencies and therefore for the user.

Enable NGOs (or other organisations) to act on behalf of service users to access their information

Your agency may hold information that is useful and relevant for an NGO (or other organisation) to be able to provide effective support for service users. Service users may not be able to recall, or may not wish to recount, relevant information when seeking a service. Instead they may wish for the NGO providing the service to act as their representative and request the relevant information from the appropriate agency or agencies. Examples might include: confirming details of benefits and entitlements; information about health or wellbeing; or information about a person's overall situation that they may prefer not to re-tell, given that doing so repeatedly can have negative impacts on a person's wellbeing.



Having an NGO acting as their representative can reduce stress for the person seeking support and can improve timeliness and the quality of the service delivered to them. It is also efficient for the agencies being asked by individuals for their information, as it provides clarity on the information needed and establishes channels and processes on how these requests can best be met.

To accommodate these situations, consider enabling direct channels between your own agency and the NGOs / service providers that people may wish to have act on their behalf.

Examples of how agencies could make it easier for people to exercise their rights to access their information via others include:

- identifying organisations and types of services for which such a provision might make sense and be practically workable – noting that expectations of volume and timeliness that are mutually agreeable will have to be worked through

- establishing local or regional relationships between staff in the agency providing the information and the organisation acting as the service user's representative, so that each party is well known to the other
- agreeing appropriate formalities (such as signed permission forms) to allow information to flow for lawful and agreed purposes when individuals wish to access and check their records, and are willing to have others act as their agent or representative
- agreeing appropriate contact/request channels and identifying who can do the work
- understanding what information is typically useful and how it can be readily retrieved
- determining response times that can be reasonably achieved for typical requests, and agreed criteria for when quicker response times are needed, for example if the request is urgent
- a telephone support arrangement for urgent cases
- privacy safeguards, for example, clarifying expectations about how people's information will be managed, who can/can't see it, et cetera, including alignment with advice within this Policy.

When dealing with a service user through digital or other channels

When considering or designing service delivery channels for service users other than face-to-face, a number of considerations and opportunities may be relevant.

Digital Access: service users in the social sector are not always practically able to access digital channels. This can be for a range of reasons (for example, language, technical confidence, meaningful access to technology that is fit for purpose, the time to do it, disability). Knowing that digital channels exist, but are not meaningfully accessible, can be a significant frustration. Consider making it easier for service providers or others to act on behalf of service users by using an agent or representative, or to complement digital channels with readily accessible alternatives.

Setting up access to digital channels: the most immediate hurdle for people may be understanding what digital channels exist, what they can do, and how to access them. Consider enabling providers to help service users establish access to these channels.

Where possible, provide access to a person's information in the form they prefer

The Privacy Act states that, where a person's requested personal information is contained in a document of any sort (which could be hard copy or electronic), the agency in question can make the information available by, for example:

- allowing the person to look at the document
- giving the person a copy of the document
- giving the person an excerpt or summary of the contents
- giving oral information about its contents.

At the same time, the Act requires the agency to "make the information available in the way preferred by the individual requesting it", unless doing that would be administratively burdensome, contrary to a legal duty over the document or prejudice a reason in the Act for denying a request.²⁸

Be careful to limit access to a person's own information

When helping people to access their information, it can be important to check that the information they're accessing is only their own information and does not contain or refer to other people's personal information. Allowing someone to view another person's information could breach that other person's privacy. Where information of the requesting person is combined with information relating to others, it may be necessary to separate or redact the other information before granting access.

Acting as an agent or representative

It may be appropriate in some circumstances for a service user to ask someone else to act as their agent or representative in relation to Privacy Act requests. Permission for a person to do so can take the form

of a letter, a signed form, or an email. Brief advice on this topic can be found on the Privacy Commissioner's website.²⁹

Reasons for establishing such an arrangement might include considerations of a person's English language ability, their culture, disabilities, whānau-based considerations, or a range of other practical issues.

Examples of things to think about – processes and systems

- How can service users be involved in creating records, for example, writing or reviewing case notes or filling out forms?
- For larger agencies, can technology plans include the provision of online portals such as *myMSD*³⁰ and *ManageMyHealth*³¹ to allow people to access and update some information?
- Can processes or practices help service users avoid needing to make formal requests for their personal information, for example, automatically providing copies of core information such as referrals, assessments, and forms?
- Does your agency have simple, well understood business practices to retrieve and provide information in response to Privacy Act requests?
- What are simple ways for service users to ask for changes or corrections, for example, in similar ways to the *AboutMe* tool?
- How can service users' ideas and suggestions be included in regular planning processes to inform how their rights can be readily exercised?
- Does your agency have simple and clear processes for service users to communicate concerns or make a complaint?

²⁸ See section 42 of the Privacy Act for the full details.

²⁹ [privacy.org.nz/further-resources/knowledge-base/view/83](https://www.privacy.org.nz/further-resources/knowledge-base/view/83)

³⁰ *ManagemyHealth* is an example of a digital portal for patients to access their health information and communicate with their general practice. It is one of a range of commercial services available for this purpose.

