

What you told us

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Introduction

The government wants to develop a new way of working with communities to support New Zealanders to live the lives they aspire to, and build people's wellbeing (the investing for social wellbeing approach). The government is also developing a policy to provide clear guidance on how personal information can and can't be used in the social sector (the Data Protection and Use Policy).

Hon Carmel Sepuloni, the Minister for Social Development, wanted to know what you think about these topics, so she asked the Social Wellbeing Agency to talk with people who use, provide or work with social services.

We asked you to tell us what you think about:

- the Government's investing for social wellbeing approach (which is about how government works with communities to support people to live the lives they aspire to)
- the protection and use of information by the social sector.

This report summarises what you told us.

During the engagement process, you talked and we listened

Over 14 weeks, we held 83 hui in 27 locations across New Zealand. We talked to people who use social services, Māori and iwi groups, Pacific peoples, disabled people, service providers, government agencies, district health boards, local government, philanthropists and academics. In total, 1,047 people attended the hui.

During the 14 weeks, we also conducted two surveys – one on investing for social wellbeing and one on the Data Protection and Use Policy. Each survey had questions for service users and questions for service providers, government agencies and others.

We received a total of 801 responses to the surveys. There were 605 responses on investing for social wellbeing and 196 responses on the Data Protection and Use Policy. For both surveys, around a quarter of responses came from service users and three quarters were from others (such as service providers and government agencies).

Through the engagement, we sought to understand what the social sector and the wider public believe is needed to:

- adopt and implement an investing for social wellbeing approach
- develop a set of rules and tools to provide a common understanding of how to protect and use information in the social sector.

Investing for social wellbeing

The investing for social wellbeing approach is based on understanding that people lead diverse lives with different needs. By better understanding these needs we can improve the choices that are made to build individual, whānau and community wellbeing.

The approach focuses on:

1. Putting people at the centre of what we do
2. Making better use of a wide range of evidence, including data and analytics, as well as peoples' stories and lived experiences
3. Engaging and working in strong partnerships and building trust
4. Providing clear goals and robust measurement.

Data Protection and Use Policy

New Zealanders need confidence that their privacy will be protected, and their safety and wellbeing is maintained when dealing with government and organisations within the social sector.

Currently, there are a wide range of laws, guidelines and codes of practice that inform how and when personal information is collected, used and shared in the social sector. They can be hard to navigate, which can cause confusion about what is and isn't appropriate with respect to using peoples' personal information.

We are developing a policy that we see as being a collection of principles, rules, guidance and tools to enable everyone to easily understand what's appropriate, what's not, how to do things safely with personal information, and how to work with data. We are calling this the Data Protection and Use Policy. It's important to know that this policy will not change legislation.

What Happens Next?

What you told us will inform the Government's approach to building wellbeing. We will let you know more once the Government has considered its approach.

Your feedback will also inform a draft Data Protection and Use Policy. We are already working with non-government organisations (NGOs) and government agencies to develop options for 'rules and tools' to enable improved protection and use of data across the sector. We plan to take these options to Cabinet in early 2019, and to follow this with a public consultation process. We will publish the final policy, when ready, online.

About this report

We listened carefully to what you told us. You provided a lot of useful feedback.

Throughout the document, we include quotes from the engagement. We have chosen quotes that best represent the range of feedback we received. In some cases, the quotes represent the words of a specific individual or organisation; in others, they represent the notes captured from hui discussion.

We promised to keep your individual comments confidential so have taken care to only include quotes that do not identify a person or organisation.

Many of your comments are relevant to both investing for social wellbeing and the protection and use of data. We have summarised what you told us under the topic of best fit, rather than repeat it.

This document reflects what you told us. The overall findings are summarised upfront, followed by separate sections to summarise what different groups told us:

- service users including disabled people
- regional service providers
- Māori perspectives
- Pacific perspectives
- government and other national organisations.

Overall findings

There are some common themes in what you told us. We consistently heard that you want us to:

Establish a different kind of relationship across the sector

Across the hui, we heard that there is a need to establish a new kind of relationship within the sector between

government, providers and service users. You expressed a desire to see behavioural and culture change in the way the social sector is working. Service users want to be treated with dignity and respect. Service providers are looking for a more equal relationship with government; they want government to better understand their work and value their skills and experience. Māori are looking for true partnership, to reflect the Treaty of Waitangi. Pacific peoples want a 'seat at the table'.

Enable locally-led solutions to deliver services that work

You want better social services that meet people's needs. You told us that this requires listening to people, and empowering communities to design and deliver local solutions. We heard that there is no 'one-size-fits-all' to service delivery and current approaches are often not meeting the needs of individuals and their whānau.

Develop funding and contracting models that promote innovative practice

We heard that funding and contracting models are one of the key barriers to providing better services that help improve people's lives. You told us that you want flexibility for providers to try new things and work with families and whānau in a more holistic way. Service providers also want longer-term contracts, funding for the full costs of service delivery and less onerous reporting requirements.

Build the skills, experience and capacity of the workforce to implement a wellbeing approach

You identified a need for training and skills development in several areas. You told us that training and skills development is needed to support the behavioural and culture change you are looking for. Providers want adequate funding to recruit and train staff to meet service need. Providers also want guidance on collecting and sharing personal information, and training in the use of data. Māori hui identified a need to expand the Māori research workforce and develop others' proficiency in working with Māori data and information.

Ensure sharing data, information and insights is a two-way street for all those involved

We heard that you want to know how information is used and the insights gained from it – and not simply be suppliers of information. Service providers want access to data to undertake their own research and evaluation and inform service planning. Service users want to understand how their personal information is used and shared.

These five themes are relevant to both the investing for social wellbeing approach and the Data Protection and Use Policy.

In relation to investing for social wellbeing, you told us that the concept of 'social wellbeing' needs further development, and the language of the approach needs to be more inclusive. You also emphasised the importance of 'turning words into practice' and implementing the approach. You provided many comments on what's needed to do that.

With regard to the Data Protection and Use Policy, you are looking for agreed safe data storage, sharing practices and tools across the sector. You also told us we need to protect service users' stories and information.

Different groups placed emphasis on different things

Service users, you talked mostly about how you are treated. You are looking for better relationships with frontline staff. You want to be respected as people (not 'a number'), and to feel that providers listen to you and understand your needs. You also want access to services that are tailored to meet your needs, rather than a 'one-size-fits-all' approach.

Regional service providers, you emphasised a need for government to work more closely with providers, and to empower communities to develop locally-led solutions. You are looking for greater flexibility in contracts, longer-term and less competitive funding arrangements, and more funding to better reflect the full costs of providing services. You also want less onerous reporting requirements and attention to building the skills and capacity of the workforce to deliver effective services to people.

For Māori, trust in government is a key issue, and very much influenced by what has happened in the past. Māori are looking for a true partnership with the Crown and government, based on Treaty of Waitangi obligations and principles. We heard that a collective approach to wellbeing is needed, which focuses on all aspects of a person and their whānau, and works towards positive goals and aspirations, not simply addressing 'problems'. You also emphasised that Māori want to own their own data, and their own measures of wellbeing.

For Pacific peoples, strengths-based and holistic approaches to wellbeing are important, which reflect Pacific worldviews. Pacific peoples are also looking for better relationships with government and to be empowered to develop solutions for their communities. Pacific peoples want to have a say about how their data is used, and by whom.

Government agencies and national organisations, you are particularly interested in how the investing for social wellbeing approach will be implemented, and what it means in practice. You want to know what it means for your agency and how you work with others.

You emphasised the extent of change needed across the sector, and the need for a good change management plan.

What service users told us

Summary

How we engaged

We held 17 hui with 138 service users in Auckland, Hamilton, Gisborne, Wellington and Dunedin. The following organisations played an important role in arranging the hui for us and enabling service users to have their say in a safe and accessible forum: Voyce, Link People, Anxiety Trust, Presbyterian Support Northern, Migrant Action Trust, LifeWise, Hard to Reach, Community Waikato, Women's Refuge and Methodist Mission Southern.

In addition, we ran surveys on our website, and at Citizen Advice Bureau's, inviting service users to share their thoughts on the investing for social wellbeing approach and the protection and use of personal information.

What you told us at a glance

Investing for social wellbeing

1. You shared your personal experiences of social services, both good and bad. You told us that you want:
 - to be listened to, and treated with dignity and respect by service providers and government agencies
 - to be informed about what support is available and have better access to services
 - services that are tailored to meet people's diverse needs, rather than a 'one-size-fits-all' approach
 - to deal with the same frontline worker every time
 - a voice in planning and developing services.
2. You are positive about the general intent of the investing for social wellbeing approach, but have questions about the language used to describe the approach and how it will be implemented.

Protecting and using data

1. You want to know why your information is being collected and how it is being used. You want staff to explain this in a way you understand and take the time to answer your questions.
2. You are generally comfortable with information being used to help you, and some of you are happy for

anonymised information to be used to help others.

3. Some of you told us that you feel you have no real choice in consenting to the use of your personal information. Others expressed concern that your information will be used against you.
4. You want access to your personal information and the ability to correct it. You also want assurances that it is being kept safe, and to know how long it is kept.

Who are 'service users'?

When we refer to service users, we mean people who use social services. Social services include a broad range of services (e.g. health, education, housing) and are provided by a range of government and non-government organisations. Most people are service users at some point in their lives. Other words commonly used to describe service users are clients, consumers, customers, users, service recipients, beneficiaries or patients.

What you told us about...investing for social wellbeing

Putting people at the centre

Much of your feedback focused on the need to improve social services by putting people at the centre.

First and foremost, you want to be treated with dignity and respect by service providers. Some of you shared positive experiences. Others told us of feeling judged, bullied or discriminated against.

"The [named provider] psychologist gave my son one-on-one attention which was successful and I noted that the psychologist spoke and behaved as if he cared. This is what made the difference for my intelligent son."

"As a 'client' of several government services over the years, I have felt undermined, neglected, and bullied at times, and always wondered why agencies of all kinds were so mean spirited and although set up for the good of all, used most of their resources on looking good instead of focusing on the people they are there for."

"It's about the people. There's a culture in services where they victimise...If I go in [to my service provider] dressed in a \$500 suit, it's going to be different if I go in how I look now."

You want to feel that you are listened to and that providers understand your needs. You want to be involved in decisions that affect you, and for providers to be working alongside you.

"Nothing about us, without us."

"There needs to be a different approach in working with whānau, to be able to actively listen and understand families, and interpret that. Whānau need to plan their own goals in regards to their realities."

"What everyone would like is very simple. First when you enter the system you don't want to feel accused, you don't want to fill out 10 forms. When you do get help, once you are referred, you actually want to feel like you are getting help - you don't want to just be a number."

