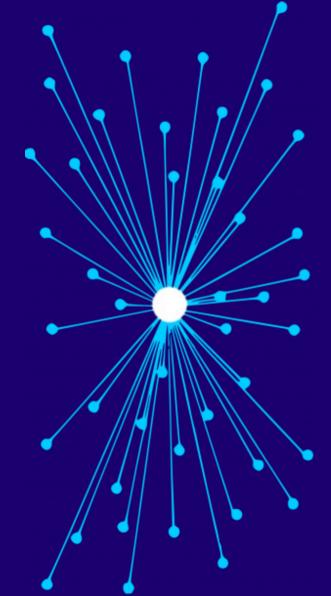
Data sovereignty in action

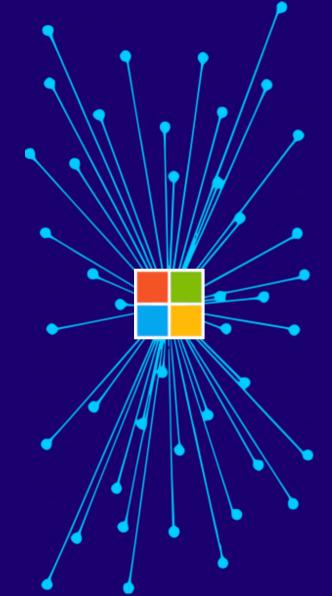


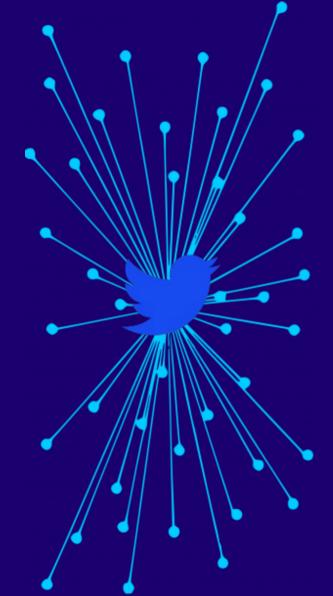
Data Sovereignty

Taking ownership of your data

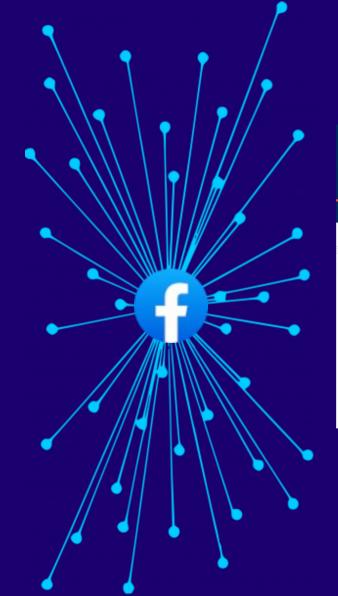
Exerting decision-making authority over your data











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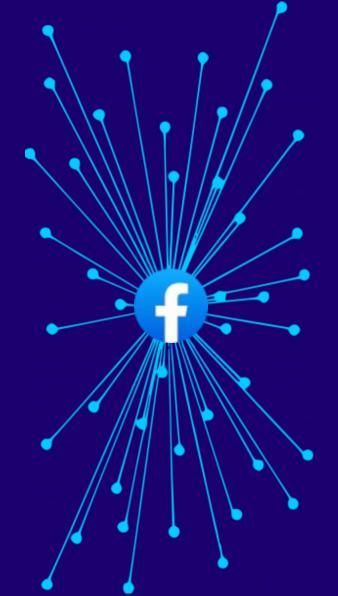
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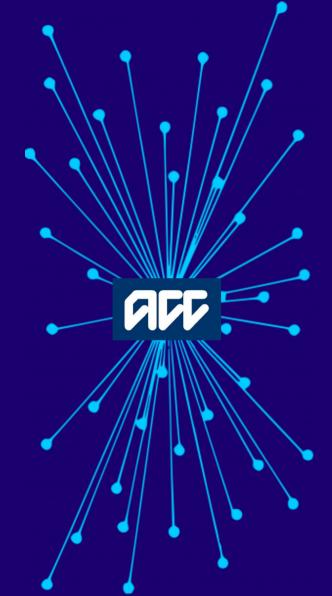




