Data, from a given, to the taken:
Theorising Māori Data Sovereignty in Aotearoa

Kiri Theresa West

A thesis submitted in fulfilment of the requirements for the degree of a PhD in Māori Studies the University of Auckland, 2022.

This thesis is dedicated to my whanau. Our stories enrich these pages giving life and meaning to the research.

Written in loving memory of my

‘’Uncle Chocolate’

Gordon Paul West

The words ‘Dr West’ never sounded so sweet as when they danced on your tongue.

You never once doubted that I would make it – I wish you were here to share in this moment.

Abstract:

Data are the single-most significant asset shaping our present and future realities. Data are driving national and global economies, and are presented as the evidential basis for the development of policies; they are framing political landscapes and radically transforming what it means to live in a democratic state. As we navigate our way through a rapidly developing digital age, one of the biggest issues we are facing as Māori is that of data sovereignty. In this thesis, I draw upon my unique perspective as a mokopuna of Pare Hauraki to consider how data sovereignty is not an abstract theory nor is it limited to a political aspiration, but it is a living, breathing reality.

This first half of this thesis considers how data has become the most powerful global resource of the digital age. Critical to this discussion is an interrogation of the factors that have contributed to data's accumulated status of neutrality and truth. Tacit assumptions regarding the capacity for data to contribute to fair and equitable outcomes for 'all' is contested in light of the experiences of Indigenous peoples. Histories of exploitative research and colonial counting highlight how the benefits of research and data have very rarely accrued for us as Indigenous peoples. Indigenous data sovereignty then is necessary for ensuring these histories do not continue to repeat themselves.

The second half of this thesis includes three distinct case studies that interrogate pressing issues in Indigenous data sovereignty. Namely, privacy, trust and access. Personal narratives and storywork is weaved through each case study to illustrate how issues relevant to privacy, trust and access are felt at the individual level and how this sits within a broader collective experience. Written in the context of a global pandemic, this thesis offers an important insight into the ways that we as Indigenous peoples continue to experience the harms (re)produced by structurally violent, oppresive, colonial structures. However, we are not defined by these systems and we have shown that when we return to our ways of knowing and being, not only do we survive, we thrive. To this end, Māori concepts of tapu, tiakitanga and whakapapa are considered as key features of a sovereign data space for Māori.

.

.

Acknowledgements

We often hear that it takes a village to raise a child – that the love and nurturing that can be offered by a community in the formative years of a young persons life are critical to their flourishing. This thesis is a testament to that whakaaro. I have been loved, nurtured, counselled, and cared for by ‘my people’ over the past 4 years, and I am eternally grateful for what you all have supported me to achieve.

Always first is my baby. Amelia you have sacrificed the most through this journey. I have missed open days at school, assemblies with certificates, weekends just chilling, holidays of fun, dinner at the table, cards and board game nights, and cuddles before bed. But you my darling are the most kind, compassionate, empathetic, emotionally attuned young wahine I have ever had the privilege of sharing space with and I marvel at the fact that you are of me. In moments of spontaneity, you remind me that you love me and that I am the best māmā, and there is no possible way that I could ever articulate in words what those precious moments mean to me – you saved me darling – you are love and love is you.

I get told often that Amelia’s grace and courage is a testament to me and my parenting – but as I have said in the pages of this thesis, I am never alone in raising this mokopuna of Hauraki. I have a lot of people to thank here (Aunty Sandra, Uncle Anthony, Uncle Gordon (oh how I wish you were here) Phil, Nana Ros, Grand-Barry Aunty Katherine – thank you for loving Amelia unconditionally). A special mention though to my parents, Kim and Daniel West. The way you love Amelia is so beautiful and I am so grateful that she has had (and will always have) you both to love and care for her while I work. You have both raised me to be the strong, driven, resilient woman I am today. I would not be where I am today if not for your ongoing love and support,

To my siblings, Steven, Michael, Rebecca and Royce – without knowing it you have all greatly influenced my journey.

Michael, you have always encouraged me to be the absolute best I can be – whether it is presenting me with opportunities to experience the world differently, socialising my name in your networks, telling me to just ‘harden up and get the work done’ or simply showing me what it takes to be the best and to succeed through your own actions. You are always the first person by my side supporting me, letting me know everything is going to be ok, you are also the first person to challenge me and encourage me to expand my thinking; and every time you introduce me to anyone, you always say that you are proud to be my brother. There will never be enough words my bro, I love you and I am so proud and so grateful to be your sister.

Rebecca, the shape my mahi has taken has been profoundly impacted by you and the stories of resilience and strength held in your body, heart and soul. When I started my PhD in 2018, it was unexpectedly by your side in Australia. You, my sister demonstrate a strength unlike any other I have ever witnessed – being with you and sharing that experience evoked a passion in me to want better for our people. You are the epitome of mana wahine and you are raising strong and resilient children. I am so unbelievably in awe of you. He aroha mutunga kore

Steven, our mataamua, our oldest. A 5-year-old ‘pepi Westis’ walked alongside you, hand in hand, singing Nirvana and Wu-Tang Clan songs at the top of her lungs. An 18-year-old ‘bub’ fled to your side when I suffered my first heartbreak. And a 31-year-old ‘nearly Dr’ stands confident in knowing that you will always have my back. You have enormous capacity for love and compassion, and I can only hope that you can feel the love and respect I have for you, as the pōtiki, the youngest in our whānau.

Royce, you and me represent the West's in our whānau. You are a person who dreams big and is committed to your vision and to your view of the world. You stand by Holly and Ariah and are never scared to express your love and admiration of them. I love watching your whanau grow together and you inspire me to see what is important in life – that family is where it's at.

Tiani. Where to start. I love you so very much cousin. You are so much like your māmā in your limitless capacity for love, kindness and forgiveness. Like Aunt, you never stop fighting and you are always willing to see the best in people. In the past four years you have picked me up and held me through tears and laughter. You hold me accountable for my actions and support me in everything I do. My world is an infinitely brighter place because of you.

To my whanau. This journey has not been without its ups and downs. Nestled deep within the pages of this thesis are stories of resilience. These are our stories, they are us and we are them. I wish I could name you all individually, cousins, aunties, uncles, grandmothers – I know that you will all be delighted to share in this triumph. Please know that I am thankful for the ways that you have all kept me grounded and kept me focused. You are all so very loved.

Now to the amazing people who I have had the privilege of sharing space with through this PhD Journey. Kapua, Aleh, Zoe F, Cinnamon, Morgan, Hot Fern, Emmaline, Briar, Zoe H, Marnie, Yvonne, Kat, Aimee, Hana, Sarah, Hera, Te Kahuratai, Mona, the extended MAI network. Thank you for holding safe spaces for me. You have all encouraged me, challenged me, inspired me, motivated me. I feel so lucky to share this journey with you all.

A special mention though to Ash. There is a reason your name graces the acknowledgements of so many theses my friend. Your tenacity and strength is more than admirable. Your generosity, love and commitment to those who are lucky enough to call you a friend is unparalleled. Regardless of how tough things are for you, you always turn up to tautoko and show manaaki. You got me over the line. I see you e hoa, and you are a sight to behold!

To my favourite person, you came into my life in the final year of my PhD and have sat with me through passion, excitement, fear and despair. Thank you for loving me through it all.

To the amazing people who have supported me in my writing, theorising, editing and pushing me over the line. Louise, I almost gave up on my PhD, but you made me feel like it was possible and that I could do it. Donna, thank you for taking me on part way through this journey. Thank you for allowing me the space to voice my frustrations and fears. Thank you for sharing in my excitement when I had new ideas, and making me feel like my work matters. Tracey, I am here because you believed in me. This thesis is a reflection of the manaaki, aroha and tautoko you have shown me.

Finally, to my Nan Angeline Ahirata Ryan. The wisdom captured in your memoirs were critical in the formation of this thesis. Through your stories I have gained a deeper understanding of what it means to be a mokopuna of Hauraki, I am so proud to be your moko.

To you all I express my deepest gratitude,

Contents

List of Tables and figures:

List of Acronyms and Abbreviations:

CANZUS	Canada, Australia, New Zealand and the United States
C.A.R.E	Collective Benefit, Authority to Control, Responsibility, Ethics
Data ILG	Data Iwi Leaders Group
DIKW	Data, Information, Knowledge, Wisdom
F.A.I.R	Findable, Accessible, Interoperable, Reusable
FNIGC	First Nations Indigenous Governance Center
HRC	Health Research Council of Aotearoa
ID-Sov	Indigenous Data Sovereignty
MD-Sov	Māori Data Sovereignty
OCAP™	Ownership, Control, Access and Partnership
PHRaE	Privacy, Human Rights and Ethics Framework
POU	Provenance, opportunity, utility
TMR	Te Mana Raraunga
UNDRIP	United Nations Declaration on the Rights of Indigenous Peoples

List of Reports Referenced:

He Whaipaanga Hou	Maori and the Criminal Justice System: A New Perspective, He Whaipaanga Hou
Puao-te-ata-tu	The Report of the Ministerial Committee on a Maori Perspective for the Department of Social Welfare
Hunn Report	Report on the Department of Maori Affairs
Tatau Kahukura	Māori Health Chart Book
WAI 262	Ko Aotearoa Tēnei: A Report into Claims Concerning New Zealand Law and Policy Affecting Māori Culture and Identity
WAI 2915	He Pāharakeke, He Rito Whakakīkīnga Whāruarua: Oranga Tamariki Urgent Inquiry
WAI 1024	The Offender Assessment Policies Report
WAI 2522	The Report on the Comprehensive and Progressive Agreement for Trans-Pacific Partnership
WAI 2575	Hauora Report of Stage One of the Health Services and Outcomes Kaupapa Inquiry

Glossary of Māori terms:

Aotearoa	New Zealand
Kaitiakitanga	Guardianship, stewardship, trusteeship, trustee
Kapa Haka	Māori performing arts
Karakia	(ritual chants) and customs for the opening of new houses, canoes and other events
Kawa	marae protocol - customs of the marae and wharenui, particularly those related to formal activities such as pōhiri, speeches and mihimihi. This seems to be a modern extension of the word.
Koha	Gift, present, offering, donation, contribution – especially one maintaining social relationships and has connotations of reciprocity
Kōhanga reo	Māori language preschool.
Kotahitanga	unity, togetherness, solidarity, collective action.
Mana	prestige, authority, control, power, influence, status, spiritual power, charisma - mana is a supernatural force in a person, place or object.
Mana motuhake	separate identity, autonomy, self-government, self-determination, independence, sovereignty, authority - mana through self-determination and control over one's own destiny.
Māori	Indigenous peoples of Aotearoa
Mātauranga	Knowledge, wisdom, understanding, skill
Moteatea	lament, traditional chant, sung poetry - a general term for songs sung in traditional mode.
Oriori	lullaby - song composed on the birth of a chiefly child about his/her ancestry and tribal history.
Pūrākau	myth, ancient legend, story.
Rangatiratanga	chieftainship, right to exercise authority, chiefly autonomy, chiefly authority, ownership, leadership of a social group, domain of the rangatira, noble birth, attributes of a chief.
Takarangi	Spiral
Tākoha	Gift, token, pledge
Tā moko	traditional tattooing - Māori tattooing designs on the face or body done under traditional protocols.
Taonga	Treasure, anything prized – applied to anything considered to be of value including socially or culturally valuable objects, resources, phenomenon, ideas and techniques
Tapu	be sacred, prohibited, restricted, set apart, forbidden, under atua protection
Te ao Māori	The Māori World
Te Mana Raraunga	The Māori Data Sovereignty Network
Te Roopu Whakakaupapa Uruta	Māori Pandemic Response Group
Te Tiriti ō Waitangi	The Treaty of Waitangi
Tikanga	correct procedure, custom, habit, lore, method, manner, rule, way, code, meaning, plan, practice, convention, protocol - the customary system of values and practices that have developed over time and are deeply embedded in the social context .
Tīpuna	Ancestors, grandparents
Waiata	song, chant, psalm.
Whakairo	carving.

Whakapapa	genealogy, genealogical table, lineage, descent
Whānau	extended family, family group, a familiar term of address to a number of people - the primary economic unit of traditional Māori society. In the modern context the term is sometimes used to include friends who may not have any kinship ties to other members.
Whanaungatanga	relationship, kinship, sense of family connection - a relationship through shared experiences and working together which provides people with a sense of belonging. It develops as a result of kinship rights and obligations, which also serve to strengthen each member of the kin group. It also extends to others to whom one develops a close familial, friendship or reciprocal relationship.
Whenua	land

(Definitions sourced from
www.maoridictionary.co.nz unless otherwise stated)

Chapter One: Introduction

Our social lives are increasingly shaped and informed by data. Data is critical in understanding the past, interpreting the present and imagining the future. Data and access to it have enormous positive potential to contribute to the development and flourishing of Indigenous communities. In the past five decades, Indigenous scholars, activists, and practitioners, alongside our allies, have utilised data to understand and transform the way Indigenous wellbeing is conceptualised. For example, in 1975, in Aotearoa, it was reported that only 5% of Māori school-aged children were able to speak te reo Māori (Waitangi Tribunal, 1986), our language had been labelled in the 1961 Hunn Report as an ancient relic (te Taura Whiri i te Reo Māori, n.d.), and English was being forced on to Māori as the supposed language of the future (Higgins & Keane, 2013). Rapid language attrition rates prompted flaxroots movements like Ngā Tama Toa and the Te Reo Māori society to take action to protect and preserve te reo Māori for our future (Higgins & Keane, 2013). As a direct result of these efforts, we now have an established pathway in education in Aotearoa New Zealand delivered entirely in te reo Māori from early childhood through to tertiary education. Te reo Māori is recognised as an official language and Te Taura Whiri i te reo Māori – the Māori Language Commission – is tasked with monitoring the health of te reo Māori and reporting back to the government. In another more recent example, the COVID-19 pandemic has highlighted how Indigenous peoples can harness the power of data to support their communities in times of crises (Kukutai, McIntosh, et al., 2021).

These two very brief examples are part of a broader shift of popular narratives away from deficit explanations and theorising toward acknowledgment of traditional knowledge and the building of repositories of knowledge and data that focuses on affirming the value of Indigenous ways of knowing and being. While Indigenous peoples have been working assiduously to use data to challenge, shift and transform political discourse, there has been a broader global movement occurring towards digital worlds and data-driven technologies. This poses significant risks to Indigenous peoples who despite immense effort continue to be represented negatively in colonial datasets.

When I first set out to engage in this PhD research, my intention was to consider the limitations of existing data governance frameworks. At the time, I considered that my personal contribution to the field would be in the development of a new model for data governance. Initially, I thought that this would be a relatively straightforward task, of stocktaking existing models, teasing out what works and what does not work and then producing something from that analysis. What I learnt early on was that this would not work for the following reasons: We currently do not have a common language for discussing data sovereignty and data governance. That is, we use the same words, but do not necessarily mean the same thing when we use those words. Given my research background in research ethics, and in particular the failings of current ethics frameworks, it was apparent to me that the same issues that we have with research ethics could be equally applied in the governance space. Consider for example, the function of the principle of consent in research ethics. It is a foundational principle of research ethics which centres the individual adult who is believed to be able to make autonomous decisions based on a specific (neo-liberal) standard of rationality. First appearing as a core principle of ethics in the Nuremberg Code, 'free and informed consent' has since been codified and formalised in institutional ethics. Despite being socialised in research spaces since 1947 there is still, arguably, no commonly accepted standard for achieving informed consent in research. Researchers have challenged the age of consent (Carter, 2009; Coyne, 2010; Harcourt & Conroy, 2011), the limitations of understanding the consent process for participants, the appropriateness of individual consent from a cultural perspective (Ermine et al., 2004; Hudson et al., 2010; Tauri, 2014, 2018; Tuhiwai Smith, 2021) and the ethical concerns around signing consent forms in particular communities (Ermine et al., 2004; Hudson et al., 2016; Tauri, 2014, 2018; Tuhiwai Smith, 2021). The lack of conceptual clarity around what constitutes free and informed consent makes it difficult to measure the extent to which research ethics actually protect participants. Returning to Indigenous Data Sovereignty, more needs to be done to ensure key elements of ID-Sov are clear before we can measure or evaluate its efficacy.

A second key concern is that data sovereignty is a relatively new field. The idea of Indigenous data sovereignty as a particular field of enquiry only emerged in 2016, two years before this PhD had commenced. Te Mana Raraunga – The Māori Data Sovereignty Network (TMR), the primary advocates for Māori rights and interests in an increasingly open-data environment, had only just been formed and the principles of Māori data sovereignty (MD-Sov) were therefore, only recently published. As an emergent movement, the key activities of MD-Sov and TMR were still primarily concerned with identifying the scope of data sovereignty, defining what Māori data is, theorising around key issues of relevance and separating the discussion from a general conversation about ethics. Further, any governance models either in place or in development were in their initial iterative phases and were the subject of debate within the Te Mana Raraunga network. Māori entities not attached to university institutions were approaching data sovereignty, not from the perspective of governance frameworks, but from action. They were needing to think on their feet, how best to protect their own communities in the process of their data activities.

Data sovereignty is an issue in administration of the state, in corporate spheres, within university research environments, among the Non-Governmental Organisation (NGO) sectors as well as amongst Māori entities like iwi and hapū. As the idea of Māori data sovereignty has been socialised across various sectors, (public sector, private sector, institutional) the call on Māori Data Sovereignty (MD-Sov) experts has been intensified with requests coming through for representation of our people on boards and committees, as well as calls for consultation, input, and advice. Importantly, the needs across each of these sectors are contextually diverse and experientially different. In consideration of these factors, it was decided that it would be unfair and frankly unreasonable to test the quality of the current governance frameworks. Primarily because, existing frameworks have not been in place long enough to be well placed for evaluation or testing. Further, it is premature to make any inferences about whether the measures in place are robust enough to protect Māori data in the long term. These points considered; the efficacy of existing models has not been tested in this doctoral research as was anticipated in the original research design.

Instead, this research responds to two key questions. First, how does the social, political and historical context of research conducted *on* and data created *about* Indigenous peoples, influence the epistemic development of Indigenous Data Sovereignty discourse. This first question is important as it provides an opportunity to consider the context in which ID-Sov has emerged and developed. The second question pivots to reflect on how we, as Māori and Indigenous peoples, can draw upon our own traditions of storytelling as a way to articulate the lived realities of MD-Sov in Aotearoa. In responding to this question, this research makes a significant contribution to the field as it draws out the connective elements of MD-Sov research; shifting the conversation away from abstract imaginings of zeroes and ones towards a discourse that is firmly rooted in the lived realities of our people.

Chapter overviews:

Chapter two describes the methodology and approach taken to produce this thesis. Here, I position myself in relation to my whānau (family) and whenua (land) and consider how these factors shape and inform my unique view of the world and how this has in turn influenced the shape of this thesis. Kaupapa Māori theory is centred in this chapter as a platform from which to speak, and a tradition to which I belong. This is also where the reader is introduced to the methods that inform this thesis. Namely, case studies, document analysis and storytelling. There is a distinct tone shift in this chapter, away from a purely academic style of writing, to one that is more personal in nature.

Chapters three to six are a series of exploratory chapters that lay the foundation for the discussion in the case study component of this thesis. They do the work of scoping the literature, defining key concepts, and identifying pressing debates in the field of Indigenous Data Sovereignty [ID-Sov]. Critical to these discussions is a consideration of the accumulated histories of these key concepts and debates, recognising that the issues we are facing now with regards to data have not emerged spontaneously.

The first exploratory chapter focuses on defining data. Canadian scholar Jodi Bruhn (2014) adopted a very broad view of data, suggesting that they are a simply a resource and a descriptive asset. This is a useful starting point; taking this kind of broad approach allows for the discussion to move across diverse sectors where data plays a critical role. Of particular interest to this thesis is the ways in which the lack of regulation in digital spaces means that individuals and communities are increasingly exposed to new risks. Generally speaking, chapter 3 centres digitised data and the capacities and capabilities of digital technologies. This aligns with the contemporary understandings of what has been considered to count as data following the 'big-data take-off' during the computer revolution (Rendgen, 2018; Rosenberg, 2013). It was then, in 1946, that the term data was first used to refer to 'transmissible and storable information by which computer operations are performed' (https://www.etymonline.com/word/data). The association of data with the computer revolution was further solidified through the 1950s with the establishment of the disciplinary field of Information Sciences (Furner, 2015). As a field, information sciences have been less concerned with defining data itself and far more interested in distinguishing data from popularised synonyms like information, knowledge, and wisdom (Ackoff, 1989; Bellinger et al., 2004; Boisot & Canals, 2004; Frické, 2009; Zins, 2007). The *'Defining Data'* chapter then, will close with a brief overview of the Data, Information, Knowledge, Wisdom (DIKW]) hierarchy and a consideration of how this aligns with, and where it differs from recent Indigenous definitions of data.

There is no denying that the current and developing data-capacities are changing the way we understand data value and certainly, digital data, big-data and open-data are artefacts of the 21st century. While the computer revolution and subsequent establishment of information sciences has had a significant impact on contemporary definitions and applications of the term, 'data' has a rich whakapapa pre-dating the 'big data take-off' which is worthwhile exploring. In the second exploratory chapter '*Data: From a Given to the Taken',* a consideration of the etymology of data offers insight into how the term has become imbued with notions of neutrality, truth, and objectivity. Further examination into the origins of the term data as 'things given', presents a unique opportunity to consider the potential theoretical parallels between data as a gift, and the gift economies in pre-colonial Māori societies. This necessitates a brief consideration of the work of Marcel Mauss (1925) in '*The Spirit of the Gift'* and contemporary Māori critique and analysis. It also opens a space for a discussion of the connection between data, gifting, koha and finally institutional research ethics.

The third exploratory chapter, '*Data Value and Advancing Data Technology',* shifts focus slightly to consider the value of data in contemporary contexts. First from a financialised commercial perspective, before pivoting to interrogate data value in relation to the development of evidence-based policy. What is increasingly evident is that in data spaces, there is a growing entanglement between corporate entities and government operations. Further, there is a clear misalignment between the public expectations of their legal data protections, and what is actually in place for the protection of data and personal information. The Integrated Data Infrastructure (IDI) is a useful example to draw upon. The IDI is a data linking software and infrastructure hosted by Stats NZ and includes microdata about people and their households (Stats NZ, 2020). As the administrative body responsible for data in Aotearoa, Stats NZ has assumed a mandate to operate the IDI under social licence. This chapter interrogates the validity of this claim in light of pressing issues such as the ethics of secondary data analysis, privacy, and prior and informed consent.

The fourth and final exploratory chapter is focused on defining ID-Sov and offering a general overview of the development of ID-Sov as a specific field of enquiry. It does so first by differentiating between the key features of data sovereignty generally and ID-Sov specifically and aligning ID-Sov with key levers such as the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and the First Nations Principles of Ownership, Control, Access, and Possession (OCAP®). Next, Māori data sovereignty as a specific field in the context of Aotearoa New Zealand is discussed with particular emphasis on the work of Te Mana Raraunga and the Data Iwi Leaders Group [ILG] as key advocates for data sovereignty. A key focus for advocacy, particularly for the data ILG, has been around establishing clear pathways for data sovereignty to be realised in policy through data governance. This has created the space for greater engagement between Māori and the Crown and therefore requires some understanding of how Māori data sovereignty can be seen within a Treaty of Waitangi context.

Chapters seven, eight and nine are a series of case study chapters comprising the research component of this thesis. Each case study engages with a pressing issue in data sovereignty and interrogates it using a specific example.

The first case study interrogates the notion of privacy in the context of the COVID-19 global pandemic. The purpose of this case study is to consider how the COVID-19 pandemic response is stretching existing norms around data and privacy in Aotearoa. Responding to the COVID-19 pandemic has necessitated radical shifts in the way that we understand the parameters of data privacy in both global and domestic settings. In what is a relatively short period of time, we have seen the deployment of new systems of surveillance, as well as the extension of existing systems, justified on the basis that the information garnered from these platforms is required to support public health initiatives. Not only has COVID-19 presented a range of new data/privacy concerns, but it has also exacerbated existing issues within our current systems. As data continues to gain currency in political spheres, privacy is increasingly transformed as a commodity for trade. Nowhere is this more evident than in the social welfare system where privacy is regularly traded for access to basic human needs. This case study reflects on the limitations of the emerging discourse around data collection and privacy for Māori, now and into the future, as Government initiated responses to the pandemic call for more detailed information. Central to this case study is a consideration of how privacy, as a basic human right is largely only afforded to individuals, sometimes at the expense of the collective. Finally, this case study closes with a consideration of tapu as the closest concept we have to privacy from a Māori perspective.

The second case study explores trust in relation to the development and deployment of automated decision-making technologies in Aotearoa. Underlying the datafication of our common realities is a persistent rhetoric that data are objective and free from bias. These claims of neutrality filter through commonplace justifications for the use of automated decision making (ADM) technologies, including algorithms, so much so that ADMs are now being elevated as a mechanism for the removal of human bias in important decision making. ADMs offer the potential for greater efficiency in sectors where there is pressure to make decisions quickly. Further, ADMs are capable of processing large datasets and turning over a high volume of decisions in short periods of time. While there are potential benefits to using ADM technologies, there is also significant potential for them to (re)produce harm for Māori. Primarily this is because ADM technologies rely on the availability of data to inform their processes. It will be brought to light in this case study that there are grounds for concern among Māori about the quality of data that presently exist about us within the system, and therefore there are concerns around the decision-making tools that these datasets inform. Given the current investment at the government level into investigating the potential use of ADMs, it is both timely and necessary to consider how Māori will be impacted by these developments. In particular, threaded throughout this discussion is a broader set of questions around the legitimacy of 'trust' as the basis of our willingness as Māori to offer up our lived experiences into systems of surveillance. Trust is contrasted with the Māori concept of tiakitanga to highlight how the locus of responsibility in the trust relationship is different in Māori and Pākehā spaces.

The third and final case study considers how poor data practices are part of the broader story in the violent disruption of whakapapa caused by the theft of Indigenous children by colonial governments. It goes on to consider how ongoing issues with access to personal data continue to compound trauma in contemporary contexts. Whakapapa takes on multiple forms in this chapter – a theoretical framework, a model for understanding our kinship networks, and as a principle of data governance. It is first theorised as the central organising principle in te ao Māori, forming the basis upon which all relationships are to be built. Key elements of whakapapa including time, more than human relations as well as our connection to ngā Atua are considered. After having highlighted the centrality of whakapapa, connection and relationships in this first section, the discussion then turns to reflect on how colonial governments have attempted to sever the connection between Indigenous children and their whanau. Looking at the efforts of iwi now to protect their mokopuna by utilising their whakapapa databases is an uplifting example of how Māori are acting in sovereign ways to protect their people. Finally, how whakapapa is operating as a principle of data governance is considered.

The discussion chapter closes this thesis by considering my unique contribution to the broader Indigenous data sovereignty discourse. I boldly assert that this thesis is, in itself an act of

Māori data sovereignty. Central to this closing chapter is a reflection of the challenges that come with taking action to assert sovereignty over our stories, our whakapapa, our bodies, our data.

Chapter Two: Methodology and Approach

Writing the introductory section of a chapter seems to me to be the most difficult part of the writing process. This is where you have to make a decision about how you will invite the reader into your story. The methods and methodologies chapter, while formulaic for some, has been particularly unnerving for me. Largely because this is where I expose my thought process; this chapter represents an opportunity for the reader to come to understand how the ideas which constitute this research came to be. This is hard, because the PhD process is totalising, all-encompassing and all-consuming, so making a decision about what is put out there as having a formative and influential impact on the research is not as straightforward as it may seem from the outset. In many ways, the formulaic approach would have been the easy option, it would have laid out very plainly (and informatively) the following:

- The researcher positions themself as a wahine Māori in the academy. They recognise that this position will introduce particular biases into the research process and indeed will also explicitly challenge biases that exist within mainstream research practices.
- The research concerns Māori issues and presupposes the validity, legitimacy, and value of mātauranga Māori, tikanga Māori and te reo Māori. The research also assumes that Māori ways of knowing, and thinking will offer insights that have not yet been considered in the field, as well as potential solutions. Therefore, this research uses a Kaupapa Māori framework.
- Whakapapa is a critical element in this research. Whakapapa is used as a tool to explain the authors positionality, as a theoretical framing and later in the thesis as a principle for data governance.
- Evidence for this research is drawn from the existing scholarship in the field of Indigenous Data Sovereignty and three case studies. The case studies are informed by pūrākau, auto-ethnography and document analysis.

Everything in the list above is, by definition, true. But this approach would have been dishonest and would have downplayed the grittiness of research and obscured the timeline of thought. The following chapter then, is a personal and intimate reflection of the thoughts and processes which have informed the production of this research. My contemplations and reflections are present throughout – there is also a strong academic voice, where I follow convention and cite scholarly works. My hope for this chapter is two-fold; first, I hope this chapter does its job in informing the reader of the research process. Second, I hope that any prospective research students can seek some comfort in knowing that research can be messy, even when you don’t expect it to be, yet this messiness can be reconciled in the research process and actually progress it, rather than hinder research outcomes.

As someone, who at the time of writing this, is in the final and turbulent throes of the PhD completion process, I can say that receiving 'how to' advice from your peers requires patience and an open mind. I liken it to having a new-born pēpi when you get advice from well-meaning people (sometimes strangers) with tips and tricks to get bub to sleep. All you can think as a māmā is how you have tried literally everything and that what you're experiencing is clearly a karmic style slap in the face for that time that you farted in class and blamed the teacher.

Confessions aside, some advice that I have found useful for getting over the beginning hurdle of writing up the methods and methodologies is to think of it as a recipe and break it down in that way. In which case, the following questions may be useful:

Where did the recipe come from?	How do you position yourself in relation to the research? What is the ontological and epistemological basis of the research? How does this influence the selection of the theoretical framework of the research?
What ingredients are you working with?	What are the key influencing factors which inform the evidence that you are drawing from?
What is the order in which the ingredients are combined to produce the desired outcome?	Considering your positionality and theoretical framework, how will you get access to and engage with the available evidence? Do you use inductive or deductive reasoning?
What does the final product look like?	Points of reflection: how has your approach to the research process influenced the final outcomes? Would a different method have produced different results? What does this say about the validity of the research

Others have suggested that I just start writing out the ideas as they emerge and think about editing and finessing at another time – this is the proverbial 'brain-dump' method. Writing this chapter has necessitated a hybrid approach, being both process-focused while still allowing ideas to flow organically. To this end, this methods and methodologies chapter will take its structure from the recipe approach, using the above questions as signposts, where I can reflect on the process of producing this thesis.

Positionality:

Positionality, in some contexts, can be looked upon negatively as it is essentially a recognition that factors contributing to your positionality also introduce biases into your research. For some researchers, operating out of Western paradigms, objectivity in research is the goal, and where objectivity cannot be achieved, mitigating factors should be in place to ensure the results are not skewed. For me, being aware of my positionality did not present a limitation to the research. If anything, it introduced an emancipatory element to my research that serves to strengthen my contribution to Kaupapa Māori research.

Understanding the position from which you are writing from is a critical component of good Indigenous research (Smith, 2017; Tuhiwai Smith, 2021; Whiteduck, 2013). This is in part a recognition of the harmful and damaging research that has historically occurred for Indigenous communities (Tuhiwai Smith, 2021). As Indigenous scholars, we need to be able to demonstrate that we are not contributing to racist research logics by being clear and open about who we are, and why we are doing what we are doing as well as foregrounding the individual and collective intent of our work (Tuhiwai Smith, 2021; Whiteduck, 2013). This is, as Fagan (2002) reminds us, our responsibility as Native writers to talk openly about the personal, cultural, theoretical, and institutional drivers in our research. For Graham Smith (2017), whether or not a researcher is clear about their positionality is a measure of the veracity of a Kaupapa Māori theory approach. On this Smith (2017) states:

> Where one speaks from is important; we need to locate ourselves in time and space. Why one speaks is important. Does the researcher or academic understand their own capacities and limitations? What is their transforming record that lends legitimacy to their work? What is my experience that supports the validity of my commentary? Who am I speaking to? How am I connected to the topic and to the audience? What and whose interests are served by my work? How do I engage with Indigenous frameworks and theorising? (p.90)

Answering these questions provides the reflexive space to consider how these factors shape how we think, the theories and methods we use and why this is important. (Tuhiwai Smith, 2021). Further, we are then in a better position to understand who our readers are, who they might be in the future, and what our responsibility to them is (Whiteduck, 2013). Understanding who our audience is and how this impacts decision-making in research is important. Are our readers Indigenous? How might we privilege Indigenous audiences? How do we call our allies to action and invoke their responsibilities? For our not-yet-allies, what role does our work play in providing an educative frame to those who want to be informed? Finally, what role does our work play in creating robust and compelling rationale and evidence to shift the mindset of those resistant to the notion of Indigenous knowledge and practice?

Ideally, these questions should be considered prior to engaging in the research (Tuhiwai Smith, 2021). As an emerging researcher though, I found that I didn't consider these questions, until I was prompted to whilst reading Graham Smiths chapter in *Critical conversations in Kaupapa Māori.* Initially, reflecting on these questions evoked feelings of anxiety and added another layer of depth to my existing feelings of imposter syndrome. Upon further reflection, it seems to me that this may be the point. That is not to say that we should encourage anxiety amongst emerging Māori scholars, but that we should be expected to reflect on why our research can be considered Kaupapa Māori. This is both a challenging and worthwhile exercise.

In the same book as Graham Smith's chapter is another authored by Carl Mika (2017) titled 'The uncertain Kaupapa of Kaupapa Māori'. In it, Mika (2017) proposes that simply being Māori is enough for research to be considered Kaupapa Māori. He states:

> My premise here is that we Māori come to an idea (whakaaro) in a Māori way- indeed, humanity is linked by whakapapa (genealogy) to whakaaro in creation narratives (Royal, 2012) and in the everyday participation with the world (Mika, 2014) – and that our arrival at an idea therefore makes for a Māori expression. Our subsequent Māori expression of that idea, of course, may look no different from that of a non-Māori person in any way that can be sensed, yet we can speculate that there is a subtle, subterranean difference in the texture if the writing (of Māori expression) that we can think of as mysterious because it is beyond our immediate access. (Mika, 2017, p. 120)

It was in the space between Smith and Mika's ideas that I found a way to reconcile and understand my positionality in relation to this research. In this liminal space, I found an opportunity to remember my connection to this whenua and to this research through whakapapa.

I te taha o tōku māmā,

Ko Moehau me Te Aroha ōku maunga

Ko Waihou, Ohinemuri me Piako ōku awa

Ko Tainui te Waka

Ko Matai Whetu te Marae

Ko Ngāti Marutuahu tōku iwi

Ko Ngāti Whaanga tōku hapū

No Pare Hauraki ahau

I te taha o tōku pāpā,

He putiputi tenei no te ao, I ngā wā o mua, kua tae mai ōku tupuna ki Aotearoa mai i a Ingarangi, Tiamana me Potukara hoki

Whakapapa, on the surface, is a recital of geographies and landscapes connecting me to the land and to my whānau. Beyond the description of place and space, whakapapa also operates at a much deeper level. To 'whaka-papa' is to place layers upon each other and build new relationships

(Jackson, 2020, p. 149). Acting as the most intimate of icebreakers, whakapapa actively reduces the space that exists between strangers, it is about relationality and positionality. In nine lines, I have positioned myself to the reader as tangata whenua and tauiwi. I referenced the maunga that knows my name, the awa that my nanny knew intimately, the waka my tūpuna voyaged upon from Hawaiki and the name of the land they would settle in. There are times where I would also add:

Ko Kim rāua ko Daniel West ōku mātua
Ko Steven rātou ko Michael, ko Royce ōku tungāne
Ko Rebecca tōku tuakana
Ko au te pōtiki o tōku whānau
Ko Amelia taku tamahine

Here, I position myself as a daughter, a sister, the youngest in my family and as a mother. In doing so, the opportunity arises to create relationality and to consider the potential for shared experiences which may connect us, you and I, in some way. These are all factors which influence my unique view of the world. And it is in this very unique and particular view of the world that this thesis emerges and is given meaning and life. In this sense the process of whakapapa works simultaneously as a method and methodology. Speaking to the specific power of whakapapa, Jackson (2020) explains:

> Because whakapapa traverses time between the past, present and future, the building of new relationships and the telling of new stories begins with the identification and 'un-telling' of colonisation's past and present lies. Stories for and about transformation rely on honesty about the misremembered stories and the foresight to see where the different stories may lead. That is the ethic of restoration. It offers the chance, or challenge, to clutch truth and justice for 'future flowerings'. It is concerned with the balance of relationships rather than the will to limit what they might be. And in giving back to Māori the right to self-determination, it offers everyone a place to stand... (p. 154)

Jackson's (2020) articulation of the purpose and potential of whakapapa here speaks to the way I have come to understand its role in my own mahi. It offers structure, in the layering of theory, drawing from the past to inform present and future realities.

Kaupapa Māori Theory

This research will be framed within a Kaupapa Māori theoretical paradigm. The conceptualisation of Kaupapa Māori as a particular way of thinking emerged in the 1980s amidst what many refer to as the Māori cultural renaissance. This was a period of heightened awareness among Māori of the need for significant political, social, and economic change that would better serve their people as Treaty partners (Bishop, 2008; Durie, 2017). Graham Smith (2017) notes that it was a period of conscientisation among Māori who were ready to move away from reactionary politics towards a proactive approach; an approach geared toward ensuring the future of Aotearoa

New Zealand had a strong sense of the priorities, needs, aspirations and preferences of Māori as the Indigenous peoples of the land.

‘Kaupapa Māori’ as theory, as research, as knowledge and as praxis, is multiplicitous in its nature, representing a diverse range of disciplinary practices and research methods. Though there is certainly diversity in the ways in which we engage with kaupapa Māori, there is also a dominant theme which remains consistent across the board, which is that “Indigenous work is inherently political and is overtly pro-Indigenous” (Smith & Tuhiwai Smith, 2018, p.11). The development of kaupapa Māori as a theoretical framework has historically been firmly rooted in the drive for emancipation of Māori from the systems of oppression regularly (re)produced through historic and ongoing processes of colonisation. This involves questioning the ways in which power and control are given effect by the State, as well as within institutional and public structures and practices (Smith & Tuhiwai Smith, 2018). ‘The Academy’ then, has become a key site for interrogation, as it acts as a powerful mediator of power and control, largely because it is seen as the legitimate site for the production of knowledge. Scholars operating within a kaupapa Māori framework then have taken it upon themselves to expose how the academy, whether it be explicitly, implicitly or complicitly, acts as a site of exclusion.

