



Just because you can, it doesn't mean you should

Dame Diane Robertson
Chair, Data Futures Partnership
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Children 'not lab-rats' - Anne Tolley
intervenes in child abuse experiment
stuff

Government demands non-profit clients'
personal data before releasing funds

**THE
DOMINION
POST**

Prisons turn to computer algorithms for deciding
who to parole

THE VERGE

How Target knows when its
shoppers are pregnant - and
figured out a teen was
before her father did

Daily **Mail**
AUSTRALIA

Samaritans Twitter app identifying
user's moods criticised as invasive

theguardian

Introduce concept of social licence – there are lots of things that can be done (legally etc.), but are they right?



Ebola: Can big data analytics help contain its spread?



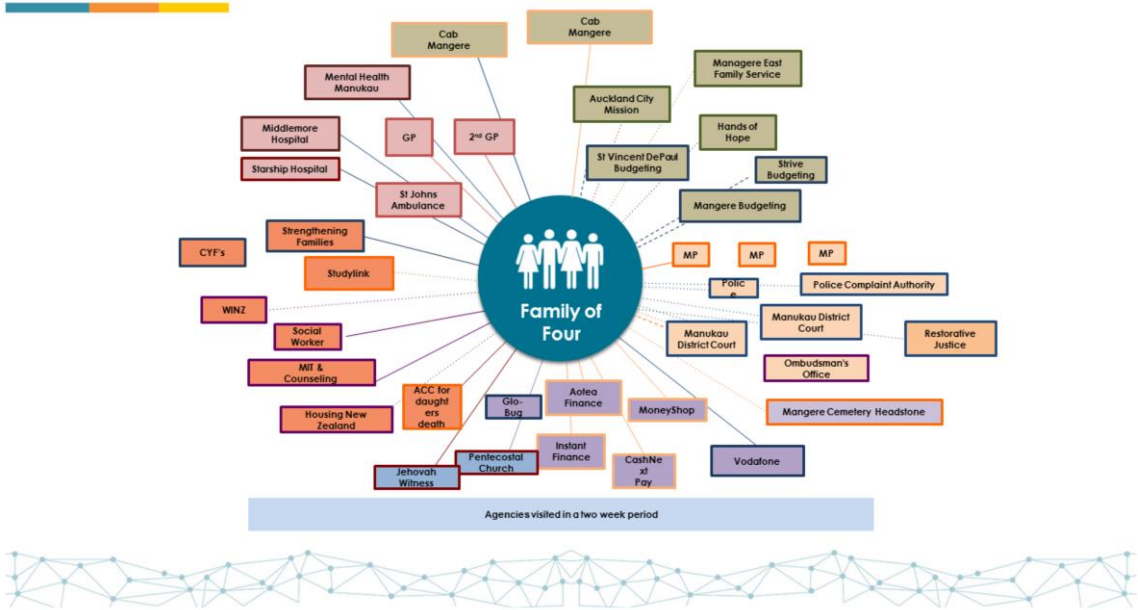
Up to Half of U.S. Premature Deaths Are Preventable; Behavioral Factors Key



When you get it right – the benefits are clear

Positive examples:

- Southern District Healthboard – worked with practitioners and patients
- Ebola – using mobile phone data to understand spread and put interventions in place to save lives
- Premature Death of babies – analysing big data to understand factors and then design appropriate interventions



Why does this matter?

Passionate about the power of data and how trusted data sharing can be used to change lives for the better.

Value and problem



The Data Futures Partnership



Dame Diane Robertson (Chair)



Stephen England-Hall



Lillian Grace



Tina Porou



Professor Rhema Vaithianathan



Professor Miriam Lips



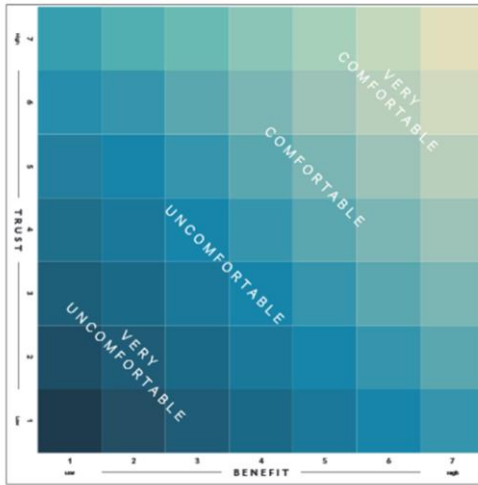
John Whitehead
(Special Advisor to the Chair)

Setup to strengthen NZ's data – trusted data use is an important part of this
Engaging with New Zealanders to develop social licence guidelines



How do New Zealanders feel about their data being used and shared?





27 workshops involving 400 New Zealanders:

From Invercargill to Whangarei
A broad cross-section of people (Pasifika, rural/urban, homeless, school students, older people)

4,000 people online

An additional Maori engagement work stream is underway

Used 3 hypothetical data-use scenarios:

- Medical data
- Education records
- Smart street lighting

- Explored people’s comfort levels and how they weigh-up trust/benefit
- Identified areas of common ground



Emerging Themes

- Purpose
- Value
- Use
- Control
- Security
- Transparency
- Governance



Why will data be used and/or shared?

- Purpose (now and future)
- Evidence and examples of benefits
- Evidence that data is the best way

What

What specific data is required

Who

- Organisation
- Criteria for selection
- Public benefit v profit

Sound use of data to make decisions

Qualifications of people using the data

Processes and controls

Security and access protocols

Governance

An independent authority that deals with complaints and breaches

Compliance

- Penalties for breaches
- Audit (evidence that data is being used as it should)

Visibility and control

Visibility of how data is used and shared

What info is held and how is it being used

Ability to access audit trail of information used and shared

Control

- Informed consent (and ability to remove permission)
- Time limits on permission

Governance

An independent authority that deals with complaints a



Genuine engagement



Feedback from people who did the online survey and participated in the workshops was overwhelmingly in favour of the workshops

Local data = local decision making

Engagement:

Must be genuine engagement – face to face
Avoid assumptions about which people will engage

Our data

Putting people first

Local data, local decision making

Genuine community involvement

Public good comes before profit

Scepticism about anonymization

Putting people first

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Public good comes before profit

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Conclusion

Just because you *can*, it doesn't mean you *shouldn't*

- What's the value?
- What's the risk?
- Collect the right data