By Gabriel J.X. Dance, Michael LaForgia and Nicholas Confessore
Dec. 18, 2018

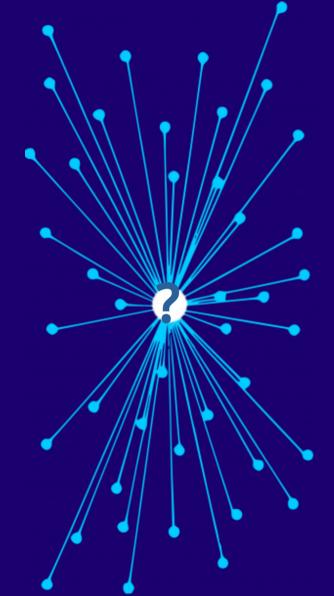




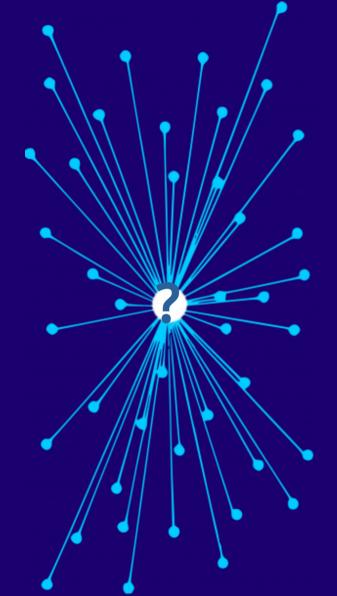






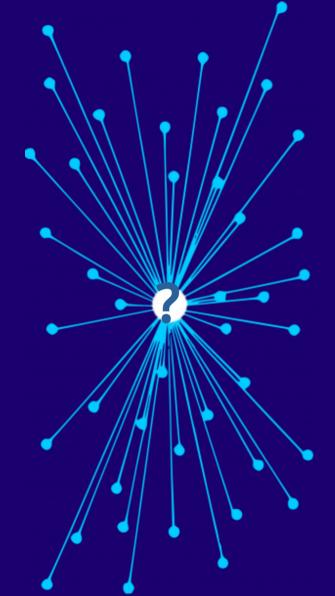


- Who is managing our data?
- Do they understand our cultural/social context?
- Do we trust them to interpret our data correctly and draw conclusions from it?
- Are we considered as equals in this data relationship?

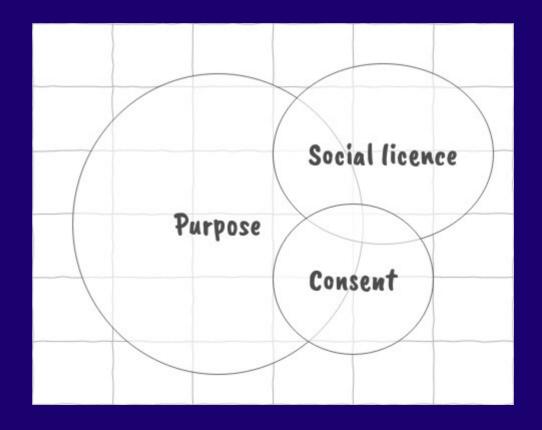


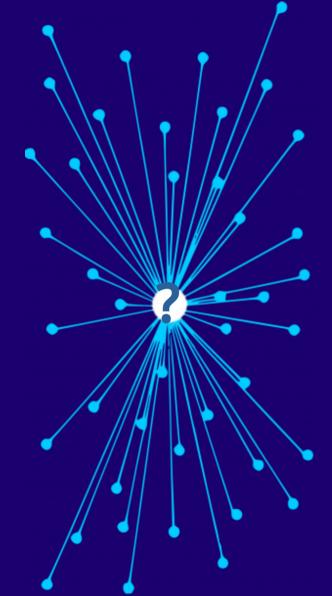
the design of the primary health system was deliberately 'permissive' and semi-devolved. While we can see that this approach was intended to foster local innovation and control, we found that it has significant drawbacks and has resulted in grave impacts on both Māori organisations and Māori patients. We found that the Crown does not collect sufficient qualitative or quantitative data to fully inform itself how the primary health care sector is performing in relation to Māori health. Furthermore, the Crown does not use the data it does collect effectively, nor does it make it easily accessible to, and understandable by, the public. Despite the significant, persisting inequities that Māori experience, Māori health outcomes are not systematically separately measured and reported on. Furthermore, we found that Te Puni Kōkiri has failed to carry out its statutory duty to monitor the health sector by failing to conduct agency reviews. While the Crown knows enough to establish that the situation for Māori is urgent and serious, it has not adequately informed itself as to why this situation might be persisting nor sought the necessary information needed to improve the performance of the primary health care sector.