> It appals us that the West can desire, extract and claim ownership of our ways of knowing, our imagery, the things we create and produce, and then simultaneously reject the people who created and developed those ideas and seek to deny them further opportunities to be creators of their own culture and own nations. (Tuhiwai Smith, 2021, p. 1)

As an emergent scholar in the social sciences, it saddens me that this is still the case. I understand this statement in the context of the 80s and 90s when Kaupapa Māori theory was a burgeoning field in the academy, when we were just beginning our journey of recovering from decades of colonial violence and assimilatory/integration policies. But we now have a Māori Centre of Research Excellence, Vision Mātauranga[1] sections in almost every funding application and specific Māori vision statements in the strategic documents of New Zealand eight universities. Yet, in August 2021, seven senior academic staff members at the University of Auckland wrote an open letter claiming that Mātauranga Māori is not science[2]. The letter was written because moves were being made to embed mātauranga Māori into the high school science curriculum, giving it parity with other bodies of knowledge. The letter claimed that although Indigenous knowledge has some role to play, it “falls

---

[1] Vision Mātauranga is part of the New Zealand Governments science policy framework and is designed to support mutually beneficial research relationships between Mātauranga Māori and Western Science https://www.mbie.govt.nz/science-and-technology/science-and-innovation/agencies-policies-and-budget-initiatives/vision-matauranga-policy/

[2] The original publication of this letter was not easily accessible – a reprint of the letter can be found here https://www.fsu.nz/in_defence_of_science_article

far short of what can be defined as science itself" and that while science may have aided colonial efforts, 'science itself did not colonise'.

What ensued was a flurry of debates, apologies, and a resignation[3]. Māori scholars and activists spent time writing out responses, appearing on television interviews and speaking back in the 'Twittersphere'. In that same month, the University celebrated the gifting of a new name Waipapa Taumata Rau for the University by the mana whenua Ngāti Whātua Ōrakei[4], and the launching of a new strategic development plan 'Taumata Teitei'. Taumata Teitei has aspirations for every graduate from University of Auckland that they will be conversant in Mātauranga Māori and the principles of Te Tiriti o Waitangi.

Twenty years on from the first edition of *Decolonizing Methodologies*, and fifty years on from the first flourishing's of kaupapa Māori as a research field, and the sentiment of Tuhiwai Smith's quote above still rings true. Research, emphasis on the 're' here, is coming out with the data that shows that Māori academics move slower up the scales than any other represented group in academia (McAllister et al., n.d.; Naepi et al., 2019). We are penalised for not publishing enough, or not producing enough research, but there is a deafening silence regarding the fact that our time is being swallowed up and consumed with 'consulting', the offering of free 'advice' and fighting to prove that our mātauranga is valid and valuable. Given the origins of kaupapa Māori in the fight for an emancipatory politic, exposing the operationalisation of power also contributes to a broader project of transformation. As Smith and Tuhiwai Smith (2018) remind us:

> It is important that we, as Indigenous communities, take over the responsibilities for naming, defining, and intervening in the crises, which fundamentally, are not of our making, but in which we have been situated and which have had on-going and enormous negative impacts on our language, culture, collectives, and families. (p.4)

In the past three decades, Māori scholars and activists, along with support from allies, have worked tirelessly to realise this vision, with great success. The example of the development of Māori education at the University of Auckland is among the most successful (Smith & Tuhiwai Smith, 2018)

In this same 30-year period though, the political and economic landscape in Aotearoa New Zealand has undergone its own transformation, that of neoliberalism. This is important because, in what are categorised as First World Countries (CANZUS states for example), colonisation has taken on new forms, largely existing within neo-liberal frameworks where exploitation and cultural oppression are reproduced via economic intentions (Smith & Tuhiwai Smith, 2018). The academy

---

[3] The resignation referred to here was not a complete resignation of the person from the university, but a resignation from the temporary position as acting head of department

[4] https://www.auckland.ac.nz/en/about-us/about-the-university/waipapa-taumata-rau-university-of-auckland.html

has not been sheltered from this broader transformation and has, in many ways, embraced its ‘neoliberalisation’. We see now the neo-liberal university, which is characterised in part by the commodification of knowledge, enthusiasm for an adherence to individually based cultural and intellectual property rights, as well as a refocus of the purpose of research as a source of revenue for university institutions.

Revisiting the sentiment raised in the earlier quote from Smith and Tuhiwai Smith (2018) regarding the responsibility we have as Indigenous scholars to be actively ‘...intervening in the crises’ which continue to have ‘…on-going and enormous negative impacts on our language, culture, collectives, and families’, it is important to reflect on the contemporary crises we are facing presently as Indigenous peoples. The breadth of crises is vast including climate change crises, ongoing human rights abuses, political, economic, and cultural crises and, critically for this research, digital crises. The point is not to completely disregard existing knowledge bases, but instead to see that:

> The interface of Indigenous wisdom, thinking, and knowledge with other knowledge(s) also provides enormous potential for new, fresh opportunities and innovative ideas that can potentially be more effective transformation of the Indigenous crises. (Smith & Tuhiwai Smith, 2018, p.18)

Emerging out of an exclusionary context, the driving force for kaupapa Māori has never been about excluding others (Durie, 2017; Smith, 2017). However, a key driver is a focus on ensuring there is space for Māori ways of thinking, being and doing to thrive; and this has been informed by Indigenous thinkers, scholars, activists and tribal community and collective groups as well as by non-Indigenous critical theory. Maintaining an awareness of the historical emergence of kaupapa Māori research frameworks will be critical for framing my research.

In the first, second and third edition of *Decolonizing Methodologies,* Linda Tuhiwai Smith (1999, 2012, 2021) dedicated a chapter to describing twenty-five Indigenous projects, which contribute to an Indigenous research agenda. At the time that the first edition was published, the Indigenous research agenda could be broadly typified as being driven by a social justice imperative for the survival of Indigenous peoples, cultures, and languages (Tuhiwai Smith, 1999). I have identified my research as contributing to six of these projects:

- Project 1: Claims Making
- Project 12: Representing
- Project 14: Envisioning
- Project 15: Reframing
- Project 18: Democratizing and indigenist governance
- Project 23: Negotiating

Kaupapa Māori provides tools for the navigation of complex issues pertaining to Māori as well as drawing on Māori and Indigenous understandings; but it is not a prescribed set of tasks. It has strong philosophical, theoretical, and applied dimensions as well as a political stance. I am able to locate myself in this work as a Māori woman and it allows me to think freely and naturally as Māori. As such, “Kaupapa Māori theory presents an academic and political platform from which to speak and a tradition to which I belong” (West-McGruer, 2016).

Case Studies:

The substantive research component of this thesis is made up of three case studies. At its most basic level, a case study can be defined as a detailed explanation of a single example (Flyvbjerg, 2006; Yin, 2003). Yin (2003) specifies that a case study is an empirical inquiry that “…investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident” (p.13). Similarly, Gillham (2000) defines a case as:

- a unit of activity embedded in the real world;
- which can only be studied or understood in context;
- which exists in the here and now;
- that merges in with its context so that precise boundaries are difficult to draw. (p.1)

In the introductory chapter of this thesis, I indicated that Indigenous Data Sovereignty [ID-Sov] was only an emergent field of inquiry at the commencement of my PhD and I highlighted how this shaped the shifts in my intentions and focus. In brief, there was limited literature or scholarship that looked specifically at ID-Sov, and what was available was largely focused on identifying and developing the scope of the field. Frameworks for data governance in Aotearoa New Zealand had started emerging, but these were largely in draft form, or had only been published as best-practice guidelines as opposed to active governance frameworks. I also highlighted that as ID-Sov has become socialised across public, private, institutional and community sectors, it has become increasingly evident that the range of data-ecosystems where there are Māori interests is incredibly diverse. In the absence of a robust and diversely applicable governance strategy, individualised approaches have been developed and trialled to try to address ID-Sov concerns. A final point worth noting here, is that data sovereignty as a field of inquiry is developing in tandem with the rapid expansion of new technologies. In the literature review chapter, I highlight how the speed at which we are seeing the development of new technologies has made it difficult for our conversations to keep up. As a result, to borrow the phrasing of Safiya Noble (2018), this PhD thesis is “...out of date immediately upon printing” (p.10). Meaning that as a scholar working across the fields of Indigenous Studies, communication, information, and technology, it is a challenge to do research that explains the impact of a process or phenomenon that is constantly changing or morphing.

With these factors in mind, the case study method for inquiry was appealing for the following reasons. First, case studies draw upon multiple sources of evidence including documents, narratives, interviews, and observations (Gillham, 2000; Rowley, 2002; Yin, 2003). Given the infancy of the field, taking a broad view of what could be included as evidence was necessary. The evidence base for each case varies slightly but generally speaking, I have included relevant reports, news media, social media, and personal narratives in my analysis. The specifics of the analysis are detailed below in the sections subtitled document analysis and storytelling in research.

Second, as an emerging researcher and scholar, there is a temptation to demonstrate a breadth of knowledge in your subject area. Initially, for me at least, this translated as a desire to know everything that has ever been written about ID-Sov as well as having an awareness of data issues as they emerged. Not only is this overly ambitious, but it is also impossible given the rapid expansion of the field. In this sense, the case study method allowed for a loose narrowing of the areas of interest, while still allowing for an exploratory approach.

A third, unanticipated benefit of doing case studies was that I was able to see how the issues I was addressing were not siloed and that it was very often the case that they were not only inter-related but inter-dependent. For example, key issues identified in the case study around Māori perspectives on trust and automated decision making were connected to whether or not systems could protect privacy. Further, privacy was broadly conceptualised in relation to whakapapa, in particular regarding the tensions between individual and group level privacy.

Rowley (2002) argues that case study research should take a deductive approach, meaning the definitions of questions and propositions are identified in advance of data collection. Taking a deductive approach, according to Rowley (2002), gives the research a firmer foundation and supports the validity and veracity of the research and provides a clear structure for data collection and analysis. My approach to case study design was quite different to that suggested by Rowley (2002), and aligned more closely with Gillham (2000) who suggests that it is not until you begin data collection that you are properly able to understand the context of the case and therefore know which theories work best or make the most sense. I took an inductive approach, meaning the questions, insights, propositions, and pictures emerged from the data collection. I went into each case study with a general focus, taken from the key points identified in the initial literature review, and my own personal questionings, and allowed the key issues to emerge out of the analysis. In this case, the purpose of the case study was clearly defined, but the questions were organically generated.

A key concern of this approach often cited in the literature is that it lacks rigour and robustness and is limited to making only a modest contribution to knowledge (Rowley, 2002). There is also the idea that the findings of case study research are not generalisable. There are proponents of the method like Flyvbjerg (2006) and Gillham (2000) who have put forward arguments in defence of the case study. Flyvbjerg (2006) for example, published a paper detailing five popular misconceptions of the method, noting that in general, critiques of the method reflected broader misunderstandings within the research community. Initially, I spent considerable time contemplating how I could make my research more ‘robust’, however after some reflection I came to the conclusion that the quality measures of validity, robustness and generalisability are all measurements of the quality of research coming from a western paradigm.

Instead, I returned to the questions put forward by Smith (2017) noted earlier in this chapter as a way of measuring the rigour of my research and the potential impact that it could have. I also reflected on the six Indigenous research projects from Tuhiwai Smith’s (2021) list as an alternative measure of my contribution to the field. The purpose of these three case studies is to highlight the pressing data sovereignty issues that we are currently facing as Māori in Aotearoa New Zealand as I see them. The combined use of personal storytelling and document analysis highlights in a very confronting way how the personal is political and the political is personalised. My specific contribution to the field is my unique insight and analysis. There is power in that and there is rigour in that power.

Document Analysis:

As the name would suggest document analysis [DA] is a qualitative research method that involves the systematic review and evaluation of documents (Bowen, 2009). DA is a common research strategy and is likely present in some form, in all post-graduate research projects. It is, at a very basic level, the method we employ to inform our literature reviews. Where a literature review synthesises key themes and ideas within the scholarship, document analysis sees texts as valuable sources of data.

The classification of texts as documents can be as narrow or as broad as the research requires. Bowen (2009) provides a long list of potential texts including advertisements, attendance registers, minutes of meetings and brochures as sources of evidence. There are some scholars who have narrower view of the classification of texts as documents. Hodder (2013) for example, is of the view that there is an important distinction between what can be categorised as a document, and what is a record. Put simply, Hodder considers any text that attests to a formal transaction (marriage licenses, contracts, any official text protected by privacy or confidentiality laws) is a record, whereas documents are more personal in nature. This is, in my view, an arbitrary distinction and does not account for instances where the personal narrative is embedded in official record. A case file of a child moving through the child protective services will include great levels of detail about the child and their family from a range of sources (e.g., police records, health information, school records, court records, family group conferences, Ministry of Social Development). Using

Hodder's (2013) approach, it is difficult to discern whether these are documents of a personal nature, or records of a formal transaction between the state and hundreds of Māori children.

I have taken the broad view that documents are simply 'social facts' (Atkinson & Coffey, 2004), which have been developed independently of the research and the researcher (Bowen, 2009). Through the document analysis process, I have engaged in the analysis of historical and contemporary government agency reports, Waitangi Tribunal reports, news media publications, survivor testimonies, previous studies, administrative forms, and some social media threads to inform my DA.

A key benefit of document analysis is the ability for texts to offer context. As Bowen (2009) puts it, texts can bear witness to past events, provide background information as well as historical insight. This is a common use of texts in Indigenous research projects, particularly those projects that look at historical events. In my research for the whakapapa and access case study for example, I engaged with a broad range of texts including Commission of Inquiry reports from Canada (The Truth and Reconciliation Commission of Canada, 2015), Australia (Human Rights and Equal Opportunity Commission, 1997), and Aotearoa New Zealand (Abuse is in Care Royal Commission of Inquiry, 2020), as well as auto-biographical research, survivor testimony and Indigenous storywork. A common theme across all of these texts was the interplay between the memories of people and communities and the legislative levers that structured their experiences of disconnection and trauma. These features are evident in the collective remembering of assimilatory policy aimed at severing children from their cultural ties, and the individual examples of people being beaten for speaking their native tongue.

A second significant benefit of document analysis is that texts provide a means for tracking change and development (Bowen, 2009) or in some cases, the lack of change or development. In the trust and automated decision-making case study for instance, I considered the shifts in the content of the dialogue that has taken place across various domains (Waitangi Tribunal reports, expert commentary, and official records) regarding the RoC*RoI[5] algorithm. In this case, there is a clear indication in the records that the algorithm was rooted in racist logics and would therefore produce racist outcomes. As a result, ethnic identity markers were removed from the system and the dialogue, yet the algorithm continued to produce the same racist results. In this case, close analysis of the documents revealed that racism in technology is not a one-off example of human error, or a coincidence but is built into the architecture of systems (Noble, 2018)

As a research process, Bowen (2009) explains that DA

> …entails finding, selecting, appraising (making sense of), and synthesising data contained in documents. Document analysis yields data – excerpts, quotations, or

---

[5] Risk of ReConviction multiplied by the offender's Risk of Imprisonment.

> entire passages – that are then organised into major themes, categories, and case examples specifically through content analysis. (p. 28)

Each case study in this research has a distinct range of texts that have been analysed. The approach to text selection was however, the same across the board. First, I started with a broad search approach, taking my case focus, and seeing what came up in a general keyword search on Google. Through this scoping exercise, I was able to get a general sense of what information had been circulated in the public sphere about each issue. This is also where I found the initial news media publications that were included in the analysis. The next step involved going to relevant government sites to collect media releases and reports and any charters or legislative levers.

C1 – Privacy and COVID-19	Ministry of Health (www.health.govt.nz). Unite Against COVID-19 (www.covid19.govt.nz). Te Rōpu Whakakaupapa Urutā(www.uruta.maori.nz) ; Office of the Privacy Commissioner (www.privacy.org.nz). Te Mana Raraunga (www.temanararaunga.maori.nz). Welfare Expert Advisory Group (http://www.weag.govt.nz/)
C2 – Trust and automated decision making	Stats NZ (www.stats.govt.nz); www.data.govt.nz ; Digital Council for Aotearoa (https://digitalcouncil.govt.nz). www.taiuru.maori.nz ; Te Mana Raraunga (www.temanararaunga.maori.nz). Waitangi Tribunal (https://waitangitribunal.govt.nz). Department of Corrections (www.corrections.govt.nz)
C3 – Whakapapa and access	Oranga Tamariki (www.orangatamariki.govt.nz). Ministry for Social Development (www.msd.govt.nz). Waitangi Tribunal (https://waitangitribunal.govt.nz). Commission of Inquiry into Abuse in Care (www.abuseincare.org.nz)

Figure 2.1 Initial sites for data gathering by Case Study

The analysis of texts taken from these sites then informed a more guided keyword database search to identify whether there were examples of existing research or studies. It also informed a second round of more directed keyword searches in Google, to get a clearer understanding of specific public responses. In Rapley's (2007) analysis of the document analysis he includes an assessment of what we, as researchers, can learn from what is not included in the text. He argues, that while texts are often considered to be purely descriptive accounts of what is going on at a particular moment in time, these "…descriptions are never neutral but produce a specific version or understanding of the world" (Rapley, 2007, p. 5). In this sense, what is omitted from the text is just as important as what is included. The Privacy Act in Aotearoa New Zealand is an interesting example in this instance. The languaging of the Act specifically protects the rights of individuals to privacy. There are no provisions in the Act which protect the privacy rights of collectives (including

Māori). In this case, while not explicitly noted, the individual is firmly centred as the key unit in society. The first case study, around privacy and COVID-19 considers how this flaw has created risks to communities and collectives, particularly in the context of the global pandemic.

In the next section, I explain how storytelling is weaved into each case study, to offer real-life examples of how issues relating to privacy, trust and access are experienced. In this case, I am the storyteller, speaking from my personal experiences and of the experiences of my tupuna.

Storytelling in Research:

The practice of storytelling, whether it be through talking, writing, or performing has become a critical source of healing for Indigenous peoples. Often, storytelling in research will take the experience of the narrator(s) and identify how these experiences sit within a broader political narrative. It is widely known that Indigenous peoples including Māori come from oral traditions, it is therefore unsurprising that we utilise our skills in storytelling as one way of understanding and expressing ‘our version of modernity’ (Tuhiwai Smith, 2012). Storytelling takes a variety of forms. Each with its own power. The following section is an opportunity to point to the brilliance of Māori storytelling, demonstrating the breadth of modalities and the capacity for Māori to be adaptive in their approach.

As an Indigenous research method, storywork often calls on the stories of our past as a way of making sense of the occurring present and coming future. Stó:lō and St’at’imc scholar Jo-Ann Archibald and Nisga’a researcher Amy Parent (2019), position Indigenous storywork as a research method which facilitates meaning making and “…exemplifies the *Hands Back, Hands Forward* Indigenous teaching” (J. Archibald & Parent, 2019, p. 3). Here the whakataukī ‘kia whakatōmuri te haere whakamua’ seems an appropriate parallel. Translated as I will walk backwards into the future with my eyes fixed on the past (Rameka, 2016), this whakataukī reminds us that our whakapapa hold within them the tikanga and pūrākau that will see us flourishing in the future. ‘Looking back’ then is a way of honouring the knowledge of our elders and the wisdom of our ancestors.

It was mentioned earlier in this chapter that whakapapa as a concept breaks down the barriers of linear time to see the past, present and future as occurring simultaneously. Indigenous storywork embodies this feature of whakapapa in the way that it can bring our tūpuna into our present conversations (J. Archibald & Parent, 2019). How we access the voices of our tupuna can vary. Our tupuna were brilliant in that they had the foresight to protect our stories in karakia, pūrākau, whakapapa, oriori and mōteatea which now all act as waka huia (treasure boxes) for the preservation of mātauranga. Now, these voices serve as bastions of knowledge, and can be drawn upon as communicators of lessons, truths, values, and histories.

Some Indigenous storywork research draw upon stories that take us back to our creation (Chilisa, 2020). Some stories implore us to listen to the voices of our more than human relations (J.

Archibald & Parent, 2019; Lee-Morgan, 2019; Yunkaporta, 2019), while other stories engage with our recent histories (Cavino, 2019; Goyette, 2013; C. Jones, 2019; Seed-Pihama, 2019) and present realities (Pihama et al., 2019). Outside of formal research, there are also modern expressions of traditional storytelling including kapa haka (Māori performing arts), ngā Manu Kōrero[6] and waiata Māori (Māori songs), as well as television shows like '*Wakahuia'* and '*Artefact'* which also draw from stories to offer insight into the history of Aotearoa. These modes of storytelling play an important role in making stories accessible and facilitating the inter-generational transmission of knowledge and the preservation of history and tradition as taonga. They fill gaps and provide "… missing literature, theories, conceptual frameworks, and research methods in a postcolonial indigenous research paradigm" (Chilisa, 2020, p. 194) and make painfully obvious the connection between the personal and the political.

Nowhere is the connection between the personal and the political more painfully evident than in the context of storytelling in testimony. Often, the stories offered in testimony are confronting and speak to trauma and harm. Tuhiwai Smith (2021, p. 165) describes Indigenous testimonies as "…a way of talking about an extremely painful event or series of events. The formality of testimony provides a structure within which events can be related and feelings expressed." The collection of survivor testimonies has been important in socio-historic landscapes for formalising collective memories and providing the space for voices to be heard in a safe and protected way. Perhaps the most well-known global example of this would be the testimonies of Holocaust survivors. A more recent example in Aotearoa New Zealand is the collection of testimonies from survivors of the terror attacks in Christchurch on 15 March 2019. These stories serve as important sites of remembrance especially for those of us who cannot begin to imagine the impact of these tragedies. The reality is that members of affected communities do not need a formal record of their suffering to remember, because they live their testimonies every day.

The sharing of testimony has also become a core feature of Indigenous claiming of rights and dues (Tuhiwai Smith, 2021). Perhaps the most prolific site for testimony in Aotearoa New Zealand would be the Waitangi Tribunal where Māori describe in detail how the state has breached their obligations under Te Tiriti o Waitangi. Another important site for the sharing of testimony is in the context of Commissions of Inquiries into abuse in care. In chapter seven, I draw upon the testimonies of Māori, First Nations, Inuit, Metis and Aboriginal survivors of state care in each respective country (Aotearoa, Canada, and Australia). Each story on its own represents an individual tragedy, yet heard together, these stories paint a confronting picture of the violence of the state. Indigenous storytelling and testimony in research can have a profound impact, especially

---

[6] Ngā Manu Kōrero is an annual secondary school speech competition hosted in New Zealand

in the way that stories challenge taken for granted assumptions about what knowledge is valued in western intellectual traditions. As Sium and Ritskes (2013) articulate:

> Indigenous stories are always threatening because they position the teller outside the realm of the 'objective' commentary, and inside one of subjective action. Indigenous stories affirm that the subjectivity of Indigenous peoples is both politically and intellectually valid. Indigenous stories also proclaim that Indigenous peoples still exist, that the colonial project has been ultimately unsuccessful in erasing Indigenous existence (Sium & Ritskes, 2013, p. IV)

There is a distinctive power that comes with the collective expression of commonly held experiences, like what is described above. The next section considers how Indigenous researchers discuss the action of writing the self into the research, highlighting the entanglement of the personal, the social and the political.

Auto-ethnography as storytelling

Writing the self into the research findings is one way of actively engaging in critical reflexivity and negotiating the "…push and pull between and among analysis and evocation, personal experience, and larger social, cultural and political concerns" (Adams & Jones, 2008, p. 373). Auto-ethnography does not simply describe an event as it happened, its purpose is to "...extract meaning from experience rather than to depict experience exactly as it was lived" (Bochner, 2000, p. 270). Adams and Jones (2008) describe it as:

> …an effort to set a scene, tell a story, and create a text that demands attention and participation; makes witnessing and testifying possible; and puts pleasure, difference, and movement into productive conversation. (p.375)

NunatuKavet researcher Julie Bull (2020) notes that autoethnographic inquiry requires the researcher to be brave and honest in the sharing of personal stories. This, Bull (2020) says, is an act of self-determination. Auto-ethnography has also been described as a style of self-narrative where the narrator looks back at their past through the lens of the present (Bochner, 2000) putting the "autobiographical and personal" in conversation with the "cultural and social" (Adams & Jones, 2008, pp. 374–375) and presenting a counter Na(rra)tive (Bull, 2020). I am interested in how the mundane experiences of my everyday life fit within broader socio-political landscapes. The sharing of story in this research is, therefore, purposeful, it is about demonstrating the links between broad concepts and real people, it is about highlighting that Māori data sovereignty is not an abstract concept, but a living breathing reality. While the self is centred in the practice of autoethnography, Indigenous storywork begins with the assertion that stories do not belong to one person (Whiteduck, 2013). They are part of a collective memory, as Bull (2020) puts it, "…when I tell my story, I am also telling stories about my family, my ancestors, my lands, and this comes with responsibilities" (p.90). For me, I acknowledge the responsibilities and accountabilities I have to my whānau, my tūpuna and my whenua in my research and I use storywork in as an act of reclamation of our collective rights to Māori data sovereignty. Taking on the wisdom of Sium and Ritskes, I consider that "if stories are archives of collective pain, suffering and resistance, then to speak them is to heal; to believe in them is to reimagine the world" (Sium & Ritskes, 2013, p.V)

A Methodology for the Reader:

The storytelling in this research attempts to evoke emotion. Who the reader is will impact the particular emotion that is surfaced in the process. Emotion is an important research outcome, which is currently under-researched (Moewaka Barnes et al., 2017). The effect of stories is as much about the person hearing or reading the story as it is about the person telling it, or the story itself. When the story is told, and for what reason, is important too. This is best illustrated with a story:

> *It's hard to imagine a time when I wasn't acutely aware of my positionality in any given context. My identity is complex, made up of a range of different features, and as an adult I have accumulated years of experience negotiating place and space and learning how best to present myself depending on the situation. Confidence is the way to a man's heart – but don't be too confident that you emasculate him. Be proud of your achievements – but also downplay them frequently so as not to come across as arrogant. These are, of course learnt behaviours and will vary from person to person.*
>
> *But there was a time where internal logic ruled and I was not yet socialised into any particular identity, I simply was.*
>
> *My dad was a stay-at-home dad while mum studied. Often, before I started attending school, dad and I would visit my grandma. I fondly remember sitting with her, our days together were punctuated by talk shows (Ricki Lake and Sally Jessy Raphael) and soap operas (Days of Our Lives, Bold and the Beautiful, Emmerdale, and Coronation Street), we played cards while grandma told me stories of when she was young (often the same ones I'd heard several times before) and we drank endless cups of tea. But I do remember one time grandma and I took a trip out to the department store 'Rendells'. Grandma always made an effort when she went out and she always looked beautiful. A red knitted cardigan, with a matching red beret, cream slacks and always a pair of sunglasses and lipstick. She was all of 4ft 8, but her presence was larger than life. I was proud to walk alongside her, and she was proud to be with me.*

> *We walked into the store, and I thought nothing of the kind shop assistants following us to see if we needed help with anything. At one point in our excursion, a lady approached me and made the kind of small talk you make with a four-year-old, before asking if I was with my 'nanny'. To which I replied 'yes', beaming with pride. But when I turned around grandma was not beaming, her shoulders had slumped, and her smile had fallen from her eyes. We left Rendell's not long after.*

Your response to this story will be largely dependent on your own personal experiences. For example, at some point in the story, you may have identified my grandma as a woman of colour. It's worth reflecting on the point at which that assumption was made. It may also be the case that you have identified me as white passing, and you might know that when the woman in the story asked if I was with my 'nanny' she was not asking if grandma was my nana, but if she was the paid help, because why else would a black woman be walking around with a white child. It could be the case that you think I'm the one making assumptions and the kind lady probably didn't mean it like 'that'. This again, is a reflection of your own experience.

In *Research is Ceremony,* Opaskwayak Cree scholar Shawn Wilson (2008), quotes Tafoya to help explain the cyclical nature of stories and their ability to grapple with our "unanswered questions and unquestioned answers" (Wilson, 2008, p. 6). The quote goes like this:

> Stories go in circles. They don't go in straight lines. It helps if you listen in circles because there are stories inside and between stories and finding your way through them is as easy and as hard as finding your way home. Part of finding is getting lost, and when you are lost you start to open up and listen. (Tafoya, 1995, p.12 as cited by Wilson, 2008, p. 6)

Upon reading this quote, my mind started racing as I rushed to find a scrap piece of paper and a pencil so that I could let my jumbled thoughts spill out as ideas on paper. This is something that often happens for me when I am reading, an idea is sparked in my mind and before I know it there is a mad swirl of 'and thens' and 'therefores' on a page and I am left with the arduous and exhausting task of translating my thoughts into comprehensible ideas and testing them out to see if they fit in my research. In this case, when I read Tafoya's words, I was reminded of an event that had happened only a week prior and the following ideas came spilling out of my hand

> *Sometimes I scroll through Instagram as a way to pass the time. I struggle with anxiety and one of the ways that I can occasionally manage acute bursts of panic is to measure my time in 10 second blocks and find ways to distract my mind enough to make it through that block. On one occasion as I was scrolling, trying not to think of all the goals I hadn't achieved that day, because I was scrolling (awful cycle) I came across a short video clip of a podcast interview between two tane Māori Raniera Rewiri (the Plant Based Māori) and Te Aorere Pewhairangi. In this clip Te Aorere was talking about how old pūrākau are often conceptualised by Pākehā according to their fallacies. To articulate his point, Te Aorere considers the story of how Māui slowed*

> *the sun, he pointed out that Pākehā are quick to point out the impossibilities within the pūrākau and subsequently disregard the story as a mere myth. But Māori, he argues, see the truth and the lessons and the values within the story. Rather than focusing on whether or not Maui slowed the sun physically, Te Aorere reoriented the framing to think about Maui as an inventor, and he invented many things like the hīnaki (eel trap), the tāruke, the kupenga (net) and the tara (barbed end of a spare), and these inventions created efficiencies in life, so that more time was available to allocate to other things. Te Aorere credited this telling of the story to Te Rawhitiroa who shared it with him.*

There are three things that I want to highlight now. First, seeing this short clip prompted a conversation with my partner about pūrākau and their function. We started by relishing the 'of course' moments and the brilliance of the Māori mind. We then expanded our conversation to consider other questions, like at what point does a story becomes a pūrākau? Storytelling in this instance created the space for critical conversation and theory building to happen in my own home. At the beginning of this chapter, I indicated that one of the more challenging aspects of writing this chapter was deciding what would be included as being formative for the research. This is an example of why.

Second, my initial engagement with the podcast happened because another person I follow had shared the clip to their 'story', which demonstrates how stories are told and retold across time and space (from Te Rawhitiroa to Te Aorere to Raniera Rewiri to a person I follow, to me and into my home and now to you). Third, Te Aorere made an important point about the ways that Pākehā are quick to imagine the story of Maui and the sun as a myth with no basis in reality.

Returning to Wilson's (2008) text, he argues that inter-cultural communication in research is often challenging because we cannot assume that people will follow our logic or reasoning. Often times, people who come from a different background to our own, do not share our experiences and therefore do not see the world in the same way that we do. We cannot expect Pākehā to understand our stories immediately, because we do not share the same thought traditions. What we can expect, is that they will listen and respect what we have to say and to recognise that just because they may not be able to understand them, it does not make the stories any less true, or any less valuable.

In sharing my stories, I am creating relationality with the reader. My hope is that in engaging with this research something is sparked for the reader. Perhaps in reading and engaging with my personal narrative, you can consider data sovereignty as it relates to you personally. As a reader, there is a need to approach this research with an open mind and be open to the idea that even if you cannot understand my experiences, you can still see that they are real. This chapter has taken a unique form and has a tone quite distinct from the introduction. The personalised tone of writing present in this chapter will return in brief interludes, primarily in the case studies; for the most part however, the remainder of this thesis is written in a more conventional tone.

Chapter Three: Defining Data

We live in a time where data is pervasive in every part of our social, political, and economic lives. Data are ubiquitous with the modern world and are arguably among the most powerful and valuable resources of the 21st century (Lupton, 2016). Data are collected daily and can contain the lived experiences of individuals, families, and communities as well as the complex social and natural environments within which we live (Kukutai & Cormack, 2019; West et al., 2020). In a modern context the recording of data is largely digital (Lovett et al., 2019). Defining data in narrow settings can be relatively straightforward. Customer data for example refers to the information held by businesses about their customers, this information can include names, contact details, and purchase histories. Businesses may also conduct market research for product development, and they may also collect customer experience data. Research data is slightly broader and includes any information that has been collected, observed, or generated to inform research findings. Where research involves human participants, data could include personal details like those captured in customer data,[7] as well as any responses offered by participants through their engagement with the research itself.

When the data context is narrow, it is much easier to develop data-governance frameworks for the management and protection of data. These frameworks take many forms and offer varying levels of protection to individuals, some of which will be discussed in later chapters[8]. Increasingly however, data contexts are not narrow and the vast scale, speed and potential for data-linking and secondary analysis are creating complexities for defining data and developing appropriate protective mechanisms. There is also a lot of passive data collection occurring that tracks our everyday movements and social interactions. While this could be potentially seen as harmless, it is also far more difficult to be forgotten in the system with new capacities for permanence, duplication, and storage of data.

Furner (2015) notes that we talk now about big data, linked data, open data, data governance, data infrastructure, data mining, data protection, data quality, data science, data visualisation and data wrangling. Of course, in the few short years since Furner came up with his list, we now have a growing list of linguistically blended words such as ‘datafication’ (Couldry & Yu, 2018; Kukutai & Cormack, 2019; Mascheroni, 2020) and dataveillance (Couldry & Mejias, 2019; Mascheroni, 2020; Zuboff, 2019). Heightened awareness of the omnipresence of data in

---

[7] Though this will not always be the case, in particular where the research promises participants anonymity. This is most likely the case with large-scale survey data

[8] Chapter 4 will look at the role of privacy policies in data management. Chapter 4 also considers institutional research ethics as well as Ngā Tikanga Paihere - the framework which governs access to the Integrated Data Infrastructure. Chapter 7 will look at Privacy law as a feature of data governance.

contemporary settings, however, has not resulted in any conceptual clarity around what data is or is not. As Rendgen (2018) articulates:

> Some technical terms are so ubiquitous and (apparently) unambiguous, that they almost become a transparent fluid: always used but never much reflected upon. Interestingly enough, the word “data” is such a term. It is an abstract, weightless and unidentified mass of numbers (mostly digitally encoded), with a potent influence on lives. (https://idalab.de/blog/data-science/what-do-we-mean-by-data)

The quote above highlights how, the ubiquitousness of data in our day to day lives seems to have given data a certain status of ‘natural’. They are there, offered as a stable and static representation of the present, an unquestionable and unavoidable aspect of our lives from the moment we are born. This thesis, however, challenges the assignment of data as natural and in fact neutral in light of the experiences of Indigenous peoples.

DIKW - Hierarchies and Distinctions

The points raised above are articulated in the developing debate in the information sciences that is concerned with the way that ‘data’ is understood as a concept in relation to information, knowledge, and wisdom. Often referred to as the DIKW hierarchy, the main debate stems from the tendency for people use these terms interchangeably with each other without any consideration of how each term is distinct. For example, ‘data’ is often referred to as ‘information’, and ‘information’ can be conflated with ‘knowledge’, however ‘data’ and ‘knowledge’ are understood to be completely distinct terms (Boisot & Canals, 2004; Zins, 2007). What is absent, or at least rendered invisible in the debate, is the assumption that all data actors will have the same baseline understanding of what data is (or isn’t). This is a flawed presumption, as Markham (2013) rightfully points out, ethnographers, for example, won’t understand data in the same way that a statistics analyst will. In recent years, Indigenous Data Sovereignty discourse has challenged conventional conceptualisations of data by referring to cultural artefacts such as stories, genealogy, songs, chants, and rituals as ‘data’. Importantly, these are also understood perhaps more commonly as cultural knowledge or mātauranga, however they are being increasingly referenced in the ID-Sov literature as evidence to demonstrate that we have always been actively involved in the process of collection, storage, transmission, and use of data (Lovett et al., 2019; Rodriguez-Lonebear, 2016; Yap & Yu, 2016).

These claims by Indigenous Peoples, including Māori, represent a political alignment of data sovereignty issues with the broader sovereignty discourses usually associated with land and resource rights, political rights, and rights to self-determination. It is important to note at this point that I am not challenging these assertions, instead, I want to understand the relationship between data and knowledge to better understand these claims. An additional flaw with the hierarchy raised by Fricke (2009) is that it is largely based on a positivistic framework and consequentially is concerned primarily with production of facts or truths. While flawed, the tensions highlighted by those working in the field of information sciences are important to this thesis and warrant further consideration for at least two reasons. First, I intend to use the terms ‘data’ and ‘information’ interchangeably as a way to limit the monotony for the reader. Second, the field of information sciences has been central to the development of contemporary conceptualisations of data and will likely be present throughout my research, so at the very least a basic understanding of these arguments is necessary.

Ackoff (1989) argued that ‘data’, ‘information’, ‘knowledge’ and ‘wisdom’ could be understood as existing on a continuum, where one could begin with data, and eventually refine their understanding until they reached a state of wisdom. The hierarchical nature of Ackoff’s (1989) theorising has been visualised by other scholars as a pyramid with data forming the foundational layer (Bellinger et al., 2004; Frické, 2009; Zins, 2007). In this imagery, each concept is distinct and has its own place in the structure. At the bottom, data are symbolic representations of the observable properties of objects and events (Ackoff, 1989; Frické, 2009). The symbols (re)presented as ‘data’ are considered to be ‘raw’ (Bellinger et al., 2004); they simply exist and hold no inherent value or significance beyond their existence (Frické, 2009). Similar to the way that data operated in early geometry and theology, from within the DIKW framework, it is possible to question the veracity or validity of data, but never their presence.