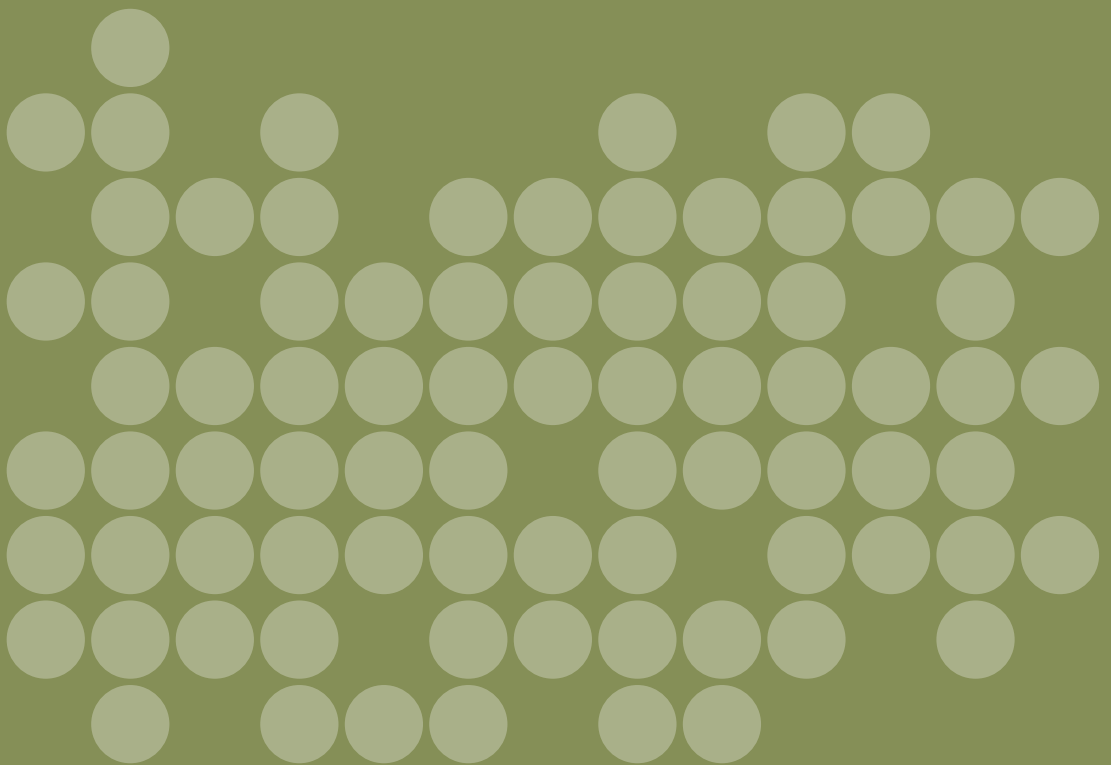
³¹ *ManagemyHealth* is a digital portal for service users to manage their health needs online managemyhealth.co.nz

Guideline

Sharing Value

Work together for better insights and outcomes

Work together and be inclusive to ensure that information used to create insights is relevant and usefully describes real experiences. Share insights that deliver value and improved wellbeing.



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About this Guideline

Why a Guideline on Sharing Value?

It is important to develop and share the value of information and insights among those involved in the delivery of services in an inclusive, useful, respectful and valuable way. A collaborative approach involves exploring the objectives of information collection and analysis (the desired insights) before information is collected or before analytical activities are carried out, and what insights will be most helpful to people and agencies working on related outcomes. It is an approach aimed at delivering value to all participants.

In this Guideline, the term **insights** means **non-personal information**, including data and data sets, analysis, qualitative or quantitative information, statistics, research³², reports or studies, that may support improved decision making. Non-personal information is information that does not identify individual people. The term **sensitive information** is used to describe information that could be misunderstood or misused, resulting in harm or embarrassment to a group or community.

This Guideline recognises a range of factors.

- Service providers are often required to share information they collect with other agencies for the purposes of accountability, research and analysis, and planning.
- Many people (decision-makers, government, NGOs, communities, and service users) are likely to benefit from the sharing of insights derived from information collected from or about people who use social services. Such insights are valuable for supporting robust decision-making and better delivery of services that support positive outcomes.
- Service providers and service users want to be involved at the beginning of the process of information collection and throughout the process of developing insights based on that information, so that they can contribute their perspectives, expertise and suggestions, and have opportunities to understand, access, and apply those insights.

³² Noting that the term 'research' should, in the context of this Guideline, be interpreted to have a broad meaning (studying a topic, analysing a topic, exploring, researching).

Intent of this Guideline

This Guideline recommends explicit collaborative actions to:

- **identify** what the most useful information will be to support the development of the desired insights, including qualitative and interpretative information to help give context to quantitative information
- **identify** people and agencies with relevant interests and experiences to contribute to the work as it is carried out and to use the relevant insights
- **share** the insights with those identified.