Waitangi Tribunal. (2019). Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry.



Conflating consent and social licence

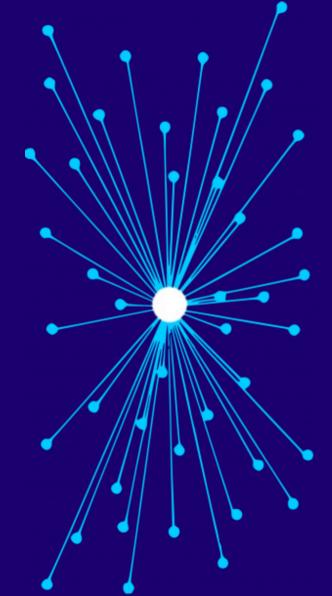




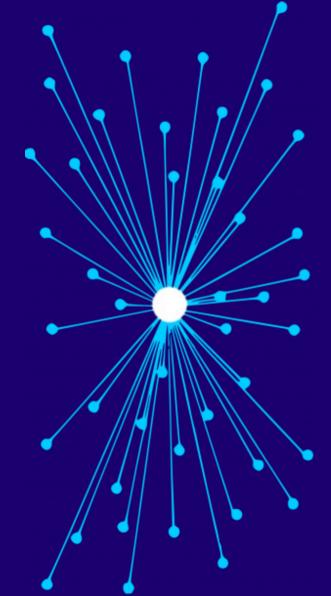
Centralisation is...

Known Proven Trusted

BUT!



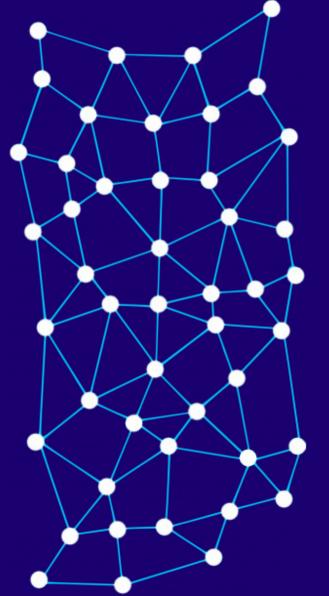
Centralisation is the enemy of data sovereignty

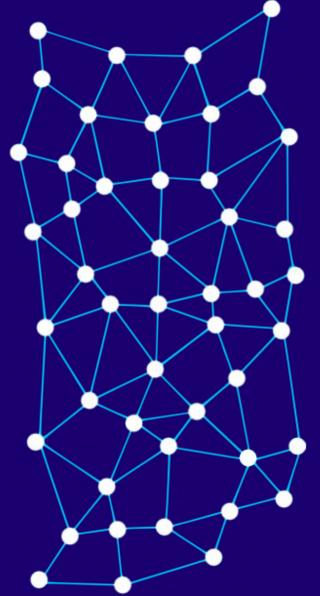


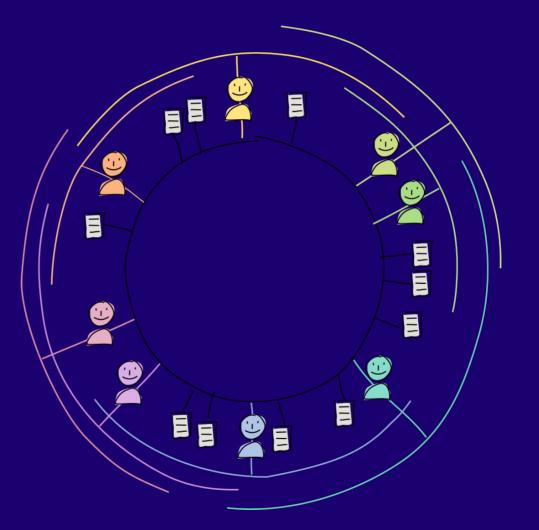
From data dependency to data self-determination