"Pay real attention to what the client is saying. Engage in greetings, looking up from PC/notes. [!] understand they have heavy workloads and time limits/targets, but they must be engaged with the person in front of them."

You want be informed about what services and supports are available, and have better access to services.

“They don’t tell you what you’re entitled to. There are so many things that people are entitled to that they’re not told about. You find out through talking to someone else who may be going through the same situation as you, and then you find out, it’s like ‘why didn’t [they] tell me?’”

“People don’t know what the services provide, they don’t advertise it.”

You also want providers to follow through with services or actions they have promised, and to respond to your requests.

“We were down for a house and got one. We didn’t even know about it for a month. They hadn’t even told us.”

“Most services I have experienced are far too complicated and frustrating when you are in a situation of need. Too many cases fall through the cracks and are not followed up appropriately. ‘Meeting the thresholds’ to obtain assistance needs to be robust and understandable by the family who ask for assistance.”

“I’ve rung a helpline before, and then a couple of days they call back, that was awesome.”

You expressed a desire to deal with the same frontline worker, rather than a different staff member every time.

“I call up [my service provider] and I say ‘can I book an appointment with so and so’, and then you go in there and they say they’re not available and refer you to someone else.”

“Once you find someone good, it’s like gold.”

You are also looking for the ‘system’ to be more joined up so it is easier to access support and you don’t have to keep providing the same information to different staff or providers.

“Not needing to repeat the same information over and over. Not getting requests for more information because it has already been provided elsewhere. Less wasting of time due to duplication.”

You want services to be tailored to meet people’s diverse needs, rather than a ‘one-size-fits-all’ approach. Services need to be accessible, and take into account people’s different cultures, languages, personal circumstances and transport needs. Some of you called for more kaupapa Māori and whānau-centred services.

“Explicit acknowledgement/recognition of the needs of disabled people in policy and system design – we’re not all exactly the same.”

“There needs to be more focus on diversity for me Māori. I go to my MĀORI mental health org and everyone I work with is Pākehā and has a western world view. It doesn’t help.”

You told us that service users should have a voice in planning and developing services.

“We aren’t even at the table, we are under the table. They [government] have the pūtea, they have all the say.”

“Co-design with disabled people and test with users through [the Disabled Persons Organisations (DPO) Coalition].”

The investing for social wellbeing approach

You were positive about the general intent of the investing for social wellbeing approach and identified a number of potential benefits for people.

“Quicker and easier access in times of need.”

“Hopefully organisations that talk to each other and cooperate so that care delivered is seamless and focused on best outcomes for recipient & whānau.”

“It will help identify New Zealanders who require more support because of a disability or high medical needs.”

“It helps prevent people ‘falling through the gaps’.”

“Investing in the wellbeing of others improves the lives of myself and society as a whole.”

However, some of you told us that the language used to describe the approach is confusing or meaningless. Some of you feel that ‘social’ wellbeing is too limiting because there are other aspects to wellbeing.

“It sounds like government jargon and doesn’t really mean anything to me.”

“People with a disability are not sick so wellbeing tends to imply they are not. I think it’s more like ‘investing in the good life’. Wellbeing is only one of the domains of a good life.”

Some of you have concerns with reference to ‘investing’.

“People who love and support their own and other families do not think of it as ‘investing’, which immediately implies gain for the investors - in other words, you do it because it will benefit YOU. In fact increased social wellbeing does benefit everyone, but not in ‘investor’ terms. Metaphors matter. Supporting social wellbeing? Sustaining social wellbeing? Developing social wellbeing?”

Some of you expressed concerns about whether, or how, the approach will be implemented.

“HOW are you going to do it? That’s a really important piece. Unless there’s a whole new way of HOW - nothing will change.”

“If done well it has the potential to add a lot of value; done poorly and with no clear direction, it could end up being a complete mess, with the customer (people) bearing the brunt of it.”

You identified a range of things that need to change to give effect to the approach and improve social services. In particular, you emphasised the need for cultural and behavioural change in the delivery of services. You suggest that staff changes or training may be needed to ensure staff have the rights skills and attributes to work with people.

“They [government] need to hire trustworthy people who really do care and show love to the people they are paid to support.”

“A significant change is needed in the way the interface is staffed. How is it that an experience in a cafe can often be more positive than in a clinic?”

“Most of them work really hard, they are understaffed, under resourced. They deserve more, but so do we too. We can’t get better until they get better.”

“Culture eats strategy for breakfast. Regardless of the changes you are making you have to make sure the people at the coalface working in the organisations responsible for the budgets, equipment and services (the power) really believe that ALL people have the right to determine their own lives and that ALL people are entitled to the same good lives as everybody else.”

Some of you identified specific issues that require attention – for example, mental health, child abuse, domestic violence and suicide.

What disabled people told us

One of the service user hui focused on understanding the perspectives of disabled people. The Disabled People’s Organisations (DPO) Coalition organised this for us.

Your feedback was similar to other service users, and placed a particular emphasis on:

- making decisions with you, not for you
- communicating clearly and speaking in a way that is easy for you to understand
- providing better information on what services and supports are available to you
- ensuring that services are accessible in practice (e.g. physically accessible)
- involving disabled people in the design of services, and at all levels of government
- improving the sector’s ability to better support and provide for disabled people.

What you told us about...protecting and using data

Collecting and sharing personal information

You want to know why your information is being collected. Many of you told us that you don’t really understand why you are asked for information; some of you are not confident that the government knows either.

You want government agencies and service providers to be clear, honest and upfront about how your information will be used. You want staff to take the time to explain this to you in a way you can understand, and to listen to and answer your questions.

“Don’t always understand why information is being collected, or how it will be stored. Would be good to have the opportunity to read through and ask questions. Would be good to get a copy to take home.”

“They could tell you why they need all these forms for and what they do with all the information when they get it from you.”

Some of you told us that you feel coerced into providing and sharing information and that you don’t have a real choice. Some of you talked about feeling vulnerable.

“Gave data to GP, was given a form to sign saying I had to agree with sharing that data with [named provider] (alternative was to find another GP). Email from [named provider] saying they were sharing that data with others (no opt-out). Facebook may have it by now.”

“Having to trust people with info because if you don't you won't get help – but don't get explained why and what will happen with it. Never any indication that you can see the information.”

“I feel that you can't do anything to stop it because it's being passed around.”

You emphasised the importance of relationships and trust in people feeling safe to share their information and stories. Reputation also matters – people get worried when they hear examples of trust being broken (for example, privacy breaches).

“Greater risks to disabled people because they don't have the same level of privacy.”

“New therapist, so she knows everything about me and I know nothing about her. No hand over, no shared sessions to get to know.”

“I would rather that my data was not used except in ways that are transparent and that I felt those using it were trustworthy and were operating from a basic of ethics and practice endorsed by the recipients of the services.”

Most of you accept government agencies and service providers asking for information to work out how to help you. You want them to explain why they need it.

“I think if you really need help you don't mind if they ask for your information. You have to provide everything that they ask in order for you to get good outcomes and you hoping that you will get the answer that she want. So for me when the social worker [was] asking about all my personal like stuff, I didn't even hide anything. I knew I trust her.”

Many of you are also comfortable with your information being shared with other providers to help you. However, what information is shared should be relevant to the role of the provider – you told us that not every agency or professional needs to have all information about you.

“Holistic approach – sharing relevant information with doctor, school, Housing NZ or WINZ.”

“I'm not happy with my mental health team knowing my finances, but I'm happy with WINZ knowing my mental health status.”

Some of you are happy for your information to be used to help others or to learn from your experiences. You want your information to be anonymous in this situation.

“So long as there is no names, it's important to [collect data].”

Some of you expressed concern that your information will be used against you. You expressed a mistrust of government agencies and how they use data.

“All data is used to catch people.”

“Anything spoken or told on phone is kept and transcribed – used against you. How we word things gets taken differently, how we communicate is different, taken without attempting to understand what we actually mean. No opportunity to rebut. Perception that agencies are several steps ahead based on their pre-conceived ideas. They cheat information out of you.”

Protecting and accessing your information

Some of you said you want to know what information is recorded about you. You want to be able to check it is accurate and correct it if necessary.

“You need to be able to have access to find out what information government has on you, and who has looked at it, for all services.”

“I think the ability of individuals to have ownership and viewing / editing of their own data – as well as a concise summary of legal requirements and protocols for organisations to refer to.”

“Counsellors have huge files but won't share that with me and it's all about me!”

You also want assurances that your information will be kept safe. Some of you expressed concern about the security of your information.

“I would like to be certain that my personal details are secure and won't be misused.”

“Don't leave my information on a paper, in a box that anyone can access.”

“I am more concerned about the security of the IT system, it would always be a target when there is a large amount of data being stored in one database.”

Some of you consider that technology helps keep your information safe. However, you told us that having everything 'online' means that some people may not be able to access their information because they lack the skills or access to the technology.

“Digital records need to be limited access solely for the purposes that the individual granted to the agency, by that agency.”

“Not all of us are great at these things [technology].”

You are unsure how long your information is kept, and want to know when and how your information is removed from agency records.

“Show how they ensure its safety and how information no longer required is safely disposed.”

“Provide me with detailed information on who is involved, how the data is handled and stored, archived and whether it would be deleted.”

What disabled people told us

Disabled people provided similar feedback to other service users.

You told us you want:

- clear information about what information is being collected, for what purpose and what information is held about you
- better understanding of people's situations when asking for identification information (for example, some disabled people do not have a driver's licence)
- more use of people's stories to help drive change
- to be involved in developing and testing tools and guidance on the protection and use of data.

What regional service providers told us

Summary

How we engaged

We held 41 hui for regional service providers, which involved 669 participants. They included representatives from non-government organisations, charities, frontline government agencies, district health boards and local government.

Hui were held in Kaitaia, Kaikohe, Whangārei, Auckland Central, South Auckland, Thames, Hamilton, Tauranga, Whakatāne, Rotorua, Taupō, Gisborne, Havelock North, New Plymouth, Whanganui, Wellington, Porirua, Palmerston North, Nelson, Greymouth, Christchurch, Dunedin, Alexandra and Invercargill.

We also met with the Whānau Ora commissioning agencies (Te Pou Matakana, Te Pūtahitanga o Te Waipounamu, Pasifika Futures).

In addition, many service providers were among those who responded to the surveys for non-service users.

