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Te Whare Wānanga o Tāmaki Makaurau  
NEW ZEALAND

# Surveys, social licence and the IDI

A collaborative project between  
The University of Auckland

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Statistics New Zealand

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Co-funded by the Data Futures Partnership

7 Dec 2016

# Structure of workshop

1. Background and introduction
2. Social licence
3. Results of interviews and focus groups
4. Results from Maori participants
5. Workshop
6. Summaries and wrap-up

I need coffee...  
Lots and lots and lots  
of coffee, with a cake  
and possibly some  
cookies.



# Why undertake this research?

- There is a strong push from central government for the inclusion of population-based surveys into the integrated infrastructure (IDI)
- The practicalities of inclusion raise anxiety levels for academic researchers due to:
  - The need to hand over data
  - Uncertainty over future use
  - Concern over impact on response rates



# The importance of ethics committees in university research

The University of Auckland Human Participant Ethics Policy:

*“No project involving human participants can be carried out by staff or students of The University of Auckland without the approval of The University of Auckland Human Participants Ethics Committee”*

The University of Auckland Code of Conduct in Research:

*“The Education Act 1989 protects the academic freedom of academic staff and students to undertake research, but this academic freedom is predicated on the need to maintain the highest ethical standards”*



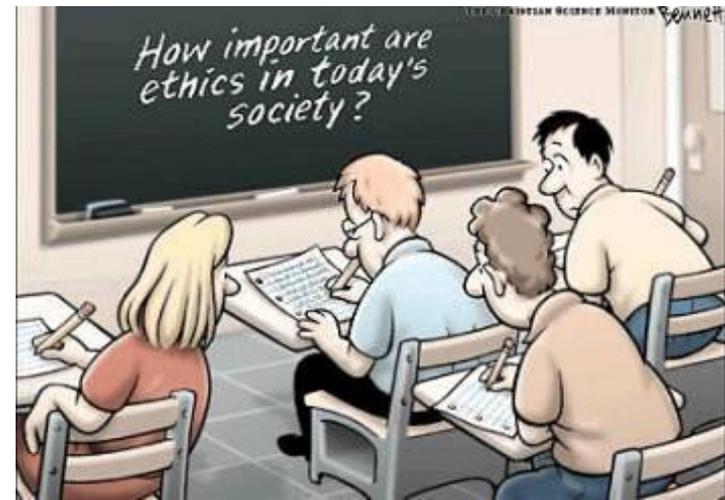
# Key ethics requirements

**(i)Autonomy** Participants should freely consent to their participation in the research

**(ii)Beneficence** acting in the public good; it includes all actions which are intended to promote the good of other people.

**(iii)Non-maleficence** research should minimise and manage risks of harm, such as the risk of physical or psychological harm

**(iv)Justice** researchers have a duty to ensure that the benefits of their research are achieved through just means; that the benefits and burdens of research are fairly distributed; and that there is fair treatment in the recruitment of participants.

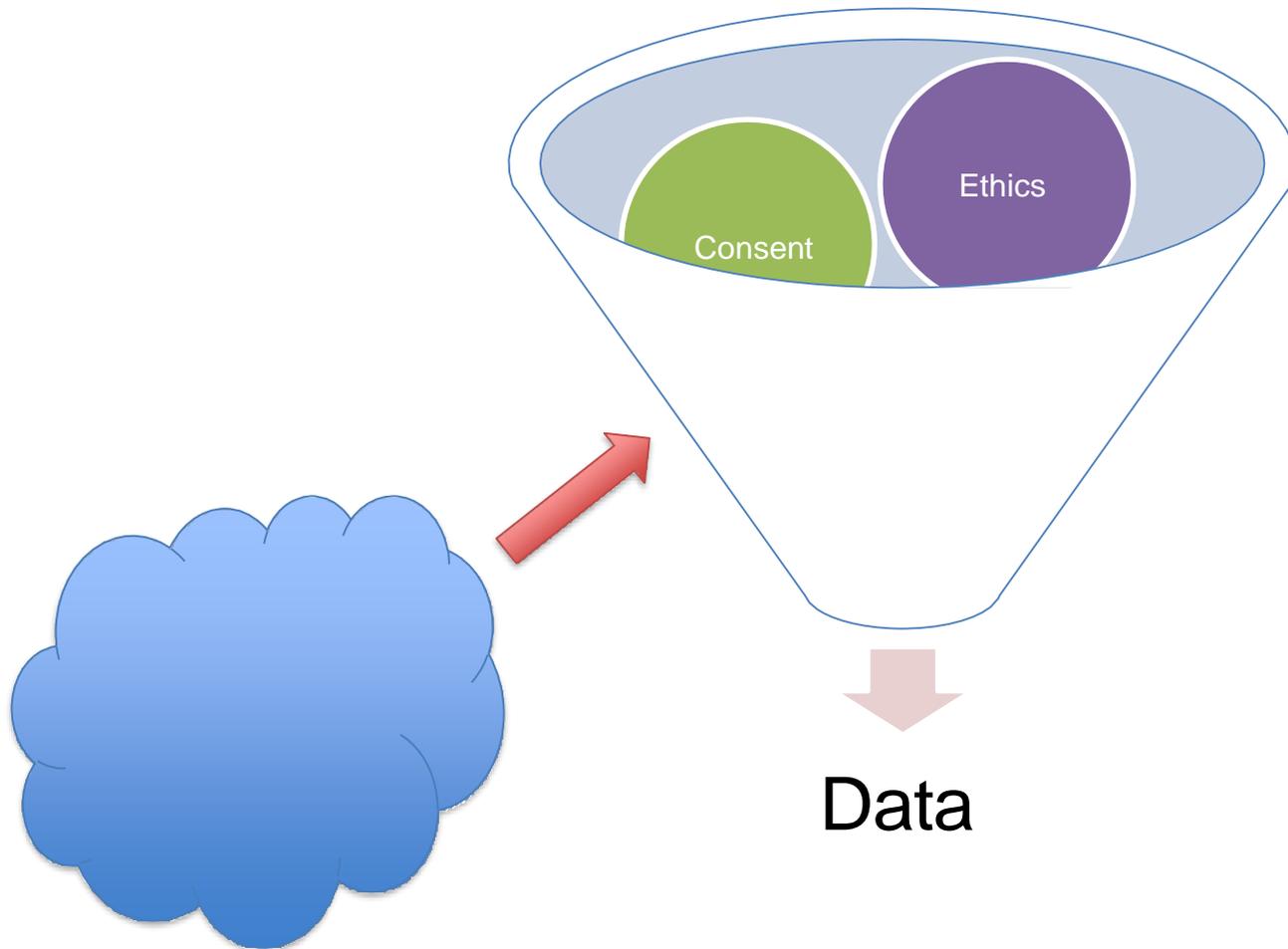


# Informed consent and data custodianship

*“the researcher must provide participants with adequate information about the purpose of the research, methods of participant involvement, and intended use of the results”*