The recommended actions in this Guideline are not only about the development and sharing of insights from new data, but also apply to insights developed from existing collections of data. The actions recommended in this Guideline are not required by law but are common to many respected codes of practice³³.

The key concepts in this Guideline

Agencies in the social sector wish to benefit from greater sharing of non-identifying insights derived from information collected from and about people who use social services, so as to improve services to these people and help their own agencies. This is best achieved by taking a collaborative approach. Involving people who have rich knowledge of the circumstances of those from whom information is collected, even if that information will only be used in a non-personal form, helps to ensure a good understanding of:

- the value of the insights that may be derived from that information
- the purposes of collection or use (see [Purpose Matters Guideline](#))
- the specific type of information that would best suit those purposes
- how that type of information can most efficiently and respectfully be gathered
- how the purposes and value can be communicated to those the information is collected from
- any risks and downsides of collecting and using that information to develop insights that may outweigh the potential value of the intended insights.

³³ A sample of these codes of practice are included in References and Useful Links.

When to use this Guideline

When working together for better insights and outcomes

This Guideline is for people involved in collecting or using personal or non-personal information for the following purposes:

- managing funding and contracting processes between service providers and funders
- carrying out analytical or research activities to support policy or service development
- developing or enabling research or analytical capability through the development of data sets
- understanding the operational performance or effectiveness of services and programmes.

This Guideline generalises these sorts of purposes as being activities which focus on the production of 'insights' (as defined in the **About this Guideline** section).

Whilst this Guideline is only concerned with sharing insights in the form of **non-personal information** it includes considerations that relate to collection of **personal information** for the purpose of developing those insights.

Relationship with the other Guidelines

Elements of this Guideline inform the three other Guidelines as follows:

Purpose Matters

Explains why it's important to be clear about the purpose for which information is collected, and how to do that.

Transparency and Choice

Is about helping people understand why their information is needed, and what their rights are.

Access to Information

Describes ways to enable people to understand and exercise their rights to access and request correction of their personal information.

Glossary

A full set of definitions used in this Policy can be found in the [Glossary](#).

Using the Policy Principles

Because this Guideline flows directly from the Policy Principles, it's useful to read it with those **Principles** in mind. These help to identify considerations relevant to sharing insights with people working on related outcomes, including service users themselves. For example:

He tāngata

What insights will help to improve outcomes for people?

Manaakitanga

In doing this work, what actions can we undertake to enhance the mana of people involved in the delivery or use of relevant services?

Mana whakahaere

How can we recognise and respect people as the source of information, and ensure that they understand, and have input into, the value of insights derived from their information?

Kaitiakitanga

As kaitiaki of the data what might the people involved in delivering or using services want from the outputs of the work?