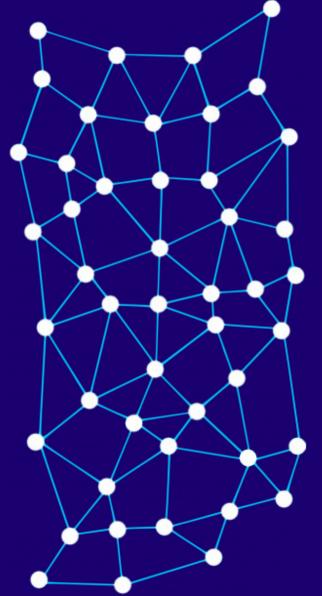
To assert that IDS is unobtainable within State structures might seem unduly pessimistic given the aspirational framing of this book, but we offer two caveats. First, we believe that Indigenous data governance (IDGov) over government-held data in Aotearoa NZ can and should be an effective mechanism for implementing a limited form of IDS. Designed carefully, and supported by legislative powers, IDGov can protect against and mitigate some data harms, and increase the visibility of Māori rights and interests in data. However, there is also a very real risk that only the weakest forms of IDGov, such as voluntary frameworks and principles, will be implemented, and will serve as both the beginning and endpoint of the state's commitment to Māori Data Sovereignty (MDS). Second, we believe there is scope for policy to support Māori and iwi (tribal) nations and communities to develop and control our own data ecosystems (Gifford & Mikaere, 2019). We

Kukutai, T., & Cormack, D. (2021). "Pushing the space" - Data sovereignty and self-determination in Aotearoa NZ. In M. Walter, T. Kukutai, S. R. Carroll, & D. Rodriguez-Lonebear (Eds.), *Indigenous Data Sovereignty and Policy* (pp. 21–35). Abingdon, Oxon, UK: Routledge.