Forming the next layer, information is data that has been processed in a relational context to produce meaning (Bellinger et al., 2004). In this sense, the distinction between data and information is functional, not structural (Ackoff, 1989; Frické, 2009). The goal of processing the data is to move it out of the ‘raw’ space and to increase its usefulness (Ackoff, 1989). In the DIKW hierarchy, Bellinger et al (2004) suggest that the ‘processing’ often begins with a question; once data is drawn upon to produce an answer, that is when it becomes information. Questions asked of the data include ‘who’, ‘what’, ‘where’, ‘when’ and ‘how’ (Ackoff, 1989). The production of answers to these questions involves a process of aggregating the raw material (data) and reducing it to only include what is relevant to the specific question (Bellinger et al., 2004). The idea that data can be reduced for relevance is incredibly important because it highlights the significance of what questions are asked, and equally as important, how those questions are asked. Austin et al (2006) demonstrated this point in their research, where they were able to take existing data sets in Canada and prove a statistically significant correlation between various health related conditions and star signs. The point was not to prove that the links existed, but to show that you can ask data any question, and as long as you have the necessary tools to manipulate them effectively, they will produce the answer you are looking for.

Knowledge is the next level in the hierarchy and is understood as a product of the synthesising of information (Zins, 2007), the subsequent result being that the meaning of information is understood (Ackoff, 1989). Zins (2007) argues that knowledge manifests primarily in one of three ways; they are practical knowledge, knowledge by acquaintance and inferential propositional knowledge. Practical knowledge refers to our learnt abilities, for example riding a bike or learning to read; knowledge by acquaintance includes direct non-mediated recognition of external objects, for example being able to identify a tree, as well as the direct recognition of inner phenomena, such as understanding what pain feels like; finally, inferential propositional knowledge refers to the knowledge we produce through inferences. It is commonplace in science for researchers to be trusted with drawing out inferences from data.

Wisdom is the final stage of the continuum, and of the four 'phases', wisdom is the least commented on in the literature. Wisdom asks questions that do not have an easily discernible answer (Bellinger et al., 2004). These are the 'why' questions, which are purposefully omitted from the information to knowledge stage because as Fricke (2009) points out, 'why' questions are often answered with a mix of '...facts and slices from the casual nexus tailored to the context and pragmatics of the question" (p.135). It also involves the exercise of judgement, which removes any basis for an argument of neutrality or objectivity (Bellinger et al., 2004). Wisdom then is a source of tension in a hierarchy that is wrapped up in a desire to produce hard lined truths, however it exists in the hierarchy because it is an important concept to understand for the ongoing development of technologies within the Information systems sphere.

Data about Indigenous Peoples

Present data records in all the areas discussed so far tell us something *about* Indigenous populations, particularly across what are commonly referred to as the CANZUS states. The data held by these nation-states about the Indigenous peoples of those lands varies in breadth, depth, and quality, however there is a common base across the board. What is consistent across the datasets is a narrative of the 'statistical Indigene' (Walter, 2016), who is marked by poor health and education, high levels of unemployment, homelessness, and incarceration as well as increased risk of morbidity and subsequently younger mortality rates (Kukutai & Walter, 2019). In some cases, access to such terrifying and dismal data may motivate and inspire the kinds of changes required to radically shift the social positioning of our people. Unfortunately, though, there is also a risk that the story dictated by these data may in fact build apathy and identify cultures and communities as the root causes of the problems, as opposed to seeing the failures of racist systems at the centre of it all (Tuck, 2009). Walter (2018) notes that presently, Indigenous data is an enigma where there is simultaneously a glut of deficit data about Indigenous Peoples on the one hand, and yet a scarcity of data for or by us on the other.

Walter (2018) goes on to highlight the need to move beyond the markers of disadvantage and reorient the BADDR data discourse to have an Indigenous voice. The notion of BADDR data, that is data that is Blaming, Aggregate, Decontextualised, Deficit and Restricted (Walter, 2018), extends Walter's (2016) conceptualisation of the 'statistical indigene' characterised in the mainstream by 5D data. Where BADDR refers to what the data does, 5D data (data marked by disparity, deprivation, disadvantage, dysfunction, and difference) speaks to who the data is about. In the case of Indigenous Peoples, 5D data produces an Indigenous caricature; weirdly obscured figures, created in the mind's eye of the 'artist', "…reflecting the dominant social norms, values, and racial hierarchy of the society in which they are created" (Kukutai & Walter, 2017, p.9).

Data sits in a cyclical vacuum continuously being produced by markers of disadvantage and subsequently producing disadvantage. Perhaps the starkest example can be seen in the justice sector; data suggests that Māori are more likely to be involved in criminal activity, therefore more surveillance of Māori communities is supposedly required, which means more Māori are being 'caught' committing criminal acts, which contributes to a data set suggesting that Māori are more likely to be involved in criminal activity – and so the cycle reproduces itself.

> The harm wrought by the dominant 5D paradigm of Indigenous data is exacerbated by the seeming objective reality of numeric data. But statistics are not neutral. They are human artefacts whose numbers, and the findings they produce, directly echo the questions asked, why they are asked, how they are asked and who is doing the asking. If the priority is Indigenous problems, then data interpretation will inevitably be framed in terms of Indigenous deficit. (Walter, 2018, p. 259)

Under these circumstances, the transformative potential of data cannot be realised as the available data is obstructive (Walter, 2018) and may actually increase inequities if built into automated decision-making processes for example.

Indigenous Data

Earlier, the DIKW hierarchy has certainly been conceptualised and articulated as a tool for understanding the transformation of digitised data to become information then knowledge, and subsequently at the human level, wisdom. However, the synthesis of raw data to become practical knowledge and wisdom is a process which our tūpuna would have engaged in to traverse Te Moana-nui-a-Kiwa and eventually settle in Aotearoa New Zealand (Williams, 2016). Even now, as their descendants, we continue to recite the navigation stories of our ancestors, and through this process of remembering, we pass on their legacy of wisdom. Where wisdom is positioned awkwardly in the DIKW hierarchy, it sits naturally in an Indigenous framework.

The example of navigational feats offered above is evidence that Indigenous Peoples have been collecting, storing, and transmitting data forever (Lovett et al., 2019; Rodriguez-Lonebear, 2016). Chants, carvings, totem poles, pūrākau and whakapapa passed across generations are all examples of data gathering and data preservation (Lovett et al., 2019). The Yawuru People of Western Australia, for example, draw upon the stories, protocols, and laws for living, handed down from the Bugarrigarra, to maintain their responsibilities and obligations to and of the land (Yap & Yu, 2016). Data expertise was also crucial for the survival of many Indigenous Peoples. Rodriguez-Lonebear (2016) notes that the recording of Winter counts on hide by the Lakota, Blackfeet and other Plains tribes was crucial for survival and in a contemporary context, are "among the earliest population and wildlife records in all of North America" (p. 255).

A strong history of data collection, storage and transmission is reflected in our own modern-day definitions of the concept from an Indigenous perspective. Just as modern western conceptualisations or definitions of data are broad, understandings of what constitutes Indigenous data are equally broad and encompass data produced by, for or about Indigenous Peoples, our ways of life including customs and traditions as well as the environments in which we live, or have ancestral ties to (Lovett et al., 2019, p. 27). Indigenous data has also been said to include "information that impact Indigenous lives at the collective and individual levels" (Rainie et al., 2017, p. 1). Taking the lead from Indigenous conceptions of data, Hudson and colleagues (2017) identified Māori data as any data generated by and for organisations and businesses, data which is used to describe or compare Māori collectives and any data pertaining to Te Ao Māori that emerges from research (Hudson et al., 2017, p. 62). Te Mana Raraunga, Aotearoa's Māori Data Sovereignty network offer perhaps a broader definition, which states that Māori data is 'digital or digitisable information or knowledge that is about or from Māori people, or language, culture, resources or environments" (Te Mana Raraunga, 2018). There are strategic benefits to having definitions which lend themselves to encompassing such a broad and diverse range of datasets. In particular, it ensures that even data which may not be overtly 'Māori' but is still of relevance and pertinence to the everyday lives of our people is captured. On the other hand, it does introduce challenges around the development of governance mechanisms that can be practically applied across complex and rapidly evolving data ecosystems (West et al., 2020).

Data as a Taonga

One way that data has been conceptualised by Māori is as '...a living taonga [with] strategic value to Māori' (Te Mana Raraunga 2016). A very basic definition of taonga is a prized possession, or treasure. This provokes some important points of reflection for Māori data sovereignty:

- If we agree that Māori data captures "…data produced by Māori or that is *about* Māori and the environments we have relationships with: (Te Mana Raraunga 2016) and this includes data derived from harmful and exploitative research *about* Māori, as well as the data that feeds the statistical indigene narrative, does the logic follow that these datasets are taonga?

- Connected to the above question, where do deficit datasets sit? Language attrition data mentioned earlier in this chapter is an interesting example to draw upon here. This is data that was born out of the trauma of language loss, but motivated flaxroots organisations to mobilise. Is this data a taonga? Critical, yes; powerful, yes; impactful, yes – but a prized treasure?

Returning to the earlier discussion of whakapapa in the *Methodology and Approach* chapter is useful here. Datasets that speak to trauma, pain and colonially derived harm are still from us. The stories they hold within them are therefore ours, even if these stories are of trauma and mamae (hurt). In this sense, taonga may not always be prized in the sense that pleasure can be derived from them but are likely to be prized in the sense that they have significance, and that value may come out of this significance.

Kahui Legal surmised that from a Waitangi Tribunal perspective, for something to be considered a taonga, it must be "...valued and treasured by Māori, and it must be significant and important to Māori" (Hudson et al., 2017, p. 66). For some, the assertion is that *all* Māori data should be classified as taonga (Taiuru, 2018). Taking a broad-stroke approach that 'all data are taonga' is a strategic move as it allows for Treaty obligations – particularly those associated with Article Two of Te Tiriti o Waitangi – to be applied to the broadest possible range of data (Hudson et al., 2017).

In 2021 the Waitangi Tribunal released the WAI 2522[9] report, in which they put forward the Tribunal position on whether data is a taonga. In the report, the Tribunal drew the connection between data and mātauranga (the Māori knowledge system) noting that "...data can record mātauranga, and mātauranga also informs and generates data" (p.52). There is already an existing Tribunal jurisprudence that recognises mātauranga as a taonga as well as the responsibilities of the Crown to ensure active protection of mātauranga. In 1999, claimants of WAI 718, the *Wananga Capital Establishment Report* noted that whare wānanga[10] were important sites for the preservation, protection, and transmission of mātauranga Māori and te reo Māori and should therefore be protected as such (Waitangi Tribunal, 1999). In this case the Tribunal found that:

> There can be no doubt that te reo Māori and mātauranga Māori are highly valued and irreplaceable taonga for New Zealand. These taonga exist nowhere else. The Crown has a duty to actively protect these taonga (Waitangi Tribunal, 1999, p. 50)

---

[9] The Report on the Comprehensive and Progressive Agreement for Trans-Pacific Partnership

[10] In WAI 718 Wananga refers to tertiary education institutions

Then in 2011, the WAI 262 *Ko Aotearoa Tēnei* report reaffirmed the Crown's responsibility to actively support kaitiaki (guardians) in the protection of mātauranga Māori and taonga works[11] noting:

> There is no doubt that mātauranga Māori and taonga works are treasured things. This wording fits with both the subject matter and an approach consistent with Māori custom. It allows for mātauranga Māori and taonga works to be shared, provided the kaitiaki retain an appropriate level of authority and control over the sharing. This allows kaitiaki to protect the integrity of the mātauranga or taonga work. It also allows them, in appropriate situations, to control at least in some measure the use and development of these things. (Waitangi Tribunal, 2011, p. 44)

In light of this established recognition by the Tribunal that mātauranga Māori is a taonga, and the connection between data and mātauranga, the WAI 2522 report found that

> We are not able to say whether all data is taonga. Rather, we recognise that, from a te ao Māori perspective, the way that the digital domain is governed and regulated has important potential implications for the integrity of the Māori knowledge system, which is a taonga. (Waitangi Tribunal, 2021b, p. 53)

The Tribunal's position here, aligns with the idea that data is a "…potential taonga in relation to its utility, through technology or usefulness to the collective" (Will Edwards as cited by Te Mana Raraunga 2018). This understanding does not universally categorise data as taonga but allows for all data to be considered as taonga.

Concluding Statements

At the beginning of this chapter, I suggested that data are '…ubiquitous with the modern world', and the validity of this statement has been demonstrated. To limit the ubiquity of data to a modern context was, however, quite presumptuous. Indigenous understandings of data presented above highlight that the collection, analysis, and operationalisation of data have always been a central feature of our lives as Indigenous peoples and in chapter four, a closer look at the etymology of data will show the ways that data have been conceptualised across various western dominant spaces too. Perhaps, what we are currently experiencing is a sense of ubiquity of the pervasiveness of data collection and the exploitation of data value. While data has always been, the speed at which we are now able to engage with data (whether it be in the creation, collection or collation) is only part of a recent history which has coincided with the rise of digital technologies. Further, recent publicised examples of the exploitation of data for financial gain have thrust new data capabilities

---

[11] Taonga works were defined as the "…tangible and intangible expressions of Māori artistic and cultural traditions, founded in and reflecting the body of knowledge and understanding known as mātauranga Māori" https://www.mbie.govt.nz/business-and-employment/business/intellectual-property/matauranga-and-taonga-maori-and-the-intellectual-property-system/protecting-taonga-works-and-matauranga-maori/

into the limelight, resulting in a far greater public awareness of the omnipresence of data in our modern world.

Chapter Four: Data as a Gift, from a Given to a Taken

Despite the rapidly rising value of data in contemporary settings, to date there has been very little interrogation of the conceptual origins of the term ‘data’ itself. This has resulted in a notable sense of ambiguity surrounding the term (Rendgen, 2018), causing concern as data becomes naturalised in both language and in life. The following section presents a brief overview of the etymology of the word ‘data’ with a particular focus on its link to the notion of the ‘gift’. Importantly, the purpose of this section is not to present a complete or comprehensive historiography of data; for that, it would be better to access the work of Rosenberg (2013), Furner (2015) or Meyns (2020), and for a more accessible read, Rendgen (2018). Instead, this section aims to consider how data has travelled through time and place, and how its history might inform and influence our current use of the term.

Data as a ‘given’

Across the literature surveyed for this review, there were three key lines of the ‘data whakapapa’ which were discussed. They are data as a temporal indicator; data as a given in mathematics; and data desuper in theology. There are of course semantic nuances across these three lines, however all begin with the same etymological base of data as a given. Though contemporary uses of the term do not directly reference the notion of ‘giving’, this whakapapa has still influenced the epistemic structure of the word in modern settings. Evidence of this influence comes through particularly when considering the implication of ‘unquestionability’ attached to data, as well as in the way that data is often incorrectly assigned as neutral or unbiased.

Etymologically speaking, data has its origins in classical Latin as the plural form of datum (Meyns, 2020). Datum is the past participle of dare, or that which is given (Rosenberg, 2013). Meyns (2020) explains that the Latin ‘data’, was used to refer to everyday instances of ‘giving’ as well as being used as a temporal indicator when noting the datum on documentation. This use is evidenced primarily in Medieval documentation, where dat. - an abbreviation of datum - would be followed by the day and time to indicate when correspondence had been delivered or ‘given’ (Rendgen, 2018). This process of recording what Furner (2015) refers to as meta-data has informed our contemporary use of the word date. There are also references to geodetic datum lines, which act as reference points in land surveying. A geodetic datum is any numerical or geometrical quantity or set of such quantities that serves as a reference base for other quantities. While it seems that this line of the ‘data whakapapa’ is only tangentially relevant, there is a sense of significance if we consider how important datum-data-dat. has been to the recording of time and place.

In addition to the day-to-day use described above, Meyns (2020) suggests that the term data was historically used adjectively in the past participle to indicate what is ‘given’ within problem solving contexts. This particular use of the term data comes through the field of geometry in the work of a Greek mathematician named Euclid. It is unclear when exactly Euclid lived, however, there is speculation that he came after the students of Plato and before Archimedes, which places his work somewhere around 300 B.C. (Ito, 1980, p. 7). In his work, Euclid had shown that “...if some items are given, some other items are also given into the bargain” (Taisbak, 2003, p. 13). Consider for example, the process of calculating the value of an angle in a right-angled triangle. So long as we are given the lengths of two sides – this is the data – it is possible to calculate the values of the remaining angles. In a problem-solving context, these remaining angles comprise the quaesita, or that which is sought (Meyns, 2020). In this sense, Ito (1980) explains that the notion of the ‘given’ has a dual purpose as it is designated to refer to what is actually given and what is given by implication. There is an inextricable link between the data and the quaesita, the meaning and value of each category defined in relation to the other. The importance of being ‘given by implication’ is further articulated in a more recent translation of Euclid’s work by Taisbak (2003), who made the following statement in reference to a reflection he made while completing his translation. He says:

> When I started to translate the Data, I found it very longwinded that a certain phrase kept popping up time and again, several times in every proposition: if this item is given, that item is also given. I decided to cancel all those alsos and restore them only where they were absolutely necessary. But then I discovered that I was leaving out an essential feature of the Data: the Givens hang together in chains, the purpose of any proposition being to produce more links to them. (Taisbak, 2003, p. 14)

Taisbak’s realisation presented in the above quote demonstrates that, at their core, data are simply tools for problem solving. They are the basis from which an answer or solution can be reached, given the right information is readily available. That is, they are not the ‘answer’ but the presumption that there is an answer to be found.

Taisbak’s reflection prompted a reflection of my own. If data are the present basis for problem solving in policy contexts, what currently comprise the starting values for what is known about Māori? Further, if it is the case that the links between the data and quaesita are inextricable, then how are ‘answers or solutions derived from data imbued with those starting values? Finally, is it possible to change the starting values to better reflect the values of Māori, and therefore produce more favourable, or at the very least more useful answers? In all fairness, the answers to these questions are straightforward. The current starting values for what is known about Māori reflect the political bias and systemic racism that exists in Aotearoa New Zealand today. Of course, biased data produces biased results and therefore biased solutions. It is possible to change our starting points if the desire to do so is there. These statements will of course be qualified in forthcoming sections of this chapter, but for now, I use them here to follow on to a second significant influence of data as a given in contemporary contexts.

In addition to the notion of being ‘given by implication’, another point worth mentioning regards the unquestionability of data. In the Euclidian sense, data is fixed in numeric form (Meyns, 2020). It is simply a statement of ‘truth’; the given is what is proposed and therefore beyond argument and outside the scope of questioning (Rendgen, 2018). Taking the lead from the unquestionability of the ‘data as a given’ in the field of geometry, the positionality of data in a realm outside of that which can be questioned was further entrenched with its use in reference to data desuper, or the word which is given from above (Rendgen, 2018). In theological texts the phrase data desuper was used to refer to scriptural truths, or God-given facts (Rosenberg, 2013). Just as Euclid had made tacit assumptions about ‘givens’ in Data, the theological use of the term is imbued with a sense of infallibility. Data desuper is God’s word and is therefore not open or available for questioning. Perhaps this makes sense in the field of mathematics or more specifically geometry where it is possible to present facts as singular truths - for example the sum of all angles in a triangle is equal to 180 degrees - however what happens when the same term ‘data’ is taken up outside of mathematics, do the same rules of unquestionability apply? In 1744, when defining data, Chambers noted the following:

> From the primary use of the word Data in mathematics, it has been transplanted into other arts; as philosophy, medicine, etc. where it expresses any quantity, which, for the sake of a present calculation, is taken for granted to be such, without requiring immediate proof for its certainty (Chambers, 1744).

And according to Meyns (2020):

> Depending on the particular discussion, one’s data may still determine a required quantity, but it may also determine (be the foundation of) or confirm or deny a hypothesis. That is, the precise epistemic relation gets broadened (dispersed) from not only one of derivation to also one of support, verification, and other options (p. 19).

Chambers’ definition and Meyns’ analysis both suggest that while we cannot assume total unquestionability of data in the arts, the presumption is that they represent enough of the truth to act as a starting point for further investigation into a phenomenon. This shift away from data as an absolute and singular truth in the context of mathematics, towards a greater focus on the way that data can used as a source of verification and legitimacy in the arts, signals an important loosening of the epistemic structure in the whakapapa of data (Rosenberg, 2013). The early stages of the whakapapa of data are certainly not linear, and there are of course many branches, beyond those explored here, however in traversing these three lines of data we discover that there are some common threads that tie the definitions and uses together. First, data are never understood to be the 'end' goal, rather they are the basis from which meaning can be derived. Second, the value of data is seen in their aggregation as opposed to in the individual units. The third and final point I wish to raise is that context matters.

Data as a 'Gift' - Marcel Mauss and the Spirit of the Gift

Within the broader western tradition of sociology, the conceptualisation of gifting as a relational process has built upon the work of French sociologist and anthropologist Marcel Mauss. Mauss's essay 'The Spirit of the Gift' opened up an anthropological discussion of the hau in Māori society (Salmond, 1999) and has been described as "his own gift to the ages" (Sahlins, 1997, p. 149). It has been lauded as an orientational tool for researchers in the social sciences. According to Levi-Strauss (1987):

> The teaching of Marcel Mauss, which remains highly esoteric while at the same time exerting a very deep influence, was one to which few can be compared. No acknowledgement of him can be proportionate to our debt... (p. 1)

The original essay by Mauss set out to answer two primary questions:

1. In primitive or archaic types of societies, what is the principle whereby a gift received has to be repaid?
2. What force is there in the thing given which compels the recipient to make a return? (Mauss 1925, as cited by Thompson, 1987)

The 'force' referred to in the second question was to become known as the *hau* or spirit of the gift. The hau of a gift was said to be that which compelled the recipient to reciprocate (Papilloud, 2018; Sahlins, 1997) in a society conducted by utu, or reciprocal exchanges (Salmond, 1999). Mauss interpreted from translations of Ranapiri's texts that the hau was a mystic and dangerous force seeking always to return to its homeland (Sahlins, 1997). The word 'homeland' in this instance was typically used to refer to the original gifter. The logic underpinning this need for the gift to be returned was that "...to give something is to give a part of oneself, and the recipient receives part of someone's spiritual essence" (Mauss 1925 as cited by Thompson, 1987). Gifts, or taonga (prized articles) like korowai (cloaks), acted as vehicles of mana "...carrying part of the spirit of the donor, their clan and their land to other people and places." (Salmond, 1999, p. 38). In his communication with Best, Ranapiri described hau in the following way:

> I will speak to you about the hau…. The hau is not the wind that blows – not at all. Let us suppose that you possess a certain article (taonga) and that you give it to me without setting a price on it. We strike no bargain about it. Now, I give this article to a

> third person who, after a certain lapse of time, decides to give me something as payment in return (utu). He makes a present to me of something (taonga). Now, this gift that he gives me is the spirit (hau) of the taonga that I had received from you and that I had given to him. It would not be fair (tika) on my part to keep this gift for myself…. If I kept this other taonga for myself, serious harm might befall me, even death. This is the nature of the hau, the hau of personal property, the hau of the gift, the hau of the forest. Kaati ena. (Mauss, 1990, p.11 as cited by Salmond, 1999, p. 38)

In this sense then, according to Mauss's theorising, the gift itself was inseparable from the owner's personality (Thompson, 1987) and the spiritual essence threatened spiritual retribution if the gift is not repaid (Sahlins, 1997). There is also an assurance for the giver that any gift they impart will not be lost to them but will be returned in due course (Papilloud, 2018); as Weiner (1985, p. 211) puts it "…attaining some measure of keeping-while-giving".

Though Mauss is credited with the theorising that underpins contemporary sociological discourse around gifting and the gift economy, the central tenets of his ideas were derived from the existing Māori concept of hau (Sahlins, 1997, p. 998). In fact, Mauss's work was largely in the analysis of letters exchanged between Tamati Ranapiri and Elsdon Best. There is something to be said here about the valorisation of Mauss's analysis over and above the original writings of Ranapiri. That the application of a western epistemological framing and colonial gaze is what designates value to the text is a problematic and flawed assertion, one which sits comfortably within a colonial research agenda (Stewart, 2017). In her critique of Mauss's theorising, Stewart (2017) asserts that the 'hau of the gift' is an example of Eurocentric appropriation of Indigenous knowledge, reiterating the point that "…language and cultural phenomena can only be fully interpreted from within the paradigm or worldview of that cultural identity" (p. 1).

The best example we have of a kaupapa Māori analysis of both Mauss's essay as well as the original texts from Ranapiri is in the work of the late Manuka Henare. In his work, Henare (2018) found that through the process of translation (from Māori to English) and analysis, Māori metaphysics had been reduced to secular materialism reflecting the values of an Anglo-world view, as opposed to the Māori worldview that the concept belonged within. This reductionism is evident in the limited view of hau in Mauss's essay (Salmond, 1999; Stewart, 2017). In the 'spirit of the gift', hau is seen to be a spiritual force evoked or awoken in the action of gifting, however use of hau in the Māori language such as hau kāinga (home) and hauora (health) indicate that hau has a deeper meaning (Stewart, 2017). Henare (1994) describes hau as the very essence of vitality and Salmond (1999) draws our attention to the example of 'ahau' meaning 'I' or 'myself'. In consideration of the link between data as a gift, and the hau of the gift, the connection to the self with 'ahau' is an interesting one. The giving of data can be imagined as a gifting of a part of our selves; this process of gifting creates a relationship of obligatory reciprocity between the giver and receiver (Henare, 1994), as well as an expectation that at some stage the gift must be returned in some way to its original source.

Along with a limited understanding of hau, Henare (2018) also found that there were some issues with the original translation of Ranapiri's text by Elsdon Best. Of particular interest to this thesis, is in the mistranslation of tō as tā:

> Māori make a fundamental distinction between ownership and what is considered temporary possession by using two versions of the possessive particle-either tō and tā in this case. By using tō, Ranapiri signals possession or ownership, rather than the alternative form tā, which signals temporary possession, which is expressed as location. Ranapiri's use of tō taonga in the text implies that the taonga is still in possession of (still belongs to) the original donor, even though the physical location of the taonga may be elsewhere. (Henare, 2018, p. 456)

Here, Henare (2018) highlights that there is an existing precedent within tikanga which allows for taonga to be gifted, without a transfer of 'ownership' from the giver to the receiver. This is important, as the next section of this literature review demonstrates how the practice of koha (gifting) in relation to research emulates a capitalist exchange of goods and has the effect of alienating people from their data, their gift, themselves.

Koha in Research:

Koha is the Māori word most regularly used in institutional settings to refer to the practice of gifting, usually in situations where there is a need to acknowledge the work of a person or group of people. It is commonly defined in the following way:

> (noun) gift, present, offering, donation, contribution - especially one maintaining social relationships and has connotations of reciprocity. (māoridictionary.co.nz)

There are, of course, definitional nuances in the ways that koha is understood or used depending on the rohe (geographical area), the context (for example at a pōwhiri or tangi) or the people involved in the exchange. Koha also takes many forms, sometimes it is a monetary acknowledgement, and other times it is in the form of a taonga or gift. For the purposes of this research, the focus will be on considering the use of koha in institutional settings, particularly universities in the context of research relationships when acknowledging the contribution of research partners and participants.

The table below presents a very basic overview of how the word koha is used in ethics guidelines of Aotearoa's eight universities.

Institution	Last update	Specific reference to koha in ethics documentation
University of Auckland	29 April 2020	Where research participants incur costs, the Committee considers it appropriate to provide commensurate compensation. Researchers must ensure they are conforming with university policy in this area. The Committee also considers recompense for participation to be ethically acceptable. However, koha, gifts, payments or other forms of compensation should not be so large as to unduly induce individuals to consent to participate in the research. In no case does compensation for research participation constitute an employment relationship with the University. (University of Auckland Human Participants Ethics Committee, 2020)
Auckland University of Technology		…" It is the offering and presentation of a gift or reward for some work or duty that has been performed by a person, party, group, or organisation. It also incurs a mutual obligation" It involves the three entities, the koha, the donor and the recipient. Certain duties and expectations are inherent in the koha concept. The main principle of the koha involves mutual understanding between the donor and the recipient. This in turn leads to an undertaking between the two parties. (This understanding and undertaking is often not written). Finally, the notion of koha includes an obligation between both parties to adhere to certain procedures When a koha (gift or present) is offered or presented to a person, group, or organisation implicit in the offering and receipt of the koha is the notion that at some later date (Time can be specified or is unspecified) some reciprocal arrangement will be made. It could be the return, or compensation of a koha. (Auckland University of Technology, n.d.)
Massey University	2017	Traditionally, koha is an acknowledgement of the knowledge and or/or hospitality extended by tangata whenua to manuhiri and is often presented as part of a pōwhiri or mihi whakatau. Koha may also be offered in line with the cultural norms of the researchers and/or participants in research. (Massey University, 2017)
Lincoln University,	June (2020)	No reference made
The University of Waikato		No reference made
Victoria University of Wellington	17 April 2018	It is not University policy that participants in research must be paid for their involvement in research. However, there are occasions where koha/small gifts or compensation for time and/or travel may be provided. (Victoria University of Wellington, 2018)

		...Participants may decline such payments and request an alternative method of compensation such as a koha/gift payment or payment to a defined organisation or service. In such cases, local protocols and practices should be carefully observed.
University of Canterbury	March (2020)	No reference made
University of Otago	(2020)	No reference made

Table 4.1 Koha in the institutional ethics policies of Aotearoa New Zealand's universities

Of all the universities, the most comprehensive articulation of koha is in the ethics guidelines of AUT. This is the only instance across the documentation of all eight universities, where there is emphasis placed on the notion of a mutual obligation created in the process of gifting. In the case of the University of Auckland and Massey University, where koha is referenced specifically, it is under the broader category of compensation and reimbursement.

Of equal importance to what is specifically stated in the documentation is an acknowledgement of what is silenced. The reality is the structure set up through these ethics documents is such that once participants have received their koha, this satisfies the requirement of reciprocity, resulting in the development of a more transactional relationship marked by the offering of payment for knowledge exchange. The researcher is then supported or at the very least enabled to claim a relationship of ownership with the data they have been gifted. This relationship is then reinforced by a series of broader laws and legislation such as intellectual property law and copyright law. Importantly, the default position is to recognise the legal ownership of the researcher and their institution, and it is up to the researcher to then acknowledge the original source of the knowledge given.

The exchange of koha then, in an institutional environment, emulates a capitalist exchange of goods (West-McGruer, 2020) and fits neatly within the broader commodification of language and culture signalled by Graham Smith in 1992. Smith (1992) highlighted that the New Right policy environment at the time was based in economic theory that directly contradicted Māori values. Of particular note was how the emphasis on the individual as the key economic unit in society actively contradicted the collective structure of te ao Māori. The centring of the individual was seen by Smith, to sit in conflict with the values implied in social practices including utu (reciprocity), hui (cooperative organisation) and aroha (respectfulness) (Smith, 1992).

> By packaging and quantifying Māori cultural items within Pakeha definitions the control over what these items might mean shifts from Māori to Pakeha, and by redefining these cultural items into self-contained components they become susceptible to market forces, in that their 'value' is more dependent upon economic considerations than cultural considerations. Freemarket principles such as individualism and competition are more easily facilitated through such commodification. In this sense commodification equates with assimilation (Smith, 1992, p. 14).

To contextualise Smith's kōrero, in 1988, the *Pu-ao-te-ata-tu* report (led by John Rangihau and looked at how Māori experienced racism in the Department of Social Welfare) and the 1988 *He Whaipaanga Hou* report (authored by Māori lawyer Moana Jackson and looked at Māori experiences of racism in the criminal justice system) had both been in circulation for at least five years and there was a strong push – at least at the surface level – to incorporate Māori values into policy responses. Over time, both *Pu-ao-te-ata-tu* and *He Whaipaanga Hou* have become seen as taonga within certain sectors of the Māori community. Moana Jackson and John Rangihau made recommendations that, had they been acted upon, could have transformed the respective systems they each interrogated and significantly improved Māori outcomes. Instead, what occurred was an arguably well-intentioned, process that involved viewing tikanga Māori through a Pākehā lens.

In contrast to the new right imagining of koha as commodity, Bishop (1995, 2011) notes that the exchange of koha is an opportunity for the expression of self-determination. Bishop (2011) explains that in the context of Kaupapa Māori research:

> By invoking these processes in their metaphoric sense, Kaupapa Māori research is conducted within the discursive practices of Māori culture. Figuratively, laying down a koha as a means of initiating research, for example, or of offering solutions to a problem, challenges a notion of empowerment, which is a major concern within contemporary Western-defined research. It challenges what constitutes "self" and "other" in Western thought. Rather than figuratively saying "I am giving you power," or "I intend to empower you" ... (Bishop, 2011, pp. 17–18)

Here, Bishop (2011) is alluding to the ways that hierarchies of knowledge are embedded into the research process, where the researcher is imagined as the expert inquirer with the power to 'give voice' and 'empower' participants, therefore structuring what truths can be spoken and by whom (West-McGruer, 2020). He goes on to say that from a kaupapa Māori perspective "…the laying down of a koha and stepping away for the others to consider your gift, means that your mana is intact, as is theirs and that you are acknowledging their power of self-determination" (Bishop, 2011, p. 18).

Understanding how koha is operationalised through ethics processes is important to the Māori Data Sovereignty conversation because in its current form, it is significant in the structuring of research relationships. In particular, the relationship between the researcher and the participants, as well as the relationship between the researcher and the data they are gifted, and finally the types of relationships that participants continue to have with that data. Koha, if practiced in the way that Bishop (1995, 2011) explains, can create research relationships centred on respect and reciprocity. While important, this still focuses on the front end of the research process. For the ongoing protection and governance of data beyond the initial collection, analysis, and dissemination phases of the research, tākoha may be better placed for assuring Māori Data Sovereignty.

Tākoha is a form of gifting that indicates that there are conditions which will be applied to the taonga being gifted (Hudson, Beaton, et al., 2016, p. 9). These conditions could be about limiting who has access – or indeed, who can make decisions about who has access – to the gift, they could also indicate a timeframe for use of the gift as well as establish the process for returning the gift. In this sense, tākoha aligns very closely with the idea of hau discussed earlier. There has been some work done to theorise the potential application of tākoha in research, specifically in the field of genomic science and biobanking (Hudson, Beaton, et al., 2016; Hudson, Russell, et al., 2016). The table below outlines how tākoha can act to emphasise the ethical expectations that are associated with looking after data – in this case genomic data – as a taonga:

Te Tuku i te Taonga (Sharing the gift)	Referring to the point in research when consenting occurs
Te Hau o te Taonga (Spirit of the gift)	Referring to the expectations associated with the use of the tissue – this is inextricably linked with Te Tuku i te Taonga and the parameters established with 'donors' in the consenting phase
Te Whakahokia i te Taonga (returning the gift)	Referring to the point in time when the consent for use of the sample has finished – involves a negotiation process with whanau around return of samples and potential for ongoing research relationships

Table 4.2 Tikanga for biobanking (Source: Hudson, Beaton, et al., 2016)

Te hau o te taonga here, works to support tākoha not only in ensuring that the original recipient of the gift acts in an ethical manner in their use of the taonga, but that they take on the responsibility for ensuring any future users also respect the spirit of the gift (M. Henare, 2007 as cited by Hudson, Russell, et al., 2016). The third tikanga, 'Whakahokia i te taonga' is perhaps the most important because it recognises that data as taonga are not ownable in which case, ownership cannot be transferred. Therefore, challenging existing parameters of Intellectual property law and copyright law by creating an expectation that the initial consent phase does not transfer rights indefinitely to researchers.

Concluding Statements

The beginning of this chapter considered the origin of the term data as that which is given or the gift. Understanding the ways in which data as a concept, has been used historically in geometry and theology, offered some insight into how data has accumulated a status of neutrality and unquestionability over time. This being said, what was also highlighted was the significance of the relationship between the ‘data’ and the ‘answer’ being sought. That is, data is given meaning only in relation to the problem it is trying to solve. The notion of relationality was then explored further as a key feature of the traditional Māori practice of koha. In particular, the way that koha creates a relationship of reciprocity between the giver and receiver, placing emphasis on the ways in which accountability and responsibility to the gift are critical for sustaining that relationship. Like many Māori practices though, koha has been absorbed into western institutional language and in research ethics settings has been reconceptualised as a form of payment. The exchange of koha in this way emulates a capitalist exchange of goods and, in effect, transfers the rights of ‘ownership’ over our stories and our flesh and our data, to the researcher and their institution. The next chapter continues this conversation and expands to consider the ways in which we are alienated from our data on a daily basis.

Chapter Five: Ethics of Data Use

Chapter four, *'Data as a Gift, From a Given to the Taken'* considered the etymology of the term data and tracked the historical development of the concept from 'that which is given' to 'that often taken'. This was necessary for establishing how data has accumulated a status of neutrality and become conflated with notions of truth. The (flawed) assignment of data as neutral underpins the next section of this thesis, where I begin to unpack the value of data in contemporary contexts. Here, value is articulated differently depending on where data are being operationalised and for what purpose. The present chapter highlights how personal information can be translated in the business sector in financial terms, before shifting slightly from the overt focus on data as a commodity to consider how value is assigned to data in policy settings and research.

Understanding Data Value in Contemporary Contexts

The monetisation of data in corporate sectors is not a new phenomenon. Businesses have long relied on the availability of data for forecasting, product development and measuring the impact of their brand. The establishment of data as an asset-class has been aided by technologies like portable smart devices and high-speed internet, which allow people to download, upload, share, save and create data on a constant and continual basis (Lupton, 2016). As a result, an ever-expanding digital glut of information is growing at rates not commonly comprehensible[12]. Big data – that is, the aggregation of digital information into behemoth datasets – has become absorbed as a core feature of business in global capitalism (Mascheroni, 2020). As users engage with technology, "…data are continuously generated in real time, registered, and stored in online corporate platforms, calculated to predict, and manipulate future behaviour and therefore be monetised" (Mascheroni, 2020, p. 800). The ability for data to be operationalised to predict and manipulate human behaviour is what makes big data so valuable. We are moving toward a data-saturated future, and short of removing ourselves entirely from all digital spaces, we cannot avoid the datafication of our new realities (Budzyn, 2019).