What you told us at a glance

Investing for social wellbeing

1. You support the investing for social wellbeing approach in principle; in particular, you support a person-centred approach and making use of a wider range of evidence to inform decision-making.
2. You told us that we need to rethink some key concepts and language and take a more holistic and strengths-based approach to wellbeing.
3. You want to work in partnership with government. You are looking for a change in culture, with better communication and valuing of providers to make this happen.
4. You want more information on how the approach will be implemented in practice. You told us there is a need for:
 - communities to be empowered to develop the solutions and services that work for them
 - more staff, more training and more resources for providers so you are better able to support people and their families to make lasting changes in their lives
 - changes to funding and contracting models – with longer-term contracts, full funding and greater freedom to deliver services that meet people's needs.

Protecting and using data

1. You identified a need for a principled approach to the collection and use of personal information, supported by clear and consistent guidance.
2. You told us that information should only be collected where it serves a clear purpose, related to improving wellbeing, and that we need to improve processes for obtaining people's consent to use their information.
3. You are looking for better sharing of information between frontline staff so they are better informed and people don't have to repeat their stories.
4. You want to see a 'two-way flow' of information between government and service providers. You are looking for:
 - government agencies to involve you in deciding what data and analysis is useful, and to share their data, research and insights
 - training and development so you can undertake your own evaluation and research.

Who are 'regional service providers'?

Social services are provided by government agencies, local government, non-government organisations (NGOs) and private organisations. In this section, when we refer to regional service providers, we mean anyone who attended the regional hui for service providers.

What you told us about...investing for social wellbeing

Key concepts

You told us that we need to rethink some of the key concepts and the language used to describe the investing for social wellbeing approach. The approach needs to be more inclusive and recognise the diversity of perspectives on wellbeing. In particular, a more holistic view of wellbeing is required that incorporates Māori worldviews.

"Needs to be quite a bit of work on what social wellbeing actually is and how a person can achieve it."

"What are the boundaries of social wellbeing? Does it include the environment or other factors beyond 'social'?"

"A lot of the concepts coming through are euro-centric. The voice of other communities Māori, Pacific peoples, migrants and refugees is lost in the approach"

You emphasised a strengths-based approach to wellbeing. Others suggested drawing on Māori models and frameworks of wellbeing or international principles and frameworks.

"Move from what's wrong to what's strong."

"If you work on 'bad', you get 'not bad.' If you work on strengths you get excellence."

"Māori models, Whare Tapa Wha, Te Wheke are good for this type of work."

You told us the concept of 'investing' needs rethinking. For many, it has negative connotations and implies a narrow focus on avoiding the financial costs associated with providing social services.

"Use of the term investing is problematic. The investment approach did not feel aligned to wellbeing and suggests a market approach, seeing families as a commodity."

"Wellbeing is more than money, take the term 'investing' out of wellbeing."

Putting people at the centre

You support a person-centred approach that puts people at the heart of everything government and providers do.

"Understanding the context of people's lives [is] key to understanding how to help them."

"Communities, families, young people, clients need to have a voice in [the] social wellbeing approach; it is through their experience and struggles we can learn from and identify their needs."

You told us that a person-centred approach is time and resource intensive; it takes time to make lasting change to people's lives.

“Turning the Titanic’ – will take a long time to shift – not just shifting government, but also how people measure success and happiness.”

“Takes time to work with people to empower them to make change.”

Some of you told us that a whānau or family-centred approach is needed, or that the approach should be both person-centred and whānau-centred.

Others emphasised the importance of understanding the perspectives and needs of disabled people.

“Need to talk directly to disabled people and ask questions about their quality of life and what they think ‘good’ looks like – people’s aspirations.”

“Know practicalities re dealing with people with disabilities and mental health issues.”

Working in partnership and building trust

You emphasised the need for government and providers to work together in partnership. Some of you described your current experiences of working with government as frustrating, contract-focused and characterised by mistrust.

“Change what is meant by working in partnership – it’s not a partnership today.”

“Need to rebuild trust with the sector. There are lots of ‘false starts’ from government that don’t go anywhere. We get consulted about a lot of things but then there’s nothing more/no follow up.”

“There is a master/servant relationship between providers and government.”

You are looking for a change in culture across the system, with a more equal relationship between government and providers. You want government agencies to communicate better with providers and to value the knowledge, skills and services provided by non-government organisations.

“Review conduct and behaviour in government and NGOs so it’s based around an [investing for social wellbeing] approach. This is only possible if staff have the freedom and resource required for an [investing for social wellbeing] approach to occur.”

“Agreed partnership mission between local agency and local NGO – guide how we work together to improve wellbeing (common goals/objectives needed).”

“We want to be listened to – we know the area and have practice evidence.”

You also told us that service providers need to collaborate better with each other.

Making better use of a wide range of information

You support the use of qualitative information such as stories to provide additional context in reporting and to inform decision-making. Some of you identified a need for greater clarity about how qualitative and quantitative information will be brought together and used in practice.

“I can use lots of data in annual reports I write, but I can’t tell a story within these reports. It lacks the narrative which can support the data. The data is sometimes immeasurable, yet qualitatively the change can be small, start of a journey. But lost/not seen in data.”

You have different views on the use of quantitative data. Some of you have confidence in such data and support using it if it makes a positive difference to wellbeing. Others are concerned that quantitative data does not reflect the realities of people's lives.

"Potential is huge. Joining up data can provide valuable insights and has already been done. It's a starting point for diagnosing and starting from which we can begin to drive decision-making."

You want to work with government and service users to decide together what information, data and insights are useful and how to create them.

"The only people who know the data are the people who give the information so need to use the data with the communities who've provided it in the first place."

"Focus groups around the IDI – agencies, NGOs in a focus group to identify what information an NGO might need in terms of data."

"Communities and people who data describes need to be involved in decisions about how it gets used – at a system design level; they should be valued participants in the system we're creating."

"What are the questions we need to answer at what level of the system and how do we join this up."

Some of you identified a need for cultural competence in gathering and interpreting data and information.

"Cultural values and nuances are quite different through different cultural lenses. You need cultural competence to analyse the data correctly."

"Lots of cultural issues in data – gets skewed because of lack of understanding."

Others called for more dis-aggregation of data to provide more specific information on different communities within regions, or different population groups.

"Need to get right down to communities to get understanding of data."

"Need framework to collect/collate data to inform planning for disability."

Providing clear goals and robust measurement

You want a clearer definition of desired outcomes and the wellbeing measures that will be used. You want to know what is being measured and why.

"Clear robust goals and measurements – what are they?"

"Measures of success need to be clear – beyond the fiscal returns."

Some of you are looking for standardised outcomes and measures; others want flexibility and individualised measures and outcomes.

"Universal measurement framework and training to use the methodology/information."

"Outcomes are so broad they are meaningless. We have our own outcomes measures that do work."

Implementing a wellbeing approach

While supportive of the investing for social wellbeing approach in principle, you want more information on how the approach will be implemented in practice. You identified a need for long-term change, and want to be involved in the process.

“A change process – how is this communicated and managed?”

“Need to make generational changes – this takes a long-term collaboration approach across all agencies.”

Some of you told us that providers are already working in ways that are consistent with the approach. You want existing good practices to be acknowledged and built on. Some referred to a ‘disconnect’ between government policy and what happens on the ground.

“Good organisations have been doing this; some small organisations have been doing this ahead of government. Government must get on board with NGOs.”

“What are you talking about? This is how we have been doing it for years.”

You emphasised the need for flexibility to meet the diverse needs of communities rather than regional approaches. You are looking for community-led and designed ways of working that draw on local knowledge and respond to differing needs.

“Keep it local, build trust, have faith in us and let us prove it by doing. Create an enabling environment rather than a prescribed environment.”

“Engage local intelligence to influence and implement the innovative solutions.”

“Empower communities to design, develop and deliver services for themselves, and build leadership capabilities for themselves.”

“Freedom to work locally – plan, invest and deliver together – as a provider we are passionate about the localisation of our approaches.”

You also want greater recognition of the value of prevention and early intervention initiatives.

“Govt. hasn’t invested in prevention/early intervention. Money is mainly positioned at late stage intervention.”

“Include investment in early intervention and specialist interventions that are evidence-based.”

You told us that providers need more staff, more training and more time to support people to make lasting changes in their lives. You also want training and resources to help you make better use of data and stories, and monitor and evaluate the effectiveness of your services.

“Community organisations need investment to increase leadership and workforce capacity – and development for increased complexity.”

“Can’t recruit the expertise we need. [There’s a] lack of money and capability. Not right skill base in outcomes and measures and evaluation.”

“We rely on volunteers and relationships. Volunteers are harder and harder to get and they need to go through vetting processes which take time and money.”

“Training would be excellent - both in terms of accessing funds to train our front-line staff (for example, in trauma work or suicide prevention), and in terms of accessing training for the whole organisation (i.e. for Treaty engagement)”

Some of you drew attention to the additional challenges and costs faced by rural service providers, particularly in recruiting skilled staff.

“Attracting staff is hard down here, plus the roles are much lower paid in NGOs than in the state sector.”

“These effects are very difficult on the Coast as attracting people in the first place is hard. If someone leaves, there may be no right person for 1-2 years.”

Funding and contracting models

You are looking for changes to funding and contracting models. You told us that current contracts are too short, lack flexibility and do not meet people’s needs. You want longer-term funding arrangements to support more sustainable services.

“Certainty of funding – we need more certainty around future funding so our services are sustainable – including people and resources.”

“Can’t plan and invest in our capability and the services we deliver when we have one year contracts.”

“Bulk funding not fee for service – can’t employ people, does not fund overall costs, prevents innovation and flexibility.”

“There is not a lot of duplication in our community, there is some frustration with government, we are so stretched we need more funding to do this well.”

You also want flexibility to innovate and try something new, and to respond to change.

“Contracts with government are so prescriptive that some NGOs are having to drop people in need off as they don’t fit the contract criteria.”

“Asked to be innovative, invest in training and application, but funder still funding old model outputs etc.”

You want to move away from competitive funding models, and for funding to be based on a more holistic approach to working with whānau, families and communities, not just a single person.

“Get funding for one issue but have to deal with all family issues – multiple issues need sustained support.”

“Small scale community, big social problems, lots of social service providers all going for the same contracts equals competitive environment.”

You also want services to be fully funded. You told us that funding should include the direct costs of delivering services and indirect costs such as reporting, training and research and evaluation. Some of you highlighted the time required by providers to meet government reporting requirements, particularly when there are multiple contracts and multiple funders.

“Contracts are contributory funding, we’re not fully funded to do the work, particularly given the amount of data we are asked for.”

You have mixed views on how funding should work. Some of you told us that funding should follow the person, or be directed by them; others consider that funding should be given to providers, but based on desired outcomes rather than the number of people served.