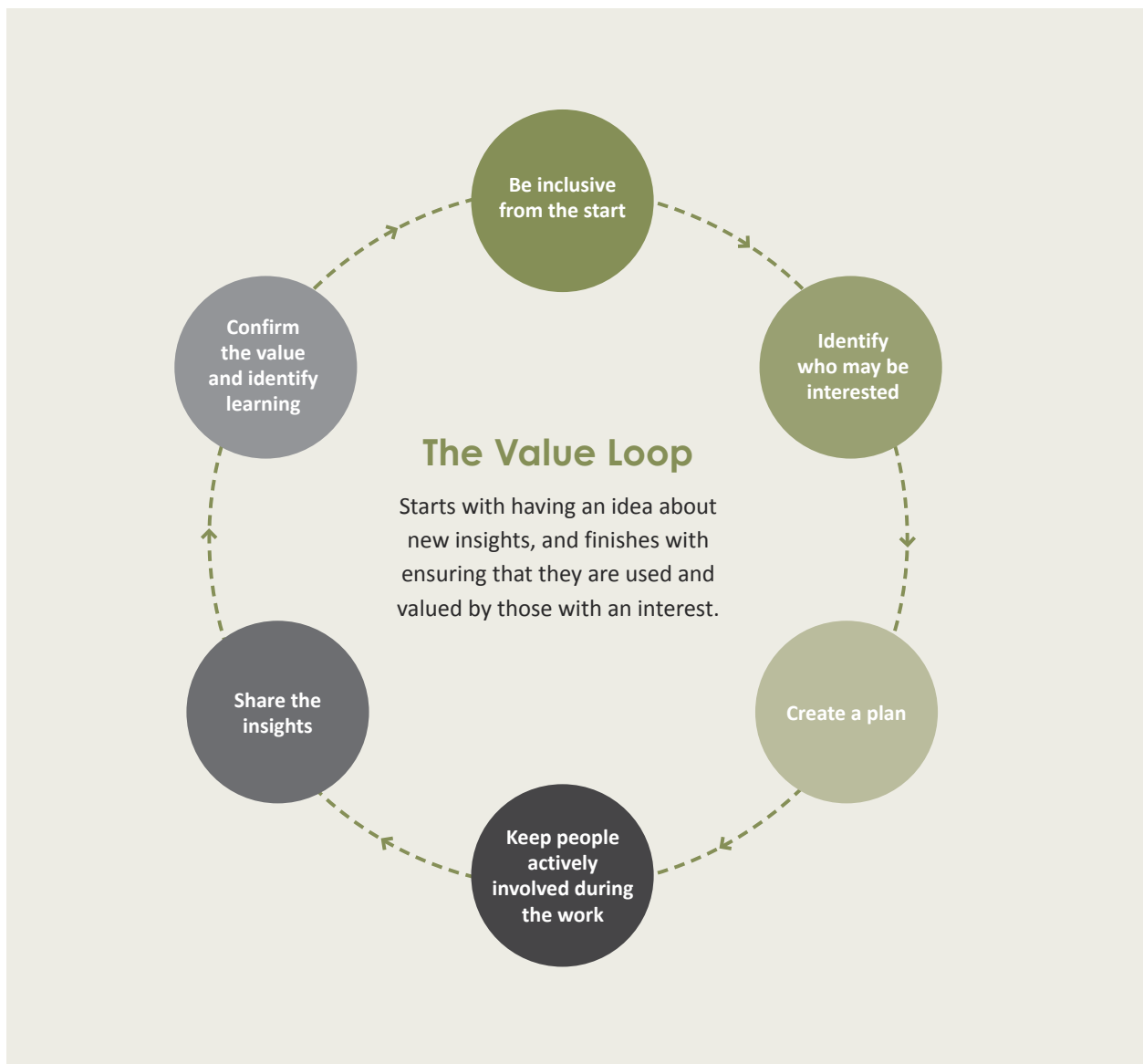
Mahitahitanga

By involving others who work on related outcomes what additional value could be created by working together?

Applying this Guideline

The Value Loop

The figure below describes the Value Loop to follow when working collaboratively to develop and share valuable insights. The following sections define each step of the Value Loop and the important things to consider at each step.



The overall objectives of the approach

Right Idea: ensure that the work is informed by a good understanding of the topic and that the work is respectful of the people whose information is involved.

Right People: ensure the people involved have interests aligned to the 📌 **He tāngata Principle**, that is, they wish to improve the wellbeing of people or communities. For example, people working in and serving their communities.

Right Information: ensure that the right data (data which is relevant to the idea, and which may include both qualitative and quantitative data: qualitative context can add significant understanding to the insights derived from quantitative data) is used or collected.

Right Use: ensure that the value of the work is maximised through not only how it is done but also who is able to apply it in their own work to achieve better outcomes for people.

... Examples of things to think about when getting started

- How will this work enhance the mana of the people the insights are about? For example, is there a development focus rather than a deficit focus in the insights being developed that considers the strengths and wellbeing of the people represented by the data, rather than disadvantages and disparity?
- Will the community support the use of the data in this way?
- How can the work ensure no one is harmed or exposed, especially vulnerable people? For example, could insights be used to target, profile or prejudice people?
- What professional codes of conduct and ethical considerations need to guide this work?
- What contextual and cultural understanding is needed to fully understand the real experiences of the people behind the data so that insights are relevant and accurate?
- Who will benefit from the insights?
- Who will contribute knowledge on the type of data that will be the most useful?
- Is there any risk that a person could be identified from the seemingly non-personal insights that might be shared? This can be particularly important when dealing with small population or sample sizes or where insights relate to something that affects only a small number of people, for example, a rare disease or disability.

Be inclusive from the start

The value of insights depends on having good information to work with, and the relevance of those insights to improve outcomes. Including people with relevant experience and involvement in the provision of services from the start of the work, and throughout it, is likely to make the greatest impact on the eventual quality and value of the insights.

There are a number of reasons to do this, in addition to improving the relevance, usefulness and value of the insights.

- It will help build capacity and capability in working with data within the social sector. This increases the sector's collective ability to apply insights for improved outcomes, and helps to build trust and confidence through an inclusive approach that recognises shared outcomes.
- It ensures that knowledge about the availability and quality of information, and what is involved in collecting the information, inform the approach.
- It can help reduce the effort that may be involved in collecting information, for example, if similar information is already collected for similar purposes and can be lawfully used or shared.

Identify who may be interested

When personal or non-personal information is collected or used for something other than directly working with a service user, consider who else should be involved. Having a range of views, experiences, and skills can help to improve the value and quality of the work.

At each stage of the work identify people/agencies with these areas of experience, so that:

Service users: those who provide the information, and are the intended beneficiaries of improved outcomes, can contribute to the thinking and provide their perspectives on the best ways of sharing insights from the information collected from them.

Frontline service delivery: those involved in the original collection of information, even when it is ultimately used in a non-personal form, can contribute to the thinking.