Investment from multi-national tech giants such as Google, Amazon, and Facebook, however, has transformed data from a functional tool into a powerful commodity for trade. The value of data in today's world is reflected in the analogous comparison of data to oil; data is the new oil of the information economy (Budzyn, 2019; Couldry & Mejias, 2019; Hirsch, 2014; Parkins, 2017). The data-oil analogy speaks to how extractive data-mining processes are, how data are increasingly subject to commodification, and how data are critical for the maintenance of digital economies.

---

[12] To offer some context, it was estimated that by the end of 2020, the number of 'bytes' in the digital universe would be around 44 zettabytes – more than 40 times the number of stars in the observable universe (Desjardins, 2019).

Unlike oil, however, data is not consumed by its use. In fact, data has exponential capacity to reproduce itself. As such, it is an asset with infinite capacity for extraction and exploitation, with significant environmental impacts in the mass accumulation and storage of data (Whitehead et al., 2014).

Microsoft (2019) state in their Privacy Statement that access to some of their products and services requires users to provide specific information. Consumers maintain a right to refuse, but actioning this right means that access to the product or service is denied. At the surface level, it is a fair assumption that there is a relatively straightforward transactional relationship occurring, where users are providing information in return for a service. That information can then be used for product improvement, product development and to support customer care teams (Microsoft, 2019). There are, however, vague references in the privacy statement to data collection for advertising, transacting commerce, and research (Microsoft, 2019), which opens users up to secondary use of their data, beyond what they may be comfortable with. Access to use popular Google services like Gmail, Google Drive and Google Maps, also requires users to provide personal information (Google, 2019). The amount of information that Google can acquire from users is extensive and indeed can be seen as invasive, with many handheld android devices coming with Google proprietary software already installed (Google Chrome, Maps, Google Playstore), Google can track users' online movements as well as their physical location movements.

The conditions attached to product and service use reflect our limited capacity to avoid the datafication of our present and future realities. Issues of free and informed consent are also relevant to this discussion. The vast majority of people do not read the terms and conditions, so while they may 'accept' by pushing a button, they are still not necessarily informed (Mittelstadt & Floridi, 2016). While it may be argued that individuals are personally responsible for reading terms and conditions, such agreements are often written in vague, complex inaccessible language that means that even if people took their time to read them, for many, this would not necessarily result in a greater level of understanding of what they are asking people to agree to.

The constrained choices around why we engage with specific platforms is another issue. Individuals may be empowered to choose which providers they will engage with for personal use, however, there are some instances where choice and ability to refuse is limited. In the workplace, for instance, there is generally a contracted service provider for communications (e.g. Outlook for email), which means employees are limited in their choice to refuse a service. These issues have been exacerbated in the context of COVID-19, where businesses have had to switch to working from home modes. Hybrid learning has also become the norm for the delivery of education, making platforms like Microsoft Teams and Zoom critical for the continuation of business and education (Teräs et al., 2020).

COVID-19 has also highlighted how corporate interests are increasingly entangled with state service provision. In May of 2021, the public was made aware that New Zealand Government websites like the Department of Conservation (DOC), New Zealand Police and the New Zealand Transport Agency were operating with Facebook's Pixel JavaScript code (Burrell, 2021; NZ Council for Civil Liberties, 2021). On sites where this "Pixel code" is operational, usage data is shared directly with Facebook for advertising purposes (Burrell, 2021; NZ Council for Civil Liberties, 2021). Use of the tool by DOC was defended by the DOC digital manager Ligs Hoffman who stated:

> They are an important and effective tool for allowing us to present safety, visitor behaviour and other relevant information to people interested in walking our tracks, staying in our campsites and visiting our huts. (Burrell, 2021)

Hoffman's defence of DOC's use of the code may be true, particularly when there are biodiversity risks that need to be communicated out to the public, but there are greater grounds for concern when the site contains potentially sensitive usage data, for example, the New Zealand Police site[13] (Burrell, 2021; NZ Council for Civil Liberties, 2021). The limitations attached to the notion of choice discussed above are magnified in this example for two reasons. First, in the case of social networking sites, individuals can choose whether they engage with a site. There is however very little choice about whether and how we deal with government agencies (Burrell, 2021). Secondly, people who do not have accounts with Facebook will have their usage data shared with the social networking giant as part of aggregated datasets.

The scale of data held by Facebook is vast, with around 35 percent of the global population on the social networking site. This opens Facebook up to significant threats from data scrapers and hackers. Facebook has also come under scrutiny in both domestic and international settings for their relaxed attitudes towards privacy laws. Key examples include the Cambridge Analytica scandal and in the context of Aotearoa, in 2018, Facebook declared that the country's Privacy Act[14] did not apply to it and that they would not comply with those legal obligations[15] (Edwards, 2018). This sits in direct contradiction to the statements made by the tech-giants founder Mark Zuckerberg following the Cambridge Analytica 'situation', where he expressed that "we [Facebook] have a responsibility to protect your data, and if we can't then we don't deserve to serve you" (Zuckerberg, 2018)[16]. In response to their decision to not abide by New Zealand's Privacy Act, New Zealand's Privacy Commissioner at the time made the following statement:

---

[13] The New Zealand Police have now removed the Facebook Pixel from their sites following criticism from the public that the use of the Pixel Code posed privacy concerns

[14] At the time in 2018, referring to the Privacy Act 1993, The Privacy Act has subsequently been updated

[15] For more details regarding the events that triggered this statement from Facebook see https://www.privacy.org.nz/blog/facebook-what-this-is-really-about/

[16] To read the full statement please see https://www.facebook.com/zuck/posts/10104712037900071

> …Facebook chose to go into bat for a hypothetical, and in doing so demonstrated not just to New Zealand users, but users worldwide a very selective approach to the privacy values it chooses to uphold. (Edwards, 2018)

The public outrage triggered by these events suggests that at some level, the public has a general expectation that there are legal protections in place to regulate the behaviours of corporate entities operating in digital spaces. However, what these scandals highlight is that these digital datascapes are largely unregulated. Circling back to the New Zealand government use of the Facebook Pixel Code, while it would be difficult to assert sovereignty rights to the data collected by tech-giants, [largely because, as outlined in the table above, individuals consent to data collection by using products or services offered by these groups], we can assert that our governments do better and not open their citizens up to the exploitation and misuse of their personal information.

Secondary Data Analysis:

Both chapters three and four provided examples of how the vast scale of digital data available and the ease with which data can be accessed has resulted in the exploitation and misuse of information beyond the initial intentions of data collection. In more recent examples, we have seen how organisations can link datasets generated across multiple platforms and exploit their findings for financial gain. In the United States, pharmaceutical companies used data harvesting techniques to determine how their drugs were being talked about on social media and patient support platforms (Lupton, 2016, p. 89). In another example, researchers analysed over half a million ‘tweets’ on a popular social networking sites to identify correlations between geographic locations and HIV prevalence (Zhang et al., 2017). In a more widely known example, organisation, Cambridge Analytica, exploited datasets to target communications during the US election, and were viewed as contributing to the election of Donald Trump. In these examples, the data used to inform the research was available and accessible to the public without restriction and therefore considered ‘public information’ (Lupton, 2016; Zhang et al., 2017).

The use of data in these ways has garnered negative attention from the public, with many people outraged with the audacity of businesses to use their data differently to how it was intended (Confessore, 2018; Kuehn & Salter, 2020). Though the general public are affronted by the misuse of their information, for many Indigenous peoples the exploitation of our data for financial or personal (researcher) gain is ‘business as usual’ and signals the continuation of extractive and often harmful practices. An often-referenced example is that of the Havasupai Nation in Arizona who, after noticing particularly high rates of diabetes in their communities hoped that engaging with researchers might offer insight into any genetic clues and assist them in combating the disease in their community (Harmon, 2010; Snipp, 2016). They agreed as a Nation to offer their blood samples for testing – the DNA information extracted from their blood samples was then shared with researchers who were not interested in diabetes (Snipp, 2016, p. 49), with one researcher using the genetic material to examine theories of the Tribe's geographic origins creating findings which contradict the traditional stories of the Nation (Harmon, 2010). Importantly, the researcher responsible for sharing information extracted from the DNA of the Havasupai people acknowledged that they did not obtain consent from the participants to use their samples for any other purpose aside from that which was set out in the initial research proposal (Harmon, 2010). Further, the researcher insisted that they were just doing good science and any person who disagreed simply "failed to understand the fundamental nature of genetic research" (p. A1).

Though this assertion from the researcher seems egregious, it is an absolute reflection of the underlying assertions of western bio-medical models of research and by extension research ethics which valorise the potential for scientific exploration and financialisation over and above the rights of people at both the individual and collective level to decide what is best for themselves. To complicate the matter further, the point at which a community (or more likely an individual) has any control over the research is typically in the consenting phase, which is right at the beginning of the project and is generally governed by the policies of the researcher's institution. In some cases, the thirst for discovery overrides the basic ethical requirement of consent. This was the case for Henrietta Lacks, whose 'immortal cancer cells' commonly referred to as the HeLa cells, continue to be cultured in vitro despite Henrietta never giving consent for her cells to be taken from her body (Ahluwalia, 2020; Gorrie, 2021; Skloot, 2011). Henrietta's cancer cells are special because not only did they survive outside of her body, but they continue to thrive and divide (Gorrie, 2021) and have lived more than twice as long outside of her body than in it (Ahluwalia, 2020). The HeLa cells are so important to the scientific community and epidemiology that Henrietta Lacks is commonly referred to as 'the mother of modern medicine', and yet, her family were not aware of the existence of the cells until 1973 – 21 years after the cells had been taken – when her children were approached for blood samples to learn more about the HeLa cells (Ahluwalia, 2020). Further to this narrative, in 2013 the genomic sequence of the HeLa cell was published without the consent of her family (Coghlan, 2013), potentially making private details about the family's genetic make-up, public (Ahluwalia, 2020). The fact that Henrietta Lacks was African-American and that she was accessing one of the only hospitals that in a segregated Baltimore provided free healthcare to African-Americans, really underscores the collective exploitation of systematically vulnerable groups, and the underlying racist beliefs and practices of scientist, researchers and the institutions to which they belong.

The Havasupai case and the ongoing use of Henrietta Lacks' cells raise important questions about notions of consent and ownership, especially that of human tissue. There are also contemporary court decisions that say discarded cells and tissues can become the *property* of physicians and research institutions (Allen et al., 2010; Truog et al., 2012). In their comprehensive overview of laws and regulations relevant to the use of human blood and tissues in biomedical research, Allen and colleagues (2010) found that, in the US context, there were no established legal frameworks that offer clear guidance around how ownership rights operate relative to human tissue. Citing eight landmark court cases (including the Havasupai v. Arizona State case), Allen et al (2010) demonstrate how the lack of a clear legal framework, has resulted in a series of confusing and ethically dubious clinical and research practices. In 1990 for instance, John Moore sued Regents University of California when he discovered that over the course of seven years (1976-1983) the research institution had been taking his cells without his knowledge or consent under the guise of treatment for leukaemia. A new cell line was developed from his excised tissue and the research institution were obtaining financial gain from it (Allen et al., 2010). The court ruled that Moore did not have proprietary rights over his own (excised tissue), and that "…giving patients property rights would hinder research by restricting access to raw materials and might destroy the economic incentive to conduct important medical research" (Truog et al., 2012). Seventeen years later in 2007 in another case (*Washington University v. Catalona)*, the court ruled in favour of Washington University to deny the request of one of the investigators (Catalona) and some of the donors for the transfer of human tissue to another research institution. The court discerned that the donors had gifted their tissue and retained no rights to direct that they be transferred elsewhere (Allen et al., 2020).

These examples should be shocking and should confront our sensibilities as researchers, as educators and as people. Unfortunately, however, these examples fit neatly into a broader history of exploitative research, particularly for structurally vulnerable communities. To be shocked by this unethical approach to physical tissue data, is to be privileged and shielded from the violent realities we experience. The problem, however, is not with the data itself, and to some extent we can argue that the research is not the problem either. Indigenous scholars have perpetually pointed out that the availability of data is essential in the development of policy to address inequalities (Davis, 2016), and when governed in the right way, data can promote mutually beneficial relationships between partners (Bruhn, 2014). The problem arises when the production of datasets occurs within racialised, colonial structures designed to systematically oppress Indigenous peoples. Data in this sense sits at the new frontier of colonialism (Couldry & Mejias, 2019). As Indigenous scholars working in the ID-Sov space, it is critical that we do not continue to label the data as 'bad' – in doing so, we run the risk of removing responsibility and accountability from the structures that produce the harm while re-framing our data, and in the cases mentioned above, our tissue, our genes, our whakapapa, as problematic.

Though the re-purposing of data has serious negative potential, there are also some benefits to secondary data analysis. When researchers opt to use pre-existing datasets to inform their research, they make a pragmatic choice. Using secondary data in this way is pragmatic because all the information that is needed to inform the analysis already exists, which means the research is both time effective and cost-efficient. These points are particularly pertinent in an academic research environment that rewards those who publish frequently. Also worth considering are the benefits to emerging researchers who are under time pressures to complete their research and are also unlikely to have access to the financial resources required to undertake primary data collection as part of their research. Post-graduate students, for example, are often faced with significant time restrictions meaning the lengthy process of securing ethics approval coupled with the time needed for participant recruitment can make existing datasets very appealing. Finally, from a participant perspective, secondary data analysis avoids the collection of the same information over and over by different people. These points considered, there is no reason why consent could not be part of many secondary data processes as well.

Data Linking and the IDI

The Integrated Data Infrastructure or IDI is a platform with the capacity to link datasets spanning multiple domains. The Integrated Data Infrastructure (IDI) was launched by Statistics New Zealand in 2014 as a 'one-stop shop' for researchers (Gulliver et al., 2018) to "...gain insight into our society and economy… [and] help answer questions about complex issues that affect New Zealanders" (Stats NZ, 2020b). Statistics New Zealand (Stats NZ, 2018a) claim that research that draws upon data from the IDI has the potential to identify evidence-based solutions to the problems facing people residing in Aotearoa, "...particularly when underlying causes are complex and funding is constrained." Initially, the IDI included the following datasets:

- ACC injury data
- Department of Corrections' [DoC] sentencing data
- Inland Revenue Department's [IRD] person and business tax data, student loans and allowances data
- Ministry of Business Innovation and Employment's [MBIE] migration and movements data
- Ministry of Education's [MoE] secondary school achievement data, tertiary education data
- Ministry of Justice's [MoJ] charges data
- Ministry of Social Development's [MSD] benefit data, student loans and allowances data
- Statistics NZ's:
    - Household Labour Force Survey data
    - New Zealand Income Survey data
    - Survey of Family, Income and Employment data
    - Longitudinal Immigration Survey: New Zealand data
    - Longitudinal Business Database data (Statistics New Zealand, 2013)

These datasets aim to capture as much of the resident population in Aotearoa New Zealand as possible. Importantly, individuals are very constrained in their choice about whether they engage with these government departments. This notion of limited choice is exacerbated when we take into consideration which segments of the population will be captured by multiple datasets. We know that Māori are over-represented in the datasets of MoJ, DoC and MSD, in this case, the Māori presence within the datasets will be undoubtedly disproportionate relative to non-Māori. In 2018, Stats NZ reported that the IDI had expanded to include an additional 38 datasets (Stats NZ, 2018a) with notable additions from the health sector, as well as information identified as ‘People and communities’ data’, which includes information collected by the Auckland City Mission, an NGO established to respond to poverty related issues in Auckland. Particularly poignant, the data from Te Kupenga – a survey of Māori wellbeing – is also included. By June 2021, there were 62 datasets held within the IDI.[17]

In a report prepared for Statistics New Zealand, which examined public attitudes towards data integration, Davison et al (2015) found that participants had an expectation the data linking across government sectors was already happening and that there was a general sense of overall comfort with this practice among the participants. However, participant responses in narrative interviews suggested that confidence in the data-linking and information sharing was often compromised. For example, while it was agreed that the sharing of data across and between government agencies could produce positive outcomes for people, participants were less comfortable with external organisations or third parties having access to linked data with one participant asking:

> Why would these other people want this information? Why would they need it if they are not part of the Ministry (of Education), or part of the Government (Davison et al., 2015, p. 6).

These questions reflect the ways in which participants felt about the data collection processes, the findings of the report show that participants believed that the purpose of data collection by government agencies was in part about improving services and targeting funding where needed, therefore, information sharing was both practical and necessary. However, the re-purposing of data by external agencies and third parties was thought by some to be unacceptable and potentially damaging to groups deemed vulnerable (Davison et al., 2015).

The IDI operates under the presumption that Statistics New Zealand as a government entity has a social licence to operate. Gulliver et al (2018), define social licence as:

> Social acceptance that a practice that lies outside the general norms may be performed by a certain agent, on certain terms. It is the result of an ongoing process of negotiating 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. (p. 60)

---

[17] For a full list of the datasets held in the IDI see https://www.stats.govt.nz/integrated-data/integrated-data-infrastructure/data-in-the-idi#list

Crucially, social licence cannot be conferred if the people or community affected are not aware that it is being sought (Gulliver et al., 2018). In the context of Aotearoa, social licence is limited when less than 25% of a surveyed population agree that they know Stats NZ reasonably or very well (Kukutai & Cormack, 2019). Further, there are additional layers of complexity for Māori because, as TMR pointed out in their statement on social licence:

> ...we view social licence as the ability of an organisation to use and share data in a legitimate and acceptable way, based on the trust that individuals have. (Te Mana Raraunga 2017)

Trust at the individual level is of course important, however, as this thesis highlights with many examples (particularly in chapter 7), what can be considered safe use for individuals is not necessarily safe at the collective level. The NZ Police's national wastewater drug-testing programme is an apt example of this individual-collective data rights tension. As part of this programme, the Institute of Environmental Research and Science (ESR) tests community wastewater to detect the levels of methamphetamine and other illicit drug use (Kukutai et al., 2020). Because the data cannot identify people at the individual level, the testing programme is compliant with privacy laws. However, the aggregated datasets do tell stories about the communities from which the data is derived, and in this case the programme can be seen as an extension of systems of surveillance into affected communities (Kukutai et al, 2020). This example highlights how a focus on social licence and trust at the individual level is not sufficient.

Beyond the social licence model, governance of the IDI is relatively limited. Researchers who are interested in accessing the IDI must first complete an application to Statistics New Zealand in which they demonstrate that their proposed research meets the following criteria:

- Research is for statistical purpose.
- Research is for the public good.
- Research will be conducted by a credible team with support from their organisation.
- Suitable data is available.
- Stats NZ can enforce an agreement.
- Research must be released publicly.
- Researchers must have the skills needed to work with the data. (Stats NZ, 2018b)

Once submitted, each application is reviewed by Statistics New Zealand subject matter, legal, and methodology teams, with final approval granted by the Government Statistician (Jonas, 2018). If approved, researchers can only access the IDI from a secure research virtual environment, in an approved Data Lab facility (Stats NZ, 2020b). Where the data being requested is specifically about Māori, the application is also assessed under the Ngā Tikanga Paihere framework (NTP).

NTP aligns with Stats NZ Five Safes framework[18] (Stats NZ, 2020a, p. 3). It draws on ten traditional Māori concepts identified by Hudson et al (2017) and was developed with the view to build and maintain public trust and confidence in the way that Stats NZ manages microdata in the IDI. A specific focus of NTP, according to Stats NZ (Stats NZ, 2020a, p. 3), is to go some way in ensuring responsiveness to Māori, and "…other under-represented sub-groups". This point of under-representation is an interesting one. Particularly if we consider the discussion from chapter three regarding 5d and BADDR data, and the idea that Indigenous peoples are in fact over-represented in administrative datasets. It seems that where Stats NZ refers to their commitment to be responsive to 'under-represented groups' including Māori, there should be a qualifying statement that indicates that we are under-represented in decision-making bodies and in the data ecosystem more generally not in the datasets themselves.

There is currently no standard ethics framework which guides the use of IDI data across the education and research sectors (Kukutai & Cormack, 2019). One potential reason is the assessment of research projects involving secondary data analysis is generally seen to sit outside the scope of the current institutional ethics committees. Further, even if there were robust ethics frameworks in place for governing access to data for secondary analysis, the IDI is also utilised by researchers and policymakers working in government departments, think tanks, and independent consulting companies who do not necessarily have their own internal ethics processes[19]. In saying this, the Five Safes and NTP criteria do speak to some of the central tenets of institutional ethics. For example, the 'public good' criteria reflects the general principle of beneficence, and the requirement that research is released publicly reflects a particular manifestation of the ethical principle of reciprocity. However, there are no provisions within either Five Safes or NTP that account for informed consent as a key feature of ethics, nor is there any consideration of privacy at the group level.

Concerns regarding a preoccupation of individual privacy to the detriment of group interests are discussed at length in chapter 7, what is important to raise here though is that the ability for data linking in the IDI poses greater risks to the privacy of some groups relative to others. In Gulliver et al's (2018) research for instance, some participants expressed that it would be difficult to ensure that data was truly de-identified, this was a concern for members of the disability community, as well as LGBTQI+ communities. Importantly, when discussing privacy issues, the participants were not concerned with direct personal adverse outcomes as much as they were aware of the ways that

---

[18] Safe people; Safe projects; Safe settings; Safe data; Safe output https://www.stats.govt.nz/integrated-data/integrated-data-infrastructure/

[19] MSD is an exception in this case as they have an established independent research ethics panel that provides ethical advice to the research and evaluation team

their information could be [mis]used to discriminate and reinforce existing prejudices (Gulliver et al, 2018, p. 68).

The differential impact of data use and the potential for data harms make issues of consent far more pressing. There are currently no standards for informed consent for data held within the IDI. To be clear, most of the data held within the IDI is initially collected for purposes that are not research related. Usually, data is collected for service provision. If, for instance, I went to my GP for a health concern, I would provide information to them to inform my personal healthcare. In this case, the collection of my data is a biproduct of my care not the primary purpose of my engagement. Regardless, this information could still be uploaded as part of the 21 health-related datasets sitting in the IDI without my explicit consent. It should be noted at this point, that given the size of the datasets held within the IDI, and the fact that all data is de-identified, informed consent is not a straightforward process. However, relying on anonymity and a social licence to operate simply not enough.

As an alternative to Social Licence, TMR (2017) proposed the notion of cultural licence which considers the sharing of data in a way which reflects the collective trust that iwi and Māori Treaty partners have (Data Futures Partnership, 2017; Te Mana Raraunga 2017)**.** Cultural Licence is a particularly useful conceptual tool when thinking about data sets which can be aggregated and used to represent groups, particularly when considering the potential risks and benefits of data (Data Futures Partnership, 2020):

> As the Māori Data Sovereignty Network, Te Mana Raraunga is committed to protecting and securing Māori rights and interests in data. Our view is that the proposed Guidelines for Social Licence should acknowledge the importance of Cultural Licence, the distinctive rights and interests of iwi/Māori as Treaty Partners, and Iwi/Māori aspirations to derive equitable benefits from data as a counterbalance to the significant collective risks. For Iwi/Māori to derive clear and equitable value from data use the guidelines would need to make provision for ‘data for governance’ (access to data for iwi/Māori decision making), and ‘governance of data’ (involvement in decisions about data access and use). (Te Mana Raraunga 2017)

While cultural licence does not directly respond to the consent issues discussed above, the emphasis on equitable data outcomes as well as the assertion for Māori to be involved in decision making does go some way in mitigating some of the concerns around group level harm. For cultural licence to have a more significant impact though, it should be seen as part of a broader shift toward Māori data sovereignty.

Concluding Statements

This chapter has demonstrated the pervasiveness of data collection in our day to day lives. Data are collected daily and can contain the lived experiences of individuals, families, and communities as well as the complex social and natural environments within which we live. The value of data in today's world is reflected in the analogous comparison of data to oil; (Hirsch, 2014; Parkins, 2017; Budzyn, 2019). The data-oil analogy firmly cements the categorisation of data as a new asset-class, the production of which is seen to be driven by the potential for corporate financial gains (Budzyn, 2019).

The establishment of data as an asset-class has been aided by rapidly developing technologies and advanced data collection strategies. While there are certainly corporate financial gains to be made from advancing data technologies, this chapter has shown that there are also significant political gains being made. Most notably in Aotearoa New Zealand, the Integrated Data Infrastructure has the technological capacity to bring multiple datasets together to tell a story. Increasingly, as data-linking software becomes more sophisticated, the information which can be derived from linked datasets is critical in the development of social and economic policies. While data certainly has the potential to inform policy where the benefit can accrue to a wider collective, for Indigenous populations globally, this has rarely been the case. Historically, data extracted out of research conducted on Indigenous peoples has been used to dispossess, displace, and disadvantage their communities.

Researcher misconduct and the inappropriate disaggregation of data has contributed to cumulative disadvantage of Indigenous communities and has unsurprisingly resulted in a well-documented sense of distrust and disillusionment among Indigenous peoples toward research and data. Therefore, as we move through an era of 'big data' and the exponential growth of datasets beyond what can be commonly comprehended, it is crucial that the rights of Indigenous peoples with regards to Indigenous data are recognised and prioritised within data-governance frameworks. The ways in which Indigenous communities are responding to this need through the establishment of Indigenous data sovereignty discourse is the focus of the next chapter.

Chapter Six: Indigenous Data Sovereignty

The following chapter closes off the exploratory section of this thesis. So far, in chapters 3, 4 and 5, I have laid the foundation for discussing why data sovereignty is a pressing issue for Māori in Aotearoa New Zealand and for Indigenous peoples globally. The present chapter builds on this discussion to consider what data sovereignty is, and how it might be actualised. This chapter is broken up into three distinct parts. It first looks at how data sovereignty has been defined. This involves a process of differentiating between data sovereignty generally and Indigenous/Māori data sovereignty specifically. This chapter then turns to consider the uptake of Māori data sovereignty [MD-Sov] across institutions and organisations, including some non-Indigenous groups. Finally, principles of MD-Sov are overviewed, including how they have been incorporated into models for data governance.

Indigenous Data Sovereignty

Data sovereignty is centrally concerned with the jurisdictional authority of nation-states to control data that is stored or is passing through their national internet infrastructure (Hudson et al., 2017, p. 62). It is not currently an established legal concept, but a shorthand referring to the desire for the retention of authority and control over information assets[20] (Irion, 2012). Full uninhibited control and authority is limited in the era of big data[21] where both private organisations and government agencies are faced with making decisions around where to store data once it has been collected. In the absence of secure and sufficiently sized data storage infrastructure within each nation-state, outsourcing data storage to cloud-based providers is often the cheapest and most efficient way to manage this challenge in its immediacy (Peterson et al., 2011). Control is limited in this case because the management of data becomes subject to the laws of the nation in which it is stored, irrespective of the origins of the data itself[22] (Snipp, 2016). Or in the case of the US, data is subject to some laws in the US if the cloud storage is with a US company, regardless of where data are stored (Bell Gully, 2021).

---

[20] While not an established legal concept, there are a growing number of legislative levers that aim to support data sovereignty. Some of these sit at the international level (GDPR for example), and others are specific to the nation-state within which they were created (OCAP® in Canada for example). In addition, there are also pre-existing legislative levers, including Privacy laws, which are important within the data sovereignty discussion – some of which will be discussed later in this chapter (OCAP®) and others which will be considered in later chapters (chapter 7 – Privacy).

[21] Exponentially large data-sets that may be analysed computationally to reveal patterns and trends in human behaviour – defined in greater depth in chapter 3 of this thesis.

[22] An additional point for consideration is that the storage of data is not the only time where data sits outside the jurisdictional authority of the nation state. Often, the use and analysis of data happens via Platform-as-a-service and Software-as-a-service solutions, which involve the offshoring of data in order for that data to be processed or 'worked on' (see https://www.data.govt.nz/docs/report-offshoring-nz-govt-data/).

According to Irion (2012), when thinking about data sovereignty, there are at least two critical questions that emerge. If, as discussed in chapters 3 and 5, digital data is the evidential basis of contemporary governance and policy implementation, does the geolocation of cloud-based storage facilities affect national sovereignty? Or perhaps more confrontingly, if crucial information is technically and legally controlled by a foreign power, does that mean that sovereign states are, in fact, operating as colonies? (Irion, 2012). A key point, seemingly absent from Irion's questioning here and the data sovereignty discussion more generally is that these questions are neither new nor emerging. In fact, Indigenous Peoples have been raising these same concerns for decades. Perhaps not specifically about data, but certainly in relation to the right to conduct ourselves as independent and autonomous nations. A strong history of challenging the imposition of foreign laws and developing mechanisms to counter them means that we, as Indigenous Peoples, have been able to do the work of defining, theorising, and socialising the concept of Indigenous Data Sovereignty relatively quickly.

Indigenous Data Sovereignty refers to the rights of Indigenous Peoples to control data that derive from them, and which pertain to their communities, knowledge systems, lands and natural resources including waterways (Kukutai & Taylor, 2016; Kukutai & Walter, 2021; Rainie et al., 2019; Snipp, 2016; Walter et al., 2018; Walter, Kukutai, et al., 2021). Captured within ID-Sov are the rights of Indigenous nations to have control over all aspects of the data eco-system from the collection, analysis, interpretation, management, dissemination, and re-use (Walter, Lovett, et al., 2021, p. 146) through to issues related to the access to, and possession of, data (Walter, Kukutai, et al., 2021, p. 692). Where data sovereignty has a preoccupation with the nation-state as the primary site for exercising sovereignty, in ID-Sov discourse, the nation can be used to describe traditional Indigenous conceptions of nationhood, which may manifest at the tribal, iwi or mob level (Lovett et al., 2019). In comparing the scope of data sovereignty generally with ID-Sov specifically, there is another important difference between the two that is worthwhile highlighting here. While data sovereignty is concerned primarily with protecting the legal rights of nation-states to data once it has been collected, ID-Sov is concerned with ensuring the protection of Indigenous rights and interests across the entire data eco-system. The broader scope of ID-Sov is reflective of the harm caused in Indigenous research[ed] histories. ID-Sov also aims to circumvent the tensions presented in the cloud service arrangements mentioned above, by asserting that the authority to govern data is not transferred to the 'host-nation', and instead, the jurisdiction over data remains with the nation from which the data is collected (Kukutai & Taylor, 2016). These rights, as Cormack, Kukutai and Cormack (2020, p. 76) articulate, "…originate in Indigenous peoples' pre-colonial rights of self-determination and are embedded in domestic treaties such as Te Tiriti o Waitangi, and global agreements such as the United Nations Declaration on the Rights of Indigenous Peoples".

Conceptually speaking, the ID-Sov movement is relatively new, gaining traction and being further socialised as a concept in academic, political and policy circles through the publication of the book *Indigenous Data Sovereignty: Toward an agenda* in 2016. However, the central ideas forming the foundation of ID-Sov have been the focus of critical engagement by Indigenous scholars and allies for decades. Developing a strong theoretical foundation for ID-Sov has involved building on the work of Indigenous scholars and allies across the fields of "…indigenous research ethics, cultural and intellectual property rights, nation-building, and indigenous governance, within a frame of tribal sovereignty and self-determination" (Hudson et al., 2017, p. 63). Speaking specifically about the emergence of ID-Sov in Aotearoa, Sporle et al (2021, p. 65) posit that "while the language of Indigenous Data Sovereignty is new, it reflects core ideas first articulated in the Mataatua Declaration on Cultural and Intellectual Property Rights and expands them to assert rights over data generated by government agencies about Māori communities."

Between 2015 and 2017, country specific ID-Sov networks were established across Aotearoa New Zealand (Te Mana Raraunga, 2015), the United States (USIDSN, 2016)[23] and Australia (Maiam nayri Wingara, 2017)[24]. With the First Nations Information Governance Centre continuing to advocate for ID-Sov rights in Canada[25], ID-Sov advocacy groups are active across all CANZUS nation-states. The reach of ID-Sov discourse has since expanded beyond the CANZUS states with the establishment of the Global Indigenous Data Alliance [GIDA] in 2019 following the workshop '*International Law, The United Nations Declaration of the Rights of Indigenous Peoples' and Indigenous Data Sovereignty'.*

> Convened by Maggie Walter and Desi-Rodrigues-Lonebear, the Oñati Workshop bought together participants from multiple Indigenous nations and tribes in seven nation states, with the representation from Columbia, Sweden, Mexico, and the Basque Country supporting ID-SOV ambitions to expand beyond CANZUS countries of Aotearoa New Zealand, Australia, Canada, and the United States (Global Indigenous Data Alliance [GIDA], 2019, p. 1).

GIDA[26], in their Communique, acknowledge that advancing ID-Sov within distinct nation-states requires nation specific advocacy groups (GIDA, 2019). A global data alliance is necessary for promoting a shared vision of ID-Sov and can support the sharing of "…frameworks, tools, and practices to help guide the practice of Indigenous Data Sovereignty around the globe" (https://www.gida-global.org/whoweare).

---

[23] US Indigenous Data Sovereignty Network https://usindigenousdata.org/about-us

[24] Maiam nayri Wingara Aboriginal and Torres Strait Islander, https://www.maiamnayriwingara.org/about-us

[25] FNIGC established in 1998 and building off the legacy of OCAP® https://fnigc.ca/

[26] GIDA is both an acronym for Global Indigenous Data Alliance and a Basque word meaning 'to guide' https://www.gida-global.org/whoweare

Recognising the considerable impact of data in decision making, it is unsurprising that there is such a strong link between ID-Sov discourse and self-determination. In an international context, the United Nations Declaration on the Rights of Indigenous Peoples [UNDRIP] is an important global, human rights instrument for the promotion and assertion of the rights of Indigenous nations to govern ourselves, and by extension, our data (Lovett et al., 2019).

UNDRIP has been described as an aspirational document (Davis, 2016) and a means of setting a 'minimum standard' for protecting the rights of Indigenous Peoples (Rainie et al., 2019). Of the 46 articles comprising UNDRIP, Kukutai and Taylor (2016) identified 13 as raising "…urgent questions about the manner in which these nations statistically represent their indigenous citizens'" (Kukutai & Taylor, 2016, p. 4). These 13 articles can be broadly categorised as those relating to the right to political self-determination (3, 4, 5 and 21(i)); the rights of Indigenous Peoples to be visible and present in decision making (18, 19 and 23); the right to determine identity (33), including the right to be represented in a way that maintains dignity (15(i)) and the responsibility of (government) signatories to give effect to the Articles set forth in UNDRIP in domestic law (28 and 42)[27]. The remaining 2 articles have the most direct relevance to ID-Sov:

Article 31

1. **Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge** and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. **They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions.**
2. **In conjunction with indigenous peoples, States shall take effective measures to recognize and protect the exercise of these rights.**

Article 32

1. **Indigenous peoples have the right to determine and develop priorities and strategies for the development or use of their** lands or territories and other **resources**.
2. States shall consult and cooperate in good faith with the indigenous peoples concerned through their **own representative institutions** in order to obtain their **free and informed consent prior** to the approval of any project affecting their lands or territories and other resources, particularly in connection with the development, utilization or exploitation of mineral, water or other resources.
3. States shall provide effective mechanisms for just and fair redress for any such activities, and **appropriate measures shall be taken to mitigate adverse environmental, economic, social, cultural or spiritual impact.**

---

[27] https://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf

UNDRIP has been useful as a unifying tool (Kukutai & Taylor, 2016) for theorising ID-Sov at an international level, however, realising data sovereignty within nation-states requires more specific legislative levers that can speak to the nuances and particularities of distinct Indigenous groups. Perhaps the most well-established example in this case comes from Canada in OCAP®.

Established in 1998, OCAP® has been operating as the de facto standard for guiding ethical conduct of research using First Nations data for over quarter of a century (Bruhn, 2014; First Nations Information Governance Centre, 2016; Walter & Carroll, 2021). Unlike many other ethical standards though, OCAP® extends its reach beyond the initial data collection moment, to also offer guidance for the ongoing ethical management of First Nations information. In this way, OCAP® is an early example of how ID-Sov might be actualised, particularly in the context of research institutions. The acronym OCAP® stands for Ownership, Control, Access, and Possession[28], and "…asserts that First Nations alone have control over data collection processes in their communities, and that they own and control how this information can be stored, interpreted, used or shared" (FNIGC 2016). The impetus for the development of OCAP® came after years of objectionable and ethically dubious research being conducted on First Nations communities in Canada. This all came to a head in 1994 when the Canadian Government launched three longitudinal health surveys that excluded First Nations peoples, despite these communities bearing the brunt of the most significant inadequacies of the health system (First Nations Information Governance Centre, 2016). In the years that followed, the federal government did create a supplementary survey[29] to collect data on reserves, and from this the RHS Steering Committee was born and would eventually become the First Nations Information Governance Centre [FNIGC] (2016). Given its beginnings as a response to the persistent failures of colonial research agendas, it is unsurprising that OCAP® addresses the deficiencies of institutional research ethics. In recognising the limitations of an overt emphasis on the individual as the primary unit in society for exercising autonomy, there is a reorientation toward centring the rights and interests of collectives in research. The act of shifting away from individualised notions of consent and privacy will be discussed in greater depth in chapter seven of this thesis. As the pioneering document for ID-Sov, OCAP® has become a key feature in the development of data sovereignty frameworks for other Indigenous collectives, including Māori in Aotearoa New Zealand (Te Mana Raraunga, 2016).

---

[28] The acronym OCAP® has been trademarked by the First Nations Information Governance Centre [FNIGC] to ensure that it is not misappropriated by non-Indigenous researchers. For greater detail of the OCAP® principles, see https://fnigc.ca/ocap-training/

[29] This survey is named the First Nations and Inuit Regional Health Survey [RHS].

Te Mana Raraunga - Māori Data Sovereignty

Māori Data Sovereignty sits within the broader ID-Sov movement and extends the theorising to consider the specific interests of Māori in relation to data. Strong advocacy for Māori data rights has been a critical element of the MD-Sov movement to date and continues to be the primary function of Te Mana Raraunga [TMR][30], the MD-Sov network in Aotearoa. Working alongside TMR in the advocacy space is the Iwi Chairs Forum Data Iwi Leaders Group [ILG], more recently operating as Te Kahui Raraunga [TKR][31]. The relationship between TMR and the data ILG has been largely guided by the mana-mahi (Governance-Operations) framework, which is a model comprised of six key principles, outlined in the Te Mana Raraunga Charter (2016); the application of this model has allowed for the groups to delineate their respective responsibilities and avoid overlap (Cormack et al., 2020; Sporle et al., 2021).