“Funding should follow the client – from their first service of care through to the last.”

“Fund a service, not per person going into it – creates unnecessary pressure on services.”

What you told us about...protecting and using data

Governance and oversight

You told us that service users, service providers and government agencies all need to have confidence that processes and systems for collecting, storing, sharing, and using data are robust and safe. Some of you described service providers and government as kaitiaki of data – or caretakers.

You shared many examples of good practice, rules and tools already in use, which can be built on. You also suggested various oversight mechanisms.

“Take extreme care with how info is shared. Ensure data is held safely e.g. the IDI data is only joined up for specific purpose and not combined when stored. Good to know a trusted and credible agency will hold info ethically – like Stats NZ.”

“There needs to be a safe and trusted broker governed by an Act and independence to collect, anonymise and make available data, as trust in the government is the challenge.”

“There should be a complaints process if NGOs aren’t happy with how they’re being treated – a process of redress (is this in contracts already?).”

“Who determines what is needed/shared? Is there a process envisaged that ‘someone’ approves? E.g. ethics committee/central agency – how do people influence this?”

Principles to guide collection and use of personal information

You identified a need for clear principles to guide the collection and use of personal information.

“What are the principles that are required for the ‘paradigm shift?’”

“Simple principles would be more useful than laws.”

You told us that, as a general principle, information should only be collected where it serves a clear purpose, clearly related to improving wellbeing.

“Be crystal clear about the why. Why is this information needed, and how will it be used for service provision.”

“Personal information should only be collected, held and shared only for the purpose of supporting people to improve their situations – at an individual, organisational and population based level – what this look like will be determined by the context”

“There’s a lack of concrete examples about the reason and benefit around what that can do...the missing part is why? What are you going to do with this data, why do you need it?”

You told us that people should have real choices about what information they provide, who it is shared with, and for what purpose. You emphasised the importance of establishing trust before seeking consent, and clear and respectful mana-enhancing communication with service users.

You questioned the genuineness of current consent processes because consent is often sought at the point a person wants to access services or at a time of crisis. You also expressed concern that people are often asked for ‘blanket’ consent to cover all information in all situations.

“Putting a piece of paper in front of people to get their signature – did they understand it? This is coercion not consent.”

“Can’t deliver services until client has signed agreements. However clients are often so stressed or vulnerable and are not able to understand ‘informed consent.’”

“Often it’s not clear if you can give partial consent eg consent to some information sharing but not others.”

“Have to have flexibility to respond to anxious clients. Providing the options and space for users to understand their rights and what the organisation does for privacy/consent.”

You identify particular challenges in obtaining consent from those with impaired cognitive ability (for example, for those affected by alcohol and drugs, or a serious mental health condition). You note that, in some cases, family members may question the ability of a person to provide consent (for example, an older person, or a young person).

“For certain groups, youth and disability, they don’t have the same opportunity to opt in/opt out. For these groups, their decisions are often made by a caregiver. The caregiver may have different motives from the individual. We need more guidance around how to deal with this.”

“People with cognitive impairment (mental health or addiction challenges) struggle to sign documents – verbal consent should be an option (but then documented by provider).”

You told us that the safety of people should override their right to privacy, and that consent should not be required if there is a risk of harm to the individual, their family or some other person.

“There are situations where we must act without consent (crisis)”

“Only share when compelled to by concern about risk. We don’t without client consent – ever, unless they have threatened to harm themselves or others – then we disclose to appropriate agencies.”

Some of you suggested there may be a ‘social good’ rationale for overriding consent requirements for research and evaluation.

You also told us that people should know more about their data, and be able to change it. You emphasised the need to ensure service users always know who their information is being shared with.

“If people give personalised, identifiable data – how do they access that data to check it has been recorded correctly and what options do they have to change it? How do they change this if their circumstances change?”

Sharing information between frontline staff

You are looking for better sharing of information between frontline services. You want staff to have a good understanding of a person’s situation, and service users to not have to repeatedly tell their stories and deal with multiple consent processes.

“The level of cooperation and information sharing is inconsistent across agencies and community organisations. There are some sector that are doing this really well e.g. disabilities sector. Generally we find that govt agencies are poor at this – they want our information but they don’t share it with us.”

“Would be helpful to have a wider understanding of multiple family challenges and what support is already being provided/or is still needed.”

You told us that frontline workers can be reluctant to share information because they are afraid of ‘getting the rules wrong’. Many of you said that information sharing relies more on personal relationships than adherence to clearly understood standards and guidelines.

“A client with mental health issues was being targeted by shopping trucks and getting into severe debt. We were not sure if we could share this info with mental health services under the Privacy Act.”

“Often relationships across and between organisations leads to ‘unofficial’ info sharing for all the right reasons, but this relies on those relationships and service delivery is compromised when it doesn’t happen.”

Sharing data, research and insights

You told us that there needs to be a ‘two-way flow’ of information between government and services providers. You want to know how data is used and you are looking for government agencies to share their analysis and insights.

“We provide a lot of information but we need two way information flows. We put lots of information in but we have to ask for information to get stuff back out and it’s difficult to get. It would be good to get information back for service delivery, planning, developing services.”

“Can I see the outcomes/new knowledge that my data contributed to?”

You also want access to the data to produce your own research and insights.

“Government can do what we can’t (the value of cross data sets not accessible to individual NGOs – make the data accessible and share it/share the value.”

What information is useful to you:

- Population information/statistics
- Community aspirations
- Proxies for wellbeing
- Outcomes, what works and how
- Service availability and gaps

Tools and guidance

Providers are looking for:

- guidance on the collection and sharing of information
- skills development for frontline staff to talk with people about data and navigate consent issues
- training in data management
- skills development to undertake your own research, evaluation and analysis
- information technology (IT) and other infrastructure to help keep data safe and provide for appropriate

sharing of information.

“Identify NGOs and champions to build up capacity to collect and manage data safely.”

“NGOs need more resources and support around what to capture, how to capture, processes etc to support the right data”

“Adequate information systems (databases), trained workforce, basic IT infrastructure (security setups, documentation storage etc.) and quality assurance of data capture.”

“A single system/service for info storage and sharing for NGOs and agencies. This system needs to be easy to use, access and secure. For example, social workers will need to use it and access it regularly. This could prevent inconsistency in info sharing and collection.”

You told us that both government and non-government organisations have training needs and require access to tools and resources. You want guidance and resources to be developed and tested with the sector, including service users.

Māori perspectives

Summary

How we engaged

We designed our engagement process to be responsive to the needs of Māori. We were able to connect with many Māori across the hui – including individuals, beneficiaries, people working in mainstream services, Māori-specific and iwi providers, Māori trusts, and Whānau Ora commissioning agencies and providers. In addition, we held five hui to explore Māori perspectives on wellbeing and data protection and use more deeply. Called Hui Rangatira, we met with small groups in Auckland, Hamilton, Palmerston North and Wellington. This section reflects what people told us at these hui.

What you told us at a glance

Investing for social wellbeing

1. You identified a need for a collective approach to wellbeing that is centred on the whānau, not just the person. You told us a holistic, more aspirational approach is required, which looks at all aspects of wellbeing and the whānau’s desired goals, not just what is ‘going wrong’.
2. You told us Māori want to develop their own measures of success and wellbeing, and their own ways of measuring things.
3. You told us that Māori are looking for a true partnership with government, to reflect the Treaty of Waitangi. Māori want to be actively involved in decision-making and not simply ‘have a say’.
4. You identified a need for changes to funding and contracting arrangements (including more kaupapa-based funding and holistic funding arrangements) to provide flexibility for Māori to design and implement services that work for them.

Protecting and using data

1. You told us that Māori want to own their own data and stories. This requires Māori governance and leadership.

2. You identified a need for more transparency about how personal information is collected and used, and assurances that it will be kept safe.
3. You told us that any data that is gathered needs to be interpreted with reference to Māori priorities, values and worldviews. This requires involving and developing Māori researchers and analysts.
4. Some of you want better access to raw data and information held by government agencies to inform iwi planning and development.

What you told us about...investing for social wellbeing

Understanding and measuring wellbeing

You told us that, for Māori, the wellbeing of a person cannot be separated from the wellbeing of their whānau and community. A collective approach to wellbeing is needed that is centred on the whānau, not just the person.

“You need to put whānau and their needs at the centre of everything.”

Wellbeing is also broader than social wellbeing. It incorporates matters such as culture and the health of the language, economic wellbeing, and the health of relationships.

From a Māori perspective, wellbeing is aspirational and not just an absence of things going wrong. It is about whānau thriving and achieving their desired goals and visions.

“Wellbeing sounds good. It’s the right idea. But when you look under the hood, it’s all ill-being measures.”

“Wellbeing – aspirational, changing the way people approach the world – shifting energy from deficit space to strength.”

You told us that individuals, whānau and iwi should be able to define what wellbeing means for them, and be supported to achieve this. This means accepting diverse views of wellbeing.

You also told us that Māori want to develop their own measures of wellbeing and success, and their own ways of measuring things. Being able to describe how wellbeing is defined and measured is part of having autonomy and tino rangatiratanga.

“We have our own cultural markers. Kaupapa tuku iho. These are our measures of wellbeing and success.”

“We are into our own measures, for our own people”

Working in partnership and building trust

Many Māori do not trust either the Crown, or government or government agencies. This reflects past experiences and impacts on relationships today.

“When you work with Waikato Tainui, you need to understand that the Raupatu/Confiscation is front and centre of our mind.”

“Princess Te Puea instructed her people not to put their children’s names on their birth certificates. This was in case the Crown tried to conscript their children.”

Māori want more equal, and less transactional, relationships with government. Māori are looking for true partnership, to reflect the Treaty of Waitangi.

“Iwi are not just any old stakeholders. We are Treaty partners.”

“Māori/Crown relationship – we understand the nature of it but government agencies do not as [they are] still working with us as just providers rather than Treaty partners. As partners we need to hold government accountable.”

“The Treaty of Waitangi should be honoured. It is about partnership.”

“Working in partnership for Māori is a Treaty conversation.”

“Partnership is only in play when power relationships are even.”

You told us that this means Māori taking an active part in decision-making with government, not simply ‘having a say’.

“A bold change from the government is required – way it thinks, operates. Māori are ready to be part of, to be involved in creating something new, something better for everyone.”

“We want to co-decide, not co-design.”

You told us that strong and enduring relationships are needed between people at all levels, from frontline staff to chief executives and ministers. These take time to develop.

“The relationship is where it’s at fundamentally, [it’s] trust.”