Community: other agencies involved in providing similar services or with similar service users can influence the work.

Contracting and funding, or partnering: those who manage, monitor or account for the performance of funded programmes can ensure their needs are met. These might include government agencies, philanthropic groups, or community trusts.

Policy / analysis / research: agencies working on related or similar insights can collaborate to reduce overall effort and increase overall value.

Cultural experts: individuals with expertise in using data in a culturally appropriate manner can assist with the development or review of insights, taking into consideration the cultural context.

Examples of things to think about

- Who should, could or must be involved given the nature of the work?
- If the potential insights may be useful to Māori or iwi groups, how might they be involved?
- If insights may be useful to other groups with specific interests, such as Pacific or disabled people, are they involved?
- What processes are in place to involve service users and communities' points of view as well as NGO and service provider input?

Create a plan

Create a plan for working together to proactively develop and share insights with people, communities and agencies with an identified and legitimate interest. This should be incorporated into standard planning processes. Doing this up-front will inform the approach and is critical to the success of the approach. Use this planning stage to evaluate the intention of the work with respect to each of the Policy **Principles**, consider any ethical concerns and relevant professional codes of practice, and identify and assess any risks or opportunities.

... Examples of things to think about

- Who could help with this planning step?
- When is the best time to discuss this? For example, when setting up a contract between funder and service provider, initiating a research activity, or during regular planning processes (yearly, quarterly) that can include a focus on existing collections of data and insights.
- Are there any legal requirements to share, or alternatively obligations to keep some information confidential? What impact will that have?
- What data is needed to derive or inform the insights?
- What understanding of the cultural context of the data is needed?
- How can outcomes of the work best be shared with service users, whānau, communities and service providers who have a legitimate interest?
- What kind of support might people need to understand or apply the outputs of the work? If there are different audiences with different needs, does the work address those?
- Does your agency³⁴ have existing collections (of data or insights) that other agencies involved in related outcomes may be able to apply in their work?
- Is it possible to use existing collections to reduce further collection or overlapping activity?

Keep people actively involved during the work

On-going involvement in the work could take a number of forms. These may include:

- seeking regular feedback from people identified at the outset
- seeking more formal review of insights in draft form, for example from an advisory group
- day-to-day involvement from other agencies to develop the insights
- periodic secondments or structured collaborative projects.

... Examples of things to think about

- How can the effort and cost of involving others be recognised or shared?
- As the work is carried out, what's the best way to monitor that the developing insights will be valuable to others, and usable by them?
- If people are interested, but only wish to be kept informed, how might that work?
- If others are working on related ideas, are there opportunities to collaborate and reduce overall effort, or enhance overall value?
- If there will be effort involved in collecting the information, are there ways to minimise this or to recognise the cost of doing so?

³⁴ This Policy uses the term 'agency' to refer to government agencies, non-government organisations (NGOs), and other providers of services.

Share the insights

Think about who might benefit, what they might need, and how they will have access.

Think about the nature of the work and talk to those identified who may be interested in it. Get their views about what approach makes sense to them as well as to your agency.

If the work is not sensitive and may have broad public interest, it may be simpler and more valuable to use an ‘open data’ approach. See data.govt.nz to find out how you can do that. In this context, to ensure that the insights can be fully used without copyright-related concerns, it may be desirable for government agencies to license copyright works containing the insights under a Creative Commons licence in accordance with the New Zealand Government Open Access and Licensing framework (NZGOAL).³⁵ NZGOAL is all-of-government guidance for agencies to follow when releasing copyright works and non-copyright material for reuse by others. If an agency takes this approach, it should follow the NZGOAL Review and Release Process to ensure that it has the legal rights required to license the copyright works and that it takes other legal considerations into account.

Even if insights are sensitive in nature, it may still be very useful to share them in an appropriate way with people who can apply them for better outcomes for service users. To ensure the value of the work is realised, the default starting point should be to plan to share the insights, with the onus on those who have the data/insights to justify why they should not be shared more broadly, whether for legal, safety, cultural sensitivity or other reasons.

Examples of things to think about

- If the information is non-personal, but still sensitive, how can access be controlled to limit misuse or misinterpretation? Alternatively, what additional support might interested agencies need to limit or reduce these risks?
- How is privacy being protected? When sharing insights with others, take all reasonable steps to ensure people can’t be identified from those insights, either from the insights alone, or in conjunction with other information. This can be particularly important when only a small number of people are affected by the subject matter of the information. For example, the small number of people affected by a particular form of disability or condition.
- If sensitive insights are being shared with specific audiences and/or there is a re-identification risk, consider whether contractual controls on use and/or re-identification would be desirable.
- Are there any limitations or bias in the data (for example, data gaps, quality issues) that need to be communicated with the insights?
- Can the methodology and the software code used to develop or yield the insights also be shared, for openness and transparency?
- Are the insights being shared in line with the original plan? If not, why not?