*“Data stored for the purpose of the original research should be accessible by the researcher and supervisor only...Storage of data for posterity and future research that involves transfer to a public repository requires a suitable release form negotiated with the participant that clarifies conditions of future access”*

# Surveys and social licence



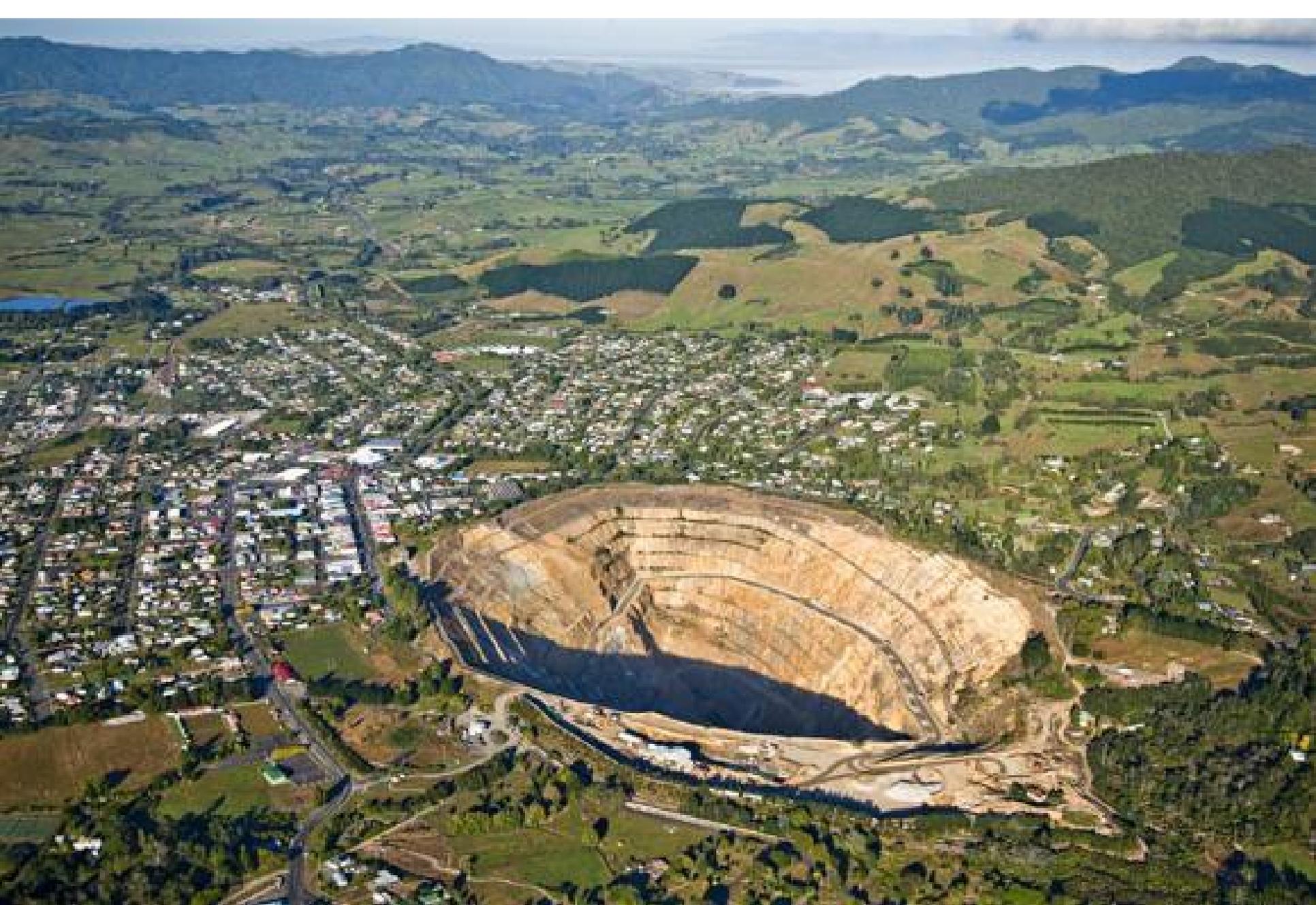


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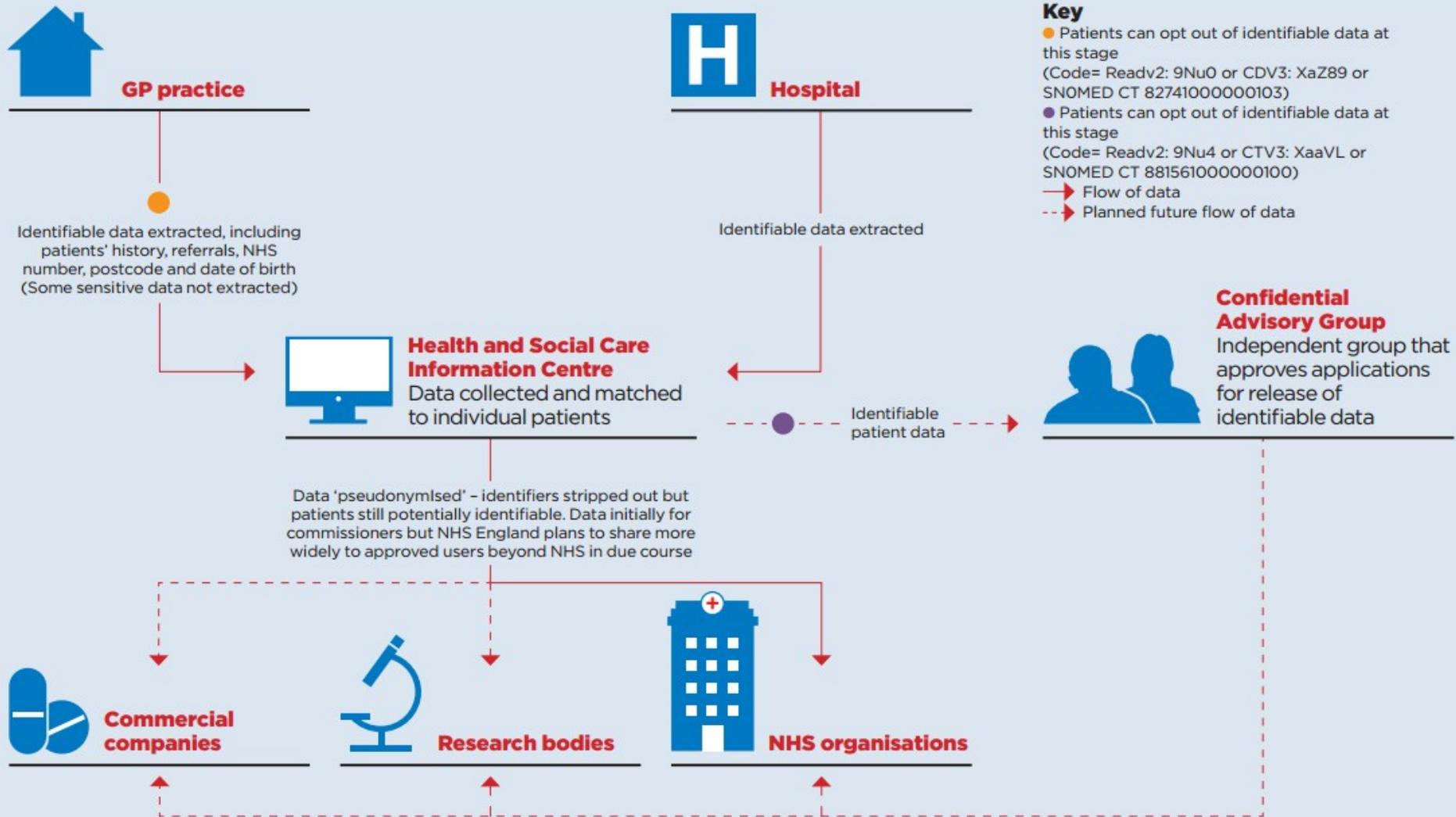
# Social Licence