Implementing a wellbeing approach

You told us that the design of the social sector system needs to change to better support Māori to achieve wellbeing. In making changes, we need to consider the ‘whakapapa’ or history of the system, and understand how and why things are the way they are, what has been and is being tried, what has worked and what shows promise.

You told us that the system should be based on a principle of mana enhancement.

“There is no opportunity for mana when we are not asked what we think is right for our tamariki and mokopuna.”

“The sense of relationship that has been discussed today must be based in a principle of being ‘mana enhancing’!!! Not that one party will engage and focus solely on achieving what it wants from the relationships.”

You said that manaakitanga matters when working with Māori, which means caring for people and supporting them to achieve their aspirations.

You identified a need for greater flexibility to enable Māori to design and implement services in a way that works for them. In particular, there is a need for changes to funding and contracting mechanisms. You are looking for more flexible and holistic funding arrangements, more kaupapa-based funding and more innovation in contracts. You want to move away from competitive funding models and towards more equitable sharing of resources.

“[Have] cross – vote appropriations that are kaupapa-focused.”

“Contract design should meet the needs of both parties – co-design and co-decisions.”

“[We have] asked for contracts to be changed – it’s too difficult, too onerous.”

“Administration costs increases but there is no funding to accommodate.”

You told us that within the Whānau Ora initiative, there are examples of good practice we can learn from. These include approaches to defining and measuring wellbeing, commissioning practices, and providers’ ability to form relationships of trust with whānau.

What you told us about...protecting and using data

Data ownership and governance

You emphasised that Māori want to own their own data and own their story, as it is their story to tell. Data is seen as both personal (individual) and part of the collective.

“You talk about your data, your say. Māori talk about our data, our say.”

“Before you democratise data, you need to decolonise it.”

You told us this requires Māori governance and leadership.

“Māori want to be at the table, overseeing the processes that govern and manage the use of data.”

“Data sovereignty is the ability to sit everywhere from the marae to the IDI.”

“Iwi want to exercise their own decisions and to collaborate with government to re-design and add value to the national engagement about data.”

Collecting and sharing information

You told us Māori want more transparency from government about the purpose of seeking data from providers, and how collecting and sharing information will benefit the community.

“Honesty of purpose is our tikanga and kawa.”

You commented that obtaining consent to collect and share information from individuals and whānau is challenging for Māori and non-Māori providers. However, some iwi and Māori providers are developing new ways of navigating consent processes (for example, whānau-based consent processes that involve obtaining consent from all family members).

You told us that relationships are essential – people need to have trust in staff before they will share information; they cannot provide genuine consent without a trusting relationship.

Timing is also important. Some of you questioned whether truly informed consent can be provided when it is sought in the middle of a crisis.

Keeping data safe

You told us that, for Māori, keeping data safe and protected is about kaitiakitanga. You identified a need for greater clarity around the protocols and rules for safeguarding data, and how these relate to Māori protocols such as kawa, tikanga, rāhui, mana and tapu.

You told us that sharing stories is not the same as sharing data, as stories are intrinsically part of a person.

“How do we best kaitiaki the pūrākau that have been so trustingly shared?” (how do we care for the stories)

Use of data and information

You emphasised that any data gathered needs to be used, interpreted and understood with reference to Māori priorities, values and worldviews. This requires involving Māori researchers and analysts in the process.

“Feel that government needs to become better aware, and build a level of proficiency in Māori concepts and paradigms of engagement and thinking. Government needs to understand the importance of ‘tinana’, ‘tapu’ of an individual.”

You also identified a need to:

- expand the Māori workforce with qualitative and quantitative research skills
- develop others’ proficiency in understanding and working with Māori data and information (including understanding and applying Māori concepts and paradigms).

“Capability of Maori in the qualitative and quantitative needs to grow.”

“Data is plentiful. How is the capability being built to use the data?”

Some of you want better access to raw data and information held by government agencies – to inform iwi planning and development, or to measure how you are making a difference to the lives of individuals and whānau. Others drew attention to the knowledge, understanding and insights that Māori organisations can contribute to help the government to achieve shared goals.

“We are at the mercy of the government agency – they hold all the data – the system needs to be shared – both owned and access to the system when we need it.”

“If the community holds the data, whānau can make better decisions about their lives.”

“Measurement of wellbeing cannot be one way – help people understand it.”

Tools, guidance and principles

You identified a need for more guidance around the collection, sharing, protection and use of data. You told us that any tools and guidance should be co-designed and include guidance on Māori principles and concepts.

“Would like guidance on better managing, updating consent formal/systems. Co-design ways to future proof these arrangements.”

“Policy, frameworks, engagement, systems, tools etc. must be whānau-focused, based, co-designed.”

You suggested the following principles to underpin the collection and use of data:

- make Māori data needs a priority
- support Māori leadership and governance in data issues
- be accountable to Māori – consider who the data being measured is for
- recognise Māori collective interests in any data collection or use and share any benefits of insights and learning
- be clear about the purpose of any data collection

- use indicators and frameworks that consider a Māori worldview – use a Te Ao Māori lens.

Pacific perspectives

Summary

How we engaged

Pacific providers were among those who participated in the hui for regional service providers. In addition, we held four hui to specifically explore the perspectives of Pacific peoples. The hui were held in South Auckland, Wellington and Christchurch. This section reflects what people told us at these hui.

What you told us at a glance

Investing for social wellbeing

1. You told us that concepts of wellbeing need to reflect Pacific views of wellbeing and recognise the diversity of views in different Pacific communities.
2. You highlighted the importance of family, community, church and relationships to Pacific peoples, as well as strengths-based approaches. You told us that trust-based relationships are needed between service users and providers.
3. You are looking for more respect for Pacific leadership, with a 'seat at the table' and a stronger role in designing solutions for your communities.
4. You want greater flexibility in contracts to do things differently, with longer-term funding that includes funding for training, research and evaluation, and information technology.
5. You support the use of a wider range of information to inform decision-making.

Protecting and using data

1. You told us that personal information should only be collected and used if it contributes to a person's wellbeing or the wellbeing of the community.
2. You are looking for clear and simple explanations for people about why their personal information is being collected and how it will be used, supported by tools and guidance for service providers.
3. You identified a need for better accountability to families and communities on how their data is used.

What you told us about...investing for social wellbeing

Understanding and measuring wellbeing

You told us that concepts of wellbeing need to reflect Pacific views of wellbeing, and recognise the diversity in what constitutes 'wellbeing' in different Pacific communities and families.

For Pacific peoples, wellbeing is multidimensional – it includes an important spiritual dimension, as well as thriving culture and language, and environmental aspects. Family, community, church and relationships all sit at the centre of wellbeing.

"A government-led definition and measurement may not capture what is important to our people."

"What holistic wellbeing is for Pasifika by Pasifika."

"Sovereignty of Pacific terms/values/cultural ideas."

You emphasised that strengths-based models are important to Pacific peoples, which means looking at positive impacts as a key measure of wellbeing. It means focusing on how people and communities are flourishing, and the ways in which they are resilient, rather than focusing on deficits and what is not working for people.

“Need to focus on and maintain what’s going well e.g. the work we do to keep our kids off the radar. We need to avoid expressing those ideas in the language of deficit and need.”

“The focus has to be on families and communities achieving their goals, based in their views of their own wellbeing. Part of that is about not having to depend on services at all. If that is what is important – then that is what we should be measuring and assessing.”

You identified the opportunity to learn from a Pacific sense of wellbeing, commenting on the importance of strong interpersonal connections in helping people remain hopeful despite struggles in their daily lives.

You also told us that wellbeing needs to cover all ages and stages of life, and reflect the diversity of experiences for different people, for example, migrants, refugees and LGBTQI+ communities.

Working in partnership and building trust

From a Pacific perspective, relationships are at the core of any work across the sector – it is through relationships between providers, between government and providers and between workers and clients that enduring positive change is made. You told us that concepts such as Va are vital to understanding relationships for Pacific peoples – this refers to the sacred space of interconnections between people, and between the spiritual aspects of people and their environment.

For you, good relationships between workers and clients involve:

- Being honest and open
- Clearly talking to people about what you are doing
- Showing you care
- Understanding people’s culture
- Talking with people about the things that are important to them
- Being face to face
- Empowering people
- Being authentic.

You emphasised the need to be thinking about partnerships (plural) rather than partnership. There are diverse Pacific groups and one Pacific voice or ethnicity cannot speak for others.

“Need to appreciate that different Pacific groups need different things and need to respect cultural differences.”

“‘Pasifika’ as if it’s a homogenous group – this doesn’t put everyone on an even place because their uniqueness isn’t thought about. It limits thinking.”

You told us that Pacific leadership needs to be better valued, prioritised and respected. Pacific people want a ‘seat at the table’, and to be empowered to design solutions and be involved in making decisions that affect their communities. You called for greater self-determination and a stronger role in setting government priorities, designing and implementing services, and collecting and using data.

“More collaborative co-design of policy e.g. policy makers learning from grassroots programmes – Healthy Lifestyle Pasifika. Agencies, people and providers working together i.e. not a dictatorship – hear our voices.”

“Community perspectives and priorities should determine what data is collected and not collected to determine Pasifika priorities.”

You consistently told us that the solutions to issues affecting Pacific communities lie within those communities – “E fofo e le alamea le alamea”. You told us that solutions for Pacific people should be created by Pacific people, working together to set the aspirations and priorities of the communities. Authentic co-design is required, based on Pacific ideas, values and concepts.

“Communities often know what they need; they just need help to access it.”

You identified a need to build trust among Pacific providers. You told us many providers are willing to believe that government agencies are there to support them but others feel they have been let down by the government in the past and are not confident it will not happen again.

“We love our partners but we do not trust them – [we must] think the same way – you’re asking us to be vulnerable – we could get hurt and let our communities down.”

“We had a co-design process for [social issue]. It was designed over 16 months – and the money dried up so it stopped. Built expectation in our community and now they don’t trust us.”

Making better use of a wide range of information

You support the use of a wider range of information, including both ‘hard data’ and qualitative information. You want more value placed on stories and qualitative information, which you see as providing important context and a richer understanding of how services are impacting on people’s lives.

“Use life stories to enrich evidence of what is happening to people and what they might need to change and what is working.”

“People are not numbers, stories create authentic data.”

“Narrative shows explanation behind data – good and bad.”

You see a need to focus on collecting information that helps to understand people’s strengths and resilience, and ‘what’s working’ for individuals, families and communities. You told us there needs to be better appreciation and protection of the cultural value of data.

Some of you told us that providers want to help create and use population-level data. For example, they want demographic information to help them understand the situation of their communities, including information on different ethnic groups.