Mana (Governance)	**Mahi (Operations)**
Whanaungatanga (relationships)	Whakapapa (Connections)
Rangatiratanga (self-determination)	Manaakitanga (Protection)
Kotahitanga (Collaboration)	Kaitiakitanga (Guardianship)

Table 6.1 mana-mahi framework (Source: Te Mana Raraunga, 2016)

Working in the ‘mana’ space has primarily been the domain of the data ILG, who have had significant success in advocating for Māori governance over Māori data, including actively engaging in national policy developments. Of particular note is the Mana Ōrite Relationship agreement between Te Kahui Raraunga (representing the data ILG) and Stats NZ (Sporle et al., 2021).

The signing of the Mana Ōrite Relationship agreement between the Data Iwi Leaders Group (represented by Karen Vercoe) and Statistics New Zealand in October 2019, was a significant step for securing recognition of MD-Sov rights at the nation-state level. The landmark agreement is based on a Te Tiriti o Waitangi-derived relationship and determines that the respective views of each party (the Data ILG and Stats NZ) are “...heard, considered, and afforded equal explanatory power.” The equal explanatory power provision is an important feature of the agreement as it signals a distinctive shift away from a relationship based in Māori consultation, towards one premised on the right of Māori to be present in decision-making processes.

---

[30] Te Mana Raraunga was established in October 2015 in Hopuhopu for more on their formation see https://www.temanararaunga.maori.nz/ - More detailed discussion of the membership base and structure of TMR can be found in Sporle et al, 2021

[31] Te Kahui Raraunga was established in 2019 to realise the advocacy of the Data Iwi Leaders Group – a more detailed discussion of the formation of TKR can be found here https://www.kahuiraraunga.io/

The shift away from consultation is significant. Māori consultation has been in policy guidelines and best practice guidelines since the 90s. The Resource Management Act 1991 [RMA] is an early example. Section 7 of the RMA includes a requirement to "…have regard to kaitiakitanga in relation to managing the use, developments, and protection of natural and physical resources" (Te Puni Kōkiri 2006, p. 3) with consultation signalled frequently as best practice (Te Puni Kōkiri 2006). Though consultation is often framed as an opportunity to ensure that Māori voices are 'heard', what we know is that the burden of consultation has largely resided with Māori and often has very little impact in final decision-making. Māori have reported feeling that their input is often part of a tokenistic tick-the-box exercise where we are expected to engage in endless hui (meetings) without financial compensation for our time (Ruru, 2009) and are left feeling ignored (Clarke, 2015) and exhausted (Rauika Māngai, 2020). In institutional research environments, Vision Mātauranga policy is intensifying consultation fatigue for Māori academics who are often asked to sit on research projects as Māori advisors, again with little to no recognition of their input (Rauika Māngai, 2020). The Mana Ōrite Relationship Agreement with Statistics New Zealand, will be critical for ensuring that Māori are involved in decision-making regarding data governance in Aotearoa.

In terms of data governance, there is considerable alignment between the principles guiding the Mana Ōrite relationship agreement, the mana-mahi operations framework and (as will be seen in the next section) TMR's principles of Māori Data Sovereignty.

Mana Ōrite. Respective views will be heard, considered, and afforded equal explanatory power.	**Rangatiratanga.** Leadership that focuses on common purpose whilst also respecting the autonomy and independence of the iwi and members of the Data ILG.
Whanaungatanga. Strong transparent relationships through respect, integrity, empathy, and commitment to kaupapa.	**Whakawhāiti.** Inclusiveness, acknowledging the respective value and roles of the National Iwi Chairs Forum and the individual iwi, hapū and Māori data stakeholders.
Kotahitanga. A culture of moving together with solidarity towards a common purpose.	**Kaitiakitanga.** A shared culture of respect, guardianship, care and protection for data as a strategic and valued resource, recognising that for the NICF, Māori data is a taonga and iwi-Māori are kaitiaki over their taonga.

Table 6.2 Mana Ōrite Relationship Principles (Source Stats NZ & Data Iwi Leaders Group, 2019)

The purpose of the relationship is stated as being to "...help create a future that benefits te oranga whanui o Aotearoa by realising the potential of data to make a sustainable positive difference to outcomes for iwi, hapū and whānau"[32]. The incorporation of the principle *whakawhāiti* or

---

[32] Full details of the agreement can be found at https://www.stats.govt.nz/about-us/what-we-do/mana-orite-relationship-agreement/

inclusiveness, can be seen to respond to the diverse needs of Māori data stakeholders, rather than resting on the presumption that Māori data interests are homogenous across the board. The Mana Ōrite principle ensures that there is a mechanism in place to prevent Māori concepts like whanaungatanga, kotahitanga, kaitiakitanga and rangatiratanga being subsumed by Pākehā or western logics. Following the signing of the relationship agreement, a joint work programme was developed to support both parties to monitor the implementation and application of mana ōrite across four workstreams.

Returning to the mana-mahi framework, 'mahi' houses the principles relevant to operations including whakapapa, manaakitanga and kaitiakitanga. Working in this space, TMR have been at the forefront of carving out theoretical spaces, defining key concepts and socialising MD-Sov across the data eco-system through hui (meetings) and wānanga (workshops), as well as advocating for Māori rights and interests through submissions and public position statements (Sporle et al., 2021). In 2018 TMR also published the Principles of Māori Data Sovereignty. While these principles (see Table 6.3) centre Māori values and provide a conceptual framework for understanding Māori interests in the context of data, there is still a strong alignment with the international principles of OCAP® (FNIGC 2016) and the data rights asserted by Maiam nayri Wingara (2017) for Aboriginal and Torres Strait Islander peoples.

01 Rangatiratanga I Authority	**04 Kotahitanga I Collective Benefit**
1.1 Control. Māori have an inherent right to exercise control over Māori data and Māori data ecosystems. This right includes, but is not limited to, the creation, collection, access, analysis, interpretation, management, security, dissemination, use and reuse of Māori data. **1.2 Jurisdiction**. Decisions about the physical and virtual storage of Māori data shall enhance control for current and future generations. Whenever possible, Māori data shall be stored in Aotearoa New Zealand. **1.3 Self-determination**. Māori have the right to data that is relevant and empowers sustainable self-determination and effective self-governance.	**4.1 Benefit.** Data ecosystems shall be designed and function in ways that enable Māori to derive individual and collective benefit. **4.2 Build capacity**. Māori Data Sovereignty requires the development of a Māori workforce to enable the creation, collection, management, security, governance and application of data. **4.3 Connect.** Connections between Māori and other Indigenous peoples shall be supported to enable the sharing of strategies, resources and ideas in relation to data, and the attainment of common goals.
02 Whakapapa I Relationships	**05 Manaakitanga | Reciprocity**

2.1 Context. All data has a whakapapa (genealogy). Accurate metadata should, at minimum, provide information about the provenance of the data, the purpose(s) for its collection, the context of its collection, and the parties involved. **2.2 Data disaggregation**. The ability to disaggregate Māori data increases its relevance for Māori communities and iwi. Māori data shall be collected and coded using categories that prioritise Māori needs and aspirations. **2.3 Future use**. Current decision-making over data can have long-term consequences, good and bad, for future generations of Māori. A key goal of Māori data governance should be to protect against future harm.	**5.1 Respect.** The collection, use and interpretation of data shall uphold the dignity of Māori communities, groups and individuals. Data analysis that stigmatises or blames Māori can result in collective and individual harm and should be actively avoided. **5.2 Consent**. Free, prior and informed consent (FPIC) shall underpin the collection and use of all data from or about Māori. Less defined types of consent shall be balanced by stronger governance arrangements.
03 Whanaungatanga I Obligations	**06 Kaitiakitanga | Guardianship**
3.1 Balancing rights. Individuals' rights (including privacy rights), risks and benefits in relation to data need to be balanced with those of the groups of which they are a part. In some contexts, collective Māori rights will prevail over those of individuals. **3.2 Accountabilities**. Individuals and organisations responsible for the creation, collection, analysis, management, access, security or dissemination of Māori data are accountable to the communities, groups and individuals from whom the data derive.	**6.1 Guardianship.** Māori data shall be stored and transferred in such a way that it enables and reinforces the capacity of Māori to exercise kaitiakitanga over Māori data. **6.2 Ethics**. Tikanga, kawa (protocols) and mātauranga (knowledge) shall underpin the protection, access and use of Māori data. **6.3 Restrictions**. Māori shall decide which Māori data shall be controlled (tapu) or open (noa) access.

Table 6.3 Principles of Māori Data Sovereignty (Source: Te Mana Raraunga, 2018)

Again, the principles of the mana-mahi framework are present and expanded. Interestingly though, with the exception of kaitiakitanga, each principle has been reframed, articulating broader aims for Māori data sovereignty. Perhaps the most notable shift would be in the reframing of whanaungatanga. Where initially, it had been used to denote the significance of relationships in te ao Māori (Te Mana Raraunga 2016) in the TMR principles of MD-Sov, whanaungatanga now centres the various obligations that emerge when we are in relation with each other, including the preferencing of and accountabilities to collective or group interests above those of individuals. The prioritisation of group interests is highlighted again in the reframing of kotahitanga as collective benefit.

The consistency of principles across the mana-mahi operations framework, the principles of Māori data sovereignty and the Mana Ōrite relationship agreement speaks to the strength of the MD-Sov movement in general. Where concepts have been added and expanded is indicative of the differing intentions of each document and/or relationship. The reframing of tikanga within the documentation is also reflective of the fact that just like the world of data, data sovereignty is living and responding as necessary to broader political, social, and technological shifts and developments.

The ability for tikanga to be dynamic and adapt to the diverse needs of Māori in the data sovereignty space, offers promising prospects for the future, as we head toward an increasingly data-driven world.

In addition to MD-Sov activities listed above, members of Te Pokapū, the executive branch of TMR, have also played critical roles in brokering direct relationships with government agencies. A significant outcome of these combined efforts of Te Mana Raraunga has been a process of policy setting by action. In a political environment characterised by barriers and limitations associated with a slow-moving bureaucracy, government funded entities and large research institutions (namely universities) are increasingly revising their data access policies to align with the principles of Te Tiriti and by extension, MD-Sov. In 2018, the Health Research Council in Aotearoa (HRC) acknowledged existing datasets as taonga and accepted the responsibility that they, alongside HRC mandated ethics committees, have to assist in the assessment of risk in research as well as in reassuring the public that access to the collective taonga that is the IDI is governed according to high ethical standards (Health Research Council of New Zealand [HRC], 2018, p. 61)[33]. Some universities are already signalling a shift towards higher data standards for their institutions. In Taumata Teitei[34] for example, Waipapa Taumata Rau[35], currently Aotearoa's largest research institution (https://www.universitiesnz.ac.nz/universities/university-auckland), indicated an intention to become a 'Māori Data Sovereignty organisation' (p.4). The Ngā Tikanga Paihere Framework (see chapter 5) is a further example of how members of Te Pokapū have worked with Stats NZ and have been involved in the development of Māori data governance mechanisms.

The work of both TMR and the Data Iwi Leaders Group has firmly cemented MD-Sov as a pressing issue within broader sovereignty rights discourses, providing clear pathways for Māori to be involved in setting the agenda for data sovereignty and data governance in Aotearoa New Zealand (Sporle et al., 2021). This is evident in the influence that MD-Sov principles have had on agency responses to data sovereignty issues, some of which are discussed above. These gains

---

[33] HRC is the statutory body responsible for managing the Government's investment in health research, and the closest we have to a centralised authoritative body for ethics in Aotearoa. If the HRC continue to move towards developing an ethical assessment tool for secondary research, this will require institutional ethics committees to update their ethics documentation and will create an assessment requirement for researchers within these institutions to complete.

[34] The University of Auckland's Vision 2030 and strategic plan 2025 https://cdn.auckland.ac.nz/assets/auckland/about-us/the-university/official-publications/strategic-plan/2021-2030/taumata-teitei-vision-2030-and-strategic-plan-2025.pdf

[35] The newly gifted name for the University of Auckland (see Chapter Two: Methodology and Approach).

are significant and encouraging, however, they are by no means the end goal. Currently, the incorporation of MD-Sov principles in data governance is voluntary, and at the discretion of organisations and structures who hold the ‘ownership rights’ over Māori data. As a result, there is no official standard for how MD-Sov might be actualised in non-Māori organisational structures. In this case, one-off aspirational references, to becoming a ‘Māori Data Sovereignty organisation’ (The University of Auckland, 2020, p. 4) though well-intentioned, are essentially goals with no action plan, budget, or measurable milestones. There is also the risk that under this model organisations are left to interpret the principles of Māori data sovereignty for themselves, which may not necessarily align with the goals of Māori data sovereignty. This risk is compounded by the fact that Māori are critically under-represented across the entire data-ecosystem. Further, a critical shortcoming of the models for data governance that have been developed (Ngā Tikanga Paihere, Te Mana o Te Raraunga and the POU) is an underlying assumption is that *all* data is available for analysis and that with the right provisions, can be accessed by *anyone*. Chapter 9 of this thesis – *Whakapapa and access* – will demonstrate that in some cases, data should not be accessible for research, when it is not even available to the people from which it is derived.

Concluding Statements

The opening line of Sophie Pierre’s foreword in ‘Reclaiming Indigenous Governance’ reads

> *If you can remember the taste, you can rebuild the recipe.*

Pierre (2019) goes on to note that the sentiment reflected in the quote above is that, for Indigenous Peoples, including her own people of Ktunaxa, moving forward is a process of looking backward, of learning from our past. A similar sentiment is echoed by Mike Ross in his chapter in ‘Imagining Decolonisation’; using the house as an analogy, Ross (2020) asks:

> If you don’t know what your house looked like, how can you recognise what is different about the colonial house? (p.42)

If, as Indigenous scholars, we are to make grandiose claims about our intentions to develop governance frameworks that are grounded in our own worldviews, it is critical that we know and understand the structures we are working within and what we wish to build. There is an enigmatic sense of terror and liberation that sits heavy in both analogies. On the one hand, it is freeing to think that the structures for Indigenous governance already exist in our past. We are simply adjusting our build to suit the requirements of a modern society; the bones of the house are strong. On the other hand, there is an equally great sense of responsibility that comes with continuing on the legacy of our tūpuna, wanting so badly to do right by our tūpuna and future mokopuna. There is a risk that we could really mess up the recipe, like thinking it will be fine if we replace cornflour with regular flour in Aunty Elna’s famous sponge cake. Sure, it might look the same, but deep down, we know the texture is not right, we have not done her proud, no one wants to eat the cake.

Critical to the strength of any structure are the foundations. The question then is, what forms the foundation of a Māori data governance structure? The following three case study chapters offer some insight in to how tapu, tiakitanga and whakapapa are critical as a basis for MD-Sov and by extension Māori data governance.

Chapter Seven - Case Study One: Privacy and Covid 19

The following chapter considers how the COVID-19 pandemic response is stretching existing norms around data privacy in Aotearoa. Privacy of the individual is reified in the legislation of settler colonial states as an essential civil liberty, and in western legal structures it is the basis upon which many other rights are built. Despite this, privacy is not a right universally afforded to everybody, resulting in differential experiences of privacy, even within the context of a nation-state. In fact, access to privacy is a feature of social stratification where those in positions of power have far greater access to privacy than those who are not. The forthcoming chapter interrogates privacy as a concept. In particular, this case study will consider the ways that privacy interacts with structurally produced vulnerability, the primary assertion being that vulnerability reimagines privacy as an asset to trade for access. Access to welfare, access to support, access to safety, and access to health are all premised on the willingness of individuals to relinquish their privacy and be open to scrutiny. This case study also considers the ways in which a focus on individual level privacy renders invisible important issues associated with notions of collective forms of privacy. The COVID-19 pandemic presents an interesting context within which to closely interrogate privacy as a concept.

Responding to the COVID-19 pandemic has necessitated radical shifts in the way that we understand the parameters of data privacy in both global and domestic settings. In a relatively short period of time, we have seen the deployment of new systems of surveillance, such as contact tracing apps and vaccine pass mandates in Aotearoa, as well as the extension of existing systems of heightened police presence to monitor compliance in environments with extended restrictions. These represent more formal, politically deployed systems of surveillance, but there are also more informal examples including increased media scrutiny of particular groups (discussed below) prompting higher levels of community surveillance. The proliferation of surveillance and the resultant data generation is argued to be necessary for informing public health interventions and controls, some of which are quite restrictive and intrusive. This case study reflects on the limitations of the developing discourse around data collection and privacy for Māori, now and into the future. Central to this case study is a consideration of the entanglement between trust and privacy in generating buy-in and ultimately compliance amongst the Aotearoa New Zealand public, in particular how narratives of ‘trust’ and community or ‘team effort’ have been powerful in reframing surveillance and data collection as a necessary process for keeping the public ‘safe’. Threaded throughout this discussion is a broader set of questions around the legitimacy of ‘trust’ as the basis of our willingness as Māori to offer up our lived experiences into systems of surveillance.

On surveillance, significant political events can alter the way that we understand the limits of privacy as individuals and as members of communities. Holvast (2007) offers the example of 9/11 in the USA where, after the fact, it became accepted practice for passenger boarding information to be used by government to monitor supposed potential terror risks (Kuehn, 2016). Aotearoa New Zealand was amongst the many (mostly Anglo) nations who followed the United Nations resolutions and passed the Terrorism Suppression Act (Jackson, 2007). The 'War on Terror' became popularised in the language of journalism globally as nations around the world were urged to increase 'security measures' to protect against the threat of terrorism.

> While the 'war' may be over in a rhetorical sense, fighting terrorism continues to be the primary justification for Five Eyes mass surveillance, and for relaxing the old intercept rules and normalising the expansion and intensification of mass surveillance to encompass new social terrains. (Kuehn, 2016, p. 45)

In these cases, sudden events can be the impetus for a re-evaluation of privacy where the right itself is not contested, but the levels of privacy we can be assured are renegotiated (Arnold, 2015; Holvast, 2007). What differentiates COVID-19 from other significant political events like 9/11, is that the disease itself is non-discriminatory, meaning that the expectation of compliance with regulatory measures – and resultant limitations to privacy – is technically universal. The impact and spread of disease is, however, differential due to the socially patterned nature of factors that affect both the spread and the ability to follow public health recommendations, so compliance measures that apply to positive cases will be disparate in their impact.

While Māori and other Indigenous populations have experienced ongoing issues with (surrendering) privacy and increased surveillance since colonial invasion, this discussion is both timely and critical as Government-initiated responses to the global COVID-19 pandemic, like the extension of systems of surveillance in health, call for more detailed information from their citizenry. Of significant concern is that COVID-19 is a disease that has expanded and mutated at an accelerated pace, requiring governments globally to make decisions in rapid response mode, based on the information they have on hand. Further, in situations of crisis, generally accepted legal conventions, like the sanctity of individual privacy are often side-lined in favour of public health and safety. This chapter reveals that under ordinary circumstances, for Indigenous Peoples in particular, the sanctity of individual privacy is a fallacy anyway. Importantly, any models developed under conditions of 'scandal and response' have historically not served minoritised populations generally, and in the context of Aotearoa, Māori specifically (West-McGruer, 2020). Consider for example, the development of institutional ethics processes highlighted in the literature review chapter of this thesis. In this case, processes developed to protect people from harm in research have not always protected people equally or equitably. We are now in a situation where it is widely accepted that Māori are a critically over-researched and over-surveilled population, with very little to show for our engagement. While COVID-19 is not a 'scandal' per se, it is a crisis that has necessitated a prompt response. Unfortunately, what the pandemic has highlighted, is that as a nation, we have not learnt from our history and there are no robust governance systems, ethical frameworks, or regulatory mechanisms in place to protect people and their data. Equally as concerning is that these laws, regulations, and policies, which have been developed in response to the requirements of the time, were often passed under conditions of urgency, without the usual processes or timeframes around public consultation.

Theorising Privacy

> The good news about privacy is that eighty-four percent of us are concerned about privacy. The bad news is that we do not know what we mean. (Holvast, 2007, p. 738)

Privacy is, as Penk (2010) puts it, a value-laden concept malleable to cultural, historical, and societal influences. It is best understood, not as a single idea, but a bundle of concepts that includes "…secrecy, anonymity, solitude, confidentiality, freedom from unwanted surveillance, freedom from discrimination, and the opposite of public life and public interest" (Penk, 2010, p. 2). Privacy, as a fundamental human right, is articulated in Article 12 of the Universal Declaration of Human Rights [UDHR] (1948) and affirmed in Article 17 of the International Covenant on Civil and Political Rights (ICCPR). Both the Declaration and the Convention reference the rights of individuals to be protected from "…arbitrary interference with his privacy, family, home or correspondence," and emphasise the "right to protection of the law against such interference or attacks" (New Zealand Human Rights Commission, 2018). It is worthwhile noting that the Universal Declaration of Human Rights was created in the wake of the atrocities of World War Two, where there was a global conscientisation of the way that personal information could be used to commit heinous crimes. It was at this point (after 1948) where there was a significant increase in both the theorising and legislating around privacy. The legacy of these atrocities is still evident in several European countries where there continues to be no data collected on ethnicity (Villarroel et al., 2019). Though this is seen as a protective measure, it makes it difficult to measure the impact of discrimination based on race and ethnicity in these countries (Villarroel et al., 2019).

Prior to the formal codification of privacy as a fundamental human right in the UHDR, there were attempts to theorise what falls inside and outside of the concept of privacy by sociologists, philosophers, legal scholars, as well as scholars from other fields (Solove, 2009). The earliest definition of privacy as we understand it today came from the work of American lawyers Warren and Brandeius who, in 1891, defined the concept as 'the right to be let alone' (Holvast, 2007; Solove, 2009). Holvast (2007) suggests that humans have always had a need for privacy, particularly on matters of a personal or intimate nature. However, this notion is contextual and contested within spaces of various cultural difference, particularly when considering understandings of how personal, intimate, and community are practised. Holvast (2007) considers that privacy is linked to feelings of shame and notes that the earliest example of the privacy-shame dynamic, within a Judaic-Christian setting, comes from the biblical story of Adam and Eve (Holvast, 2007). The type of privacy being referred to here may be broadly understood as relational privacy, or the ability to control, through various actions, who has access to your body, home, or thoughts.

Another important dimension of privacy often discussed in the literature is informational and is related to the collection, storage, and processing of personal data (Holvast, 2007). Perhaps the most well-known definition of informational privacy comes from the work of Westin (1976), where he states that:

> Privacy is the claim of individuals, groups or institutions to determine for themselves when, how, and to what extent information about them is communicated to others. Viewed in terms of the relation of the individual to social participation, privacy is the voluntary and temporary withdrawal of a person from the general society through physical or psychological means, either in a state of solitude or small-group intimacy or, when among larger groups, in a condition of anonymity or reserve. The individual's desire for privacy is never absolute since participation in society is an equally powerful desire. Thus, each individual is continually engaged in a personal adjustment process in which he balances the desire for privacy with the desire for disclosure and communication of himself to others, in light of the environmental conditions and social norms set by the society in which he lives. The individual does so in the face of pressures from the curiosity of others and from the processes of surveillance that every society sets in order to enforce its social norms (Westin 1967 as cited by Austin, 2019, p.58-59).

The first half of Westin's definition highlights the right of an individual to be self-determining and to take action by withdrawal, to assure that their privacy is maintained. The second half of Westin's definition speaks to the relational elements of privacy – that our right to privacy makes sense only in respect to our participation or belonging within society. The core tenet of Westin's definition though is control. In order to feel secure in our right to privacy, individuals require a certain level of control over information relevant to us.

In addition to the theoretical development of privacy as a concept, there were also examples of domestic policy shifts that had the effect of increasing individual privacy. The introduction of the secret ballot in Aotearoa New Zealand in 1871 is one such example. Importantly, privacy was not the primary driver in implementing the secret ballot. Rather, secret voting was seen to reinforce the individual right to vote, and to do so without fear of intimidation. In this case, privacy was a biproduct of this policy, not its purpose.

As early ratifiers of the ICCPR in 1978, Aotearoa New Zealand became legally bound to uphold the Covenant and ensure that its legislative levers aligned and were consistent with the Covenant. As such the ICCPR is referenced in the Privacy Act 2020, which states that:

> The purpose of this Act is to promote and protect individual’s privacy by –
>
> (a) Providing a framework for protecting an individual’s right to privacy of personal information, including the right of an individual to access their personal information, while recognising that other rights and interests may at times also need to be taken into account; an
> (b) Giving effect to internationally recognised privacy obligations and standards in relation to privacy of personal information, including the OECD Guidelines and the International Covenant on Civil and Political Rights.

Here, the language of the Act clearly identifies privacy as a right afforded to individuals and does not extend the application of the right to collectives or groups. Further, the Act is not designed to protect individuals from having to give over information that would otherwise be considered private, and instead creates legal conditions around the protection of information once handed over.

Despite the formalisation of privacy as a legal concept in 1891, as a fundamental human right in 1948, as well as the expansion of relevant legislation in Aotearoa New Zealand since 1978, this has not resulted in any conceptual clarity around what privacy is or what it protects. One potential reason for this is that there is a clear and significant link between privacy and the development of technology, particularly technologies that have the capacity to increase the levels of surveillance in society. Therefore, as technologies develop in speed, capacity and capability, the parameters of privacy are stretched, requiring a reimagining of the concept.

Māori Conceptualisations of Privacy

The complexities associated with theorising privacy are present and expanded when we consider how Māori conceptualise and experience privacy. A pressing issue for Māori and indeed other Indigenous Peoples, in relation to privacy involves the inadequacy of current privacy laws for the protection of privacy at the group level (GIDA, 2019). There is a presumption in a western legal setting that protecting individual privacy will, by extension, protect groups. However, there are group harms that end up impacting people at the individual level, even when their privacy is technically secure.

> Where anonymised data subjects are grouped according to geographical, socioeconomic, ethnic or other characteristics, the anonymisation of individuals matters little if outcomes affect the groups to which they belong (Mittelstadt & Floridi, 2016, p. 318)

Even when the data is anonymised, the group-level harms associated with discrimination and stigmatisation within the system continue to present risk for some groups (Mittelstadt & Floridi, 2016). We saw this in the US (in Albuquerque specifically) when a COVID-19 hospital policy used zip code data to racially profile pregnant Native American women (Carroll et al., 2021; Furlow, 2020). The zip code data had been made public on an online dashboard and identified areas that had cases of COVID-19 in the community (Furlow, 2020). Expectant mothers who were socially prescribed or assumed to be Native American by the hospital staff had their zip codes cross-referenced with the database and if there was a match to a listed zip code, she would be designated as a “person under investigation” (Furlow, 2020). The policy exposed these women to additional COVID-19 screening checks, including COVID testing even when there was not an elevated risk that they had been exposed to the disease (Carroll et al., 2021; Furlow, 2020). In some cases, when negative tests weren’t returned before the baby was born, mothers were separated from their new-born babies during the important post-partum bonding stage (Carroll et al., 2021; Furlow, 2020). A subsequent section in this chapter also highlights how racialised media reporting around COVID-19 outbreaks Aotearoa, limited privacy for Māori and Pasifika and exposed communities and individuals to heightened levels of racism.

Despite a relative widespread recognition that individual privacy laws are inadequate, collective privacy or group privacy is still poorly defined. In canvassing the literature, it was immediately apparent that privacy is not a concept that has been closely interrogated by Māori scholars on its own. Though there is a burgeoning body of scholarship concerned with highlighting the limitations of individual privacy, there is virtually no literature that looks specifically at what privacy means for Māori. The paucity of theorising in this area is an indication that ‘privacy’ is not an intrinsic value for Māori. There are however analogous Māori concepts that are useful to draw from when thinking about privacy. In particular, tapu and associated tikanga practices like rāhui are useful starting points for considering a Māori conceptualisation of privacy.

The following section draws upon the work of prominent Māori legal scholars such as Khylee Quince (2010) and Jacinta Ruru (2016), as well as Māori academics and tikanga experts (Macfarlane et al., 2020; Mead, 2003; Tomas, 2006) to consider how elements of the Māori concept of tapu may share similarities Pākehā understandings of the function of privacy. Through this discussion, key distinctions between tapu and privacy are also noted. Finally, rāhui as a particular practice for the preservation of tapu is also considered. In the broadest sense, tapu refers to that which is sacred, prohibited, or unclean (Quince, 2010). Tapu is intimately connected with the Māori concept of mana (prestige) and mauri (life force) (Mead, 2003). Concerning how tapu applies to people, Macfarlane et al (2020) define it as a:

> …cultural marker […] concerned with the sanctity of the person; the special attributes that people are born with that contribute to defining one’s place in time, locality, whānau and society (p. 200).

The sanctity of the person, or te tapu o te tangata is connected to the notion of respect for an individual (Mead, 2003, p. 61) as well as notions of self-worth and dignity (Quince, 2010). Preserving the sanctity of and respect for the individual seems to sit in contrast with the broader ongoing emphasis on the rights of the collective in Māori societies. Mead (2003) considers this tension, asking “can one be an individual in Māori society?” (Mead, 2003, p. 58). In answering, Mead (2003) cites the work of Firth (1959) who noted that in:

> …rivalry between persons in work, the insistence on utu or an equivalence for gifts and service, quarrels over land and property rights of a personal kind, theft of valuables, gluttonous consumption of food, idleness and the like indicate a definite sphere of action determined primarily by individual interests (Firth, 1959 as cited by Mead, 2003, p. 59)

This, Mead (2003) suggests, is indicative of the fact that it is possible to be an individual in Māori society. In a similar vein, Tomas (2006) reflects on the role of tapu in pre-colonial contexts noting that “in a society where group welfare often overrode individual concerns, the idea of inherent tapu served an important purpose. It enabled value to be given to privacy of the person” (p. 97). This is probably where we see the most congruence between the western concept of privacy and Māori ideas of tapu.

In research contexts, MacFarlane and colleagues assert that the recognition and preservation of a person’s tapu is not hinged on the Eurocentric notion of ensuring individual autonomy but is always about protecting the sanctity of the individual (Macfarlane et al., 2020). So, though tapu – in the contexts discussed here – is, like privacy, primarily concerned with individual interests, these interests are still located within the context of whānau and whakapapa (Mead, 2003).

There is key distinction here between the tapu of a person and the designation of an object, resource, or place as tapu, particularly when tapu is incorporated into legal structures. This is what Quince (2010) refers to as intrinsic and non-intrinsic tapu. People, land and natural resources such as water are thought to have intrinsic tapu because of their connection and belonging to ngā Atua (the Gods). This kind of tapu is permanent, inviolable, and is of spiritual origin (Quince, 2010). Specific forms of tapu can also be assigned temporarily to an object by human proclamation, and these temporary designations fall under non-intrinsic tapu. When an object is considered tapu, the implication is that it must be actively protected or managed (Hudson, Beaton, et al., 2016). One way of achieving this is seen in the tikanga of rāhui.

Rāhui refers to the prohibition of a specific human activity from occurring or continuing (Mead, 2003). Rāhui are described by Mead (2003, p.193) as a “creative tool” that can be applied in a broad range of situations for a variety of reasons[36]. In the New Zealand legislative context, rāhui have functioned as a means of regulating human activities for the purpose of sustaining resources and restoring productivity to the land (Ruru & Wheen, 2016). There are also occasions where rāhui have been instated informally to preserve the mauri of an area. We saw this when a temporary rāhui was placed in the 27,720 hectares of the Waitakere ranges to help stop the spread of kauri dieback disease that is attacking the native kauri tree (https://waitakererahui.org.nz/). The purpose of rāhui is to protect the intrinsic tapu of the resource itself as well as the intrinsic tapu of the communities that rely upon it (Quince, 2010; Tomas, 2006).

When Aotearoa New Zealand went into level four lockdown in response to the COVID-19 pandemic, the Ministry of Health published specific guidelines for tangihanga (traditional Māori funeral) that were communicated out to iwi with the title "*Covid-19 – Kua rāhui te motu"* (Ministry of Health, 2020). Pihama and Lipsham (2020) also note how Māori communities took it upon themselves to initiate rāhui as a means of protection from COVID-19. Examples will be reflected on later in this chapter, but very briefly, these included the instatement of protective boundaries and iwi checkpoints to restrict movement in and out of rural communities where the disease would have a greater impact on the health of Māori (Manuirirangi & Jarman, 2021; Milne, 2020; Pihama & Lipsham, 2020; Rewi & Hastle, 2021).

Rāhui, discussed here as a tikanga practice and as a feature of our legal system, are often applied for the purposes of protection and ensuring the ongoing sustainability of natural resources. In more recent examples with COVID-19, rāhui have been instated to protect our whakapapa. With this in mind, if we consider rāhui as a tikanga for the active protection of tapu, it becomes evident that the sanctity of the individual exists in relation to that individual's relationships within their whakapapa and as part of their environment. This relational element of tapu is key in distinguishing it from the western notion of privacy. The discussion in this chapter shifts back now to consider how western structures continue to privilege individual privacy. Further, it considers that while privacy is considered a civil liberty and a fundamental human right, it is not a right experienced evenly by everyone.

Privacy in Administrative Spaces

I begin this section with a personal narrative. I want to tell a story about how COVID-19 created the conditions that would make my privacy an asset for trade. In a time where I was most

---

[36] McCormack (2011) explains: "Typically, Māori draw a distinction between different types of rāhui which have different purposes. In the literature these are categorised as follows: to serve conservational ends, when a death occurs and to advance political objectives". (p.44)

vulnerable, I was also the least protected by the most basic of civil liberties. My story is important to this case study because it takes a concept that is often theorised in quite abstract ways and personalises it, teasing out the limitations of ‘privacy’ and its attachment to notions of trust and choice. It very clearly demonstrates how imbalances in the distribution of power also impact our access to privacy, as well as how easily vulnerability opens us up to surveillance. My pūrākau is important because I am a Māori woman, a māmā, a tamahine, a mokopuna, and a future tupuna. Though my story belongs to me, it also belongs to those before me, after me and next to me. In this sense, it is a story of how Māori data sovereignty is stripped away from our communities on a daily basis. It is also an example of the reassertion of Māori data sovereignty, and the challenges and opportunities for healing that come with this act.

My ability to engage in doctoral study was largely facilitated through my access to a scholarship. I have relied on the income from my scholarship to support me through my studies and have supplemented this income with work as well as support from government schemes such as tax credits[37]. The precarious nature of employment in institutional settings has meant I have lived with heightened levels of stress through the duration of my doctoral studies. The COVID-19 pandemic significantly impacted the progress of my research and I had to apply for an extension to my doctoral scholarship. Included below is the justification I submitted to the University to plead my case for an extension of my scholarship to allow me to complete my doctoral studies:

> *When I started my PhD, I was in a relatively secure position with my whānau and mahi. I was able, in the first year, to maintain good progress with my research, including being an active member of relevant research networks, contributing to research publications, and working on my PYR documentation[38].*
>
> *Following the successful completion of my PYR, I have experienced a series of significant and traumatic life events which have impacted the progress of my studies. These events include, but are not limited to, separation from my spouse and father of my daughter, family illness and death, relationship [involving] intimate partner violence, miscarriage, PTSD, and anxiety, all in the context of a global pandemic.*
>
> *Aside from the immediate trauma and suffering that these events have caused, there have been related ongoing issues which have had a continued effect on my ability to focus on my research.*
>
> *For example, separation from my spouse has meant that I have had to adjust to co-parenting, while balancing mahi and my studies - this has been particularly challenging through the various lockdowns we have had as a result of the COVID-19 pandemic as I have also had to take on the role of teacher for Amelia. It has also meant that I have lost a significant source of financial support, and as the scholarship is not enough to cover my rent, I have had to spend time finding ways to support myself and my daughter financially. Family illness has required me to be available to support whānau. The PTSD I have experienced*

---

[37] https://www.ird.govt.nz/working-for-families/about

[38] Provisional year review

> *following my miscarriage has been debilitating at times and has limited my capacity to actively engage in the research process.*
>
> *Despite these challenges, I have continued to maintain a positive outlook that I am capable of completing my PhD and have continued to work, albeit in a limited capacity, on my research. I have started seeking support for my PTSD and have been noticing a significant improvement in my mental health in the past two months. With this in mind, I feel that the additional 6 months of financial support would enable me to focus on getting my PhD done and submitted by December.*

Almost immediately after submitting the extension application, I felt anxious and exposed. I did not know who was going to have access to my application and I was worried about the potential that my performance of pain would not be considered enough. As an Indigenous woman, the centring of damage and trauma in my lived experience and the disclosure of pain as a source of legitimacy seems frighteningly natural. Often Indigenous women are required to highlight and expose our trauma in intimate detail in order to be deemed worthy of support we have a right to. Tuck (2009) discusses this de-facto reliance on Indigenous pain as a feature of ‘damage-centred research’, which seeks to convince people of our harm in order to justify reparation. In research contexts, Indigenous Peoples – as subjects – are socialised to “…only speak from that space in the margin that is a sign of deprivation, a wound, an unfulfilled longing. Only speak your pain” (bell hooks, 1990, p.52 as cited by Tuck, 2009, 413). Over time, these discourses of pain have become so dominant and ubiquitous that people can only see Indigenous Peoples through narratives of pain and damage. Though my disclosure was not situated in the same research contexts considered by Tuck, the key elements of documenting pain and loss in order to obtain a particular result were still present. I wanted to produce a feeling of discomfort so confronting to the reader that I would not be questioned or burdened by an expectation to produce evidence deemed sufficient by the University, a state institution that simultaneously positions the state as the coloniser and provider of support and as a healer (Million, 2013). I was desperate to be seen by the institution. And yet, despite being more exposed than ever to the system, I remained paradoxically invisible to it, acutely aware of my positionality as a colonised body.

My invisibility was confirmed and evidenced in the template style institutional response that I received congratulating me on securing my extension. In any other circumstance, if a person disclosed to you what is detailed in my application above, would your first response be to congratulate them? I felt that no one even read my application, which prompted me to wonder: how do we, at the institutional and individual level, determine what is sufficient or insufficient disclosure to affect a result? How does this influence what we keep private and what we share in particular situations? The notion of willingness to disclose is also a point worth questioning here. The commodification of vulnerability and trauma and the trading of privacy for access is not a new narrative and is not unique to me. Privacy has become subsumed by market logic (Arora, 2019, p. 367) and this is blaringly evident in the context of the welfare state.