A conceptual Analysis

Wednesday, 7 December 2016



## How care.data works





# Integrated Data Infrastructure (IDI)

Discover

# Structure

1. What is Social Licence and When is it Needed?
2. What Norms Are Infringed by the IDI?
3. Mandate
4. How Does Social Licence Work: 2 examples
5. Lessons and Implications for the IDI

# What is Social Licence and When Is It Needed?

- Norms confer permissions and prohibitions
- Prohibited activities are liable to sanction
- Social licence needed to perform prohibited activities without sanction.

*‘A professional has a licence to deviate from lay conduct...it is an institutionalized deviation, in which there is a certain strain towards definition of situation and roles.’(Hughes 1963:656)*

# Conceptualisations of Social Licence

‘A social licence to operate refers to the ongoing acceptance and approval of a mining development by local community members and other stakeholders that can affect its profitability’ (Moffat and Zhang 2014: 61).

‘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 social licence.’ (Data Futures Partnership 2016: 3)

# What Social Licence Is and Is Not!



**NOT:**

A tool for pacifying dissenters



**IS:**

Genuine and needed  
authorisation from wider  
group- who have the authority  
to give or withhold licence

## Social **Licence**: A proposed working definition

‘Social licence is societal acceptance that a practice that lies outside general norms may be performed by a certain agent, on certain terms. It is the result of a process of negotiation with a wider societal group, and means that the practice can be performed by that agent without incurring social sanction. ’

# What norms are **infringed** by the **IDI**?

- Privacy
- Respect for Autonomy (control over projects to which one contributes)

# Mandate

a power, implied by the licence, for the agent:

*‘to define what is proper conduct of others towards the matters concerned with their work’* (Hughes 1958:78).

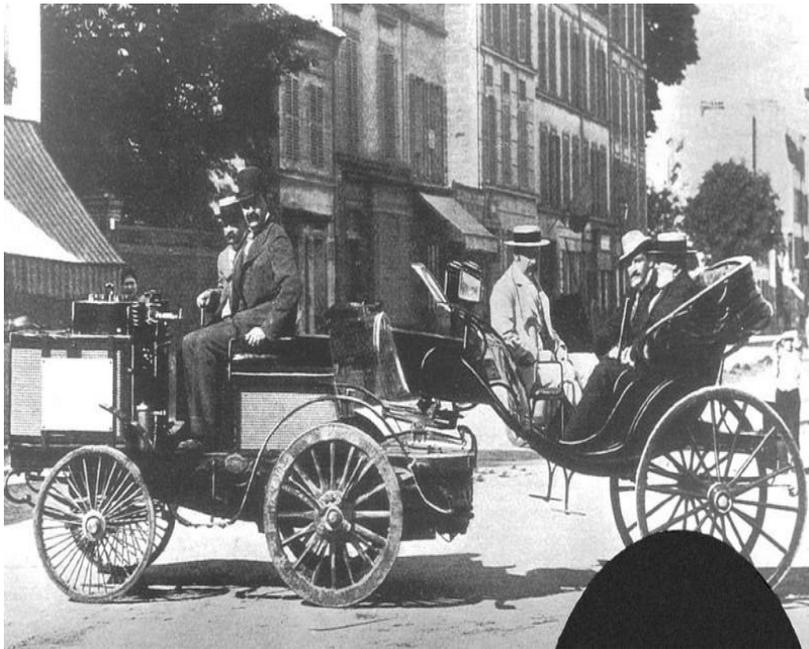
- Terms of the licence and the mandate are open to negotiation.
- What is the content of the licence and mandate sought for the IDI? (What powers would it give, and what would it demand of the public?)

# Revised Working Definition:

‘Social licence is societal acceptance that a practice that lies outside general norms may be performed by a certain agent, on certain terms. It is the result of a process of negotiation terms with a wider societal group, and means that the practice can be performed by that agent without incurring social sanction. Social licence confers a mandate upon the licensee to ask things of others in relation to the licensed practice.’