LESS ACCESS / LESS OPEN

MORE ACCESS / MORE OPEN

	LESS ACCESS / LESS OPEN		MORE ACCESS / MORE OPEN	
WHO will have access?	Just your team/agency	People directly involved	Interested stakeholders	All public
WHAT will they have access to?	Final results of findings (PDF or word version)	Data tables	Structured data	Unstructured raw data (qualitative or quantitative)
HOW will they have access?	In person with no ‘takeaways’ (eg: presentation)	Closed access (eg: password protected)		Open access (eg: public website)

35 New Zealand Government Open Access and Licensing framework: data.govt.nz/manage-data/policies/nzgoal

In particular, close the loop with those directly involved

This may be the service users themselves, agencies involved in the original collection or creation of data, and people directly involved in doing or reviewing the work.

Each should be given an opportunity to understand the insights created, and to use them. There may be other parties who have an interest, but it's particularly important for trust and confidence reasons to ensure that the loop is closed with those *directly* involved in the work. It recognises their contribution and increases value through broader application.

Confirm the value and identify learning

For most agencies, the work of developing and applying insights is ongoing. There are multiple 'loops', in which we explore, consider, and apply a growing understanding of how services can work better for people.

Regularly check-in with agencies and communities you've shared insights with, to understand what worked, and what didn't, and to use this learning to further inform the next cycle of thinking. This process will enable a greater understanding of the value of insights and how they are being used to improve the wellbeing of people. The value of these outcomes can then be communicated back to people who provide their information (see [🔗 Transparency and Choice Guideline](#)).

Glossary, References and Useful Links



Glossary

Agency

This Policy uses the term 'agency' to refer to government agencies, non-government organisations (NGOs), and other providers of services.

Aggregated Information

The term aggregated information can mean two different things, depending on how it's used. It can mean summarising information by adding it together into statistics, for example by counting the number of service users accessing a service over a period of time. Alternatively, it can mean larger collections of information produced by taking multiple sources of information and putting them all together (adding or 'aggregating' them together). Aggregated information can be personal (still contains people's identifiers in some form), or non-personal.

Consent vs. choice

'Consent' is given when a person voluntarily agrees to something based on a good understanding of the consequences. However, consent can have specific definitions in fields such as medicine, research and law. For this reason, this Policy uses a plainer word – 'choice' – and focuses (in part) on the processes that help give people choices and enable them to act on those choices.

De-identified

This means information that could identify an individual, like names, dates of birth, and addresses, has been removed. Numbers that can be used to identify people, like IRD and NHI numbers, are removed or encrypted (replaced with another number).

Design Group

A range of people who attended the original engagement hui were invited to contribute to the design phase of the work during October and November 2018. This included NGOs, government agencies, and other providers. Design workshops were held in Wellington, Auckland and Christchurch, to identify how best to honour the engagement feedback, and to define early content for the draft Policy.

Frontline

Refers to activities that take place in direct contact, often face-to-face, with service users.

Funding agency

Agencies that fund the delivery of social sector services by other organisations. The typical example in the context of this Policy is NGOs being funded by government agencies to deliver a range of services.

Information

A broad term that encompasses data (such as facts and statistics), the outputs of analytical work and research, reports and studies, case notes, and narrative information. Includes both quantitative information, as well as qualitative information, and may be either personal, or non-personal.

Insights

Non-personal information, including data and data sets, analysis, qualitative or quantitative information, statistics, research, reports or studies, that may support improved decision making.

IPP

Information Privacy Principle. Refers to one of the 12 key privacy principles in the Privacy Act 1993.

Layered privacy statement

A privacy statement that a person can choose to view at a number of different levels, starting with a summary, and offering greater detail for people who would like to see it.

NGO

Non-government organisation. In the context of this Policy, NGO refers to social sector organisations established to support people facing challenges across the core areas covered by this Policy, such as welfare, health, education, justice, child wellbeing, housing and disability support services. Examples include the Salvation Army, Barnardos, and Presbyterian Support. There are thousands of such organisations in New Zealand.

Non-personal information

Non-personal information is information that does not identify people and that can't be used, even if combined with other information, to identify individual people.


OPC

The Office of the Privacy Commissioner. See [privacy.org.nz](https://www.privacy.org.nz) to understand more about OPC in general, and many aspects of privacy.

Personal information

Personal information has the meaning in the Privacy Act, which is information about identifiable individuals. It includes information relating to a death that is maintained by the Registrar-General under the Births, Deaths, Marriages, and Relationships Registration Act 1995 or any former Act (as defined in section 2 of the Births, Deaths, Marriages, and Relationships Registration Act 1995).

Privacy statement

A privacy statement, or privacy notice, lets service users know, among other things, what information an agency is collecting from them and what it will be used for. Typically, a privacy statement will be on a website, and/or in printed form, and is one of a variety of tools to support the recommendations in the  **Transparency and Choice Guideline**.