The theorising of privacy as a basic civil liberty is called into question when we consider the notion of privacy in the context of administrative spaces such as social welfare. Social welfare in Aotearoa New Zealand is, in theory, available to support people who require assistance from the state. All citizens and residents are eligible to apply for benefits and will receive support if they meet certain criteria and conditions. Accessing social assistance is often the outcome of a traumatic or difficult life event, for example the end of an intimate relationship, life-threatening illness, or needing to care for whānau including tamariki, parents, as well as members of extended family units (McGowan, 2019; Welfare Justice, 2010). These events are often unforeseen or unanticipated, yet there remains a persistent rhetoric that people who are in receipt of welfare are in these positions because of poor life choices (McGowan, 2019; Welfare Justice, 2010). Access to welfare requires that people participate in disclosure and the performance of pain, thus significantly limiting access to relational privacy (Eubanks, 2018).

> “I had to explain my medical conditions to a different case manager every three months, who is a complete stranger. It is totally humiliating” (Welfare Justice, 2010, p. 11)

> “I have dropped off documents at my WINZ office while barely avoiding violent client outbursts, witnessed broken people weeping helplessly without any privacy” (McGowan, 2019)

The performance of pain and disclosure of trauma referred to in my own story, resurface here in the experiences of structurally vulnerable people who need to access welfare. Holvast’s (2007) notion of the privacy-shame dynamic is also at play, with embarrassment, humiliation and helplessness centred as key features of the above experiences. The Welfare Expert Advisory Group [WEAG] ‘*Whakamana Tangata’* Report (2019) also found that high levels of disclosure and the foregoing of privacy were key features of beneficiaries’ experiences, often resulting in [re]traumatisation and poor outcomes. Young people identified as being Not in Education, Employment or Training [NEETs], for example, are expected to produce evidence of a relationship breakdown with their parents in order to access financial assistance in the form of a Youth Payment from the state (WEAG, 2019). Receipt of the Youth Payment requires that young people are partnered with a Youth Service Provider who is responsible for managing the young person’s money and choices (Social Security Act 2018, 2021 MSD), further embedding and normalising the limitation of privacy in young peoples’ lives.

The limitations of relational and informational privacy are also prevalent in the persistent monitoring and surveillance of people in receipt of welfare. Beneficiaries are expected to regularly hand over personal information such as medical records and bank statements as evidence of ongoing need (McGowan, 2019; Nightingale, 2020; WEAG 2019; Welfare Justice, 2010).

> “Caseworkers at WINZ will often demand bank statements so I always feel like WINZ is looking over my shoulder... It’s become part of my life, an everyday buzz in the static of my anxiety” (McGowan, 2019)

In 2017, bank statements were used in court to pursue a single mother for benefit fraud, where the changes in the regularity of ‘food shops’ indicated on the bank statements were presented as evidence of indirect financial support from a partner (*Benefits Review Committee v XXXX*, 2017). Where MSD are unable to acquire this information from welfare recipients directly, they are legally supported to bypass individuals and obtain information from third party providers (*Social Security Act 2018*, 2021). In 2019, an inquiry conducted by the Office of the Privacy Commissioner (2019a) found that MSD had “...systematically misused its investigatory powers while pursuing benefit fraud, unjustifiably intruding on the privacy of many beneficiaries” (Office of the Privacy Commissioner [OCP], 2019b). The Inquiry process involved OCP interviewing beneficiaries who had been subjected to the invasive fraud investigation process and found that MSD had been using its:

> …powers to collect large amounts of highly sensitive information about beneficiaries from third parties without approaching those beneficiaries first. Information collected included but was not limited to, text message content, domestic violence and other Police records, banking records, and billing information from a range of providers (OCP 2019a, p. 4)

In one example MSD had acquired an intimate picture shared by an individual through a third-party telecommunications provider and presented the image in the context of an investigation seeking an explanation (Nightingale, 2020). In other examples, expecting mothers have been questioned around the fathers of unborn babies. The blurring of lines between Westin’s definition of informational privacy and Holvast’s conceptualisation of relational privacy are evident. The same legal structure that purports to protect individuals from “arbitrary interference with his privacy, family, home or correspondence” (*Privacy Act* 2020) simultaneously supports the commodification of the privacy of structurally vulnerable citizens and residents.

‘Poor choices’ and the notion of ‘welfare dependency’ have become persistent in the institutional languaging around our social services sector in Aotearoa New Zealand (WEAG, 2019; Welfare Justice, 2010), with people receiving welfare framed in policy settings as ‘problems’ to be solved. The institutional languaging of ‘welfare dependency’ has then been reframed in the public over decades as ‘dole-bludging’, with media outlets frequently drawing out high-profile cases of bad behaviour that have the impact of tarring everyone with the same brush (Welfare Justice, 2010). The quotes below are from news media articles and are indicative of the way that the accumulation of public rhetoric stigmatises people and has real life impacts:

> “I am sick of being called a parasite, dole bludger or liability to this country’s future when all I need is a little help.” (Hart, 2015)

> “Beneficiaries are being stereotyped as bludgers, parasites, lazy, selfish, that we all neglect our kids and would rather spend money on drugs and alcohol” (Yates, 2012)

Though the issues with welfare systems mentioned above and the stigma indicated in the quotes pre-date the COVID-19 pandemic, they are important to include here for two reasons. First, because they speak to pre-existing assumptions about who is afforded the right to privacy in society. COVID-19 has exacerbated the vulnerability of some groups and therefore exposed people to greater levels of surveillance and scrutiny than they were exposed to prior. Importantly, structurally vulnerable communities are already framed in the public mind as having less rights to privacy because their lives are supposedly ‘funded by the taxpayer’. When you then add to this the need to respond to a global pandemic, it becomes harder to challenge invasions of privacy, because public health concerns trump all other concerns. Second, in the context of COVID-19, in a similar way to how media reporting on welfare in Aotearoa New Zealand has produced adverse outcomes for recipients, the way that COVID-19 reporting has occurred has adversely impacted communities, with Māori, Pacific and Asian communities noting heightened levels of racism since the first lockdown in Aotearoa New Zealand (Nielson, 2021; Thaker, 2021). What we see then is a clear example of how an over-emphasis on maintaining the privacy of individuals fails to account for the potential consequences of diminished privacy at the group/community level. These issues are discussed in greater detail in the next section.

COVID-19: Stretching the Parameters of Privacy

Data – including real-time data and pre-existing datasets – has been framed as a critical resource in the fight against COVID-19. Health data has been used for monitoring the spread of the disease, as well as modelling the impact of various intervention options. Existing health data has also been used to inform the development of algorithmic tools to support decision making in the event that hospital systems become overwhelmed (discussed further in chapter eight). The public is also regularly exposed to real-time (or close to real-time) data around prevalence rates of the disease, locations of interest, and more recently vaccination uptake.

There are also data-generating activities that have increased in the context of COVID-19, where the production of data is not the purpose but the biproduct of an action. Where our physical movements have been largely restricted – as they were in alert levels 3 and 4 in Aotearoa[39] – people were forced to transition to online modes of communication for employment, education, and socialising. Online communication services like Zoom, Facebook Messenger, Microsoft Teams, and Skype for Business (among others) became important tools for maintaining connections and carrying out day to day activities like exercise. For Māori, there was also the use of technology to

---

[39] https://covid19.govt.nz/about-our-covid-19-response/history-of-the-covid-19-alert-system/#about-the-covid-19-alert-system

connect during critical times, such as for tangihanga (digital.govt.nz, 2021). There was also increased reliance on online platforms for things like grocery shopping, as well as accessing necessities like heaters and warm clothes during winter months. Digital technologies were critical for supporting some form of continuity, but this shift was not without its risks.

COVID-19 and the subsequent reliance on digital connectivity for even basic tasks also highlighted how significant digital inclusion is for wellbeing (digital.govt.nz, 2021). When Aotearoa New Zealand first went into lockdown in March of 2020, it required everyone to shift online. In this sense as a 'team of five million' there was a shared experience of being 'in this together'. However, the impact of this shared experience was differential, particularly in circumstances where digital exclusion is an issue. A 'digitally included person' was defined in 2017 in a report to New Zealand's Ministry of Business, Innovation and Employment [MBIE] as:

> …someone who has access to affordable and accessible digital services at a time and place convenient to them, as well as the motivation, skills, and trust to use the internet to pursue and realise meaningful social and economic outcomes (Digital Inclusion Research Group [DIRG], 2017, p. 5)

Using that definition as a baseline, the most digitally excluded groups were identified as "adults with disabilities, children with special needs, Pasifika, Māori, senior citizens, people from low socio-economic backgrounds and those living in regions or communities with low internet uptake rates" (DIRG 2017, p. 8). Again, in 2019 a digital inclusion report from Motu identified Māori as being disproportionately represented among the most digitally excluded groups with around 12.23% of Māori noting no internet access compared to 8.89% of Pākehā (Grimes & White, 2019, p. 21). Finally, in 2020, digital.govt.nz reported that Māori continued to be adversely impacted by digital exclusion with many Māori citing affordable internet and device access as key barriers to inclusion (digital.govt.nz, 2021).

What is evident across the three reports referenced here is that digital exclusion itself is not a product of the COVID-19 pandemic. Limited access to internet and devices for connectivity have been ongoing concerns for Māori. There was, however, a drastic shift from a gradual reliance on digital technologies over time, to a dependence on them which was brought about by the pandemic. Given what we know about digital exclusion, there is significant cause for concern when we consider the potential impacts this shift is having in terms of access to education and employment outcomes for Māori[40]. Further, there are additional concerns regarding privacy that are not captured in the reports mentioned above. When we shifted the delivery of primary, secondary, and tertiary education online, there was an immediate blurring of lines between school and home, where

---

[40] It is important to note that there was an effort by the Ministry of Education [MoE] to bridge the digital divide by providing devices and internet access to families in need. More detailed information on this role out is available here - https://www.digital.govt.nz/showcase/tackling-the-digital-divide-during-covid-19/

teachers and fellow classmates were brought into our personal living space (Enari & Matapo, 2020; Gillon et al., 2020). This gives rise to a new range of privacy concerns associated with the lack of distinction between public and private spheres. Given the contemporaneous nature of COVID-19, there are currently no formal research reports that indicate the potential impact of this blurring.

In general terms, individual privacy continues to be protected under the Privacy Act 2020 in Aotearoa. There are, however, provisions within the Act that allow for a more permissive approach to information sharing than would otherwise be tolerated outside of the context of the pandemic. Principle 10(f) specifically, states that

> 10) An agency that holds personal information that was obtained in connection with one purpose may not use the information for any other purpose unless the agency believes, on reasonable grounds, -
>   f) that the use of the information for that other purpose is necessary to prevent or lessen a serious threat to –
>   i) public health or public safety; or
>   ii) the life or health of the individual concerned or another individual.

The ‘Serious Threat to Public Health’ exception in the Privacy Act 2020 permits the collection use and disclosure of personal information, where it is deemed necessary for public health and safety (Office of the Privacy Commissioner [OCP], 2020). Questions of whose health and whose safety are important and are discussed here.

Our ‘team of five million’[41] are regularly reminded of our collective responsibility to be active in the fight against COVID-19; a significant contribution to this ‘effort’ has been through recording our physical movements using contact tracing apps. Contact tracing is the process whereby people who have been exposed to an infectious case are identified and isolated to track the potential spread of the disease and minimise the risk of widespread transmission (Verrall, 2020). Contact-tracing has been recommended by the World Health Organisation and the use of tracing apps has been a key component of successful COVID control in countries like Singapore, South Korea, and Aotearoa. Where Aotearoa New Zealand has made the use of contact tracing apps a voluntary (but strongly encouraged) feature of their response, Singapore has introduced strict mandatory contact-tracing (BBC Asia, 2020; Sato, 2021). From an intervention perspective, this mode of case-identification has been successful in supporting efforts to identify potential cases early, test and limit the transmission of the disease. The long-term impact on privacy, however, is still to be determined. Namely because, there is no clear indication of when the data will be ‘forgotten’, or to what extent the data will be made available for reasons other than contact tracing. In Singapore, data from the

---

[41] The team of five million was a unifying phrase used to refer to the New Zealand public by the Prime Minister to denote our collective responsibility to take action against COVID-19. For more detailed information see https://doi.org/10.1016/j.ssaho.2021.100209

mandatory tracing system has been made accessible to the police for criminal investigations (Sato, 2021) and in one case, tracing data was paired with "…parking records, credit card statements, call records and CCTV…" (BBC Asia, 2020), resulting in the prosecution of a 65-year-old woman who had not complied with contact tracing laws.

Nothing of this nature has been reported publicly in the Aotearoa New Zealand context, however information derived from contact-tracing has been made publicly available in ways that have been harmful for communities. In August 2020 for example the Congregational Christian Church of Samoa were the centre of media attention when they were labelled as the centre of a 'cluster'. Similarly in 2021, with the Delta variant outbreak in Auckland, the Assemblies of God Church of Samoa was outed as the epicentre of the largest Auckland cluster. In both instances, Pasifika communities were subsequently exposed to online racial hatred (Kerr, 2021; Pickering-Martin, 2020, 2021; Samasoni, 2021). In her commentary and analysis of COVID-19 and racism, Pickering-Martin (2021) noted that amidst the Delta variant outbreak, where the index case was Pākehā man, there were no media reports that commented on his ethnicity. Contrastingly, when the outbreak began effecting a Pacific community, every related news report included 'Samoan Church' in the title. Differences were also present in the public responses where the 'Devonport man' was praised as a 'legend' and 'top lad' for being tested while Pasifika communities were labelled as 'coconuts' – a derogatory term used to refer to people from the Pacific Islands – and blamed for 'breaching big' on COVID-19 restrictions (Pickering-Martin, 2021). In another example, also during the Delta outbreak, when children of a remand prisoner contracted COVID, media reporting named the high school they attended and provided details regarding the prison their father had been detained in as well as elements of his electronic monitoring bail conditions (RNZ, 2021). Importantly, the whānau impacted came from a very small community and the children were attending a small school. The media report not only outed their COVID status, but the prisoner status of their father. Finally, in September 2020, the full names and iwi affiliations of two brothers who had contracted the coronavirus and subsequently passed away were published in an online media report (RNZ, 2020b). This sits in stark contrast with reporting of the first death from COVID-19 in Aotearoa New Zealand in March 2020, of a "…woman in her seventies" (RNZ, 2020a) and the youngest death of a "…person in their 30s" (Xia, 2021) in December 2021. In these cases, no further information was provided in respect of the privacy of the individuals and their families (RNZ, 2020a; Xia, 2021). Tuhiwai-Smith (2020) notes that:

> The power of narration is that ordinary members of the public have been immersed in the story and taken ownership of its messages. The story's official legitimacy, aided by a government with emergency powers, harnesses the public in ways that foster compliance while masking inequities (p.375)

These examples demonstrate how ethnicity and 'race' have structured access to privacy in the context of COVID-19.

Analysis of a national survey conducted in early 2021 found that 41% of participants felt that incidents of racism had increased during the COVID-19 pandemic (Thaker, 2021). Reports of racism were skewed towards Māori, Pasifika, and people of Asian descent. This also aligns with research conducted by the Human Rights Commission that revealed that Māori, referred to in the report as Tangata Whenua, along with Chinese communities reported the highest rates of discrimination since the start of COVID-19 (Nielson, 2021).

It is worthwhile reiterating that there is a genuine need for data, including good quality ethnicity data not only as part of the public health response, but also as part of the broader national recovery response (McLeod et al., 2020). In fact, Te Rōpū Whakakaupapa Urutā assert that access to information for Māori is essential for ensuring that the mana and authority of whānau, hapū, Iwi and Māori communities is upheld. Not least because good quality datasets can be used to inform how Māori can allocate resources to support Māori interests at this time, but they can also be used to hold the government to account for their actions and equally as important, their inactions (King et al., 2020). Since the beginning of the COVID-19 pandemic, Māori health professionals have continued to hold the government accountable to ensure that Māori are not left behind. It was raised early on that Māori would be at a heightened risk of experiencing worse outcomes if COVID was to enter our communities. We knew this because we remembered the devastation left by the 1918 Influenza Pandemic, where mass graves were filled with Māori dying at seven times the rate of non-Māori (Tuhiwai-Smith, 2020); we knew this because we know that COVID-19 has more severe impacts on people with existing health conditions and Māori experience health inequities in usual (read non-pandemic) circumstances (R. Jones, 2020; King et al., 2020; McLeod et al., 2020; Talamaivao et al., 2020). Modelling suggested that if infected with COVID-19, Māori communities were 2.50 times more likely to require hospital level care than non-Māori (Steyn et al., 2021). This scenario is especially concerning when we consider that Māori in rural communities have limited access to healthcare in general, let alone hospital level care. Despite all this knowledge, the government in Aotearoa New Zealand still needed to be challenged to collect ethnicity data "…reinforcing the idea that in a crisis everything gets set to 'default' and the default setting excludes us" (Tuhiwai-Smith, 2020, p. 373).

Concluding Thoughts

So far, this chapter has considered the limitations of individual data privacy for Māori, and has presented examples to illustrate how privacy, and the protections it purports to offer, are not experienced evenly by all people. This has been somewhat negatively focused and potentially positions Māori as passive agents in the data/privacy pipeline. The concluding section of this chapter flips this narrative to demonstrate how Māori have been actively involved in responding to COVID-19, using data to ensure that communities, not just our own, are kept safe through the pandemic. It is worthwhile noting that, in the forthcoming examples, privacy is not the paramount concern, and is side-lined in favour of community health responses. At face value, it is reasonable to assume that the same issues regarding privacy and consent in western spaces that have been critiqued throughout this chapter could also be present in these examples. There are however significant differences that mean that the potential for harm to occur as a result of limited privacy is differentiated.

When it became apparent that the COVID-19 pandemic would hit Aotearoa, Māori began responding immediately (Te One & Clifford, 2021). Te Rōpū Whakakaupapa Urutā was established to provide information and resources specifically for Māori about COVID-19; Māori statisticians and epidemiologists started working to build an evidence base, demonstrating the potential impact that the disease could have on Māori if it got into our communities (discussed above); online spaces became important sites for maintaining connection and knowledge sharing with terms like 'zui' (zoom hui) becoming a regular part of our lexicon. Digital platforms were also part of our toolkit as Māori tikanga adapted amidst a global pandemic and tangihanga (traditional Māori funerals) went online (Tuhiwai-Smith, 2020; Pihama and Lipsham, 2020).

At a flaxroots level, iwi began enforcing rāhui and utilising databases such as social media and iwi websites to reach out to iwi members to make sure people were safe, healthy and fed. Iwi initiated checkpoints were established on public roads and became a prominent feature of hapū responses in the Taranaki region (Manuirirangi & Jarman, 2021; Pihama & Lipsham, 2020), Murupara (Rewi & Hastle, 2021), Gisborne (Tuhiwai-Smith, 2020), as well as in the far North region of Te Tai Tokerau (Ngapuhi Iwi, 2020). Whakapapa databases also became an important part of iwi responses, with many iwi calling their members to see what the needs were and whether the iwi could respond with resources (Te One & Clifford, 2021), such as food parcels (Kāi Tahu, Tainui, Ngāti Porou, Ngāti Awa, Ngaiterangi), healthcare packs (Milne, 2020) or iwi information packs (Ngaiterangi). An oft referenced driver for these initiatives was the protection of our most vulnerable communities, including our kaumātua (Manuirirangi & Jarman, 2021; Milne, 2020; Pihama & Lipsham, 2020; Rewi & Hastle, 2021).

Above, are examples of active expressions of sovereignty and self-determination (Te One & Clifford, 2021). Tuhiwai Smith (2020) suggests that iwi responses reflect a legacy of courage and strength left to us by our ancestors and were embedded in principles of:

> Collectivity – Acting collaboratively to ensure the wellbeing of the whole. Requiring at times that personal needs of individuals are put aside
>
> Intergenerationality – Seeing ourselves as 'ancestors in the making' and recognising the responsibilities we have to one another. Who do we want to be in the future and how do we want to be regarded?

> Reciprocity – in the radical expressions of love for the people around us and that reciprocity is experienced intergenerationally and collectively.
>
> Creativity – Pooling resources and redistributing according to need.

What we can learn from these principles is that the courage displayed by our tūpuna in the face of epidemics, pandemics, and colonialism is written into our bodies and bones and this data is a gift which can be reimagined as resources of survival and resilience. Knowledge of our abilities as Indigenous Peoples to respond to the needs of our communities more effectively than our national governments is driving the call of Indigenous Peoples globally to be part of the COVID-19 decision making processes (C. C. Austin et al., 2021; Carroll et al., 2021; R. Jones, 2020; King et al., 2020; Kukutai, Clark, et al., 2021; McLeod et al., 2020; Tuhiwai-Smith, 2020). This is the same drive which underscores assertions of Māori data sovereignty rights in the following two case studies.

Chapter Eight - Case Study Two: Trust and Automated Decision Making

Automated decision-making (ADM) is a catch-all term that can be conceptualised to include all the processes involved when an algorithm or artificial intelligence (AI) is mobilised to make a decision, from the collection, processing, modelling, and use of data in decision-making, through to the ways in which machines draw on feedback loops to learn and improve themselves (Araujo et al., 2020). ADMs can be narrowly defined as decisions made through technological means without human involvement; or more broadly as "...the process through which the ever-growing amount - and variety - of personal data are subsequently processed by algorithms, which are then used to make (data-driven) decisions" (Araujo et al., 2020, p. 612). In practice, ADM technologies can work to support human actors in their decision-making – we see this for example in the case of RoC*RoI in Aotearoa New Zealand – and ADMs can also be fully automated and designed to make decisions on behalf of an organisation without any human involvement – similar to what we see in the algorithm utilised by ACC[42]. In theory, the former model of decision-making support is meant to give greater agency to human actors by having people make the final actionable decision.

The purpose of this case study is to unpack the logics that sit behind the development of algorithms and machine learning systems. It does so first by presenting four examples of operational algorithms either currently in use, in development or abandoned after pilot, in Aotearoa. The purpose of these examples is not to interrogate the technological design of the algorithms themselves, but to consider how each ADM contributes to embedding existing power relations in Aotearoa. It is important to remember that ADMs, including algorithms and artificial intelligence, do not work autonomously. These technologies are created by human actors and are therefore encoded with human intentions, embodying the social values of their creators (Lindgren & Holmström, 2020). The social intentionality set within these new and emerging technologies mean that ADMs should be examined as sites of power. Further, while there are certainly many potential benefits to using ADM, there is also significant potential for these technologies to (re)produce harm

---

[42] Perhaps one of the more widely known – and less risky – examples of a State-driven ADM in the context of Aotearoa New Zealand is the operational algorithm currently in use by Aotearoa's Accident Compensation Corporation (ACC). Deployed in 2018, ACC's automated claim system relies on two statistical models working in tandem in the assessment of claims (see Gavaghan, 2019 for a more detailed description of the technical aspects of the algorithms). ACC use these algorithms to auto-approve 92% of all general cover claims (Accident Compensation Corporation [ACC], 2020), claims that are eligible for auto-approval, are those which are considered by the system to be straightforward. Prior to the implementation of these ADMs, ACC staff would manually process more than two million claims every year (Gavaghan et al., 2019), meaning decisions could take weeks. The application of this new system has had the benefit of reducing wait times for decisions from weeks down to seconds (Health Informatics New Zealand [HINZ], 2019). In the remaining 8% of claims where the decision is seen to be more complex, like with sensitive claims, these cases are deferred to people who can then complete the process manually.

for Māori, primarily because ADMs rely on the availability of data to inform their processes. As has been highlighted in earlier sections of this research and will be considered further here in this case study, there are grounds for concern among Māori about the quality and partiality of data that presently exists about us within the system, and therefore there are legitimate concerns around the decision-making tools that these datasets inform. This case study will unpack the social assignment of algorithmic decision makers and the data that inform them as neutral in light of the experiences of Māori. It will consider the necessity for public trust in the implementation of automated decision makers, especially in the public sector, maintaining a particular interest in how trust in the State operates among Māori. A focus on trust will allow for the expansion of this discussion into other critical concepts such as transparency, accountability and will open it up for a reconsideration of the notion of a 'social licence' to operate. Māori views on trust and ADMs, including those of Te Mana Raraunga: The Māori Data Sovereignty Network, are also considered with particular emphasis on the ways in which we can (or possibly cannot) see the implementation of the principles of Māori Data Sovereignty.

ADMs and the Health Sector

The use of automated decision makers in the provision of public health services is driven by the claims that ADMs offer the potential for greater efficiency, particularly where there is a high demand for decisions to be made quickly. Further, in clinical settings, where 'either-or' decisions need to be made in the rationing of healthcare, ADMs are purported to be better placed to make fair and unbiased decisions about who might get access to life-saving care and who would be refused. For example, in the face of the healthcare system being overwhelmed by COVID-19 patients requiring ICU beds and ventilator support, the 1000minds decision-support system was configured – in just ten days – to provide prioritisation recommendations for these patients based primarily on clinical criteria (1000 Minds, 2020). According to 1000Minds:

> Clear guidelines and prioritization tools – potentially for integration with existing hospital systems – enable clinicians to more effectively identify patients in most need and likely to benefit treatment, and support clinicians when decisions with difficult ethical implications have to be made (1000 Minds, 2020).

The "…decisions with difficult ethical implications…" being referred to here may be life and death decisions and include judgements about withdrawing critical ICU support from one patient in favour of another (Roy et al., 2021, p. 2). The ADM is designed to take into consideration a range of factors or 'criteria' to determine who is more likely to benefit (clinically) from treatment. In their research using the 1000minds tool, Roy et al (2021) identified eight criteria of relevance for judgements about the prioritisation of ICU support during COVID-19. Some of the criteria included in the tool were whether a patient had a pre-existing cardiovascular or respiratory condition, as well as the body mass index (BMI) of the patient[43] (Roy et al., 2021). Importantly, the tool does not include Māori ethnicity as a predictor of risk, however, it does not need to do this explicitly. The social patterning of the variables within the system mean that Māori are still more likely to be negatively impacted by the tool, because of the pre-existing health inequities present within the system.

In 2015 the *Tatau Kahukura Māori Health Chart Book* (Ministry of Health, 2015), reported that in 2012-14, Māori were more than one-and-a-half times as likely as non-Māori to be hospitalised for cardiovascular disease, and four times as likely to be hospitalised for heart failure. Further Māori aged 5-34 years were almost twice as likely to be hospitalised for the respiratory condition of asthma, and overall Māori adults were more likely to be classified as obese as measured by the BMI scale (Ministry of Health, 2015). In this case, the criteria embedded within the 1000minds tool mentioned above, can act as a proxy for ethnicity. In designing the tool, Roy et al (2021) indicated that there was an awareness amongst the research team that Māori and Pacific health inequities were an issue which needed to be addressed. In response, there was consideration for a higher degree of priority for Māori and Pacific Peoples to be included in the tool, but this was subsequently rejected with the following reason offered

> …doctors' respect for the principles of the Hippocratic Oath may prevent them from differentiating between patients based on ethnicity… which, in practice may result in social equity considerations receiving no weight at all (Roy et al., 2021)

Meaning that, because the 1000minds tool is designed to support human decision making, not replace it entirely, the value judgements of individual clinicians making the final decision, may override any additional weighting given to Māori within the tool anyway.

The health inequities experienced by Māori are not novel, nor have they come about by accident. Māori health inequities are "…influenced by the cumulative effects of colonisation" (Waitangi Tribunal, 2019, p. 20) and represent a "…health legacy from previous Treaty breaches" (Professor Papaarangi Reid as cited by Waitangi Tribunal, 2019, p. 20). The decision of whether or not to allocate an ICU ventilator to a COVID-19 patient will significantly impact the chances of that patient surviving. Problems arise then when the decision support tool is optimised to maximise the number of likely survivors with predictions based entirely on clinical criteria. This is evident to some extent with the nzRISK pre-operative mortality risk prediction model, which calculates the mortality risk of a patient within 30 days, one year or two years of undergoing one of a large number of non-cardiac surgeries (nzRISK, 2020). The model contains an explicit ethnicity variable, which has a weighting indicative of worse mortality outcomes for Māori than for those of European ethnicity. A

---

[43] For a full list see: https://journals.lww.com/ccejournal/Fulltext/2021/03000/Rapid_Development_of_a_Tool_for_Prioritizing.15.aspx?context=LatestArticles

comparison of the variable weightings in the model shows that Māori ethnicity impacts the predictions of mortality from the model approximately the same as taking a patient of European or Asian descent and adding nearly 10 years to their age (Campbell et al., 2019). That is, a 30-year-old Māori patient will have approximately the same risk profile for a particular surgery as a 40-year-old patient of European ethnicity with the same clinical conditions. Under these circumstances, the tool would continue to advantage those groups for whom the health system is already working.

A further issue, not often considered in the development of ADMs for health, nor in the evaluation of these models, is that the variables input into these systems are primarily centred on the patient. In doing so, external factors that influence health outcomes are not able to be taken into consideration, even if the potential impact of these factors is significant. There is strong evidence that demonstrates that racism within the healthcare system impacts health outcomes (Talamaivao et al., 2020). In this case, the likelihood that a patient may be exposed to racism in the course of their care should be a variable within the system – or perhaps a variable that takes into consideration the clinician's success rate in providing care according to ethnicity could be used as a measure of risk.

Returning once again to the 1000minds example, if operationalised[44], the COVID-19 decision support system is unlikely to respond meaningfully to Māori health needs and would likely have negative impacts on Māori patients because of pre-existing health inequities. These are ethically confronting and morally challenging decisions to make, especially when we are talking about poorly conceived ADM systems being implemented in historically biased systems.

Predictive Risk Modelling and Child Protection

Predictive risk models [PRM] are a specific type of ADM that run calculations on large datasets to determine the likelihood of adverse events occurring in a particular situation (Gillingham, 2016). The accuracy of any PRM depends on the availability of data – that is, the more information the tool has, the more accurate the results it can produce. Despite the labelling of PRMs as 'predictive', Gillingham (2016) cautions that they are actually incapable of predicting anything in the traditional sense of the word. Instead, PRMs are designed to make a calculated assessment of risk based on pre-determined variables. They are therefore primarily used to support human decision-making, not to replace human actors entirely. They are used most often in health settings (nzRISK and PREDICT for example) and have been operational in Aotearoa New Zealand's justice sector since 1999 (RoC*RoI examples are discussed below). It is only within the last decade, since 2012, that PRM tools have been developed specifically for use in child protection. The specific tool

---

[44] At the time of writing, the tool had not been trialled as public health measures were controlling the spread of the virus

discussed in this section – The Vulnerable Children PRM (Dare, 2013) – was the first of its kind globally (Vaithianathan, et al, 2012) and was developed for use in Aotearoa New Zealand by Dr Rhema Vaithianathan and her team. The model was never implemented in Aotearoa, as it had been intended, but was picked up and modified for use in Allegheny County (see Eubanks, 2016). There is significant appeal to the idea that it may be possible to identify harm before it happens and intervene to stop children being exposed to abuse or maltreatment. The story below, however, illustrates how the approach to predictive risk modelling in the Vulnerable Children PRM would have exposed whanau to unnecessary interventions and surveillance.

> *I am the youngest in a family of five children – a blended family. My mum is Māori but has lived a life burdened by the weight of dislocation and disconnection from her whenua and her whakapapa. When mum and dad got together, she was a single mum with three kids (3,8 and 9). Dad was born and raised in Tamaki as a second-generation New Zealander, and he came into the relationship with one son (2). Two years later, I was born and would become affectionately known as 'pēpi-Westis' (pēpi meaning baby, and Westis coming from my last name 'West) or 'bub'. In the early years my whānau struggled financially and relied on assistance from the state in the form of benefits to survive. I also remember when I was quite little, mum and dad wrapped soap to get by and leaned on friends and family for support raising us kids. Eventually, though as we got older, mum and dad found work which allowed them to improve their financial situation. I was quite an awkward kid and had a hard time fitting in at school, but thankfully I made it to the end, and had done well enough to gain university entrance – I had grand plans of studying ancient history and classics and I was going to live abroad and visit Egypt. Life though, had other plans for me, and within months of turning 18 and starting university, I found out I was pregnant. I remember the day that I got confirmation that I was pregnant. I was a terrified, sobbing, blubbering mess - the nurse had to call my aunty to come and calm me down before I could leave. I knew who the dad was, but I didn't know him well – he stuck around though but based on the story from the 'Privacy and COVID-19' chapter, I think we all know how that worked out. 16 days after my 19th birthday, I gave birth to the most beautiful baby girl who has ever graced this earth. Being a young māmā was a challenge, but thankfully I lived with mum and dad, so I had whānau support. When baby was five months old, her dad (who was in the army) was posted away from Auckland and just like that, I was a solo mum. I knew I wanted to go back to university and so I needed to apply for what was then called the sole-parent benefit to support myself and my daughter.*
>
> *So, there I was, a young Māori mother, who had started her own life with parents on a benefit and now herself was relying on a benefit.*
>
> *Years later, in 2015, it would be brought to my attention that, according to a predictive risk modelling tool, those two little lines of information above, would be enough to classify my baby as at-risk of harm and child maltreatment.*

There is nothing necessarily unique about my story above, in fact, I assume it is a story that will resonate with many people, if not in its entirety, then certainly in its fragments. There are of course stories nestled within stories here, this is a much-abbreviated version of the events that took place. I contemplated whether it was appropriate to share this story on such an open platform, and in the end, as confronting as it was, it was important for me to be able to reiterate how deeply personal the issue of data sovereignty is for all of us. Highlighting the entanglement of the personal and the political is especially critical in this case study because algorithms and predictive risk models are designed in ways that simultaneously strip us of our stories and strip our stories of us. We are laid bare before the system, disjointed from our digital selves, represented as a series of zeros and ones in exponential datasets, sitting within machines designed to learn from our mistakes.

In 2012, the White Paper for Vulnerable Children [The White Paper] was released by the Ministry of Social Development [MSD], setting out what actions would be taken by the New Zealand government to protect vulnerable children deemed to be at risk of maltreatment. The White Paper framed child maltreatment as an issue of poor prioritisation skills among some parents stating:

> Most parents put their child first, second and third in their order of priorities. They invest all they have in their health, education, and wellbeing, and in their hopes and dreams. They nurture, support, and encourage, in good times and through bad. And when they struggle, they will go without to ensure their children have a better start and more opportunities than they did. Most of all they want their children to be happy and fulfilled.
>
> …
>
> Too many children live far below the norm, most of them let down by the very people, often the only people, who they should be able to trust and rely on to love and protect them.

The White Paper indicated that access to "… more intensive and cross-cutting interventions to address the depth and breadth of vulnerabilities present" (MSD, 2012 p.58 as cited by Blank et al., 2015, p. 1) would be significant in reducing child harm. The need for greater access to services though was balanced against a perceived need to deliver value for money in the use of taxpayer dollars. Part of striking that balance involved a need to be able to identify at risk populations for targeted intervention. With this in mind MSD commissioned Dr Vaithianathan to develop a tool that could be used to identify when children may be at risk of future abuse and neglect (Eubanks, 2018).

The prototype tool that was developed was an algorithm that linked public benefit data with child protection data and would be applied to families who were in receipt of a benefit or social welfare for financial support. Every new entry of a child (via their parents) into the welfare system would prompt a new calculation and would generate a score that estimated the likelihood of future maltreatment for the child/ren (Vaithianathan et al., 2012). Families who received high scores would be offered 'support services' to 'reduce this risk'. In 2014, the Ministry of Social Development made accessible two reports with more detailed information pertaining to the development of the tool. In one report, the primary risk factors for child harm and maltreatment were proposed as follows:

> On their own, mother or primary caregiver's time on benefit in the last five years, relationship status of caregiver, caregiver's care and protection history as a child and care and protection history of other children have the greatest association with [the] dependent variable (MSD, 2014, p. 12).

The fact that the greatest predictors of risk of harm in the model were all associated with the receipt of a benefit is unsurprising, given that the algorithm was trained primarily on data from the public assistance benefit database (Gillingham, 2016). This limitation of the tool was acknowledged by the development team who stated that:

> Non-Beneficiaries are Not Risk-Assessed. Due to the current limitations of data, we are unable to implement a Predictive Risk Model that captures all children who are at risk – in particular those children who never appear on a benefit. This means that beneficiary status and child maltreatment assessment become linked (Vaithianathan et al., 2012, p. 33).

At the time, in 2012, there were very limited provisions for data-sharing in the Privacy Act, and the IDI had not yet been developed so data linking was not possible in the way that it is now. Therefore, the accuracy of the prototype was only around 76% (Gillingham, 2016; CARE 2012). Eubanks (2016) asserts that though 76% seems relatively good, this figure is "…only halfway between a coin toss and a perfect prediction" (p.145). They go on to argue, that at that rate of accuracy, in Allegheny County of the 15,139 reports of abuse and neglect in 2016, the model would have produced 3,633 incorrect predictions. It must also be reiterated that these predictions are further limited by the dataset which only captured children whose caregivers accessed social welfare, not all children at risk of harm. Emily Keddell (2019) cautioned against the use of limited (and limiting) datasets noting that:

> Without a database that reflects incidence, the racial and class disproportionalities within the child protection system contact are likely to reproduce inequities that relate as much to surveillance biases as they do to differences in true incidence. Poor and ethnic minority families will therefore be subjected to higher rates of state intervention than real disparities in rates, while other children at risk may be incorrectly assumed to be low risk. (Keddell, 2019, p. 298).

Keddell's commentary resonates with other research, which attributes part of the disproportionate prevalence of Māori child maltreatment data (relative to Pākehā) to heightened levels of surveillance in Māori communities. So, what we saw reflected in the Vulnerable Children PRM was yet another model that supports the over-surveillance of poor brown families and contributes to the continued accumulation of inaccurate datasets.

