

Foreword

We know that more effective data use and sharing in New Zealand will generate a wide range of benefits for the country. Not only will this include the additional economic value but improved use of data will help to ensure our institutions are more accountable, public services are more efficient, and Government spending is better targeted. Private companies can also use data to better understand consumer behaviour and tailor products to suit our needs.

Many organisations (across the public and private sectors) are already using data extensively, but their operating environment and the relevant rules and regulations, are not widely understood by the general population. Indeed there is even a lot of misunderstanding on the part of organisations collecting data around the actual requirements of existing legislation.

While the Partnership works to champion increased data use in New Zealand, we also understand people's concerns. There are important questions around privacy and security and potential misuse of data which must be addressed by those seeking to use people's personal information. Making sure we have the right kinds of protections in place will help create an environment where data can be safely and sustainably used.

The Data Futures Partnership has been tasked by the Government to draft guidelines which public and private organisations can use to develop a "social licence" for data use. These guidelines will set out the ways in which those working with data can build confidence by using data safely and in a way that will be of benefit to individuals and the wider public. Our guidelines, which we hope to draft by the end of 2016, will seek to address people's key concerns and set out steps organisations should take to use data in a way that is understood and trusted by individuals.

We are clear that that the guidelines we draft must be built on the views of New Zealanders. That is why we will be having conversations with people across the country – not just those who work on these issues every day. Through workshops, seminars and social media we will test people's preferences and tolerance and examine the measures that need to be in place for them to be comfortable sharing their data.

The Partnership will use what we learn to inform our work as we draft the social licence guidelines. It is our expectation that the drafting of the guidelines will be an iterative process. We will consult and continue listening to New Zealanders throughout the drafting exercise.

I am looking forward to meeting people across New Zealand and listening to what they have to say.

Dame Diane Robertson

Chair – Data Futures Partnership



Introduction

The Data Futures Partnership wants to engage with New Zealanders and have meaningful conversations about the ways in which data can be used and shared. We know that effective data use presents New Zealand with exciting opportunities with wide reaching benefits. But there are also challenges and big questions which need to be considered. The Partnership is exploring these issues and supporting New Zealand into becoming a world leader in the trusted use of shared data to deliver a prosperous, inclusive society.

What is 'social licence'?

When people trust that their data will be used as they have agreed, and accept that enough value will be created, they are likely to be more comfortable with its use. This acceptance is referred to as a social licence.

Social licence is dynamic and the level of acceptance can change over time, or indeed be suddenly lost. It is particularly dependent on the extent of trust the subjects hold in the data user, and their acceptance of the particular data uses.

Our Goal

The Partnership is not seeking to develop a social licence for all data use across the whole of New Zealand. This would be impossible. Social licence cannot be forced on individual people and organisations. It must be developed for different data use situations and is dependent upon the risks and values involved.

Instead, the Partnership will use what it learns through its conversations with New Zealanders to propose a set of guidelines. It is envisaged that these will include a set of principles which should apply when personal data is used and can be easily understood by users as well as the subject of data.

The guidelines will set out steps organisations working with data should take to build a social licence.

Our approach – topics and principles

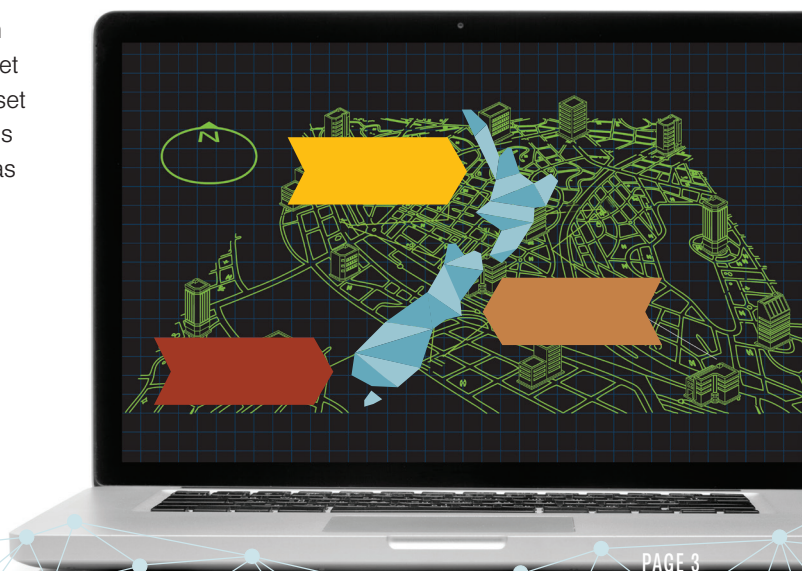
The sharing of data and how it is used is a complex issue which is the focus of lots of academic debate and high-level discourse. As a result, discussions about the subject risk excluding ordinary New Zealanders – despite the fact that it is often data about them that is at stake.

The Partnership is committed to having meaningful discussions about data in a way that enables those without expert prior knowledge to participate. We recognise that everyone shares personal information and regularly interacts with organisations requesting more data about them. It is therefore vital that a broad cross-section of New Zealanders are able to participate fully in our conversations.

