# THIRD DATA HUI: COMMENTARY ON MORNING SESSION

## 19 APRIL 2016

* Nga mihi ki a koutou. [Ko John Whitehead ahau.]
* Thank you for the opportunity to comment on this morning’s proceedings. I’m conscious that I stand between you and lunch, so I’m going to do my best to be brief, but there’s a huge amount to cover, because we had so much on offer this morning.

## Brendan Boyle

* Brendan got us off to a great start.
* I love the phrase he used: “Interrogating the data until it confesses.”
* Brendan drew our attention to the sheer quantity of data now available, but also to ensure that among all the data available, we need to find the “right” data, and ensure it is of good quality too.
* He emphasised the importance of good access to data in achieving really good outcomes, and that it is critical to know what to do with the data when we’ve got it.
  + There’s a big task ahead for all of us in raising our analytical capabilities.
* He demonstrated how we can use data to identify the problems, but it is also good to see the increasing emphasis on what works – we need more of this.
* Brendan, I thought it was really positive the way you said you were “up to sharing data”. As a former official I can tell you all this is a big shift for government, and critical to improving outcomes for people we serve.

## Hon Bill English

* The speech by Minister English represents a major watershed: in terms of data sharing in New Zealand; in terms of relationships between the government and the non-government sectors; and most importantly in the potential for better outcomes for the individuals and whanau that we all serve.
* In announcing the Data Access Service, Bill English on behalf of the Government has sought to address a number of issues that have been raised at our two previous huis, and of course elsewhere on numerous occasions:
  + He has picked up on the **Data Sovereignty** issue – shifting the default to sharing individual data held by government with individuals or their authorised agents such as you. It will need a very good reason not to share.
  + He has sought to address the fact that **government data is far too hard and costly to access** – by announcing a one-stop shop for access to anonymised and properly authorised identified data on clients. I’m assuming that as part of this initiative, the one-stop shop would produce a map of what data is actually held where, together with relevant meta-data.
  + He has signalled that the purpose is to achieve **greater joining up and interoperability of NGO and government-held data** including among government agencies themselves. This will be crucial for the outcomes we want to achieve.
* If the announced intent is turned into reality, and while I don’t underestimate the challenges, if it is hopefully progressed with some momentum, then I think it stacks up well against good principles of data use:
  + It provides for much greater **value** to be obtained from the data. Every time you add one field to matched data you potentially increase its value by an order of magnitude, in terms of better targeting, better design and better evaluation all leading to better outcomes.
  + It allows for much greater **inclusion**. The biggest value will come from the application of this enhanced data availability to clients who need it most.
  + By clearer understanding of the conditions of access and use, **trust** can be built among all players, from clients onwards though the chain.
  + The initiative ultimately provides for individual client and entity **control**. Those whom the data is about potentially get to control what it can be used for.
* All of this is good stuff, but the devil will be in the detail of course, and there is a lot of detail to be worked through. For example:
  + The Minister spoke about **conditions underlying access rights**. There will need to be conditions – clear conditions - and I am pleased to hear that he proposes to seek input from the Data Futures Partnership, the Privacy Commissioner and the Government Statistician. Speaking for the Data Futures Partnership we would want this to be an open discussion – we will want to hear what you think.
  + Another aspect of the detail will be the **data quality**. I think the Minister signalled that the days when an agency might go as far as saying “Yes, we hold data on that individual” but provide no further detail, will be gone. Don’t assume, however, that all government data will be good quality – a lot of work and some investment may be necessary to make it really useful, not least in terms of interoperability and granularity.
  + A third issue the initiative poses relates to the potential for **sharing of research capability**. What plans, if any, are afoot in this area? Sometimes it may be essential to achieving better outcomes if sharing goes further than just sharing the raw data.
  + Finally, how do we make sure that we take a **strength and opportunity view of data**, rather than focusing on a deficit and risk view. Maybe that it is largely up to us to set the tone.
* Indeed, I think the announcement today also poses some real challenges for us as data users and service providers. Briefly:
  + The Minister made it clear that the initiative was not for the purposes of promoting the interests of NGOs, iwi, Pasifika groups or public agencies, but only for the purpose of **reaching the people who need our help** and making a real difference for them. In the words he used: “We need to change more lives”. Do we buy in to that Vision? For example, will we be willing to share our data, appropriately authorised, with other agencies, public or private, if that will lead to a better outcome for those who need help? Are we prepared to make the partnership real?
  + Are we prepared for the **opportunities and value extraction** that will be possible? Some may come as a shock.
  + Are we **ready to meet the conditions** that will likely be required for access to data? Will our people be trained and see the importance of respecting those conditions and maintaining the integrity of the data?
  + **How fit for purpose are our existing systems** in terms of security, for example preventing hacking, and for ensuring that our legislated and ethical requirements to protect privacy are met?
  + What systems do we have in place to ensure **client control on the use of data**? For example, do we have a clear understanding with our clients on how long data will be stored, what it can be used for and under what conditions? What arrangements or permissions will we need for those with whom we plan to share data?
  + Are we willing to share the data we hold with the people we serve? Are we prepared in turn to be more open with access ourselves?
  + And so on…There is huge opportunity here, but we must be ready to meet our responsibilities too.
* Finally, one issue raised by the Minister concerned considering strengthening the rules against the **re-identification of de-identified data**. I agree we should debate this question, and normally data will have been de-identified for good reason.
  + Let me be provocative, however: first of all, it is going to be increasingly difficult if not impossible technically to prevent re-identification of data. According to the CIA Director, for example, it is already possible to identify me from the fitbit I wear and my unique way of walking – and not just me - that means everyone of course. The more critical issue, perhaps, is whether any data (either accidentally or deliberately re-identified) is put to good or bad use.
  + Secondly, maybe there are times when – preferably with permission of course – re-identification may be in the public or private interest. For example, let me quote from a recent Smithsonian Smart News article:

“…over the past three years, researchers at the Icahn School of Medicine in New York examined the genomes of almost 600,000 healthy adults, finding 13 lucky individuals who had the genes for fatal or severe childhood diseases, but who somehow managed not to develop the illnesses. It seems like the start of a huge medical breakthrough, but there’s one big catch—because the genome databases are protected by privacy agreements, the researchers are unable to identify or follow up with the patients.”