Implementing a wellbeing approach

You have questions about how the investing for social wellbeing approach will be turned into practical change, and how the affected ‘sector’ will be defined.

Some of you told us that the approach will be working well when no one is turned away from receiving the help they need due to criteria, budgets or narrow contracting requirements. You also want to see more support for early invention and prevention.

You raised many concerns with current funding and contracting models. You told us that:

- Pacific providers provide holistic support but funding comes in ‘silos’ from different organisations with firm boundaries on how it can be used. You want more flexibility to ‘seize the moment’ when faced with someone who needs help.
- Funding is often based on providing service to a person, but helping them often requires helping the wider family. You told us that many providers work beyond their funded contracts because it is the only way to meet a family’s needs.
- The contracting system can be difficult for providers and communities to navigate so those who ‘speak the language’ get the contracts. This does not necessarily result in the best services for Pacific peoples. You want more funding of services ‘for Pacific people by Pacific peoples.’
- Longer-term funding arrangements are needed to support the sustainability of services.
- Pacific providers struggle to keep good staff because of a lack of money for competitive salaries.
- Funding for innovation is needed. Current funding only provides for services already being delivered and does not enable providers to grow or try new things.
- Funding is also required for training and development, research and evaluation and information technology.

“Boundaries and pots of funding (both topic and geography) place a huge burden on communities to navigate those boundaries and make sense of them.”

“Need to address the distance between the funding pool and the community or the group (very localised) who are actually doing the work.”

You want greater flexibility in contract reporting requirements to place a higher value on a wider definition of success, and measure the things that matter to communities. Some of you point to the Whānau Ora model, which you see as more enabling for providers and families and an example of a strengths-based model that works.

“Have wellbeing for the whole person and the whole family – this needs integrated funding models. Whānau Ora already allows this and works like this.”

“Remember that it’s typical that you often find yourself on a 30-minute appointment for a single person, and 2 hours later you find yourself working with multiple members of the family on a range of inter-related issues. That’s our reality, and we need to accept that this is often the true nature of the work. They don’t care what you know until they know that you care.”

Language used to describe the approach

Some of you told us that the language used to describe the approach needs to be easy for people to understand. You told us that reference to ‘social’ wellbeing may mean overlooking other important aspects of people’s lives.

“Social wellbeing = disconnecting from economic wellbeing, environmental wellbeing.”

“Review social wellbeing holistically – needs to be defined and understood what holistic wellbeing is for Pasifika, by Pasifika.”

Some of you questioned the appropriateness of referring to ‘investment’, commenting on its association with the government’s financial liabilities. Others noted that investment can refer to time, community development, workforce development, growth, opportunities, seed and support – which are positive things.

“Worries about definition of investment but agree with ‘social investment’ because it is channelling investment for where it is needed.”

What you told us about...protecting and using data

Collecting and sharing personal information

You told us that information should only be collected and used if it contributes to a person's wellbeing or the wellbeing of their community.

"Use it for the benefit of people and communities."

"Using data for benefit – sharing when it will help, but not when it will harm the person."

You told us that government agencies need to clearly and simply explain what people's information will be used for. People need to understand what information will be used by the provider to help them, and how, and what information will be used by others, and for what purpose.

"Clearly explain how their info would be used."

"Policy makers provide examples of how data is being used for benefit. If our organisations can show how data is being used to benefit your individual life, they may be more willing to provide data."

You emphasised the importance of building trust, establishing a relationship and having an ongoing conversation with people about how you can help them and will work together. You see this as essential to obtaining consent to collect and use personal information, and to working effectively with people and their families. Some of you highlighted the importance of continuing to check with people over time.

"Building relationships with people for information purposes...Relationship building also maintains trust with information."

"Sometimes it needs to be delayed to allow a trusting relationship to be formed between them and our staff."

You commented on the power imbalance between service users and providers, particularly government agencies. You told us that people may not be comfortable with providing consent, or with questioning their consent options. You drew attention to the role of history (for example, the legacy of dawn raids) in shaping how people feel about giving and sharing their information with government agencies.

"Sensitive information may not want to be shared for fear of negative consequences."

"Fear of information passed on to immigration."

You noted that repeatedly asking people to provide the same information is a burden to both service users and providers. You told us this makes people feel they have not been listened to, and they may 'disengage'.

"People have to share their story and information so much – but they don't get anything out of it – it becomes a tick box."

Tools and guidance

Some of you identified a need for guidance about collecting, sharing and accessing personal information. You told us that service users are confused, providers do not understand their obligation and responsibilities, and different professions approach confidentiality and privacy issues differently.

“Currently no guidelines, no consistency for sharing/synthesising data, no guidance on what is appropriate to gather, currently collect qualitative narrative but report most often on quantitative.”

You want to see clear principles and guidance – created with a Pacific lens – with practical examples that providers can use when talking with people about their personal information. You told us there should be guidelines for different audiences (agencies, service users) from different worldviews and in different languages and formats.

Your suggested topics for guidance:

- The different laws, what they mean for providers’ work and how they align with codes
- A clear way to explain the benefits and implications of data sharing
- How to figure out who needs to know what when sharing information
- Examples to share with families to help their understanding
- How and when to make data anonymous
- Best practice around data issues

You identified a need to build capacity to understand and use data from an appropriate cultural perspective, and to invest in ongoing training of Pacific providers to undertake their own research and analysis.

“Train us to be able to use and analyse the data we have.”

“Invest in the skills and capacity for us to do innovative things and research our work so we and everyone else can learn.”

You told us that providers require funding to develop their IT systems, with minimum standards or guidance, to ensure safe and reliable tools across the sector. Some of you suggested a centralised data system that all providers can use, or systems that can ‘talk to each other’.

“Infrastructure – how will people on different systems be able to talk to each other? Will all providers need to be able to fund and install systems, and will it be integrated with government systems?”

“Everyone should have access to minimum support standards for data security and tools (NGOs – community organisations).”

Governance and accountability

You told us that Pacific peoples should be involved in data governance. Pacific peoples want to have a say about how their data is used and by whom. You also want to see accountability back to families and communities for the use of data.

“Need to feedback results or show examples of how prior data have informed development or procurement of beneficial programmes.”

“Trust is important – data visibility is one way back and enacting reciprocity, but there is also a feeling of limited trust in the way some accountability measures are implemented.”

You identified a need for principles to guide data protection and use. Your suggestions include the following:

- Any collection and use of data should benefit people and their communities.
- The cultural value of data must be protected.
- Stories and experiences should be used in a way that maintains integrity and respects the person providing

them.

- Decisions about what to collect and why should be done with providers, communities and users – not just by government. Communities' priorities and needs should drive what is collected.
- Communities should have access to the knowledge that is created – having this knowledge is about empowering them to participate.
- We need to understand what is working, which requires evidence about what is being achieved.

Summary

How we engaged

Pacific providers were among those who participated in the hui for regional service providers. In addition, we held four hui to specifically explore the perspectives of Pacific peoples. The hui were held in South Auckland, Wellington and Christchurch. This section reflects what people told us at these hui.

What you told us at a glance

Investing for social wellbeing

1. You told us that concepts of wellbeing need to reflect Pacific views of wellbeing and recognise the diversity of views in different Pacific communities.
2. You highlighted the importance of family, community, church and relationships to Pacific peoples, as well as strengths-based approaches. You told us that trust-based relationships are needed between service users and providers.
3. You are looking for more respect for Pacific leadership, with a 'seat at the table' and a stronger role in designing solutions for your communities.
4. You want greater flexibility in contracts to do things differently, with longer-term funding that includes funding for training, research and evaluation, and information technology.
5. You support the use of a wider range of information to inform decision-making.

Protecting and using data

1. You told us that personal information should only be collected and used if it contributes to a person's wellbeing or the wellbeing of the community.
2. You are looking for clear and simple explanations for people about why their personal information is being collected and how it will be used, supported by tools and guidance for service providers.
3. You identified a need for better accountability to families and communities on how their data is used.

What you told us about...investing for social wellbeing

Understanding and measuring wellbeing

You told us that concepts of wellbeing need to reflect Pacific views of wellbeing, and recognise the diversity in what constitutes 'wellbeing' in different Pacific communities and families.

For Pacific peoples, wellbeing is multidimensional – it includes an important spiritual dimension, as well as thriving culture and language, and environmental aspects. Family, community, church and relationships all sit at the centre of wellbeing.

“A government-led definition and measurement may not capture what is important to our people.”

“What holistic wellbeing is for Pasifika by Pasifika.”

“Sovereignty of Pacific terms/values/cultural ideas.”

You emphasised that strengths-based models are important to Pacific peoples, which means looking at positive impacts as a key measure of wellbeing. It means focusing on how people and communities are flourishing, and the ways in which they are resilient, rather than focusing on deficits and what is not working for people.

“Need to focus on and maintain what’s going well e.g. the work we do to keep our kids off the radar. We need to avoid expressing those ideas in the language of deficit and need.”

“The focus has to be on families and communities achieving their goals, based in their views of their own wellbeing. Part of that is about not having to depend on services at all. If that is what is important – then that is what we should be measuring and assessing.”

You identified the opportunity to learn from a Pacific sense of wellbeing, commenting on the importance of strong interpersonal connections in helping people remain hopeful despite struggles in their daily lives.

You also told us that wellbeing needs to cover all ages and stages of life, and reflect the diversity of experiences for different people, for example, migrants, refugees and LGBTQI+ communities.

Working in partnership and building trust

From a Pacific perspective, relationships are at the core of any work across the sector – it is through relationships between providers, between government and providers and between workers and clients that enduring positive change is made. You told us that concepts such as Va are vital to understanding relationships for Pacific peoples – this refers to the sacred space of interconnections between people, and between the spiritual aspects of people and their environment.

For you, good relationships between workers and clients involve:

- Being honest and open
- Clearly talking to people about what you are doing
- Showing you care
- Understanding people’s culture
- Talking with people about the things that are important to them
- Being face to face
- Empowering people
- Being authentic.

You emphasised the need to be thinking about partnerships (plural) rather than partnership. There are diverse Pacific groups and one Pacific voice or ethnicity cannot speak for others.

“Need to appreciate that different Pacific groups need different things and need to respect cultural differences.”

“‘Pasifika’ as if it’s a homogenous group – this doesn’t put everyone on an even place because their uniqueness isn’t thought about. It limits thinking.”

You told us that Pacific leadership needs to be better valued, prioritised and respected. Pacific people want a ‘seat at the table’, and to be empowered to design solutions and be involved in making decisions that affect

their communities. You called for greater self-determination and a stronger role in setting government priorities, designing and implementing services, and collecting and using data.