To have meaningful conversations with New Zealanders, the Partnership has decided to choose three topics and use these to explore the value of data use and understand people's concerns. Through these topics we aim to explore questions in a way that is tangible and relates to people's daily lives.

Through these topics the Partnership will work to focus the discussions around its four principles; trust, control, value and inclusion as well as identifying key themes which emerge as the conversations progress.

The topics selected relate to live issues which highlight the potential value of data innovation, but also test people's tolerance around how their data is shared and used.



The topics

The topics selected by the Partnership's working group are:

Social Investment

By using data the Government has an opportunity to use public money more effectively and spend it on interventions which are likely to be more successful and save taxpayers' money in the longer-term.

Social investment refers to work led by the Social Investment Unit, a cross-agency team, to exchange data about at risk people to target effective social support.

The social investment approach should be seen in the context of government activity undertaken on the basis of a return on investment justification – in other words, looking at the long term impacts of social sector programmes and spending, and identifying ways to make sure spending and interventions make a real difference. Under such an approach, funding is made available on the basis of:

- » data quantifying the issue or challenge
- » the likelihood of the proposed interventions addressing the issue or challenge
- » measurement and reporting to decision-makers on the outcomes achieved by the interventions to enable calculation of the benefits¹

Social investment involves exchanging data held by government and non-government agencies including health, education, justice sector and social sector data.

“We need to get much clearer about what our rules are so that we can deliver better services but people can feel confident that their data is being used appropriately.”

Hon Bill English, 19 April 2016

Giving community organisations and iwi access to government held data could allow them to work with clients more effectively and deliver improved outcomes for communities. This may also save taxpayers' money with funding being more effectively targeted. But others worry about the security of such sensitive data, and whether this might result in fewer resources being available to support vulnerable people.

¹ KPMG, Social investment for our future, 2016



Sharing Health Data

Effective data use and sharing could prove revolutionary in the way health care is delivered and lead to exciting breakthroughs in medical research.

Personal health data is wider than just the medical records kept by health professionals. It includes data collected by individuals, by devices such as fitbits and smart phones, in research contexts, and by insurance companies or other third parties. Genomic information, behavioural data, and relevant environmental information also form part of the complex health data ecosystem.

The sharing of such data can pave the way for more personalised health care, enable individuals to make better-informed lifestyle choices, and help researchers to develop new treatments. But for many people, health data is deeply personal and they are nervous about it being shared – even if it has been anonymised.

“As we begin to generate our own health data, our relationship with our bodies will change, and the way we understand and seek healthcare will be transformed.”

The Guardian, 17 May 2016

The development of the Fitbit has enabled people to monitor their lifestyle. The information collected could also be shared with health services to support clinicians and also strengthen medical research. However, the same data could also potentially be used by insurance companies to make assumptions about people's lifestyles and provide cover accordingly.

Internet of things

The Internet of Things refers to the increasing array of previously offline devices, such as TVs, fridges, cameras, sensors and wearable devices that are now connected to the Internet, as well as smartphones that collect and exchange data from diverse locations. This includes, for example, smart environmental monitoring, intelligent lighting and connected vehicles. It has been estimated that by 2020 there will be over 26 billion connected devices.²

On a broader scale, the Internet of Things can be applied to things like transportation networks: “smart cities” which could help reduce waste and improve efficiency.

“Businesses that operate in a trusted way can pass on the benefits to society as a whole, and give an improved user experience and product to the individual. That sounds like a reasonable trade.”

Computer Weekly, June 2015

“The internet of things represents a major data opportunity ... there's just no other data opportunity that comes close.”

Nova Spivack, Chief Executive of Bottlenose

The development of driverless cars is very exciting. They present the opportunity to create more efficient and safer transport systems. But what will happen if things go wrong? Imagine a driverless car collides with a pedestrian. Who would be to blame? Perhaps the programmers who wrote the computer algorithms?

² See Gartner press release <http://www.gartner.com/newsroom/id/3165317> (November 2015)

Our principles

The Partnership will be guided by its four key principles to explore big questions:

Value

Effective data use and sharing can benefit individual people's lives as well as wider society. When people understand this value, they are more likely to be prepared to share their data.

We will explore:

- » What benefits do New Zealanders and New Zealand organisations expect from increased data use?
- » How can data make a difference to people's lives (benefits and disadvantages)?
- » What benefits are New Zealanders seeking from data use?
- » What trade-offs are people are willing to make in different contexts?

Inclusion

All parts of New Zealand society should have the opportunity to benefit from data use. When incomplete data sets are used or particular groups of people are excluded from the data collection, poor decisions may be made.

We will explore:

- » Who's missing from New Zealand's data eco-system?
- » How much do people know about the data environment?
- » How people would like to be involved?
- » How would people like to access data?
- » What's needed to make data accessible to different groups?

Trust

Data management in New Zealand should build trust and confidence in our institutions. Data breaches can undermine trust and reduce people's willingness to share their data. But people also need to understand the purpose of sharing their data and the implications of doing so.