* It’s surely a valid question whether there is a case for re-identification in such circumstances, and similarly where the reverse may be the case and intervention could save an individual from an impending fatal disease.

## Presentations

* One of the things I love about these hui are hearing of some of the ideas and achievements already being progressed by providers. This emphasises the point made by the Minister that there is real capability existing and developing in the wider social servicing area.
* We’ve just had six excellent presentations, which importantly contained several common themes and I think included strong hints of how much more could be achieved if we share and use data in the right ways.
* **The Methodist Mission Southern**
  + Although Laura did not focus on her first slide, I really liked the “data-information-knowledge-insight-wisdom” continuum it highlighted.
    - Data use and sharing is an essential component but it is ultimately the application of wisdom that can make a difference to outcomes. With the application of the right skills and attributes sharing data can help push us further toward the wisdom end of the continuum.
  + The presentation effectively highlighted Brendan’s point about interrogating data again and again to help in the drive toward wisdom – in other words an evidence-based approach.
  + We need to bear the human factor in mind: it is not always easy to accept that our favoured approach is not working. Laura’s example of 90% of people considering they were above average should remind us that we are all capable of making that same mistake.
* **The National Hauora Coalition**
  + Simon and David presented statistics that both made the case for why we need to intervene, and presented some pretty dramatic impacts.
  + These illustrate the huge value that can be added, and the benefits for inclusion that can come, from the use of both de-identified and identified data
  + Not directly measured of course are the extra benefits to individuals and society that will flow from healthier and more productive children and adults, including over 10 years of extra life – this is the big gain as the Minister pointed out in reference to “the 10,000”.
  + Finally, it was good to hear the criticality of being whanau focused getting such emphasis. So often in the past the client has not been involved in decisions and delivery.
* **Pasifika Futures**
  + Debbie’s presentation demonstrated how data works through the “chain of delivery” – culture focus, outcome identification, solution focus, identifying the positive, evaluating the effectiveness of delivery.
  + I was struck by the real clarity of vision, and the fact that it is such a positive aspiration.
  + Particularly important was the emphasis that it all starts with the people/families, identifying the strengths you can build on and finding out from them what they want.
  + This is also essential to knowing what data you should be using so you will be able to find out “what makes the difference”.
  + Finally, the presentation picked up very positively on the importance of families knowing what agencies think and know about them – genuine access to data.
* **Te Whanau a Apanui**
  + This presentation gave a good example of the positive possibilities of partnership – in this case Ministerial and iwi.
  + I really liked the *tena koe* juxtaposition of “I see you” and “Here I am”. Once again, the emphasis is on starting (and ending) with the client.
  + A key insight from the strength-based approach is that communities can tell us things we won’t have collected as part of official statistics. In turn, this reinforces the importance of finding the right data and then learning from the process of layering other data sets on top. This creates the “order of magnitude” effect I referred to earlier.
* De-identified data sets can be really useful in helping you to drill down to the “hotspots”, but delivering services to individuals or whanau ultimately requires identification.
* **Te Pou Matakana**
  + The title of the Te Pou Matakana presentation really hit the spot – “Measuring what matters”. Again the work they are doing is outcomes focused, whanau-centric, and emphasises the value of partnership.
  + That focus on measuring and assessing that John and his team spoke about is the same message as we’ve heard in other presentations about repeatedly interrogating the data to establish what is working and what is not.
  + The results Te Pou Matakana are getting emphasises the value of a real time and integrated approach.
* **The Wise Group**
  + The Wise Group have been doing partnership and data sharing for a long time.
  + Over time they have developed many tools – this raises the point that perhaps it is not just data we can be sharing, but also coding, tools and learnings about how to approach problems and solve them.
  + I thought the presentation gave a great example of clients being involved as part of the team from the determination of which outcomes to pursue right through to data entry and correction.
  + More generally, it demonstrated well how with human-centred information sharing and partnership we can begin to tackle some of the most difficult problems we face.
* **Summary**
  + A number of common themes emerge from the set of presentations and speeches we have heard this morning. In particular there is the importance of:
    - Client focus – starting with the client and involving them throughout the process
    - A strength-based approach rather than one that is deficit-focused.
    - Data sharing – the real value that can be generated from sharing data with clients and partner agencies: the order of magnitude effect.
    - Evidence-based approaches, and tracking outcomes.
    - Taking a continuous improvement approach.
  + Also coming through were the advantages offered by taking a partnership approach. After all, we have the same objectives, or at least we should have.
  + And of course we are working with people and all that this means, not just data and statistics…
  + Overall though, the strongest message this morning was that there is a real opportunity opening up on data sharing. Let’s be ready to take advantage of this.

## Conclusion

* I think we can all agree that we have had an extremely interesting morning. May I thank Brendan Boyle, the MSD folk, and all those involved in the organising of this third data hui for the excellent work they have been doing.
* The afternoon looks every bit as interesting and there’s some great speeches and sessions to come. Let’s make the most of them.
* Kia ora tatou.