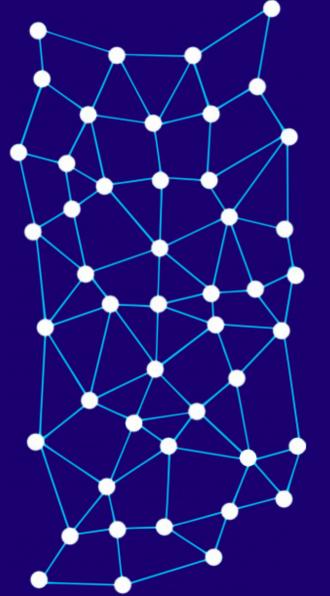




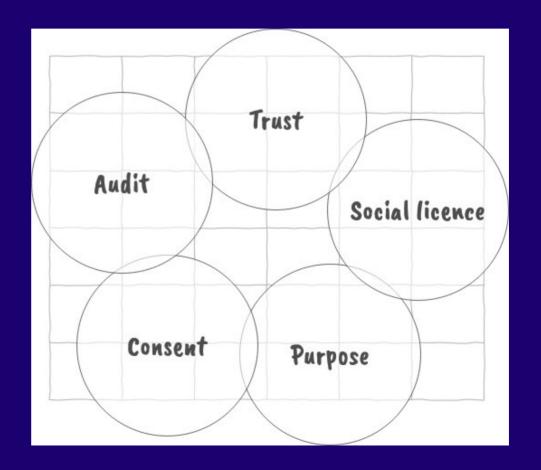


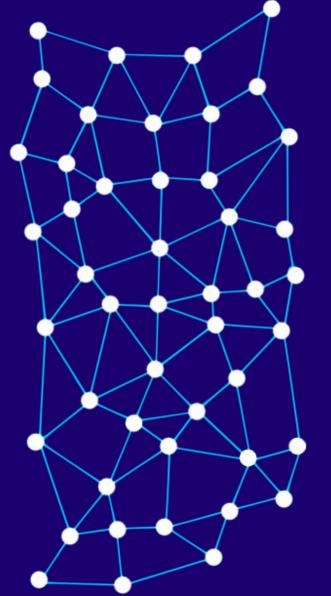


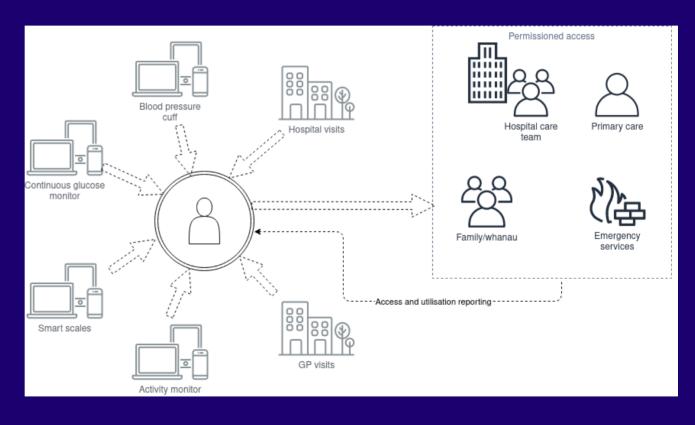


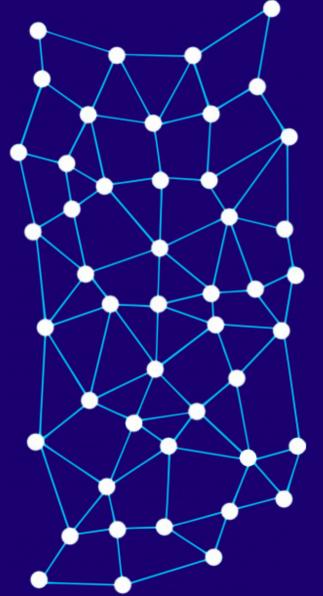


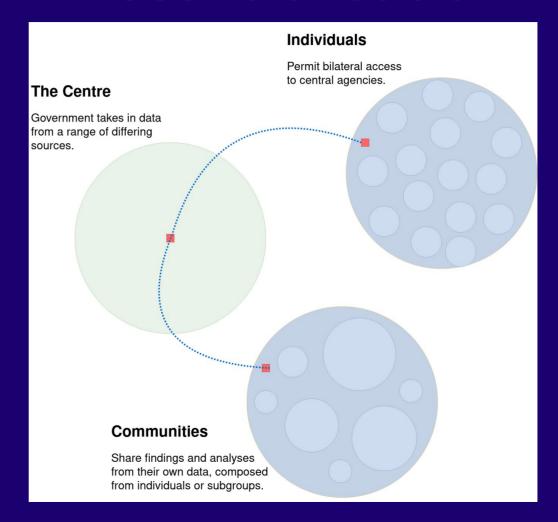
A virtuous circle of trust, consent and use

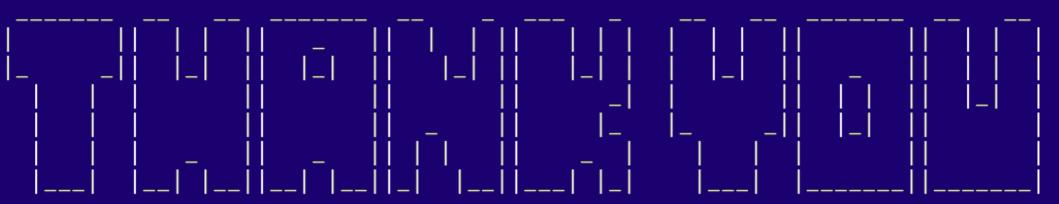












Email: alex@robot5x.com

Demo video: https://vimeo.com/680251596#t=949s

Source code: https://gitlab.com/alexpoor/radhis

App: https://gitlab.com/alexpoor/radhis/-/releases

What is Holochain?: https://www.youtube.com/watch?v=EUfyHNGvnDo