We will explore:

- » What does responsible data use look like?
- » What would people like to know about data projects?
- » What happens if something goes wrong?
- » The factors that might impact on trust such as the end use of data, the type of data, who holds the data, transparency.
- » How easy is it to correct data when it's inaccurate?
- » What are the risks to privacy and how can they be addressed?

Control

Individuals should have greater control over the use of data about them. In different situations, people expect to have different levels of control over how their data is used. In some cases, people are comfortable with others to make decisions affecting the use of data about them.

We will explore:

- » What is meant by 'informed consent'?
- » When are individuals able to opt out of a data sharing arrangement?
- » What do individuals and organisations consider to be sensitive data?
- » What kinds of control do people and organisations want to have over personal data and other types of data?
- » In what circumstances are people happy for others to make decisions on data about them?
- » What is the impact of different situations on the kind of control people want?

Māori values

Engagement with Māori will be an integral element of our work.

Particular Māori values that relate to a trusted data-use ecosystem include:

Manaakitanga

Data users show mutual respect. Through the exercise of reciprocal rights and responsibilities, access and use of data is for the benefit and well-being of all New Zealanders.

Kaitiakitanga

All New Zealanders become the guardians of our taonga by making sure that all data uses are managed in a highly trusted, inclusive and protected way.

Other Issues

The Partnership has also identified a number of other important issues which cut across the chosen topics. Through its engagement, the Partnership hopes to delve into these issues and discuss them with New Zealanders

This includes:

Re-identification

- » One issue with data sharing is the potential of previously anonymised data to be accidentally or intentionally “re-identified” – that is linked back to the individual. So we want to talk to New Zealanders about where they think the right balance is between sharing data for the country’s benefit and privacy rights of individuals.

Data sovereignty and extra-territoriality

- » Cloud-based (online) data storage is a simple and affordable way to store data (as opposed to hardware data storage). But if the cloud-based software is hosted outside of New Zealand, that data would be privy to the laws and jurisdictions in that country. For example, the Patriot Act in the US can oblige any organisation with a presence in the US to secretly release information to US authorities. With that in mind, what type of data are New Zealanders comfortable with being hosted overseas?

The New Zealand Government recently passed legislation enabling IRD to share data with the Australian Tax Office who are then able to provide IRD with the contact details of Kiwi student loan borrowers living in Australia. Governments and private companies are now sharing personal data across national boundaries.

Next steps

We have three paths of engagement:

Online

Initiating and participating in online conversations about data sharing.

Evidence gathering

Commission a series of workshops and/or focus groups to explore people’s views on data sharing in depth.

Road show

Members of the Working Group will be travelling around the country and engaging with a broad cross-section of New Zealanders via workshops, seminars and community events.

A record of all our engagement activity will be made and published. If you are holding an event and would like a working group member to speak, please let us know. We are also keen to meet with organisations and groups grappling with some of the challenges posed by data – do get in touch if you’d be interested in meeting with us.

About the partnership



The Data Futures Partnership was established by the New Zealand Government in October 2015 and has two key objectives:

1. To create the right environment for trusted data use in New Zealand – by building a forum for different voices to come together to identify and resolve issues and build trust in the data-use ecosystem.
2. To increase the value being generated by New Zealand's data-use ecosystem – by facilitating catalyst projects, brokering and stimulating more data-driven innovation, and solving system problems.

We operate through four interlinked work streams:

Work stream	Summary
Catalysts	Data-use projects that address real-world problems, demonstrate value and generate system learning.
Social licence	An inclusive, two-way and balanced conversation to clarify the issues and inform the drafting of guidelines for public and private organisations to support them to develop a social licence for data use.
Diagnose & fix	Independent advice to inform policy and practice, interventions for key problems in the data eco-system.
Champion	Broker and stimulate increased data sharing and use.

Who we are



**Dame Diane Robertson
(Chair)**

Diane is a successful social sector entrepreneur, giving her a unique combination of strong business and financial skills with strong social sector credentials. She is a former City Missioner at the Auckland City Mission.



Stephen England-Hall

CEO of Loyalty NZ, and a member of the Cambridge University Vice-Chancellor's Advisory Board on Communications.



Lillian Grace

CEO and Founder of Figure.NZ, the first organisation globally to designate everyone as a user of data and to build systems and software to deliver to this standard.



Tina Porou

Of Ngati Porou and Ngati Tuwharetoa descent, Tina is the Head of Sustainability at Contact Energy.



Professor Rhema Vaithianathan

A Professor in Economics at the Auckland University of Technology and a Senior Research Fellow and Visiting Professor at the Singapore Management University.



Professor Miriam Lips

Professor of Digital Government at Victoria University of Wellington's School of Government.



**John Whitehead
(Special Advisor to the Chair)**

John chaired the Data Futures Forum and is a former Secretary to the Treasury, and distinguished public servant.

Get in touch

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We issue a regular e-newsletter to keep people up to date with our work. You can sign-up on our website.