Research

Research, in the context of this Policy, has a broad meaning – studying a topic, analysing a topic, exploring, or researching.

Service delivery organisation

An agency responsible for direct delivery of services to service users. This includes agencies like MSD and ACC, and organisations like the Salvation Army, but does not include agencies like the Social Investment Agency that don't deliver services directly to service users.

Service provider

Another term for 'Service delivery organisation'.

Service user

A member of the public who applies for, receives or otherwise uses services delivered by service providers.

Social sector

The social sector comprises government agencies, non-governmental organisations (NGOs) and other providers of services to support New Zealanders' wellbeing across a range of areas including welfare, education, health, justice, child wellbeing, housing and disability support services.

Working Group

The Data Protection and Use Policy working group is made up of representatives from NGOs and government agencies, and client advocates/representatives. They have provided guidance to the work from the start and continue to be actively involved.

References and Useful Links

The links included here contain further information that is likely to be useful, depending on the nature of your agency's work. In each case, the references include guidance and advice on how to think about, and adopt, relevant practices that relate to the respectful use of people's information.

Privacy resources

Privacy Act 1993 is available at legislation.govt.nz

The Office of the Privacy Commissioner (OPC) has a range of general advice that is particularly helpful in understanding the Privacy Act 1993 and a wide range of issues that arise under it privacy.org.nz/privacy-for-agencies/your-obligations

The Privacy Commissioner's Inquiry into the Ministry of Social Development's Collection of Individual Client-Level Data from NGOs (2017) is available at privacy.org.nz/assets/Files/Reports/2017-04-04-Inquiry-into-MSD-collection-of-individual-client-level-data-OPC-report.pdf

Health Information Privacy Code 1994 sets specific rules for agencies in the health sector that covers health information collected, used, held and disclosed by health agencies. This takes the place of the information privacy principles for the health sector privacy.org.nz/the-privacy-act-and-codes/codes-of-practice/health-information-privacy-code-1994

Guidance on Privacy Statements can be found on the OPC website, including how to go about developing a layered privacy notice. The OPC also provides a tool you can use to get started privacy.org.nz/privacy-for-agencies/privacy-resources-for-agencies/essential-resources-for-agencies

For website privacy statements, government agencies should also review the privacy section in the **Web Usability Standard 1.3** digital.govt.nz/standards-and-guidance/nz-government-web-standards/web-usability-standard-1-3.

Good examples of layered privacy statements include **MSD's layered privacy statement** workandincome.govt.nz/about-work-and-income/privacy-notice/index.html#null, and **ACC's layered privacy statement** acc.co.nz/privacy/privacy-notice-your-personal-and-health-information/?smooth-scroll=content-after-navs.

Māori data resources

Te Arawhiti, The Office of Māori-Crown Relations has described the responsibilities of public sector agencies to ensure that engagement with Māori is meaningful. They provide an **engagement framework** tearawhiti.govt.nz/assets/Maori-Crown-Relations-Roopu/451100e49c/Engagement-Framework-1-Oct-18.pdf and a **set of principles** static1.squarespace.com/static/58e9b10f9de4bb8d1fb5ebbc/t/5bda208b4ae237cd89ee16e9/1541021836126/MR+Ma%CC%84ori+Data+Sovereignty+Principles+Oct+2018.pdf that provide advice on the importance of early engagement, and how to go about it. These are specifically relevant when Māori interests are involved, and generally useful as a summary of good practice.

Te Mana Raraunga, the Māori Data Sovereignty Network, puts forward principles to consider for trusted use of Māori data, including a **Māori Data Audit Tool** temanararaunga.maori.nz/tutohinga

Te Ara Tika: Guidelines for Māori research ethics is a framework for addressing Māori ethical issues for researchers and ethics committees hrc.govt.nz/resources/te-ara-tika-guidelines-maori-research-ethics

The 5 Safes Framework & Tikanga aligns Māori tikanga against the 5 Safes Framework static1.squarespace.com/static/58e9b10f9de4bb8d1fb5ebbc/t/5b884980032be4a36066e8f0/1535658381150/Stats+NZ_IDI+5+Safes+%26+Tikanga_Final.pdf

Pacific peoples resources

The Ministry of Pacific Peoples publishes a range of advice to support effective engagement with Pacific Peoples, for example in **Kapasa** The Pacific Policy Analysis Tool mpp.govt.nz/assets/Uploads/2-Kapasa2017-A4-Pages-WEB4.pdf

Disabled people resources

The Office of Disability Issues publishes a range of advice on effective support for, and engagement with, disabled people, including information on the role of **Disabled People's Organisations** odi.govt.nz/guidance-and-resources/disabled-peoples-organisations and how to seek their involvement in the policy advice process. They provide guidance for policy makers seeking to understand the 'social model' of disability, and how to include a disability perspective odi.govt.nz/guidance-and-resources/guidance-for-policy-makers