“More collaborative co-design of policy e.g. policy makers learning from grassroots programmes – Healthy Lifestyle Pasifika. Agencies, people and providers working together i.e. not a dictatorship – hear our voices.”

“Community perspectives and priorities should determine what data is collected and not collected to determine Pasifika priorities.”

You consistently told us that the solutions to issues affecting Pacific communities lie within those communities – “E fofo e le alamea le alamea”. You told us that solutions for Pacific people should be created by Pacific people, working together to set the aspirations and priorities of the communities. Authentic co-design is required, based on Pacific ideas, values and concepts.

“Communities often know what they need; they just need help to access it.”

You identified a need to build trust among Pacific providers. You told us many providers are willing to believe that government agencies are there to support them but others feel they have been let down by the government in the past and are not confident it will not happen again.

“We love our partners but we do not trust them – [we must] think the same way – you’re asking us to be vulnerable – we could get hurt and let our communities down.”

“We had a co-design process for [social issue]. It was designed over 16 months – and the money dried up so it stopped. Built expectation in our community and now they don’t trust us.”

Making better use of a wide range of information

You support the use of a wider range of information, including both ‘hard data’ and qualitative information. You want more value placed on stories and qualitative information, which you see as providing important context and a richer understanding of how services are impacting on people’s lives.

“Use life stories to enrich evidence of what is happening to people and what they might need to change and what is working.”

“People are not numbers, stories create authentic data.”

“Narrative shows explanation behind data – good and bad.”

You see a need to focus on collecting information that helps to understand people’s strengths and resilience, and ‘what’s working’ for individuals, families and communities. You told us there needs to be better appreciation and protection of the cultural value of data.

Some of you told us that providers want to help create and use population-level data. For example, they want demographic information to help them understand the situation of their communities, including information on different ethnic groups.

Implementing a wellbeing approach

You have questions about how the investing for social wellbeing approach will be turned into practical change, and how the affected ‘sector’ will be defined.

Some of you told us that the approach will be working well when no one is turned away from receiving the help they need due to criteria, budgets or narrow contracting requirements. You also want to see more support for

early invention and prevention.

You raised many concerns with current funding and contracting models. You told us that:

- Pacific providers provide holistic support but funding comes in ‘silos’ from different organisations with firm boundaries on how it can be used. You want more flexibility to ‘seize the moment’ when faced with someone who needs help.
- Funding is often based on providing service to a person, but helping them often requires helping the wider family. You told us that many providers work beyond their funded contracts because it is the only way to meet a family’s needs.
- The contracting system can be difficult for providers and communities to navigate so those who ‘speak the language’ get the contracts. This does not necessarily result in the best services for Pacific peoples. You want more funding of services ‘for Pacific people by Pacific peoples.’
- Longer-term funding arrangements are needed to support the sustainability of services.
- Pacific providers struggle to keep good staff because of a lack of money for competitive salaries.
- Funding for innovation is needed. Current funding only provides for services already being delivered and does not enable providers to grow or try new things.
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- Communities should have access to the knowledge that is created – having this knowledge is about empowering them to participate.
- We need to understand what is working, which requires evidence about what is being achieved.

What Government agencies and other national organisations told us

Summary

How we engaged

We held 28 hui with national organisations, involving 246 participants.

The following government agencies participated in the hui: Ministry of Social Development, Te Puni Kōkiri, Ministry of Pacific Peoples, Housing New Zealand, Tertiary Education Commission, New Zealand Qualifications Authority, Ministry of Justice, Department of Internal Affairs, Oranga Tamariki, Department of Corrections, Ministry of Health, Ministry of Business, Innovation and Employment, Office for Disability Issues, Inland Revenue Department, Statistics New Zealand.

We met with the Privacy Commissioner, the Human Rights Commission, Office of the Children's Commissioner and the Education Council. We also attended a Te Mana Raraunga hui sponsored by Statistics New Zealand on Māori data sovereignty.

In addition, some national organisation staff were among those who responded to the surveys of non-service users.

What you told us at a glance

Investing for social wellbeing

1. You told us that a clear definition of wellbeing is needed, along with a description of the characteristics of wellbeing.
2. You are positive about the investing for social wellbeing approach in principle but have many questions about how it will be implemented in practice. You want to know what it means for your agency and how agencies work together.
3. You told us that the approach requires a big shift in the way that government agencies and the wider social sector work – in skills, culture and resources.

Protecting and using data

1. You identified a need for shared principles to guide the collection and use of personal information. As general principle, you told us that information should only be collected for the purpose of benefiting service users.
2. You told us that tools, guidance and 'upskilling' of staff are required to support good practices for collecting, storing and sharing information.
3. Some of you identified scope for better sharing of data and insights with service providers, and jointly identifying priorities for research and analysis.

What you told us about...investing for social wellbeing

Key principles and concepts

You are positive about the investing for social wellbeing approach in principle but have questions about how it will be implemented in practice (discussed below). Many of you told us that you are already incorporating aspects of the approach in your organisations, or that it aligns well with your organisational values.

“Conceptually the approach is awesome, pragmatically there might be some implementation issue.”

“Fundamentally can agree in principle to four factors but the challenge is to make it work for each agency and across agencies.”

“This already resonates with [agency’s] strategic direction...”

“The approach connects with [agency] work in terms of wellbeing focus, the partnerships narrative.”

You told us that a clear definition of wellbeing is needed, along with a description of the characteristics of wellbeing. Some of you suggest drawing on existing models and frameworks of wellbeing, including Māori and Pacific frameworks for understanding and measuring wellbeing.

“What’s the definition of social wellbeing? Doesn’t reflect individuals cultural and personal perspective of wellbeing.”

“Doesn’t reflect greater importance of ‘cultural wellbeing’ within which ‘social wellbeing’ comes next.”

“There are multiple wellbeing frameworks being worked on i.e. living standards, MSD welfare reform, Whānau Ora review. These create competition.”

Some of you questioned what being person-centred means in practice. Others commented on the power imbalance between government agencies and the people they serve, and the need to better engage and listen to service users. Some of you told us that the approach should be whānau-centred and person-centred.

“We [government agencies] talk about being customer centric for our own agencies – but what is being customer centric as a public service when the same person interacts with lots of different agencies and they are all ‘the government’?”

“Talk to service users, talk to service providers, if we are talking social wellbeing, we’re not just talking services. The bigger picture requires an enabling environment/ecosystem so that people can make the best decisions for themselves.”

“It’s ‘whānau’ not ‘people’ at the centre.”

You see benefit in using data and information to provide better outcomes for New Zealanders. You generally support using a wider range of information to inform decision-making, but have questions about how people’s experiences and stories can be captured and integrated with other data.

“Enables better information and more effective interventions.”

“Agree that telling the stories is so important – numbers have never shown everything.”

“Heart based dialogues don’t lend themselves to big data collection. We need to find the balance in how we understand people experiences so neither big data, nor heart doesn’t get in the way of a complete picture.”

“Would be helpful to have ‘tools’ to align with other agencies how & what is collected.”

“We need to ensure that we’re collecting the important stuff well.”

You have mixed views on the concept of ‘investing’. Some of you consider that the term is too limiting; others like the term and see it as a way of directing resource in expectation of positive outcomes. One suggestion is to place more emphasis on the social (rather than financial) return on investment.

“The language change from the ‘old’ social investment is good it’s more human, gentler, and more interpersonal, but still has a way to go.”

“The word investing is confusing in this context.”

Some of you identified things you consider are missing from the approach. These include reference to Treaty of Waitangi obligations and principles, acknowledgement of alternative sources of investment (such as philanthropic organisations and the private sector) and a more visible emphasis on a strengths-based approach that balances both risk and resilience factors affecting people’s lives.

Implementing a wellbeing approach

Much of your feedback related to implementation of the approach. You are looking for more detail about how the approach will be put into practice. You want to know what this means for your agency and how agencies work together.

“The challenge is seen as turning these words into practice. Acknowledging that this isn’t the first time this kind of thing has been tried so what is working/has worked, what can we learn from and just do differently?”

“The smell of motherhood and apple pie, but is it real?”

“This is either a fundamental change of the machinery of government OR its principles that agencies aspire to within the existing system. So which is it?”

In particular, you want to know:

- who is going to own and lead the approach
- what that means for the ownership and leadership of specific interventions
- where and how resources will be spent
- whether the approach is a long-term initiative and will endure across governments
- what the approach means for agency budgets, and how shared funding arrangements might work
- how the success of the approach will be measured
- what change management and transition planning arrangements will be put in place to make it happen.

“Detail on how it will actually change anything and be put into practice – what will success look like? What will we see differently operationally?”

“How will the balance of power shift to really let partnership happen?”

“Prioritisation and focus – agencies have other priorities over and above [investing for social wellbeing]. How will prioritisations occur? Where will government put its money? What is the role of each agency?”

“Accountability is missing. How will agencies be held to account to make this happen and to work on the same page and goals? There are lots of examples where agencies and CEs just ignore what they agreed to do in their own interests. We use the terms but don’t actually act in that way.”

You told us that the approach requires a big shift in the way that government agencies and the wider social sector work – in skills, culture and resources. Some of you questioned whether change is achievable.

“Acknowledge people and agencies self interest in the current system, this will make it difficult to change – people are very invested in ‘how they have always done things’.”

“We need to look at the structure of government services. They are broken into functional capabilities now – that structure is going to be very hard to change. I’m not sure there’s the know how in government to know how that can be done.”

“Shared outcomes and goals is a challenging thing to do – implementation of joined up agencies at a system level won’t work.”

“Joined up goals across government are difficult to implement because different agencies have different needs for data, access to data and use it differently. This is a barrier to implementation, e.g. results-based accountability contracts across agencies with different goals are difficult to manage / implement.”

Many of you emphasised the role of communities in identifying solutions and helping bring about change to people’s lives. You want government to work more closely with communities to develop solutions.

“Sometimes the government’s role is to ‘get out of the way’ and let ideas grow and prosper without being so directive.”

“We need to better enable and support NGOs to do the right thing – contracts often mean they can’t practice in the way that could make a difference. Doing ‘work-arounds’ to be able to do the right thing.”

“The solutions might look different in different communities and there needs to be room in [investing for social wellbeing] for this. It’s not a cookie cutter solution.”

Some of you identified a need for staff training and development to enable agencies and providers to make better use of data and information. Others noted that the way information is currently collected may not align well with the approach.

“We may need to think of a different way to interpret and analyse qualitative data. Our current processes won’t work with the [investing for social wellbeing] approach.”

“Need for some robust approaches to tie service responses/interventions to data sets – reduce bias and subjective judgements.”