# How Does Social Licence Work?

## Example 1: Driving



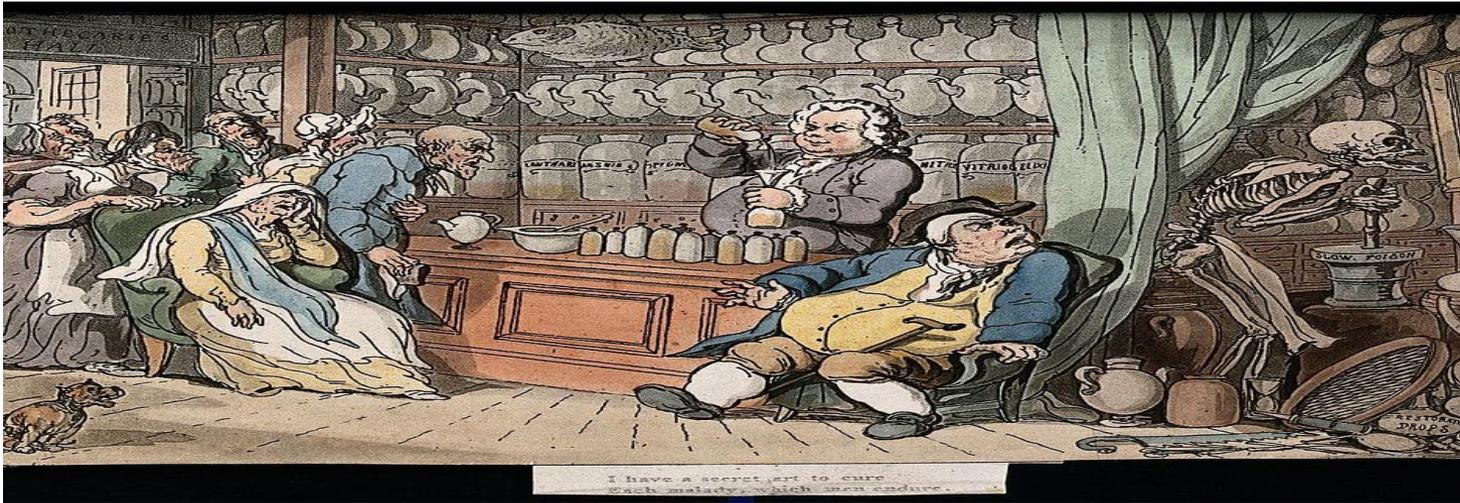
Obvious physical threat

Legislated early:

Low initial tolerance of risk gradually increased

Macro and micro aspects to licence (authorities and drivers)

# Example 2: Medicine



- Physical and social/reputational risks
- Hypocratic oath: early recognition of social licence?
- Unregulated practitioners & dubious benefits led to public suspicion
- Professionalisation and regulation have led to more trust
- Terms of social licence tightened after scandals

# Corfield on the growth of trust in apocatharies:

3 main drivers:

- Strong demand for treatment
- Demonstration of public good
- Increasing professionalization

*'The medical professions wielded influence over their patients, but the practitioners were also themselves regulated. It was and remains an intensely socialised process, based upon negotiation and trust. Such an outcome was only possible after a long pre-history of micro-change in the reputation and practices of eighteenth-century medicine.'*

(Corfield 2009: 17)

# Implications/Lessons for IDI:

- Social Licence takes time to earn
- Cautious beginnings can lead to greater latitude
- Demonstrable social benefit supports social licence
- Maintaining social licence requires ongoing responsiveness
- Social licence has macro and micro dimensions
- Formal regulation can assist, but does not guarantee, social licence
- Social licence is ambiguous and transitory
- IDI could inherit trust and/or distrust from associated agencies



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# Project aims and our approach

# Aims

- To develop an understanding of the added securities necessary for linking “sensitive” as opposed to “neutral” data.
- Consider recommendations for the development of appropriate and trustworthy data management systems for linking data into the future.

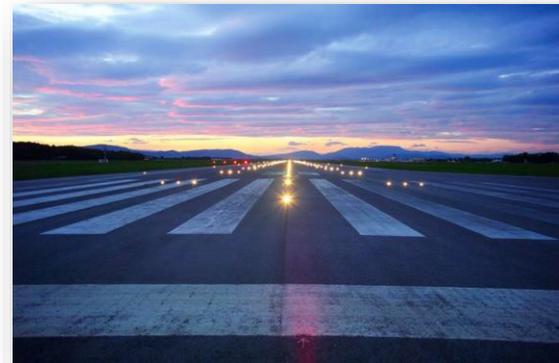


# Our approach

Exploratory:

- Semi-structured questions following an interview that “primed” respondents about the type of questions asked.
  - Predominantly face-to-face; some online (n=12)
- Focus groups, discussion points included
  - Understanding of *“Public Good Research”*
  - Understanding of the types of data collected by government agencies
  - Factors that would influence the likelihood of consenting to have survey data linked with government agency data

Ethics approval provided by the UoA Human Participants Ethics Committee



# Participants

## Census respondents

- Convenience sample recruited through poster ads, facebook ads, key contacts

## Sensitive survey respondents

- Recruited to represent key “at risk” communities.
- Convenience sample recruited through:
  - Email
  - Reference groups
  - Key contacts



# Interview participant characteristics

	Census	Sensitive
Age		
15-24 yrs	2	9
25-34 yrs	12	7
35-44 yrs	4	4
45+ yrs	13	11
Sex		
Male	13	11
Female	17	20
Gender diverse	1	1
Ethnicity		
NZ	25	14
European	0	8
Maori	6	10
Other		
Total	31	32

# Focus groups

- Disabled persons
  - LGBTIQ+
  - Mothers of young children
  - New Migrants
  - Young people
  - Young Maori Men
  - Maori Women (x2)
  - Men
  - Survivor advocates
  - Maori (mixed)
  - Mixed (general)
- Transcribed
  - Thematically analysed
  - Consensus approach to analysis





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# Results from interviews and focus groups

## Quick reminder of what we did

### **63 x short individual interviews**

- To understand whether survey context influences consent to link
- Asked post exposure to either a 'sensitive' or 'less sensitive' survey

### **12 x focus groups**

- An in-depth understanding of participants' social license to link survey data with government agency data

## Definitions

### **“Shared” data**

Data shared within and across government agencies, often at an individual level for a service delivery outcome

### **“Linked” data**

Data from different government agencies linked together in a database for a research/policy outcome

## Data **sharing** is **expected** and **accepted** for the purposes of **service provision**

- Assumption that data is currently shared
- Potential for greater sharing than currently exists
- Sharing must be for personal benefit

*"I am hugely in favour of this – it is hugely invaluable"*

*[Man]*

*"It depends if it is just between practitioners and you agreed that they send it over is one thing but if they start to share it with say your employment or boss or something"*

*[New migrant]*

*"I have heard stories of people having difficulty accessing things from the doctor that they needed, they haven't been able to share information that I thought you could"*

*[Mum]*

## There is a lack of understanding about data **linking**

- General misunderstanding on difference between linked data and shared data
- When explained many could see the value of a linked dataset
- There were common concerns about who would have access and for what/whose benefit

“I think its really important, they have to have the information from somewhere. Policy development – its important they get it right”

[mums]

*“decision makers don’t always act positively on the good information”*

[Men]