Another limitation with the accuracy of the model was that it was trained around the idea of 'substantiated claims', which would also capture children who were not themselves victims of abuse (in the system) but who were siblings of children who were (Gilligham, 2016). Finally, whether or not a report of abuse is ‘substantiated’ rests less on a consistent threshold, and more on the values and judgements of social workers involved in the assessment. This becomes incredibly problematic for Māori in Aotearoa New Zealand, especially when evidence suggests that social workers perceived Māori children as being exposed to greater levels of ‘risk’ when compared to non-Māori children in the same situation (Keddell & Hyslop, 2019). The development team made the decision that there were too many ‘issues’ around racial profiling to include ethnicity as a variable (Vaithianathan et al., 2012, 2013). The fact that this would be even included as a consideration though indicates that there is some belief that ethnicity is an inherent marker of risk.

In chapter seven, it was noted that privacy was a privilege not afforded to the structurally vulnerable. This is very evident in this context where, if implemented, families would have been subjected to this system, purely based on their need for financial support from the state. Engaging with one arm of the state would have immediately made not only your life as an applicant, but also the lives of your children as your dependants, open to the scrutiny of a separate arm of the state. There is also the critical issue of consent, which is not considered in the model (Blackstock, 2014; Blank et al., 2015; Gillingham, 2017; Keddell, 2014, 2019; CARE 2012). The Vulnerable Children PRM took information that had been collected for purposes often not related to child protection and ran calculations based on that information without the consent of those who supplied the information or the families to which it pertains (Dare, 2013). 57,986 children were captured in the dataset, with enough data on each child available for 132 variables to be identified in the initial phase of the research (Keddell, 2014).

> Data were provided to the research team in 2012 under confidentiality agreements with the University of Auckland. The university’s ethics committee deemed that this project was exempt and did not require ethics approval, as the data were de-identified. (Vaithianathan et al., 2013, p. 355)

If, as was noted in chapter five, the western legal system privileges informed consent as the primary means for ensuring that the agency and autonomy of individuals can be realised, what does that say about the ways in which we understand welfare recipients in the context of the Vulnerable Children PRM? Not only is this unethical from the perspective of informed consent and privacy, but it also removes the opportunity for people to challenge the system or include any additional contextual information of relevance. On this note, in their assessment of the PRM from an Indigenous perspective Blackstock (2014) highlighted that:

> The roots of poverty in Indigenous communities are often linked to historical and contemporary disadvantage and thus it is important that the PRM and other risk assessment tools distinguish between personal and societal locus of control to better target interventions and ensure that families are not held accountable for factors beyond their control (p.5).

Blackstock's (2014) point here is accurate and insightful, but the Vulnerable Children PRM was developed under a neo-liberal agenda (Keddell, 2014, 2019) and was therefore not capable of identifying systemic failures, or a history of colonialism as being the root cause of the problem. The heavy emphasis on targeting services based on need, value for money, poor parenting decisions and the individualisation of child harm leave very little room for a consideration of broader systemic harms.

The limitations discussed above reflect a critical failing of all ADMs, algorithms and PRMs in that all of these tools are designed, developed, and coded by people. So, despite being lauded as a means to mitigate bias and discrimination in human decision-making, these biases become further embedded within the systems and stripped of the accountability often placed on human actors. They (the tools and the systems they support) end up being reclassified as neutral and value-free, further supporting the responsibilisation narrative of neo-liberalism (discussed in a subsequent section of this chapter).

Reflecting back on my own story, yes, I am Māori, yes, I was a young mother, yes, I started my life with parents on welfare, but if I could speak back to the system I would say:

> *Yes, I am Māori, I was born because of the resilience of my tūpuna. Mine is a legacy of strength*
> *Yes, I am a young mum, but remember I am Māori, so I will not be alone in raising this mokopuna of Hauraki*
> *Yes, I started my life with parents on welfare, but remember I am Māori, we are industrious and intelligent people and I plan on using these characteristics to pursue higher education.*
> *The 'risk' of my Māori-ness is manufactured in your vitriol and your hate and your racism and the bitter aftertaste of a failed plan to end my people. 'Inherently risky' not because of the whakapapa etched in my bones or any biological factors, but because of the way my body and mind is surveilled in a systemically racist colonial context.*
> *But this system does not define me, nor will it define my daughter because we are wāhine Māori and that is the safest thing I know*

Ministry of Social Development - NEET

The Ministry of Social Development use a statistical predictive modelling tool to identify school leavers who are not in education, employment or training (NEET) or at risk of becoming NEET (Algorithm-assessment-agency-submissions-June-July-2018.pdf (data.govt.nz)). The model considers factors including age, where the young person lives, whether they have a parent on a benefit or have been involved with Oranga Tamariki and their school histories to inform its output. Though ethnicity is not included as a variable indicating risk in this model, as it has been demonstrated in the RoC*RoI example below, it is possible, and in fact probable, that the variables that are in the system simply become proxies for race. We know, for example, that Māori are more likely than Pākehā to be identified as NEET, with data suggesting that between 2004 and 2018 the rate of Māori identified as NEET varied between 15.6% and 27.5% compared to 8.3%-13.4% for Europeans (Apatov, 2019, p. 4). We know that rangatahi Māori are more likely to have parents who are in receipt of a benefit, given that Māori make up 36% of the population receiving a benefit (Welfare Expert Advisory Group [WEAG], 2019); we know that Māori are more likely to have engagement with Oranga Tamariki comprising 57% of the total number of children in care (Oranga Tamariki, 2021); and that they are more likely to have been failed by the education system (Berryman et al., 2016). This being the case, the NEET model run by MSD is more likely to impact rangatahi Māori.

The logic proposed by the Ministry of Social Development for the use of this model is that it allows MSD to identify young people who may need more 'active case management' and wrap around support to reduce the likelihood that they will become long-term unemployed. Further, MSD consider the number of school leavers each year to be so large that manual review of each case is not feasible[45]. It could be argued that the use of this model increases the likelihood that rangatahi Māori will be supported to ensure that they have the best opportunity to secure employment and that this is a good thing for Māori in general. Though this may be the case, there is also the risk that we are exposing rangatahi Māori to a system of surveillance and normalising the presence of surveillance in their lives. It also means that if Māori are identified as needing more active case manager engagement, there are more opportunities for data gathering to occur; again, resulting in greater levels of surveillance and scrutiny for Māori moving forward.

Department of Corrections - RoC*RoI

The Risk of Reconviction / Risk of Re-imprisonment (RoC*RoI) model is an operational algorithm currently in use by the Department of Corrections in Aotearoa. The tool was developed in 1999 and was trained on data containing the histories of over 130,000 individuals (West, et al., 2020). Given the high engagement of Māori with the Department of Corrections, RoC*RoI is arguably the operational algorithm with the most potential for harm to occur for Māori. RoC*RoI references around 30 individual variables to produce a risk score expressing the probability that a person will be reconvicted and re-imprisoned for new offending within the following five-year period (Algorithm-assessment-agency-submissions-June-July-2018.pdf (data.govt.nz)). A full list of the

---

[45] See (Algorithm-assessment-agency-submissions-June-July-2018.pdf (data.govt.nz)

individual variables was not available in public facing documentation, there was however an abbreviated list provided by the Department of Corrections in their algorithm assessment report in 2018. Some of the variables include:

- Current age;
- Sex;
- Age at first offence;
- Frequency of convictions;
- Number of court appearances and convictions;
- Current offence category (10 possible; e.g., violent, sexual, drugs);
- Number of convictions in each crime category;
- Sum of seriousness ratings for all crimes (seriousness defined by average length of sentence in days imposed by offence type);
- Weighted past seriousness measure (places greater weight in seriousness of most recent offence);
- Maximum serious measures for the past time period;
- Mean seriousness measures for the past time period;
- Number of previous imprisonments sentences;
- Maximum sentence length handed down to offender in past (years);
- Total estimated time (years) spent in prison;
- Time at large (length of offender's most recent time at large).

The original iteration of the RoC*RoI model in 1999 weighted Māori ethnicity as a risk marker for recidivism (Bakker et al., 1999). As a result, simply being Māori would increase the value of the risk score produced by the algorithm (West, et al., 2020). This is significant because the risk scores produced by RoC*RoI are used to inform decisions around:

- Level/intensity of management required while on a community sentence
- Eligibility for rehabilitation programmes
- Prisoner security classification
- Suitability for release on parole
  Algorithm-assessment-agency-submissions-June-July-2018.pdf (data.govt.nz)

Including ethnicity as a marker for risk was discriminatory and resulted in adverse outcomes for Māori moving through the system (West, et al., 2020). This is a clear example of how ADMs, though lauded for their efficiencies and ability to be neutral in their decision making, still produce bias, and in this case, racist outcomes. Technologically speaking, the algorithm itself is not racist, however, it has been designed in such a way that engenders prejudice, and is populated with biased data, so will therefore produce racist outcomes. The injustice of discriminating by ethnicity resulted in the WAI 1024 Waitangi Tribunal claim in 2002 by Tame Pirika (Tom) Hemapo on behalf of Ngāti Kahungunu (Waitangi Tribunal, 2005). The basis of the claim made by Hemapo was that RoC*RoI disadvantaged Māori offenders in terms of type and length of sentences they received (Waitangi

Tribunal, 2005)[46]. In doing so, Hemapo submitted that three Principles of Te Tiriti were being breached; they are partnership, active protection, and participation.

The Tribunal compiled a list of questions (See Appendix A) to communicate, in the report, the essence of the dispute between both parties (claimants and the crown). There were eight questions specific to the RoC*RoI tool; questions ranged in focus from the design of the tool itself, consultation and evaluation, validity of the data going into the system and department responses to accusations of racism. The subsequent *Offender Assessment Policies Report* completed in 2005 noted:

> In the time between the filing and hearing of Mr Hemapo's claim, the RoC*RoI tool was reviewed, and the ethnicity variable altered so that it no longer contributed to the predictive power of the tool (Waitangi Tribunal, 2005, p. 2).

The removal of the ethnicity variable prior to the review by the Tribunal is intriguing and was met with considerable speculation around whether the move was made to allay fears that the model might be discriminatory towards Māori (Waitangi Tribunal, 2005). Especially given that in response to questioning from the Tribunal the Department of Corrections stated:

> The impact of ethnicity does not have a direct and constant influence on the probabilities expressed in either ROC [risk of conviction] or ROI [risk of imprisonment]. Rather its influence varies in relation to other variables, and the value of those variables. For instance, the influence of ethnicity will differ for males and females, for older and younger persons and for various types of crimes… (Department of Corrections as cited by Waitangi Tribunal, 2005, pp. 41–42).

Despite the removal of the ethnicity variable, detailed review of RoC*RoI showed that even taking into account the reduction, the results produced by the algorithm remained the same because of the over-representation of Māori in the other variables (for example low socio-economic status) (Waitangi Tribunal, 2005). The Tribunal made the following interpretation:

> From the evidence on this complex matter, we understand that the ethnicity variable would have remained in roc*roi but for the fact that the concerns raised about its negative connotations caused a re-examination of its particular contribution to the tool's predictive accuracy. It was then found that, because of the high correlation of ethnicity with other variables, the predictive accuracy of roc*roi could be maintained by recalibrating other variables and reducing the effect of the ethnicity variable to zero. This is what was done. Had it been found, however, that the effect of the ethnicity variable on roc*roi's accuracy could not be replicated by such changes, it would have remained. (Waitangi Tribunal, 2005, p. 126)

It was found that removing the ethnicity variable was sufficient to address that part of Hemapo's claim (West, et al., 2020). However, re-weighting the other variables to absorb the effect of the

---

[46] Hemapo's claim also included another psychologically based assessment tool referred to as the Māori Culture Related Needs (MACRNS) tool, which is not discussed here

original Māori ethnicity weighting does nothing to address the problems identified in the claim. If the accuracy of the model remains, then the modified weightings of the other variables simply act as proxies for (Māori) ethnicity. It is misleading to assert otherwise. Rather than addressing the underlying problem, the “fix” has simply masked the issue and made it more difficult to audit (West, et al., 2020).

Automated Decision Makers and Trust:

Aotearoa New Zealand’s Algorithm Charter claims that “…algorithms can be used to help government better understand New Zealand and New Zealanders. This knowledge helps government make good decisions and deliver services that are more effective and efficient.” (Stats NZ, 2020c, p. 1). This statement is similar to one made in the *Algorithm Assessment Report*[47] (Stats NZ, 2018a), in which Stats NZ commented on the potential benefits of utilising algorithms, noting that:

> The increased sophistication and number of algorithms allows for increasingly linked government services, a better understanding of what works and for whom, and more opportunities for collaboration and efficiency gains. These represent tangible benefits for all people in New Zealand (p.8).

The claim made by Statistics New Zealand in the quote above, that increased opportunity for linked services and efficiency gains facilitated by the use algorithms, represents tangible benefits for ‘...all people in New Zealand’, is a bold one and requires further interrogation. When the language of universalism is applied to reference ‘all people’ or ‘New Zealanders’, does it reflect a genuine desire to move toward a more fair and equitable society for all, or is ‘all people’ simply a proxy-phrasing to refer to “the people who are seen to matter the most.”? (Ranginui Walker as cited by Jackson, 2021)**.** It is possible that there is potential for technology to be developed and deployed in such a way to ensure the distribution of burdens and benefits is fair across society and does not negatively impact one group. However, as the examples presented in this chapter have demonstrated, this is not currently the case in Aotearoa.

Presently, there are no specific legal frameworks that guide the development of algorithms in Aotearoa. This is unsurprising, as digital spaces are currently, largely unregulated. We saw this to some extent in the discussion in chapter three regarding the IDI and the lack of a formal or specific legal structure governing access to that data. The Algorithm Charter does however, offer some very basic aspirations for algorithms and is a voluntary document that signals a commitment

---

[47] The last stocktake of operational algorithms in use by government agencies in Aotearoa New Zealand identified 14 agencies who utilise ADM technologies in their service delivery (Gavaghan et al., 2019). In total, there were 32 operational algorithms said to be in use at the time of the publication.

from government agencies in Aotearoa New Zealand to “…carefully manage how algorithms will be used to strike the right balance between privacy and transparency, prevent unintended bias and reflect the principles of the Treaty of Waitangi” (Stats NZ, 2020c, p. 1). This reference to the Treaty is the only provision within the Charter for protecting Māori interests. Towards the end of the document, there is also a mention made to the importance of Māori Data Sovereignty, however these are seen as ‘complex’ issues that require separate consideration (Stats NZ, 2020c, p. 3).

At the surface level, there has been some investment from the current Labour Government to try and understand how the digital future might be inclusive and equitable for all. A key element of this investment was in the establishment of the Digital Council (DC) in February 2020. The Digital Council is an independent group tasked with advising the government on “…how to maximise the societal benefits of digital and data-driven technologies to increase equality and inclusivity, wellbeing, and community resilience” (Digital Council for Aotearoa, 2020). Trust, inclusion, and innovation were the three workstreams identified by the Digital Council to support Aotearoa New Zealand to becoming more digitally inclusive[48]. With this in mind, in 2020, the Digital Council engaged in a research programme geared toward understanding the perspectives of people in Aotearoa New Zealand on trust and automated decision-making. Initially, the Digital Council had a working definition of trust as being “…about whether people are comfortable in a situation where they are vulnerable to the consequences of someone else’s actions” (West, Wilson, et al., 2020) This definition of trust often relies on an existing positive relationship between two parties where there is a founded expectation that whoever is in the dominant position of power, will act in the best interest of all parties (Brainbox Institute, 2020)**.** In the final report, trust was defined as “…people feeling comfortable and confident when they are affected by other people’s decisions or actions” (Digital Council for Aotearoa New Zealand, 2020, p. 12).

What is apparent in the DC’s definition of trust, is that the locus of responsibility is on individuals to be trusting of the system. In contrast, the Māori word for trust is tiaki,[49] which translates to guard, keep, look after, and protect. The addition of ‘tanga’ to become tiakitanga, denotes an action and refers to the act of guardianship, caring of, protection and upkeep. In the context of Māori data sovereignty, Te Mana Raraunga use kaitiakitanga in the following way:

> Kaitiakitanga speaks to the hapū, iwi responsibility to be an effective steward or guardian and relates to actions that ensure a sustainable future for all people. Underpinning our existence is the need to protect and enhance Māori knowledge and practices, to strengthen whānau, hapū and iwi and to create sustainable futures. Kaitiaki have a social contract and are responsible to the communities they serve.

---

[48] https://medium.com/@digitalcouncilnz/digital-council-for-aotearoa-new-zealand-weeknotes-3-43ed558814c9

[49] https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=trust

> Identifying appropriate data guardians and the principles by which they will operate is a key consideration.

Here, the right of Māori to act as Kaitiaki for data is derived from a responsibility to protect and guard that information as opposed to a right derived from ownership. The notion of kaitiakitanga also introduces the idea of an inter-generational responsibility and obligation to protect data (Kamira, 2003). In Māori definitions then, the responsibility of trust is not on individuals, but on whoever has been placed in a position where there is an expectation that their actions will engender trust.

Even if we did accept the Digital Council's definition, on what basis could we, as Māori, trust the State to develop and implement ADMs in a way that we could feel 'confident' and 'comfortable' with the decisions being made? Earlier chapters have discussed how data collected, held, and mobilised by the State has served to emphasise Māori difference and justify systemically racist policy interventions. In the relatively short time that ADMs have been operational in Aotearoa New Zealand, we have seen the ways that bias has been built into the systems and how even when ethnicity is not explicitly factored into the equations, independent variables can become proxies for ethnicity. Ruha Benjamin (2013, 2019) talks about this in terms of trustworthiness. Speaking to the experiences of Black Americans, Benjamin (2013) asks the question:

> Perhaps...distrust on the part of the dispossessed is a rational response to, and a defense against, a society that justifies penalizing the poor so that everyone else can feel safe and secure. When life is lived under a state of physical and symbolic siege... it is little wonder that widespread distrust persists. It would perhaps be more curious to find people expressing trust in social institutions, including science and medicine, under such conditions (p.138).

In a socio-legal environment obsessed with the notion of precedent, one must ask themselves what is the precedent that has been set by the state and government agencies, which can inform our assessments of trustworthiness? So far, this thesis has demonstrated that there is no basis for trust from Māori towards the state, in which case, there is no basis for Māori trust in ADMs. This profound sense of distrust was also reflected in the final report from the Digital Council.

A key factor influencing trust, identified by the Digital Council in the report, was the idea of transparency. That is, people are more likely to trust a decision if they understood how the decision was made (Ngomo, 2019; Quince, 2020). The centrality of transparency in public understandings of trust is also reflected in Aotearoa New Zealand's Algorithm Charter, which identifies transparency and accountability as critical for "...ensuring that the public can trust and support the government to use these tools in appropriate ways" (Stats NZ, 2020c). It is clear that there is widespread acknowledgement that transparency is critical for building trust, what is less clear is what satisfies the requirement for transparency. For example, an organisation could release their algorithmic code for public access and claim that they are being transparent; however, without knowledge of how the code operates, this information is useless to the layperson. In *'Weapons of Math Destruction'* O'Neill (2016) considers this and reflects on how "…human victims of WMDs [Weapons of Math Destruction, or ADMs] are held to a far higher standard of evidence than the algorithms themselves" (p.10). We saw this in the findings of WAI 1024, the report on the Waitangi Tribunal claim against the Department of Corrections. Challenging the system required an in-depth knowledge of how the system itself works. Despite overwhelming evidence that the algorithm was producing biased results, seeing this was not enough.

Each of the ADMs discussed in this chapter are examples of predictive risk modelling. An appealing feature of this approach, that was discussed earlier, in most cases the systems are not designed to make final decisions and are instead implemented to support human decision making. In their research, the Digital Council found that there was a general sense amongst the public that algorithms were useful and appropriate to use when the decision being made was straightforward (Digital Council for Aotearoa New Zealand, 2020). This is the case with the ACC algorithm, where 90% of the time, the ADM is making a yes or no decision. When decisions were more complex or nuanced however, workshop participants expressed lower levels of comfort with an algorithm having control and indicated that a 'human approach' is more favourable in these instances. Interestingly, the underpinning logic in the public responses was that, because algorithms are trained on old datasets, bias can be embedded into the system. Further, there is currently no capacity for the PRM tools to take into consideration contextually relevant information that may influence outcomes on an individual level. This was reflected in the quotes of several workshop participants, in relation to the RoC*RoI and NEET algorithms:

> *"The term risk sends up a flag; it's producing a risk score from my history. Do these factors that you haven't had any control over follow you around all your life? I was so young, just a kid. What if we change, the data is still there, always there, but it doesn't mean that I'm that person now."* (Māori and Pacific youth, youth support scenario as cited by Digital Council for Aotearoa New Zealand, 2020, p. 24)

> *"Everyone deserves a second chance. But the system seems way too old to analyse all of this — it's from 2001, aye? It needs an update because people evolve and change. The things that society values also change."*(Pacific youth leaders, criminal justice scenario, as cited by Digital Council for Aotearoa New Zealand, 2020, p. 24)

> *"People don't focus on the negative things like these algorithms do. Who wants their life to be based on stink stuff from their past, that came from things from their parent's past that they had no control over? Stop focusing algorithms on what you think is the matter with us. Instead focus them on what matters to us, the changes we want to make. Ask us, and start collecting that data."* (Whānau Ora navigators, youth support scenario as cited by Digital Council for Aotearoa New Zealand, 2020, p. 24)

I flagged this finding because the very issue that algorithms are being designed to respond to – that is, minimising human bias – was raised by participants as an issue about the systems themselves. Machines do not have a heart or a conscience, and any value judgements made by them are a reflection of the values they have been imbued with, in both the data variables and the relative weighting of the variables. As Keddell expressed:

> The ethics of the PRM thus prompt a much wider conversation regarding the overall direction of systems development, as many of the ‘within paradigm’ ethical issues around duties and consequences are difficult to settle without acknowledging the ‘outside paradigm’ ethical issues of knowledge production, national orientation, and the politically contestable views of what the aim of social policy should be. (Keddell, 2014, p.84)

This quote from Keddell (2014) was made specifically about the pilot child protection PRM discussed earlier, but it is true for all ADMs. This is evident especially if we look at the ways that ADMs are being designed in Aotearoa New Zealand to reflect neoliberal values of ‘responsibilisation’, efficiency and individualism.

The Algorithm Assessment report identified “improved efficiency, which reduces cost for the taxpayer…” and “proactively targeting specific support to an individual based on data...” (p.27) as deliverables of clear public benefit in the development of algorithms. In this case, whatever social good that might come from an ADM’s decision, whether it be the protection of children or successful provision of resourcing for a young person leaving school early, can be reconceptualised as the exhaust fume or biproduct of a cost saving measure. In the development of the child protection PRM, Vaithianathan acknowledged that there was no single factor that could deterministically predict maltreatment but argued that “…correctly assessing the likelihood that a child will be the victim of future maltreatment would enable scarce resources to be strategically targeted” (Vaithianathan et al., 2013, p.354). The languaging of cost-efficiency and targeting of resources is present across the documentation.

Keddell (2014) extends this idea of neo-liberalism in PRMs suggesting that these systems are designed to individualise the problem, emphasising personal responsibility, and limiting the role of the nation-state. She goes on to note that this is a form of ‘responsibilisation’, which rewards ‘prudential citizens’ who are able to respond appropriately to the demands of modern life, while punishing anyone who makes ‘bad or risky choices (Keddell, 2014). This represents an important yet under-researched element of ADMs, which is that they are designed to identify and intervene in ‘future risk scenarios’, yet they do nothing to address the factors which are seen to contribute to that risk in the first place. In RoC*RoI, NEET and the child protection PRM, socio-economic status and poverty are included as factors contributing to risk, yet the logic of intervention is still geared towards individuals, rather than addressing the structural issue of poverty.

Concluding Thoughts

Thirst for efficiencies cloud the fact that when we talk about feedback loops and the production of biased results, we are talking about people's lives. When RoC*RoI produces a score that influences parole decisions, or access to rehabilitation programmes; or when we use predictive risk modelling to consider whether a person is a NEET, or if they should have access to ICU support in hospital, there is a person being impacted by that decision. How are we supposed to trust an algorithm that effectively reduces people to scores and acronyms? It is critical to remember, that while each agency uses algorithms independently (across these examples these are Department of Corrections, MSD and Oranga Tamariki) that the outcomes produced by these ADMs are not siloed. That is, it is likely the case that many Māori will be subject to the decisions made by multiple algorithms across their life course. Therefore, it is of significant concern that Māori are not directly involved in the design, development, or implementation of these systems. We cannot control what controls us.

Chapter Nine Case Study Three: Whakapapa and Access

This chapter covers a range of issues that may cause distress for readers, including the uplifting of children from whānau, experiences of abuse in state care and the ongoing implications of these events.

This chapter engages with the critical concept of whakapapa. In reflecting on whakapapa, it will also consider the issue of access. The impetus for writing up this case study came about in the initial scoping period of this research, where I looked at the etymology of the term data as gift (discussed in the literature review chapter) and considered the notion of whakapapa as the first gift we ever receive as we come into being. From this emerged a further set of questions around what happens when we are separated from the knowledge of our whakapapa as has happened for too many Māori who have been institutionalised under the guise of 'care and protection'? Who mediates access to our stories that are held in administrative databases? And how do we negotiate the reality of the state knowing more about us then we know about ourselves?

As with the other case studies in this thesis, this chapter includes a story. So far, the pūrākau shared in this thesis have been taken from my own life and have purposefully centred myself. This case study veers slightly from this path to consider stories from my own whakapapa. It is a distinct honour and privilege for my whānau that we have a collection of memoirs written by my great grandmother Angeline Ahirata – in my immediate whānau, we knew her as 'old nana Ryan', in hindsight it probably was not a title she embraced fully – Nan wrote these stories in her old age as a way of making sense of her life and all that it was, the joy, the laughter, the pain, and the sadness – she named the collection *Children of the Pa: Memories of my childhood.* The following is a direct extract from this collection.

'Children of the Pa: Memories of my childhood'.

We children loved the idea of having our own Pa. Well it must have belonged somewhere in the family, some members of an old Hauraki Tribe still having ownership of the property – My Mother, Uncle Alf, and Peter Grace of the tribe of Te Matahau of Hauraki. So to Us Kids it is "Our Pa"

These pages are filled with names of Aunts, Uncles, Cousins and other relatives. You may have heard their names spoken of by a family member at some time. Over the years these people have moved away, grown old, out of reach or long gone.

Though you may never have met them, I bring them here for a brief acquaintance, for those of you who may have found spare moments to take a glimpse into the Duck Creek memories of your own mum, grandma, Great Grandma who lived these stories that you may wish to read.

For those who have the time and inclination to pick up these pages and read what is hereby

revealed by one who has lived through this time in history.
There may be surprises and secrets that hitherto were unknown and now made clear. Some fact of your ancestry that may or not be of future usefulness.
Please read these bits and pieces with kindly patience. Repetitions here and there, quite unavoidable in the very style of your ninety year old Matriarch, whose eyesight is limited to half an eye, and fingers growing less willing to hold a pen.
Don’t be put off by that as the computer (my head) is stacked full of the bright images that childhood holds to its self. Never fading, becoming clearer with age as that is now what’s left for us to reflect on.
Myself being one of the fortunate children, having had a wonderful childhood and many happy things, some very unusual to dream on.
But given the accomplished literacy ability and the pen of Catherine Cookson or Barbara Cartland, in the following pages would be a whole plot of the kind of love story their fans would delight to read.
But being true stories taken from the script of childhood memories, they just become the very true facts, a mundane little old lady’s memories.
The story of Charlotte (the coloured woman (Maori) and her white lover (husband,)
What happened to coloured Sarah?
Why did they steal baby Gertrude Violet?
Charlotte’s secret children.
It all happened to our family, told just the way it was and nothing fancy about my way of telling it.

The complexities of feeling and emotion attached to identity are present throughout Nan’s stories. When I first started writing this chapter, I had intended only to use one story **WHITE FATHER – WHITE PREJUDICE,** because I thought that it so aptly described the violence of disconnection. As I continued reading, I realised that there was so much more to the story that held relevance for my thinking. For example, as I started organising my ideas around how to articulate whakapapa, I saw synergies between the way that Māori scholars had theorised whakapapa and the way that Nan understood herself in relation to the world. In ‘Trees of Hauraki’, I understood what Burgess and Painting (2020) refer to as our ‘more than human relations’ and the link between whenua and whakapapa made sense. ‘Our Pa’ was critical in my sense-making around the connection between whakapapa and time and the non-linearity that Rameka (2016) and Mahuika (2020) refer to in their mahi. There are three excerpts included in this chapter, some full and some partial. There was no system for the selection of stories or poems that have been included. Instead, I allowed myself to be fully immersed in my Nan’s storytelling and to get excited when a connection was made. The relevance of each excerpt is explained in turn and summarised in the concluding statements for this chapter.

The substantive section of this chapter begins with a discussion of whakapapa and how it has been theorised by Māori. Whakapapa is highlighted as critical for understanding how Māori make sense of the world and their place within it. In acknowledgement of the centrality of whakapapa within te ao Māori, this chapter then moves on to think about how the State has been implicated in the violent disruption of whakapapa. Here, I include the final pūrākau. It is sad, it speaks to the ways in which colonisation and racism have violent impacts on whakapapa and the mamae that emerges and festers when we are involuntarily severed from our whakapapa. It is within this section that we see the power of storytelling in research, where the personal narrative is tied in with the broader socio-historic, socio-political landscape. Examples are also drawn from Residential Schools in Canada and the Stolen Generations in Australia to highlight how the theft of children by the state is not a single aberration, but a sustained feature of colonial violence.

While conducting the research for this chapter, I listened to the contextual evidence given by my supervisor (Tracey McIntosh) to the Royal Commission of Inquiry into abuse in state care[50].

In her evidence, she reminded us, that the people who have given testimony are the experts of their own conditions. They know better than anyone the devastating impact of disrupted whakapapa and the struggle of trying to access what is known about them on record. Quotes, reflecting this expertise, have been drawn from reports, videos, and stories, and are included throughout this chapter as evidence. Of particular interest to this thesis is the way that access to our own whakapapa has, since settlement, been mediated through the state.

The penultimate section of this chapter considers how iwi Māori are approaching the storage and management of whakapapa records. Further, some brief consideration is given to how larger, relatively well-resourced iwi entities including Ngāpuhi, Ngāi Tahu and Tainui are using their whakapapa databases to protect their mokopuna from the violence of upheaval. The operationalisation of whakapapa as a principle of data governance is also critically considered. As a principle of governance, whakapapa is positioned as the primary vehicle for the maintenance of relationships. It is a case of whakapapa as a concept, protecting our whakapapa as people. What is evident in this section is that data sovereignty cannot be disentangled from other sites of sovereignty.

Whakapapa:

Whakapapa has been theorised as the central organising principle of all things and beings in te ao Māori (Barlow, 1994; Burgess & Painting, 2020). The term whakapapa is derived from the root word papa meaning earth or foundation (Burgess & Painting, 2020). With the addition of the causative prefix ‘whaka’ which can be translated as ‘to enable’ or cause to happen’ (Rameka, 2016), whakapapa then, refers to the placement of one thing upon another from the foundation (Barlow, 1994; Burgess & Painting, 2020; Mahuika, 2019; te Rito, 2007). Definitionally speaking, whakapapa is analogous to the Pākehā ‘genealogies’, however there are some key distinctions. For example,

---

[50] https://www.abuseincare.org.nz/library/v/74/statement-of-professor-tracey-mcintosh

genealogy is used primarily to refer to lines of descent from an ancestor down to the most recent descendent. This has the effect of constructing genealogies as timebound and as artefacts of history (Burgess & Painting, 2020). They tell us something about where we have come from but nothing of where we are going. Whakapapa, on the other hand, transcends time and space (Lawson-Te Aho & Liu, 2010) and is therefore less concerned with focusing on linear or chronological time as a way of ordering relationships. In other words, the focus is more on connection itself, as opposed to the order in which that connection was established. Nan's story, *'Our Pa',* captures this delineated notion of time and place that sits within whakapapa and brings forth the various ways that we can connect with our tūpuna.

OUR PA

You can tell by the way I write it on the page, that we children are proud to belong to this place. "**OUR VERY OWN PA."**

We have no hesitation in proclaiming to any stranger unfamiliar with it. --- This is "**OUR PA."**

Some may smile or wonder as we pass it on our way up or down river, seeing only huge pine trees and a glimpse of Pakeha houses hidden behind them.

[51]" when she visits. She has the **MOKO ON HER CHIN – SHE IS OUR CHIEFTANESS** spoken by me with the knowing certainty of a child.

Those who are familiar with "**OUR PA"** and our family will know some of the story. The stranger will pat us on the head and smile at the inventiveness and imagination of a child …… **A PA, HA HA.**

But they don't know what we know. They don't know how the wave washed mud has revealed many of the old secrets, sealed in time like the page of an old history book.

Things we pick out of it into our very own hands, to wonder and marvel about.

What is it? Who made it and why?

Our parents tell us it is something belonging to **"THE ANCIENT ONES,"** those who lived here long, long ago. **"OUR ANCESTORS."**

With only stone tools, sand and water to work with and their own great patience, they

Where is **THIS PA?.** That's it we will say, while there is bound to be family waving and shouting to us from the bank.

Where is the **CARVED MEETING HOUSE-?** The **TRIBAL TOTEM POLE,** is there a **TATTOOED CHIEF? –** tattooed **OLD KUIA?**

We have two chiefs we will say, our Uncle Peter Grace and our Uncle Alf, and neither have tattoos. The only bit of tattoo you are likely to see is "**THE GRANNY ALL**

shaped and fashioned these things for use or decoration, and for you to wonder at.

We are only children, but we feel so proud to hold these things in our hands. Things made by our very own people and preserved here for us. Not things factory made and bought from shops and supermarkets, but made with the clever ingenuity of people, who found out for themselves, the way to make things like these, that could survive the countless years, so that their Mokopuna would find them and see for ourselves, the beauty and intricate joy in the art of their own craftsmanship.

After being washed and polished, we stared at them and wondered about **OUR TREASURES, OUR ANCESTORS,** and how we came into being from those very people, linked to them with the bits and pieces that the wind, waves and time flung literally, at our feet!

Something to think about as children, something to dream about when we grow old!

---

[51] I was puzzled for weeks reading these stories of 'Granny All' searching through our whakapapa trying to find where she sat within it. It was only after reading further in my Nan's stories that I realised Granny All was actually Nanny Matuku, who was gifted the name Granny All (though i'm still not certain whether this was a name used only in *Children of the Pa)* because she was a Granny to All.

Many bits and pieces of “**OUR PEOPLE”** also
being dug up with the spuds and Kumara.
History out of the garden, the river and hereabouts that tell us the story of “**OUR PA.”**
We know by the feel of the ground we walk upon that this is the true site of a once great fortified Pa.
Every little piece discovered here, links us to the people who left it to us.
Some of the ancient fortifications still faintly visible after the big easterly gales.
The authenticity of it being a Pa never in question, -- “and it is ours.”
Now I could shed tears, to think these treasures we children found, were thought so little of to be given to some “**WHEEDLING PAKEA”** for his own prized collection!
(Mum dearest Mum, you were much too kind.
You gave away our history.)

Here, Nan reflects on the ways that our whakapapa are nestled within the whenua and preserved in the layers of the earth. The unearthing of these objects, broken and unfamiliar yet instantly recognisable as a connection to our past, serves as a reminder of our simultaneous position in temporality and permanence. Referencing the wave washed mud and wind, Nan reminds us of the environmental dimensions that sit outside of human time reinforcing our connection to our ancestral lines, our whenua and our awa. Nan also highlights how meanings attached to items can change over time – how tools once crafted for utility, become prized treasures of ‘the Ancient Ones’ when placed in the hands of an inquisitive mokopuna. The memories held within *Children of the Pa* act as the metaphoric earth beneath my fingernails. They connect me to my Nan, and she connects me to the Ancient Ones.

A second key distinction lies in the structuring of relationships and connection between people and our more than human relations (Burgess & Painting, 2020). Though every living organism can technically have genealogy, in Pākehā knowledge systems, for non-human beings, these are often understood as evolutionary phases and are regularly siloed – meaning the relationships across species is not always recognised. In te ao Māori, we are intimately connected with our non-human relations through whakapapa (Barlow, 1994; Burgess & Painting, 2020; Evans, 2020; Salmond et al., 2019). Salmond, Brierly and Hikuroa (2019) explain that the different ways that we (Māori and Pākehā) relate to our environments has its origins in our creation stories. In explaining our relationship with waterways, they state:

> In te ao Māori – ancestral Māori ways of living – rivers and lakes are the tears of Ranginui, the sky father, mourning his separation from Papatūānuku, the earth mother, and people are their descendants, joined in their complex whakapapa that links all forms of life together (Salmond et al., 2019, p. 45).

This is then contrasted with the Genesis story in Christian traditions where God gifted Adam and Eve with dominion over the earth and all non-human life forms were created for human purposes.

These two radically different understandings of human relationships with our environments are also present in Nan's story below.

TREES OF HAURAKI

Our parents tell us that all that land, all that empty space that we look upon as far as the eye can see, once belonged to Our People.

The way they tell it. It was once covered with great majestic trees that stood shoulder to shoulder as they marched together from one side of Hauraki to the other, like noble chiefs defending their land, holding it firm for the joy of their people, their heads in the clouds as they sifted the rain.

Green and bright as the waves of the ocean, so said Granny All as she told us with tears shining between the wrinkles of her wise old eyes.

That carried the moon like a child on their shoulders,
The stars to shine like jewels in their hair.
That gave us canoes fuels and shelter
That sang in the wind and lulled us to sleep
Wave after wave, fold after fold,
To the farthest horizons, no boundaries to hold
In their sun speckled shadows a thousand birds sang
Kauri, Totara, Rimu, Puriri, Matai all of those others
Where are they now? – says old Matuku,
Fed to the axes, saws and the mills
While the mills sang in glee that were hungry for trees
The song of the mills was heard far and wide
Their greed never ending, never appeased
'Till the land was laid bare to the gaze of the stranger
As hungry for land as the mills for the trees
Where are they now, so say the children?
The trees of Hauraki, where are they now?
The white man knows, they will soon tell you
Gone to the axes, saws and the mills
Gone to the world for its use and it's needs,
Timber for houses and ships of the sea
Tables and chairs for mansion and cottage
A hundred new ways for the trees of Hauraki
A hundred new lands where the timber will be.
In churches and halls and fine polished walls,
Panels and furniture fit for a queen.
While the lands of Hauraki sells cheap to the stranger A new breed of people with new words and ways
And new kinds of trees on the land of Hauraki
Where cattle and pigs and horses are seen

"That carried the moon like a child on their shoulders – and the stars to shine in their hair." "That gave us canoes fuel and shelter. "That sang in the wind and lulled us to sleep." Exchanged for timber, blankets, biscuits and guns??