Leading the way in accessible information gives guidance on providing accessible information for disabled people msd.govt.nz/about-msd-and-our-work/publications-resources/accessibility-guide/index.html

Child resources

The **Child Impact Assessment Tool** has been developed to help assess whether policy proposals will improve the wellbeing of children and young people msd.govt.nz/about-msd-and-our-work/publications-resources/resources/child-impact-assessment.html

Sharing personal information of families and vulnerable children provides guidance for inter-disciplinary groups on whether sharing information is appropriate and legal childmatters.org.nz/file/Resources-page/privacy-sharing-personal-information.pdf

Ethics resources

The Ministry of Social Development's **Privacy Human Rights and Ethics framework** is a set of capabilities and tools to ensure that issues of privacy, human rights and ethics are considered from the design stage of a new initiative. A summary of this work is available at msd.govt.nz/documents/about-msd-and-our-work/work-programmes/initiatives/phrae/phrae-on-a-page.pdf

The Data Ethics Advisory Group enables government agencies to test ideas, policy, and proposals related to new and emerging uses of data data.govt.nz/about/government-chief-data-steward-gcgs/data-ethics-advisory-group

Health and Disability Ethics Committees check that proposed health and disability studies meet established ethical standards in order to protect participants. Guidance can be found at ethics.health.govt.nz/guides-templates-forms-0

Codes of Practice

New Zealand Royal Society details the Code of Professional Standards & Ethics in Science, Technology, and the Humanities royalsociety.org.nz/assets/Uploads/Code-of-Prof-Stds-and-Ethics-1-Jan-2019-web.pdf

The Clearing House describes a Code of Practice for the community and voluntary sector communityresearch.org.nz/wp-content/uploads/2011/01/COP-v2.1.pdf

Aotearoa New Zealand's Association of Social Workers' Code of Ethics provides helpful guidance, for example, dealing with client confidentiality anzasw.nz/code-of-ethics-2019

Wider government guidance

Information sharing to support tamariki wellbeing and safety provides guidance for sharing information across the child welfare and protection sector in line with the Oranga Tamariki Act 1989 [orangatamariki.govt.nz/assets/Uploads/Information-sharing/information-sharing-Guidance-OT-Act-1989.pdf](https://www.govt.nz/assets/Uploads/Information-sharing/information-sharing-Guidance-OT-Act-1989.pdf)

Sharing information safely provides guidance on sharing personal information under the Family Violence Act 2018 [justice.govt.nz/assets/Documents/Publications/Family-Violence-Information-Sharing-Guidance.pdf](https://www.justice.govt.nz/assets/Documents/Publications/Family-Violence-Information-Sharing-Guidance.pdf)

The Data Futures Partnership published **A Pathway to Social Licence: Guidelines for Trusted Data Use** in 2017, based on broad engagement with New Zealanders static1.squarespace.com/static/58e9b10f9de4bb8d1fb5ebbc/t/598d014fdb29d6ff0d50c317/1502413147674/A-Path-to-Social-Licence-Guidelines-for-Trusted-Data-Use-August-2017.pdf

Stats NZ and OPC jointly published **Principles for the safe and effective use of data and analytics** in May 2018. These Principles note the criticality of ensuring that data is fit for purpose and that the right data is used in the right context, and the importance of transparency and inclusion through consultation with stakeholders stats.govt.nz/assets/Uploads/Data-leadership-fact-sheets/Principles-safe-and-effective-data-and-analytics-May-2018.pdf

The Human Rights Commission's 2018 publication **Privacy, Data and Technology: Human Rights Challenges in the Digital Age** addresses the impact of digital technology on the right to privacy; providing information on the International Human Rights Framework, safeguards and emerging issues hrc.co.nz/files/5715/2575/3415/Privacy_Data_Technology_-_Human_Rights_Challenges_in_the_Digital_Age_FINAL.pdf

The Ombudsman provides resources on fair interactions with government agencies and resources to assist agencies, including guidance on the rights of people with disabilities and the Official Information Act [ombudsman.parliament.nz](https://www.ombudsman.parliament.nz)

New Zealand Government Open Access and Licensing framework (NZGOAL) provides all-of-government guidance for agencies to follow when releasing copyright works and non-copyright material for reuse by others data.govt.nz/manage-data/policies/nzgoal

The New Zealand Government's customer-centred **Service Design Principles** provide advice on designing services with empathy and understanding of service users' experiences, needs and desired outcomes digital.govt.nz/standards-and-guidance/design-and-ux/service-design/service-design-principles

SIA Initial Engagement

From Listening to Learning describes how SIA analysed and summarised what was heard in the 'Your voice, your data, your say' engagement on investing for social wellbeing and the protection and use of data sia.govt.nz/assets/Uploads/From-Listening-to-Learning.pdf

What you told us is a record of the findings from the SIA facilitated engagement on investing for social wellbeing and the protection and use of data, that informed this Policy sia.govt.nz/assets/Uploads/what-you-told-us.pdf