*“I’m not sure what you would do with it, maybe it could identify someone that would be in a situation of [ ], and then do what, a knock on the door, find it hard to imagine how it would work”*

[Survivor]

## Limited awareness & mixed response to IDI

- Most participants were unaware of the existence of IDI
- Some can rationalise the benefit as long as sufficient safeguards are in place
- Some were alarmed: data quality and anonymity were key concerns

## Participants may be less likely to consent to linking data they consider particularly sensitive

- There is no set definition of what constitutes 'sensitive' data
- Most participants would consent to link 'sensitive' data if sufficient safeguards in place
- Participants that provided information they considered particularly 'sensitive' may be less likely to consent to linking
- Awareness of linkage may impact respondent disclosure, thus impacting data quality

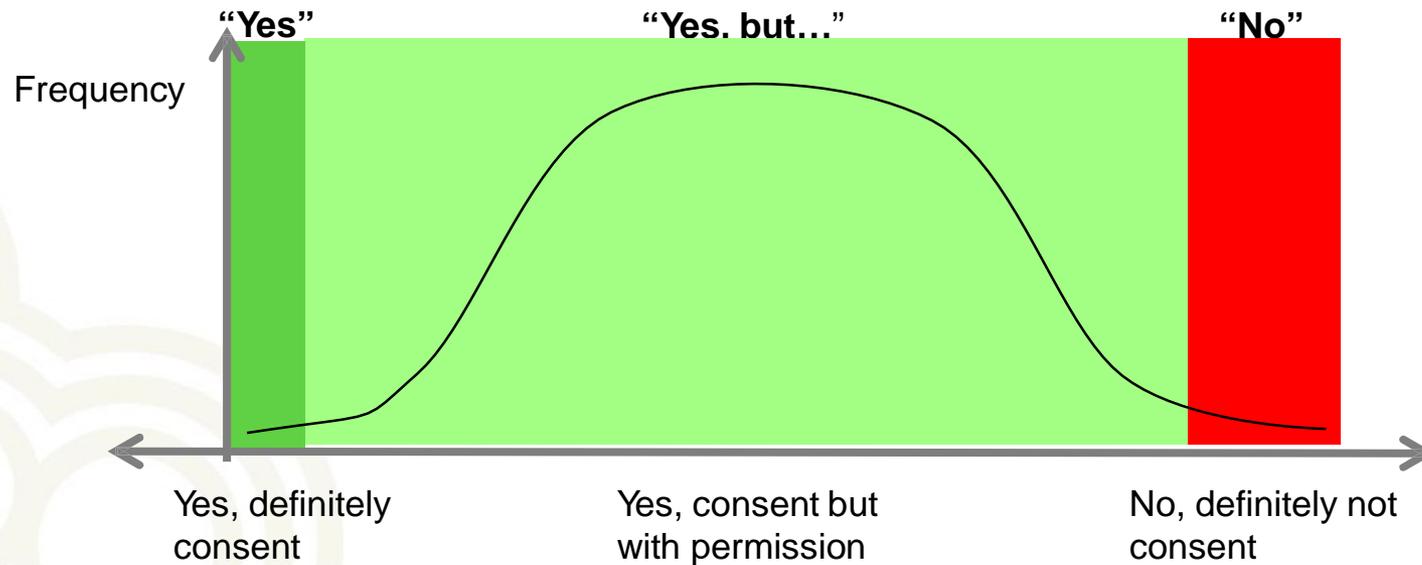
*"I have heard parents say you don't want to get involved with the mental health system because if that information is shared there is a stigma attached, so that is going to negatively influence outcomes in other areas of their life"*

[MUM]

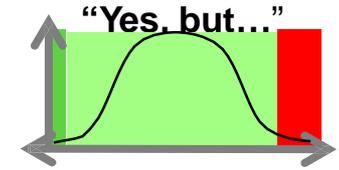
*"I think the more people think that bugger is creeping into your personal life the less they are going to disclose"*

[LGBTIQ+]

Most participants would consent to having their data linked....



Please note: for illustrative purposes only, not based on quantitative data



## Participants want informed consent

- Permission should be obtained for **all** data linkage
- Sufficient safeguards need to be in place and communicated
- The data linkage must be for a beneficial purpose (personal or public)

*“if you are doing things for my improvement, or for my betterment, then it’s fine”*

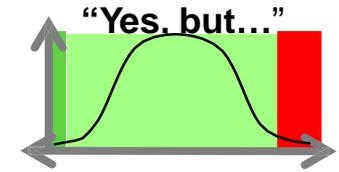
[New Migrant]

*“This is for the benefit of New Zealand...I would not have a problem with it at all”*

[Mum]

*“as long as safeguards were in place and appropriate processes were in place to make sure that information is only accessed and used in a certain way, that has to be really clear”*

[New Migrant]



## Data linkage must be for a beneficial purpose

### Personal Good

- Reduce respondent burden
- Personal data “one stop shop”

*“the cost in the sense that you collect it once then lots of people can, if it’s safe, use the information instead of asking again”* [Mum]

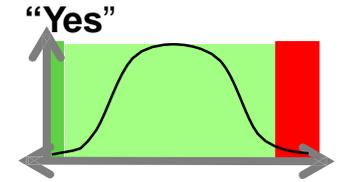
*“its amazing ... for service providers to know exactly what’s gone on with a person”*  
[New Migrant]

### Public Good

- Policy shaping
- Helping communities
- Adds richness to analysis
- Longitudinal research

*“Basically it should be that it’s part of developing society and making society better”* [New Migrant]

*“the findings may help, may get the numbers to put things in place to help families to see how they can be helped”*  
[Mum]



## A few participants would consent by default

- Got nothing to hide, don't care, don't have a view, my info is already out there

*"I guess I am a bit of a push-over"*

[Maori men]

*I couldn't care less as long as you can't pinpoint me"*

[Men]

*"I don't know if that is a bit of an inter-generational difference because we do openly share, and we do quite a lot of information out there without thinking about it, you know on social media and that, and we know that people can trace it, but I think, I don't know I am not really bothered by it, as long as it's anonymous"*

[Mixed]

# Participants shared common concerns

## Fear of surveillance

- Data used to **check for wrong doing**, or to deny services...
- Fear of “**big brother**”, of the government having “your whole story”

*“the risk comes when it becomes personal and disclosing personal information that might be scrutinized by a government department for their purposes”* [LBGTIQ+]

## Fear of discrimination

- Concern about **profiling analysis**
- **More** data collected on those in **greater need** of government support

*“negative stereotypes that get potentially reinforced by the data”*  
[New migrant]