You also told us that providers need adequate funding to enable them to invest in appropriate infrastructure for collecting quality data, and to meet reporting requirements.

“The responsibility we place on our frontline staff to collect information and spend time with their clients is not right, there’s better ways to collect information and take the burden off our staff.”

“We are naïve about the ‘digital exhaust’ and forget about the collection issues and burden facing frontline staff and NGOs.”

What you told us about...protecting and using data

Principles to guide collection and use of data

You identified a need for shared principles to guide the collection and use of data across the sector – by both government agencies and non-government providers.

You told us that being clear about the purpose of collecting and using information is essential to determining what information is collected and how it may be used. You emphasised the value of focusing on good quality information that meets a specific purpose, rather than ‘blanket’ approaches that gather a lot of information for multiple uses.

“We over collect because we haven’t defined what the purpose of collecting is.”

“Move away from ‘more is better.’”

“Is govt really clear on what info is actually needed and why?”

As a general principle, you told us that information should only be collected for the purpose of benefiting service users.

“As a principle it’s all about ‘do no harm’.”

You raised concerns about current processes for obtaining consent from people to collect and share their personal information. You expressed concern that people do not understand what they are consenting to or what their options are, and that people do not feel they have a real choice when accessing services. You identified multiple barriers to providing genuine consent including language, culture, the volume of material people are presented with, automatic ‘opt-in’ processes and the power imbalance, particularly with government agencies.

“No one reads the privacy statements in enrolment forms. This means we can feel transparent but are we actually doing that? We just assume people read it.”

“If you want a service, you need to give consent”

Some of you told us that consent is not always a straight ‘yes’ or ‘no’. For example, providing information to determine eligibility for a service might be acceptable, but use of that information for research purposes might not be.

“Need to distinguish between info needed for primary use (service delivery) and for secondary use (evaluation) – different consents may be needed.”

Others commented on the need to consider the ‘life cycle’ of consent, and clarify how often providers need to check back with people and get their consent again for a new use of information.

Some of you identify a tension between empowering people to make their own choices about what information they provide and share, and the broader societal need for information to support analysis and research on effective social services.

“There is a distinction between baseline information needed to give a service and all the additional uses – the common good. Are we saying people can / should opt in to both?”

Sharing personal information

At the individual level, you told us that government agencies are not always good at sharing information with each other, or with non-government organisations. You commented that agencies do not help each other, which means that they are not helping the client. A shared approach to information sharing is needed to avoid agencies ‘locking down’ information.

“There is a lack of trust with sharing information with other agencies because there isn’t a common goal/purpose for how data is used.”

“Lack of appropriate information sharing isn’t just about a technical solution it’s also about behaviour and culture – it’s hard for people to get the balance between over and under sharing when working as part of a team with children and families. Frontline staff need help and guidance about this – they are afraid of getting it wrong and over sharing.”

You also told us that government agencies need to get better at sharing people’s information back with them and helping them to access it.

Sharing insights and identifying data needs

You told us that developing a shared understanding and strengthening data practices require government agencies to improve their relationships with providers and communities. Agencies need to build trust, and be prepared to ‘co-design’ systems for collecting and using data so they meet everyone’s needs.

“Currently there can be a mismatch between what groups need (in terms of data) to measure progress and what is collected. For [agencies] this means we need to understand and collaborate up front. There is sometimes a tension between what we collect based on international reporting and what’s important on the ground.”

Some of you told us that government agencies need to better explain and share the value that they get from data. Government agencies need to proactively share research, data and insights with non-government organisations, community groups and other agencies, and make research findings publicly available.

Some of you commented that communities would be better placed to make their own decisions if agencies provided them with more information and support to understand their communities.

“Not enough info/data goes back to those who provided the info/data. Because the value of whānau having that info could create changes that could be bigger than what government could do.”

“NGOs feel they can’t do such a good of a job, because they are not getting the information that will help them do a good job.”

You also said that government agencies should ask service users and providers what research and analysis would be helpful for them. You suggested that a more equitable conversation would provide government with a better understanding of the wants and needs of communities and non-government organisations.

“If you want to share value go to providers and ask them is valuable to them. Ask the service users too! They don’t hear anything back either.”

“Compared to NGOs government agencies have massive research, evaluation and data analysis capability – but we don’t share that – how can we do the work they would find useful? How can we give information back that they need?”

Tools and guidance

You told us there is a need to ‘upskill’ staff across government and non-government agencies to ensure a common understanding of privacy laws, and support good practices for collecting, storing and sharing information. You identified inconsistencies in practice and a lack of knowledge and use of existing guidance (for example, Office of the Privacy Commissioner guidance).

Suggestions for tools and guidance include:

- tools to navigate the multiple codes of practice already in place
- guidance on the age and circumstances in which children can give consent, and how a child or young person’s right to privacy should be balanced with the parent’s right or need to know
- simple explanatory material for service users, provided in different formats and languages
- use of technology to simplify consent processes or to enable better sharing of personal information across agencies and reduce the number of times a person is required to ‘tell their story’ (for example, a common database IT platform used by government and non-government organisations)
- guidance for providers on how to correctly identify, match and de-identify data, so they can provide information to government and undertake their own research and analysis
- common data definitions to improve the quality of information collected
- guidance and skills development for government and non-government organisations on understanding and interpreting research findings
- a ‘hub’ for sharing research and publications across government and/or the wider sector.

Implementing a Data Protection and Use Policy

You see a Data Protection and Use Policy as an opportunity to identify and fix what is not working, but note that it will require a big cultural shift in government agencies. You told us that a change management strategy is required, along with the capacity, tools and resources to enable implementation. Some of you identify a need to consider the cultural lens applied to implementation options (for example, a kaupapa Māori framework).

“There will be cultural issues to deal with across some agencies.”

“Consider what are the transition costs and time – make sure adequate time and resources is given to changing.”

“A lot of providers will struggle to meet requirements or have the capability – the risk is that only the large NGOS will ‘make it’ which isn’t good for anyone. Therefore need to fund.”

You told us that policy should be relevant to organisations, but the emphasis should be on what the policy means for individuals and their communities. You consider that the policy should apply in the same way to all organisations, with flexibility to accommodate rapidly changing views of data and technological change.

“Make sure agencies consistently adopt – or it will create more confusion.”

“It has to be about everyone in the sector, not just government.”

Some of you favour a strong enforcement approach to implementation – for example, through legislative requirements, compulsory codes, an ombudsman or watchdog role, reporting requirements or using funding as a

lever. Others consider such approaches lead to 'token compliance' and prefer creating incentives for change and persuading people of the value of the policy.

"You've got a sales job – you need firm guidelines, sanctions to back it up and big launch so that citizen knows that if my rights are violated, I can complain to someone and they will sort it out for me."

"Given the history and level of distrust a 'hard' option won't help. At the core of this issue is trust – so fixes need to be relationships based not mandated."

Some of you suggest considering the Government Chief Data Steward's role in relation to the policy.

Where to from here?

Throughout the engagement we consistently heard that you want a different kind of relationship across the sector. You told us that to provide services that better meet people's needs, communities need to be empowered to design and deliver local solutions that work. You told us you are looking for funding and contracting models that promote innovative practice. You identified a need to build the skills and capacity of the workforce to implement a wellbeing approach. You want to ensure that sharing data, information and insights is a two-way street for all those involved.

What you told us points to a significant opportunity the Government shares with the social sector, to do what works for better lives.

We've published this report because it's important more New Zealanders know what you told us about Government's approach to investing for social wellbeing, and how the social sector uses data. Importantly, we've published this report before Cabinet considers the findings of the engagement, and ahead of Government considering its approach to investing for wellbeing. What you told us will inform that approach. What you told us will also inform a draft Data Protection and Use Policy. At the time of publication, we are working with non-government organisations and government agencies to develop options for 'rules and tools' to enable improved protection and use of data across the sector. We plan to take these options to Cabinet in early 2019, and to follow this with a public consultation process. We will publish the final policy, when ready, online.

So many of you were generous with your time and spoke frankly about your views and experiences.

Kia ora and thank you all.

Glossary

Data: Facts and statistics collected for reference or analysis. Data may be qualitative (information that describes a topic rather than measuring it – for instance stories, opinions, attitudes or impressions) or quantitative (facts that can be measured and written down using numbers).

Hui: Gathering, meeting; to gather, meet

IDI: Integrated Data Infrastructure, a large research database containing data about people and households. Data is from a range of government agencies, Statistics NZ surveys including the 2013 Census, and non-government organisations. Researchers use the IDI to answer complex questions to improve outcomes for New Zealanders.

Kaitiaki: A steward or caretaker

Kaitiakitanga: The act or process of taking care of something

Kaupapa: A purpose, cause or important thing, idea, theme or piece of work

Kaupapa tuku iho: Something important like a process or an idea that has been inherited

Kawa: Process or approach, particularly tribal in nature

LGBTQI+: Refers to persons or their community identifying as Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, or Intersex

Mana: Influence, importance, prestige

Manaakitanga: Caring for or looking after others. It literally means nurturing the importance of others

Mokopuna: Grandchildren

NGO: Non-government organisation; may be funded or part-funded by government to provide social services

Pūrākau: Stories

Pūtea: Fund, sum of money

Rāhui: A process whereby you restrict access to a place or a thing due to an event or situation

Raupatu: Land confiscation by the Crown

Service provider: Government agencies, NGOs and private organisations that provide social services

Service user: A person who uses social services

Tamariki: Children

Taonga: Treasure, something special, precious or prized

Tapu: Special, sacred, restricted

Te Ao Māori: Maori world, as in view

Tikanga: Custom, practice

Tinana: Body, person

Tino rangatiratanga: Authority, power

Whakapapa: Genealogy

Whānau: Extended family

Thanks

You were generous with your time and spoke frankly about your views and experiences. We appreciate that.

We also acknowledge the many people who helped us to organise the hui around the country.

“I want to thank you all for taking the time to talk with us. Improving the wellbeing of New Zealanders is a priority for the government. We want to make sure we have the right supports in place, and are working with the social sector in the right ways. It is therefore essential that we hear the voices of those who use social services and those working to support people every day. You have given us a lot to think about and I look forward to sharing our ideas on next steps soon.”

Hon Carmel Sepuloni, Minister for Social Development

“For me, the engagement provided a valuable opportunity to meet people and understand what is important to you and your communities. You shared your stories, your successes and your frustrations. You gave us an insight into the challenges you face and the things that need to change. Your knowledge is a true gift and I thank you for sharing it with us.”

Dorothy Adams, Acting Chief Executive, Social Wellbeing Agency

From all of us...**KIA ORA** and **THANKS**.