*“doesn’t target the elite as much as people in low socio-economic areas”*  
[LBGTIQ+]

## Fear of disclosure of personal info

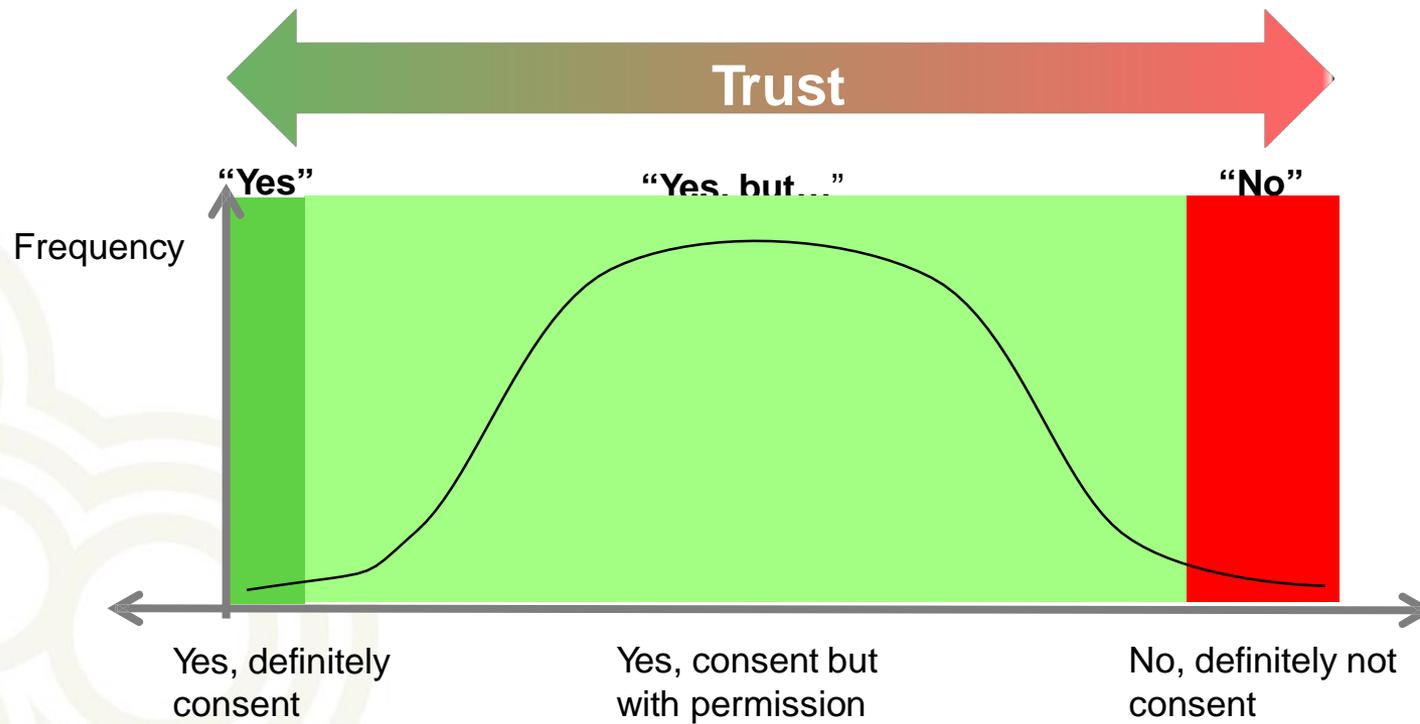
- How **anonymous** can data from minority groups be?
- Sold for **commercial gain**
- How will my data be used in the **future**?
- **Hackers**/deliberate misuse

*“It’s really difficult to keep confidential and anonymous with people who have a degree of difference in the community.”* [Disability]

## Participants shared common concerns

Poor data quality	Appropriateness of reusing data	Appropriate use of data by researchers
<ul style="list-style-type: none"> <li>• <b>Subjective data</b> incorrectly recorded</li> <li>• Poor data quality = meaningless results</li> </ul> <p><i>“I have seen hundreds of CYFS files from woman that have asked the ministry.....and ask them what’s written about them and honestly ...mm and none of it based on fact”</i></p> <p>[Survivor]</p>	<ul style="list-style-type: none"> <li>• Can data collected for one purpose be re-used for another?</li> </ul> <p><i>“[the data] becomes kind of powerless because all the information ...is completely different...so [can] easily...get distorted..out of context”</i></p> <p>[LGBTIQ+]</p>	<ul style="list-style-type: none"> <li>• Access to data</li> <li>• How is it used to inform policy?</li> </ul> <p><i>“we have no way of know how accurate information is that’s being shared; so typically people in the deaf community are being misinterpreted, or not asked or whatever.”</i></p> <p>[Disability]</p>

## Trust is an enabler of consent



# Institutional trust and an optimistic outlook mean consenters expect good outcomes despite being able to identify concerns



## Institutional trust

*“it is going to come down to trust and you’ve signed something that says you’re not going to do this, and you been in the job this long, and you’ve passed all the checks so presumably you can be trusted with that”*

[Mum]

## Optimistic outlook

*“I don’t have anything to hide, so unless someone has bad intentions I don’t know what they can do about it”*

[Mum]

## Distrust of institutions

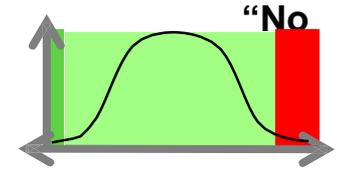
*“If you let go control of your personal information now, you’ll never get it back”*

[Men]

## Negative experiences with service providers

*“when you have received a bad response from the service, it doesn’t understand the situation, you are very uncomfortable about sharing at all, to anyone”*

[Survivor]



The key concerns of the non-consenters are so great that they can see no value in linking data

## Data quality too poor

Subjective data not accurately recorded, e.g. police, courts, child records

*“well the information is still stuffed”*

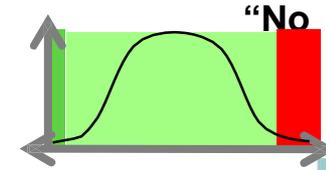
[Survivor]

## Can never be anonymous

Unusual records will always be identifiable even if data is de-identified.

*“As soon as you put my age, my impairment... there are some people who would know exactly who I am”*

[Disability]



## Negative experiences with government agencies drives distrust and generates a very emotional response

### Distrust

Don't trust government:

- to securely hold or make sensible use of the data
- Not to use the information against people
- To change the data to suit its own need

### Lack of control over my story

Its not right to link up “my story” from separate sources – its an invasion of privacy

*“when you’ve got agencies taking that story and sharing it around it just feels like its another thing that you are losing”*  
[Survivor]

## Key take outs

- There is limited understanding of data linkage and limited awareness that the IDI exists
- The research suggests that most people will consent to having their data linked for a **beneficial purpose** (personal or public), and as long as sufficient **safeguards** are in place
- Participants would like an **informed consent** process to linking their data
- **Anonymity** is expected, but reassurance is needed
- Institutional trust is an enabler of consent



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# Māori responses

# Acknowledgements

- Led by Tracey McIntosh (Ngā Pae o Te Maramatunga)
- Stephanie Palmer

# Public good research

Concept closely aligned with “mainstream” health

*I typically associate that with...the idea of majority who we are not really a part of when they talk about things like the mainstream, upper middle class Pākehā, urban dwelling people. That is what I think of.*

The level of concern and distrust of data was apparent.

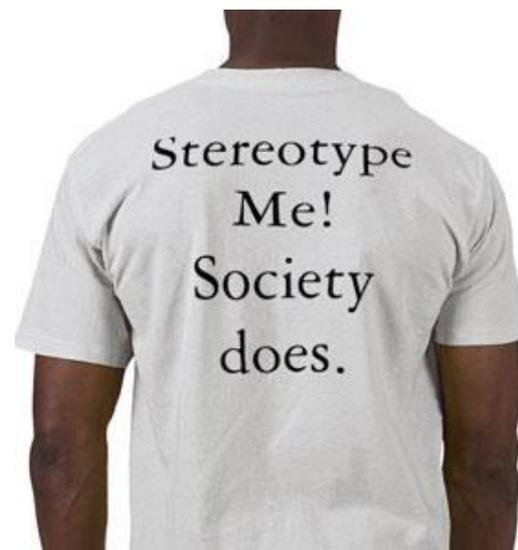
- distrustful about research process.
- concerned how data could be used to further embed negative stereotypes
- creating an environment for over-surveillance

# Admin data and policies for Maori

*it's going to highlight our problems*

*It is often used just to prove cultural deficits.*

*if we are perceived as a minority and as long as everyone else is trucking along then let it keep going*



**Any data can  
be sensitive**

# De-contextualising data

*“data that is given in say an interview can be de-contextualised and alienated from what the kaupapa was”*

*“you’ll just be another statistic to .... They put you in the category of New Zealand Maori,  
yeh yeh and you are part of that group yeh, yeh.”*

*“...my police record, I didn’t quite understand how they got all that information,  
...I didn’t know that they held against me what I had done when I was 15 to when I was 19 and had a kid .....so they told me I was a drunk and drug and alcoholic when I was 16...they were still holding that against me when I was 19...  
if they had asked me first because I would have had time to explain myself that behaviour was when I was 15. I was being silly and stupid and now I am 40 and I want to get a job, you know in between these years if you look through those years and I was really good”*

# Researchers as kaitiaki

*I would hope that it has gone through ethics and stuff and whoever is collecting the data would be bound by those guidelines as well.*



Given your previous discussions do you think that linking data will get better outcomes for Maori?

At what stage do you define an outcome by?

If things are ...changing, new technologies then that should be emphasised. I feel this would inform the way that people choose to participate. Issues of confidentiality and anonymity seem to [be] fading away.

it might just be old school yeh, to be honest. Oh can I use your...um glasses please you know, instead of just going and taking them and.....come in and oh you've got my glasses on didn't even ask



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# Workshop

(your turn)

# Three options

1. People are comfortable with their data being shared for their care. What process do we need to go through to acquire that social licence for the IDI?
2. Take the results literally and seek consent in every case – what are the implications?
3. Consider the sensitivity of data – should we be taking a different approach depending on the sensitivity of the data collected?

Structure:

15 Minutes discussing the topic

Brief presentation back to the group



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# Workshop discussions

(Notes)

## People are comfortable with their data being shared for their care. What process do we need to go through to acquire that social licence for the IDI?

- Establish (making visible?) a transparent governance process
- Public education on the IDI
  - What it can do
  - What it can't do
  - Difference between sharing and linking
  - Demonstrating the value of the IDI
  - Protections that are currently in place
- Transparency about the policy uses of the data
- Communicating the independence of StatsNZ and the Government Statistician.

# Take the results literally and seek consent in every case – what are the implications?

- Consent at collection, i.e. MSD and MoH
  - Include consent statements
  - For health survey, don't link if don't consent
  - For admin data "consent" is agreed via a contract for services => opt out is to opt out of
- **\*\*\*This is not consent (coercion) – could risk isolating more people**
- But, points where we would need individual consent include:
  - Collection
  - Integration
  - Project applications
- Radical options:
  - Enable individuals to opt out of IDI or specific uses?
  - IDI uses a "My Data" type of portal enabling access to and perusal of, control of and options to opt out
  - Seek consent for types of data use (rather than project by project)
- Challenges:
  - Would need to verify identity for safe access
  - Data is probabilistically matched, what if it is not right?
  - IDI is full population coverage – opt out could skew / create bias
  - Who would consent for rights of children? Deceased?
  - Logistical challenges: Full population, admin data collection. How? Real Me?

## Consider the sensitivity of data – should we be taking a different approach depending on the sensitivity of the data collected?

Who decides what data is sensitive? What is the threshold?

OPC / HRC / Referendum / Govt Statistician / Peers

Process:

- Vetted and approved purpose
- Authorised people
- Some data further restricted
- All projects through an ethics lens
- Transparency – education and debate to lead to informed trust (issues around budgets, channels and interest)
- Don't try and separate operational vs research data because all data should lead to improved outcomes and follow a similar process.



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# A guest presenter

Kevin Sweeny

StatsNZ

Data Quality

## Steady States (Quality) Criteria

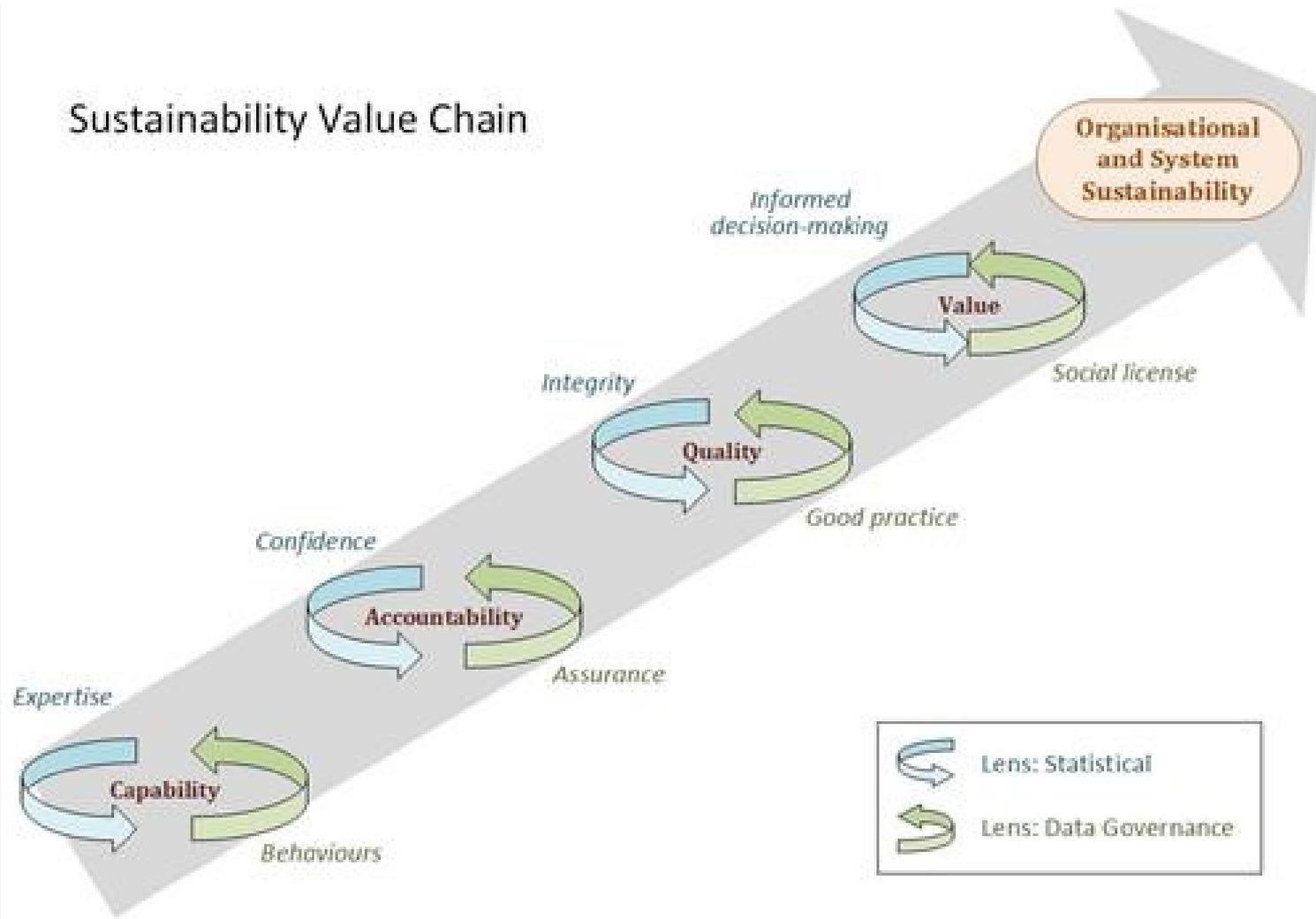
### Quality Dimensions - Statistics NZ Quality Model

- Relevance
- Accuracy
- Timeliness
- Accessibility
- Consistency
- Interpretability
- *Safety (proposed)*

Increased LOB Granularity  
and (Measures)



## Sustainability Value Chain





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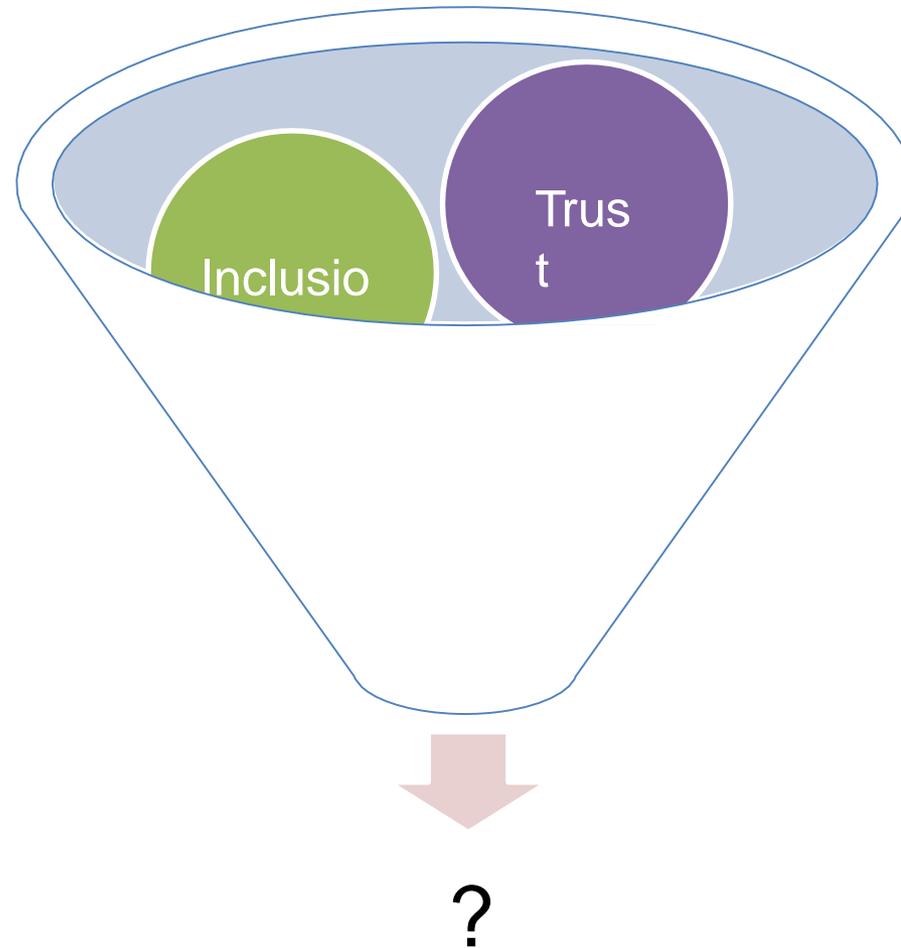
# The wrap-up

# Key Messages



- Many people are willing to consent - consent is seen as an important step.
- Groups with negative experiences are less likely to do so.
- Data quality matters
- Trust needs to be built - recording of information must be
  - Relevant
  - Accurate
  - Neutral
- There needs to be safeguards across all stages of the research process.
  - De-identification doesn't remove all of the risks.
  - Consider consent, storage, access, analysis, reporting
  - Clarity of purpose
  - Context of data collection

# Data Futures Principles



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