[…]

For some reason or another, one large Kahikatea tree had been spared from the mill. It was a "Truly Magnificent Tree" – Sometimes for some special Tapu, the Maori would believe a certain tree had spiritual significance and it must not be cut or injured in any way. So here stood this "Noble Tree"

[....]

I was so upset to hear older Maori talking about "My Tree"… They were saying it was dying at the heart and should now be felled

[…]

Our Granny All would mourn the tree as though it was a loved Ancestral Chief, dying, even though it looked so strong and green.

[…]

Granny gathered all our little commune together before she went back to Coromandel, for the special ceremony of farewell to the tree. As far she was concerned it was an ancestor.

This would be one of those real emotional Maori rituals and are apt to become too much so, aue – aue and all, we had to listen to the old time thing, that the Kuia have known all their lives. They the ones that kept the proper tradition alive with great regret and sadness. Oh Tree, aue, aue, what a wonderful ancestor you have been. Knowing in your time our greatest ones, out living them all. Watching over their children from your own great height, filling their lives with the strength of the trees, your own children, holding them all together. Alas, alas your greatness has been, and now sadly come to an end, but you will not lie

rotting on the forest floor, you will be renewed a hundred different ways. With new life in the timber saved from decay that would have befallen your magnificent body.
There will be many beautiful things come from your body, and timber for ships of the sea.
It will be blessed with usefulness and we will rejoice in the kindness bestowed upon us.
.
This noble gift will be remembered for the gifts it has left.
This is a very emotional thing and no one could participate without feeling a real spiritual surge, weeping like it is a real living being which we now farewell.
This could be the last one of the noble Trees of Hauraki and worthy to be fare-welled by one of Hauraki's oldest and most respected Kuia

In this story, Nan brought that Kahikatea in to our whakapapa as a tupuna. This is not uncommon in te ao Māori, where maunga, awa and rohe are often referred to as tupuna. In fact, in 2014 following lengthy Treaty settlement negotiations, Te Urewera, the largely densely forested region that is the heart of Tūhoe iwi in central North Island, was the first natural feature in Aotearoa New Zealand to be granted legal personhood, meaning the region has the same legal status as an individual does. In 2017, the Whanganui Awa was granted the same legal status, an international first for a river, and an agreement was made between the government and Taranaki iwi that expressed the intention to bestow personhood status on Taranaki maunga. This allows for the mana whenua in those rohe to be able to protect these natural features as their tupuna. Legal personhood is one way that iwi have actively sought to protect their awa, maunga and rohe, however there are also elements of lore or tikanga which protect our more than-human relations. Rāhui or the act of protecting through prohibition (discussed in chapter eight) is one example. Hoskins and Jones (2017) articulate this connection of all things in the following way:

> The identity of 'things' in the world is not understood as discrete or independent but emerges through and relates to everything else. It is the relation, or connection, not the thing itself, that is ontologically privileged in indigenous and Māori thought. Indeed, the general term for Māori people, tangata whenua, refers literally to land-earth-placenta-human: each forms of the other. So, the vitality of things is possible not because of the intrinsic qualities of one object alone but because of its relationship with the mauri of others. (p.53)

Our connection as Māori to the whenua is intrinsic and is present in our creation stories. The first person, Hine-ahu-one (meaning earth formed woman), was moulded from the clay like earth in Kurawaka and made to resemble the curves of the 'Earth Mother' Papatūānuku (Royal, 2007). In this case, our tupuna are of the earth and, therefore, so are we.

In the literature, whakapapa is held in the highest esteem. It is intimately connected with key Māori concepts like mana, tapu and mauri and is commonly accepted as essential for Māori wellbeing. Conceptually, whakapapa is what structures relationships in te ao Māori placing emphasis not on individuals, but on the collective and the responsibilities that are tied to our belonging within whānau, hapū and iwi units (Lawson-Te Aho & Liu, 2010). Knowledge of one's whakapapa is understood to be an important expression of Māori identity and connection to kinship networks (Mahuika, 2019). Barlow (1994) for example, emphasises the importance of whakapapa in the following way:

> Whakapapa is one of the most prized forms of knowledge and great efforts are made to preserve it. All the people in the community are expected to know who their immediate ancestors are, and to pass this information on to their children so that they too may develop pride and sense of belonging through understanding the roots of their heritage. (p. 174)

In this quote, Barlow (1994) ties knowledge of one's whakapapa to a sense of pride and belonging. This raises two questions of pertinence to this particular chapter; what happens when there has been a violent intrusion in a whakapapa line? And, if pride can be derived from knowing your whakapapa, is it equally the case that shame can be derived from not knowing too?

State and the Severing of Connection to Whakapapa

The following section goes some way in responding to the questions above. It was an emotionally challenging section to write, and I feel there is no real way to fully prepare the reader for the next story. So instead, I invite you to sit with me and my Nan and hear this story of Hauraki as hard and as painful as it may be. I want you to know that through the pain and loss, we survived.

WHITE FATHER- WHITE PREJUDICE

It gives me great pain to even put pen to paper for this, but it is based on truth and part of my family history I will give here the bare scenario, which is somewhat complicated and not too easy to place the coherent facts together that are really a story of their own.

It concerns, White Husband, Maori Wife.

Cruelty of White Husband to her small Maori Child.

White husband marries Maori Wife who has been previously married to a Maori Man, to whom she has several children.

White husband dislikes these children – can't stand them, so most of the time they go to stay with relatives.

Then the couple have a baby daughter, Gertrude Violet.

The wife has medical problems and has a personal appointment at the Hospital, leaving the Husband with the youngest Maori child and their own baby daughter.

She arrives home to find her little Maori girl screaming in terrible pain, badly burned on her back and bottom.

The wife rushes her to Hospital, the burns are quite horrific. The Doctor finds Kerosene has been rubbed on her burns! !

Wife has to spend much time with child at Hospital and caring for her later.

In the meantime, Grandmother (Husbands Mother) takes baby.

Wife's sisters and relatives offer to care for the baby but Grandmother (Husbands Mother) hides her away and will not give her up, not even to the child's own Mother when she comes for her.

White Husband is arrested and charged with intentional injury to Maori child and gets six months jail.

His defence was, she had fallen on the fire and he rubbed Kerosene on the burns thinking that was the right thing to do.

Sarah was old enough to say, he had pushed her and she had fallen backwards onto the fire.

Can you imagine any educated person thinking that Kerosene is a good cure for burns?.

Anyway he got six months for that.

His Mother and their family go for custody of the baby. They state in court that the child's own Mother is not a suitable person to bring up **A WHITE CHILD.**

They get total custody of the baby, even though the father, Ted Boxall is serving six months in jail for cruelty to the other child! (It appears that judge is also prejudice against Maori).

The aunts taking the baby to Auckland. They don't want Maori people near it.

In spite of Mum's white husband having been accused of this horrific cruelty to her little girl, and his family stealing their baby, she still continued a strange sort of love hate relationship with him .

"She never got to see that baby again".

The Maori relatives disapprove of her association and forbid him ever to be seen anywhere near the Pa where she lives.

I was born fourteen years after this happened, my sister Ruth, eight years after me. – was this monster our Father?? … I hope not.

Four children later our Mother is <u>still</u> married to this man.

Sister Sarah wore the scars on her back and bottom until the day she died.

Mum remained married to **<u>THAT MAN</u>** until I was seventeen or eighteen years of age, they then divorced. At that time he wants to marry another woman.

Ruth and I never met our Sister Gertrude Violet until we were old. By that time she had started to seek her family but unfortunately mum had died many years ago.

The White People who had kept her from us had also passed on, their prejudices had died with them. She had been told many and lies about her Mother and other relatives which made her very sad. Pride and Prejudice can do this sort of thing to kind and ordinary people.

Ruth, myself and all of our other Brothers and Sisters were blessed with a kind, loving Mother and our Maori relatives were as good to us as any White Parents and relatives could ever have been.

I have tried hard to write this complicated story in a straightforward manner. I hope you will understand it all.

At first I thought it didn't belong in these pages – but it is all a part of my childhood memories. I had heard bits and pieces of this account many times, but being just a child I thought nothing of it. After hearing further gossip at a later date, it began to make sense, and yet even then not entirely understood.

So much fell into my open ears of their own accord. Me, not listening at keyholes or doorways, but had I been able to put two and two together, there and then the whole painful thing would have been quite clear.

Just as well children do not always comprehend the things that adults go on about, though sometimes I would come out with something I myself never understood, but seemed to grown up people quite surprising to hear repeated by me or by other kids.

Where did you get that?, someone would say, forgetting they themselves discussed that very thing in the hearing of kids.

Adults should be quite aware that kids are good at remembering things long forgotten by adults , often putting things together and coming up with answers that adults would not credit them with.

Yes, I heard about this bloke Ted Boxall and his Mother, who had stolen my Mother's baby all those years ago and would not give her back. Then thinking, this Maori Mother was not good enough to raise her own little **WHITE** child.

Mum had kept Me and my Sister, who was eight years younger than myself, away from **<u>HIM</u>** and **<u>HIS</u>** family.

Ruth and I had never been with Mum when she went to **<u>HIS</u>** place, as she never trusted him or his family not to try and get his other **WHITE** children from her. Needless to say, I never, ever met **<u>HIM</u>**. Yet this Ted Boxall bloke still remained her husband. She had four other children, Elsie, Victor (died in infancy) Myself and Ruth.

Poor Sarah, she wore those scars on her back and bottom until the day she died! It really upsets me to this day to think about it ! !

Was this man really our father? ….. I hope Not!!

The violent severing of connection from whakapapa, like that experienced by Aunt Gertrude in '*White Father—White Prejudice'* is, unfortunately, not an uncommon experience for many Māori in Aotearoa. In the case of Aunt Gertrude, the courts considered that a Māori whānau were not suitable parents for a white child; and that it was in her best interests to be placed with a family that would raise her 'Pākehā'. The logic underpinning that decision mirrored the now infamous sentiment of General Richard H. Pratt (1840-1924), founder of the Carlisle Indian Industry School in Pennsylvania to 'kill the Indian and save the man'. A champion of assimilationist policies, Pratt believed it was possible to 'relieve them of their savagery' and civilise young Indians into white American culture. The separation of children from their parents and wider family network and into Residential schools became critical in the 'civilising mission' (Carlson et al., 2013). Education in name only,[52] residential schools were designed with the expressed intent of interrupting the inter-generational transmission of Indigenous knowledge and destroying the basis of the culture (The Truth and Reconciliation Commission of Canada, 2015). These institutions were operational for 138 years between 1863 and 1998. Poor record keeping means that knowing the exact numbers of how many Indigenous children ended up in residential schools is not possible. It is estimated though that at least 150,000 First Nations, Métis and Inuit students passed through the system (The Truth and Reconciliation Commission of Canada, 2015)). Many of these children never made it back home, some of these children never made it to adolescence. Devastatingly, the unmarked graves of children's bodies from residential schools continue to be found across Canada – so far there are over 1100 (Honderich, 2021; Weisberger, 2021).

In Australia, the Aborigines' Protection Board Act provided the legal basis for the theft of Aboriginal children of 'mixed-race' from their kinship networks. The actions that resulted in what is now known as the 'Stolen Generations' involved the violent rupturing of Aboriginal communities[53]. As was the case with the residential schools in Canada, poor record keeping means that the exact number of children that were stolen is not available. Over time, researchers have attempted to capture the extent of upheaval[54], for example, drawing from data across four separate sources of official record, Read (2006) estimates that in New South Wales alone, around 6225 children were

---

[52] As stated by Moana Jackson in his contextual evidence to the Royal Commission of Enquiry into abuse in state care https://www.abuseincare.org.nz/our-progress/library/v/82/statement-of-moana-jackson

[53] A short documentary overviewing the findings of the bringing them home report can be found here: https://aiatsis.gov.au/explore/stolen-generations#toc-bringing-them-home

[54] A detailed description of key attempts can be found at https://humanrights.gov.au/our-work/bringing-them-home-chapter-2#Heading26

stolen between 1883 and 1969. National health surveys and surveys from the Australian Bureau of Statistics have also attempted to come up with a figure (Human Rights and Equal Opportunity Commission, 1997). In 1989 a national survey of Indigenous Health indicated that 47% of respondents had been separated from their parents in childhood[55] (Human Rights and Equal Opportunity Commission, 1997). Surveys, however, cannot capture the experiences of deceased persons nor can they "…capture the experiences of those people whose Aboriginality is now unknown even to themselves" (Human Rights and Equal Opportunity Commission, 1997, p. 31). In light of the range of figures available to them, the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) indicate that the Stolen Generations has affected anywhere from 1 in 10 to 1 in 3 children, meaning that there are very few Aboriginal families who have been left unaffected.

The stories of the Residential schools in Canada and the Stolen Generations in Australia are eerily similar to our own histories in Aotearoa. These stories are being brought to the attention of the public through the recently established Royal Commission of Inquiry into abuse in state care. The Commission has been tasked with investigating what happened to young people and vulnerable adults in New Zealand institutions between 1950 and 1999. A key distinction between this Commission and those that were established in Australia and Canada, is that there is not a specific focus on Māori as the Indigenous Peoples. However, there is documented recognition by the Commission that Māori were disproportionately impacted by the care system in this period (Abuse in Care Royal Commission of Inquiry, 2020). This is reflected in the numbers of Māori survivors registered with the Commission, representing 25.2% of the survivors.

The failure of the state and mandated authorities such as care institutions to maintain meaningful records has compounded the trauma of Indigenous Peoples who, in some cases, do not even know basic information about themselves. In *White Father – White Prejudice,* Nan remembered how 'so much fell into my open ears of their own accord' – this prompted me to contemplate how we come to know the stories of ourselves in the whisperings of others. Sometimes, those whisperings are loud and embedded in the social fabric of our society and for some, those whisperings are the only reference points of who we are and who we come from. In the Tāwharautia report, published by the Royal Commission, some survivors shared that they had been told their records no longer existed (Abuse in Care Royal Commission of Inquiry, 2020). Where records were available, there were some survivors who:

---

[55] This finding includes a disclaimer that this figure should be read with caution as 'separation' also referred to hospitalisation and juvenile detention and could also include time spent living with family members other than parents

> …expressed resentment at receiving copies of their records that were full of redacted or blacked-out sections, thereby frustrating efforts to learn what was held on file about them. Many of those who received unabridged copies said they felt their records had been altered and did not fully reflect their experience in care. (Abuse n Care Royal Commission of Inquiry, 2020, p. 64)

The testimonies of survivors, and the reports produced by the Commission so far, highlight the significant gaps in the data, which limit the ability to paint a complete and accurate picture of the level of harms produced by the state in the period being investigated by the Royal Commission. Despite a general failure of the system to collect relevant and necessary data on the number of Māori children in care during this time, there is widespread acknowledgement that Māori have been historically over-represented in state care (Keddell & Hyslop, 2019; Stanley, 2016; Waitangi Tribunal, 2021a). This was alluded to in the Pu-ao-te-ata-tu report in 1988 and continues to be an ongoing concern in 2021 (Waitangi Tribunal, 2021a). There is an interesting point to be made here about who counts and what is counted. They were not counting how many tamariki Māori were being forcibly removed from their whanau yet were collecting ethnicity data in the Department of Corrections, the Department of Social Welfare, and the Ministry of Education. This is somewhat unsurprising as the data collected by these agencies could be broadly categorised as 5D data and as such could contribute to the construction of the statistical Indigene.

Reports like 'More and More Maoris' and the Hunn Report, produced by the State in the 60s capitalised on the statistical Indigene to promote an assimilatory or integrationist approach to the 'Māori problem'. The Hunn Report for example, made explicit that relative to Pākehā, Māori had lower life expectancy, higher rates of unemployment and were much less likely to participate in higher education (Walker, 2016). Despite producing a range of recommendations geared at integration, in the 1980s reports like Puao-te-ata-tu (1988) and He Whaipaanga Hou (1988), highlighted a continued failure of the system to address the over-representation of Māori in these negative social indicators. For the purposes of this chapter, Puao-te-ata-tu was a particularly important report. In this report, deficiencies in the child protection legislation were identified. Within the report, the voices of Māori were included to highlight the impact that racist policies were having on whanau, hapū and iwi and therefore whakapapa. In what the report described as a 'litany of sound', the following quotes were placed to communicate the expressions of grief and frustration expressed by Māori regarding the then Department of Social Welfare:

"Department has taken over children in large numbers"
"Violence done to tribal structures; violence done to cultural values"
"Their childcare processes are undermining the basis of Maori [sic] society or have already done so"

> “People have been institutionalised and rendered helpless”
> “Rendered children and parents helpless at a great cost to racial, tribal and personal integrity”

A key outcome of the Puao-te-ata-tu report was the Children Young Person and their Families Act, which was an attempt to create legislation that reflected the recommendations of the report. Despite this, Māori have continued to be disproportionately represented in child protective services.

It is now commonly accepted that trauma and its effects are passed down inter-generationally and that we, as Māori, still wear the burdens of colonial trauma (Lawson-Te Aho & Liu, 2010). Reading and writing out **WHITE FATHER --- WHITE PREJUDICE** was traumatic. My heart ached for my nannies, I sobbed a guttural sob, the kind that leaves your body exhausted, the raw flow of hupe and roimata as I felt the violent loss of connection. A loss that was immediate for Nanny Lottie, Nanny Gertrude, Nanny Hera and ‘Old Nana Ryan’ as I her knew her as a moko. But it is not as simple as a loss of connection to kinship links, it can often also mean disconnection and alienation from the wider culture. When I first connected this pūrākau to my research, I spoke to my māmā about my intention, and she shared with me that she was a teenager before she knew she was Māori. Loss of connection to whakapapa and te ao Māori can produce serious and severe consequences and has been linked to negative social outcomes such as disproportionately high rates of suicide (Lawson-Te Aho & Liu, 2010). However, Linda Tuhiwai Smith reminds us that the courage and resilience of our ancestors is also carved into our bones, etched into our whakapapa. The strength and resilience of my nannies in this pūrākau is the same strength and resilience that I draw upon every day, it is the strength and resilience that pulled me through the despair I retold in my privacy chapter.

Iwi Māori Reasserting Data Sovereignty over Whakapapa

The Treaty settlement context has necessitated the development of iwi databases to keep a record of registered members meaning most, if not all, iwi keep such records (Walling et al., 2009). Whakapapa register data is a significant resource in allowing iwi to support their members, especially when many Māori live away from their traditional tribal rohe. The value of these databases has been highlighted as iwi have become critical in the COVID-19 response. Where some iwi, like my own, were able to use the database to reach out to registered members to do wellbeing checks, other iwi utilised the data to get kai parcels out to kaumatua. Here we see how whakapapa is not just about relationships and connection, but about a responsibility and ethic of care attached to that relationship.

Robust whakapapa databases have also been important in the protection of tamariki Māori whose whānau have been brought to the attention of Aotearoa's child protection agency Oranga Tamariki (OT). At the time of writing this chapter, OT had strategic partnerships with Ngāi Tahu, Ngāpuhi, Waikato-Tainui, Ngāi Tūhoe and Ngāti Kahungunu, as well as a Memorandum of Understanding with Ngāti Porou and Ngāti Tūwharetoa. Each partnership is unique and has been designed with iwi leaders. Ngāi Tahu, for example, have whānau care arrangements that are established to ensure that in instances where uplift is considered the safest option for tamaiti, the goal is to place mokopuna in the care of whānau, hapū or iwi members. Whānau care is also part of the official relationship that OT have with Te Rūnanga-ā-iwi-o-Ngāpuhi. Other iwi like Ngāi Tūhoe, have agreements which require OT to notify the iwi when Tūhoe children come to its attention (https://www.ngaituhoe.iwi.nz/Protection-for-Tuhoe-tamariki). Chief negotiator for Tūhoe, Tamati Kruger, made the following comment about the partnership:

> Tūhoe's knowledge of whakapapa and our families means that we can provide insights into wider whānau and hapū connections than a state agency could be expected to be aware of and find safe and loving homes connected to our children (ngaituhoe.iwi.nz, 2019).

The lifelong benefits of these partnerships are not yet measurable as the agreements are young, however, they do provide an example of the potential that arises when Māori have control over their data assets.

Whakapapa in Data Governance

Given the significance of whakapapa in te ao Māori as a tikanga, a research tool and as an organising principle, it is unsurprising that it is a key feature of Māori ethics frameworks generally and Māori data governance models more specifically. Te Ara Tika guidelines for Māori research ethics (Hudson et al., 2010), for example, identify whakapapa as one of four tikanga underpinning a Māori ethical framework (alongside mana, tika and manaakitanga). Within this framework, whakapapa is a principle used to refer to the importance of relationships in the research process, and the responsibility that emerges once a relationship has been established. The practice of consultation is considered the bare minimum for ensuring the ethic of whakapapa is upheld, engagement constitutes good practice and kaitiaki is best practice. Te Mana Raraunga (2018) also include whakapapa as one of the six key overarching principles of Māori Data Sovereignty:

> **Whakapapa | Relationships**
>
> 2.1 *Context.* All data has a whakapapa (genealogy). Accurate metadata should, at minimum, provide information about the provenance of the data, the purpose(s) for its collection, the context of its collection, and the parties involved.

> 2.2 *Data disaggregation*. The ability to disaggregate Māori data increases its relevance for Māori communities and iwi. Māori data shall be collected and coded using categories that prioritise Māori needs and aspirations.
>
> 2.3 *Future use*. Current decision-making over data can have long-term consequences, good and bad, for future generations of Māori. A key goal of Māori data governance should be to protect against future harm. (Te Mana Raraunga, 2018)

The principles do not, in and of themselves, constitute a data governance model, however, they do form the basis of many frameworks, guidelines and models including the Te Mana o te Raraunga model (Hudson et al., 2017), the He Tangata kei tua Model (Hudson et al., 2016), and the mana-mahi framework (Te Mana Raraunga, 2018).

The Ngā Tikanga Paihere framework, which governs access to the Integrated Data Infrastructure (discussed in greater detail in the literature review chapter), uses whakapapa to emphasise the status of the researchers' existing relationship with the data and the communities of interest. It goes further to also consider:

- How these relationships will be leveraged to ensure insights and community perspectives contribute and add value to the research.
- Stakeholder engagement, including processes that allow communities to engage with researchers throughout the research lifecycle.

A significant factor discussed in the literature, which is not necessarily captured in the guidelines and frameworks mentioned here, is how relationships, whether they are new or pre-established, create a responsibility on behalf of the researchers. It is important at this point to acknowledge that there are principles within these frameworks which emphasise researcher responsibilities to 'communities of interest'. I contend that this is a critical shortcoming of the current governance frameworks.

Concluding Thoughts:

We now have decades of accumulated data, a lot of which is sketchy at best. This data indicates that Māori are significantly over-represented across a range of negative indicators. This data has informed research and reports that indicate the magnitude of the problem. There is a vast body of knowledge now that demonstrates that Māori are not the problem, but that the root of the problem is in broader oppressive systems and structures. The validity of this knowledge is only strengthened by the fact that the experiences of Māori in Aotearoa New Zealand are reflected in the experiences of Indigenous Peoples globally. In the past, with data in hand, government reports have suggested that the best option for moving forward is forced assimilation of Māori in to Pākehā society. In this case, if parents were a lost cause, then at least we could save the children, by uprooting them from their whānau and placing them in ‘care’ institutions. We see that so far, these systems have demonstrated an ability at maintaining the status quo and continuing to produce the same devastating outcomes for Māori.

The PhD journey is a complex one, and while each individual’s journey will be unique and specific to that person, there are some key features which appear, on observation to be shared across the board, certainly amongst the students I had the privilege of sharing space with. For example, there is a general sense of imposter syndrome and the incessant inner questioning of whether there is any value in your research and whether it is worthwhile doing it. I really struggled with this question. There are many reasons for this. Reading my nannies’ stories, I realised the value of my mahi, data are more than singular observation points as they are often purported to be. They cannot be time-stamped as a reflection only of the present because all data has whakapapa. This story is a story of Hauraki.

Chapter Ten: Discussion

*It's dark outside tonight. My living room [read office] is illuminated by the blue light of my computer screen. My eyes have sunken in, rimmed red and bordered with deep purple circles signalling sleep deprivation. My mind wanders off – when was the last time I watered the plants? I should put some washing on while I'm here, what's the time? 3:30am, *groans* I'm going to be tired at the gym tomorrow. Head in hands now - FOCUS! Every so often I remind myself to relax my tensed shoulders and breath. I'm anxious, I want to give up – but the light at the end of the tunnel beckons me – I'm almost there.*

I'm writing the final chapter of my thesis – the discussion and concluding thoughts. This is where I have to make it make sense – connect the dots and make it cohesive. This is the final hurdle before I release my mahi. This is my final story – it is a story about writing a story.

I remember when I first thought it would be a good idea to do storywork as a core feature of this thesis. I was at a writing retreat with other Wāhine Māori also doing PhDs – Inspiring. I was applying for a scholarship extension (see chapter 7), and I was exhausted, angry, and broken. I had the bones of my thesis in place but every time I thought about it, I was left wanting, there was something missing – I needed more meat on these bones.

An intensely raw and honest conversation with one of the most resilient, awe inspiring, loving wahine I know made me realise that I was living out my thesis.

I had spent all of this time writing about the relationship between privacy and vulnerability, the audacity of the state to demand our trust and the cruelty of a system that writes our stories before telling us we can't read them. But these were not abstract concepts that apply to 'us' [read Māori] in the royal sense – they were happening to us, to me and my whānau – and I saw myself reflected in my mahi, I saw meat on these bones.

It inspired a passionate response in me – I put pen to paper (metaphorically – more like fingers to keyboard) and for the first time my writing flowed – it flowed like the river that carried Nan from Duck Creek to Thames in her stories. I was excited and I felt like these stories would strengthen my research even more. I spoke to my supervisors about my idea – they liked it. I let out a breath I didn't know I was holding.

I have spoken to the struggles I had with making decisions about what to include, and whether it was ok to share these things in a public forum – and these moments were challenging. There were beautiful moments in the process where I felt a deep and intimate connection to my Nan that I never felt when she was with us ā-tinana. Then there were times that my emotions overwhelmed me, and I wrote from a place of fury and frustration – a big F you to the system. In these times, the writing flowed rapidly like the awa that carried Nan's sister Elsie away – treacherous and terrifying.

Still, I was emboldened in these moments, I felt powerful, and like my work mattered.

Now though, it has dawned on me, in a way that I had not anticipated, that very soon, someone will read this, and they will know about lost land, lost language, lost dignity and lost babies.

Do they see me differently now? Do they judge me? Is their pity in their eyes? Did they stop talking when I walked in the room? Was this what I really wanted?

Nan says, ***TRUST NOT THE RIVER,*** *maybe she was right:*

Deep river, wide river running so still.
Quietly flowing by farm and green hill.
Beguilingly tranquil, glossily calm,
Serene reflections, the joy of its charm!
Green hills, green trees, blue face of the sky,
On its bright mirror surface so peacefully lie.

I know well this river, its great force and might,
So deceptively hidden away from our sight.
Trust not the river, with shimmering sheen.
It's a witch, it's a bitch, it's ugly and mean.
It has teeth, it has claws, it can be a fiend.
With its dark under-tows, though it looks so serene.

Trust not the river, though gently it flows,
Be wary, and watch the way that it goes.
It may rush through your house when you least expect it,
Then run on its way when its rubbished and wrecked it.
Yes, I know this river, the way that it flows,
It can burst through its banks and rampaging goes.

It loots like a vandal, takes what it will,
It even comes up to my own window sill.
It says "How do you do? What have you got?
I've come here for loot and I'm taking the lot!"

A Ryan

I've dipped my toes in the river, but It's dark outside, I can't see where I am going, or what lies beneath the surface. Has the water always been this freezing? I thought it was warming up! This is tough.

This thesis is itself an act of Māori Data Sovereignty. Chapter six: *Indigenous Data Sovereignty* highlighted how ID-SOV has established itself as an independent field of inquiry, research, activism, and action. I indicated small and significant shifts happening in the context of Aotearoa New Zealand, linking these in with important global ID-Sov movements. These are largely ‘big-picture’ changes, pushing to assert our rights as Māori and Indigenous peoples in an increasingly digital world. In the three-and-a-half years that I have been doing my PhD, I have been in a range of different social settings where I would often be asked what do I do? and what does that mean? I have become very adept with my PhD elevator pitch; the conversation often went like this:

> **What do you do for mahi?**
>
> *“I’m doing a PhD, based in Māori studies looking at data sovereignty*
>
> **...oh... I have no idea what that means**
>
> *Oh, well I’m interested in understanding the types of relationships that we have with the information that exists about us, like government data and data that is accumulated from our engagement with social media – stuff like that. And the types of relationships we want other people like policy makers and researchers, to have with our data, and whether it’s possible to govern access to the data in such a way that recognises the importance of data for development, but also our rights as kaitiaki*
>
> **... hmm, ok... cool**

Often, this is where the conversation would end, as their eyes searched the room desperate for an out. What I learnt in these conversations is that despite the fact that I was spending all of my time contemplating the huge impact and influence that data has on our day-to-day lives – both in its minutiae and in large-scale decision making – data sovereignty is not conceptually relevant to most people. Most people had no idea that the IDI existed, most would not have known that if they were injured at work and needed ACC cover those decisions about access would be fully automated, most people (myself included) accept all cookies, all privacy policies, and all terms and conditions (without reading) to be able to participate in their online activities.

This thesis offers a unique and generative contribution to the broader MD-Sov discourse, as it takes these concepts, often discussed in distinctly ‘high-level’ places (for example in universities, policy sectors and at the iwi level in decision-making bodies) and demonstrates how they impact us in our everyday lives. In sharing my personal entanglement with data sovereignty issues, there is a shift away from viewing ‘Māori’ as a particular group represented in datasets, towards seeing ourselves as Māori and our whānau as Māori being [re]presented in datasets. Often, these datasets are comprised of what Maggie Walter refers to as 5d and BADDR data. These were discussed in

Chapter Three: *Defining data* as obstructive datasets that sit in a cyclical vacuum reproducing the harm they cause.

The power of these harmful datasets to significantly influence our lives is heightened in political environments where there is a strong emphasis on evidenced-based policy as well as targeted interventions. Further, as Chapter Five: *Ethics of data use* highlighted, there is an increasing capacity and appetite for data-linking in Aotearoa New Zealand within research, policy, and political spaces, which serves to strengthen claims that intervention is urgent At the same time, we, as individuals have diminishing capacity to opt-out of participation in the digital world and many forms of data collection, this has only been exacerbated in the context of COVID-19. Importantly though, COVID-19 did not create this diminished capacity, especially for Māori.

When we talk about data, there is a tendency to imagine it in purely numeric forms sitting in predominantly digital spaces. However, we know that Māori have always been active in the collection, storage, analysis, and transmission of data in a multiplicity of forms. The fact that we still have stories as evidence of navigational feats is one example of this. Data as a concept also has a rich history that pre-dates the computer revolution, overviewed in Chapter Four: *Data as a gift, from a given to a taken.* In that chapter, the etymology of data as a gift was considered in parallel to Māori conceptualisations of gifts and gifting from a tikanga perspective. Critical to this discussion was a consideration of the way that koha as a particular form of gifting is premised on the importance of relationships and relationality. To receive a gift then is to also receive the responsibilities and obligations associated with that gift. A second critical element of gifting, theorised in Chapter Four, was that when something was gifted, this did not alienate the gift from the giver, nor did it transfer ownership to the receiver. This is point is particularly important when we are thinking about data as a gift, whakapapa as an illustration of gift and data shows the complexities of the ways in which Māori conceptualise, protect, and enact data (sovereignty).

Perhaps it is time, to revisit our tikanga and insist that in keeping with the tradition of koha, it is time to whakahokia te taonga: to return the gift, or at the very least renegotiate the terms for continued use and access to our taonga. Gifts are characterised as being freely given; however, we saw in Chapter Seven – *Case Study One: Privacy and COVID-19,* that in our current westernised socio-political environment, this is rarely the case; that often data is taken. The ways in which Māori are constructed as vulnerable in racialised colonial structures aids in the taking of data. Especially when we need to turn to the state for support. The expectation of high levels of disclosure and the performance of pain by Indigenous women in particular is as an affront to our dignity and our inherent tapu as individuals and as Māori. Chapter Seven introduced the placement of rāhui as a means to protect that which is tapu. In this case, I propose that rāhui, in expansive forms, should be put in place by Māori to protect Māori data, while we (read Māori) work toward developing the necessary governance mechanisms to ensure that our digital future is safe and supports the ongoing flourishing of Māori.

The temporary restriction on access to Māori data would allow the time and space we need to shift out of the continuous reactionary mode we have been in, to think about our future data needs and rights. It could be argued that if we did this, Māori would be 'left behind'. Yet if we consider recent developments in ADM technology discussed in Chapter Eight – *Case Study Two: Trust and automated decision making,* we are already being kept behind. Systems designed to reduce the impact of human bias, were shown to actually maintain the racism, yet remove the human accountability. Continuing to invest in these systems and to build them on top of inaccurate and deficient datasets runs the risk of making racism and discrimination even more insidious in that it looks like the output of a neutral and objective machines.

Finally, Chapter Nine: *Whakapapa and Access* considered how many have made obstructed from their own stories. Some of these stories inform the machines discussed in Chapter Eight, serving to perpetuate harm and to recreate themselves in a series of feedback loops. Change needs to happen and fast. Drawing upon the stories in Children of the Pā was healing. My whakapapa was the first gift I would ever receive, it was the story I could tell before I could speak. Gifted to me by my grandmothers to carry with me through life and to be gifted to my own children. It may be given but will never be taken from me.

As a Māori researcher, theorising Indigenous data sovereignty has been a series of journeys, through the pā, down, around, and across the river, transcending westernised notions of time and space, through layers of papa. In theorising Indigenous data sovereignty, the use of pūrākau, and storywork, our data, in the multiplicity of forms it is created, maintained, protected, gifted, and treasured, have illustrated the complexity within which our data is embedded with all that we are, and the right and responsibility we have to ensure it remains sovereign.

The struggles I have had in deciding what to include, whether it was ok to share our stories in such a public forum, all stages of the journeys, are enactments of reclamation and sovereignty.

> *Do they see me differently now? Do they judge me? Is their pity in their eyes? Did they stop talking when I walked in the room? Was this what I really wanted?*
>
> *They see me differently now. They judge me. No pity in their eyes. They start talking when I walk in the room, of Indigenous data sovereignty, of rivers, and pā, of whakapapa and time, of koha and givers, of pūrākau and kōrero. This is what I really wanted.*
>
> *Living, breathing, changing, expansive, data sovereignty.*
>
> *Nan says,* ***TRUST NOT THE RIVER,*** *maybe she was right:*

I’ve dipped my toes in the river, it’s dark outside, but I know where I am going even if I can never know the entirety of what lies beneath the surface. The water is warming up. This river is my own.

References

1000 Minds. (2020). *Covid-19 prioritization | 1000minds*. https://www.1000minds.com/sectors/health/covid-19-prioritization

Abuse in Care Royal Commission of Inquiry. (2020). *Tāwharautia: Pūrongo o te Wā - Interim Report*. Abuse in Care Royal Commission of Inquiry. https://www.abuseincare.org.nz/assets/Uploads/Abuse-in-Care-Volume-One.pdf

Ackoff, R. (1989). From data to wisdom. *Journal of Applied Systems Analysis*, *16*, 3–9.

Adams, T. E., & Jones, S. H. (2008). Autoethnography is queer. In N. K. Denzin, Y. S. Lincoln, & L. Tuhiwai Smith (Eds.), *Critical Indigenous Methodologies* (pp. 373–390). Sage.

Ahluwalia, M. (2020). *Genetic privacy: We must learn from the story of Henrietta Lacks*. New Scientist. https://www.newscientist.com/article/2250449-genetic-privacy-we-must-learn-from-the-story-of-henrietta-lacks/

Apatov, E. (2019). *The drivers behind the higher NEET rate for Māori and Pacific youth: Insights from administrative data*. [Occasional Paper 19/02]. Ministry of Business, Innovation and Employment. https://www.mbie.govt.nz/dmsdocument/10355-the-drivers-behind-the-higher-neet-rate-for-maori-and-pacific-youth-main-report

Araujo, T., Helberger, N., Kruikemeier, S., & de Vreese, C. H. (2020). In AI we trust? Perceptions about automated decision-making by artificial intelligence. *AI & SOCIETY*, *35*(3). https://doi.org/10.1007/s00146-019-00931-w

Archibald, J., & Parent, A. (2019). Hands back, Hands forward for Indigenous storywork as methodology. In S. Windchief & T. San Pedro (Eds.), *Applying Indigenous Research Methods: Storying with Peoples and Communities* (pp. 3–20). Routledge.

Arnold, B. B. (2015). Dignity, trust and identity: private spheres and Indigenous intellectual property. In M. Rimmer (Ed.), *Indigenous Intellectual Property*. Edward Elgar Publishing. https://doi.org/10.4337/9781781955901.00031

Arora, P. (2019). Decolonizing Privacy Studies. *Television & New Media*, *20*(4). https://doi.org/10.1177/1527476418806092

Atkinson, P. A., & Coffey, A. (2004). Analysing documentary realities. In D. Silverman (Ed.), *Qualitative research: Theory, method and practice* (2nd ed., pp. 56–75). Sage.

Auckland University of Technology. (n.d.). *Applying for ethics approval: guidelines and procedures*. Retrieved May 27, 2021, from https://www.aut.ac.nz/research/researchethics/guidelines-and-procedures

Austin, C. C., Bernier, A., Bezuidenhout, L., Bicarregui, J., Biro, T., Cambon-Thomsen, A., Carroll, S. R., Cournia, Z., Dabrowski, P. W., Diallo, G., Duflot, T., Garcia, L., Gesing, S., Gonzalez-Beltran, A., Gururaj, A., Harrower, N., Lin, D., Medeiros, C., Méndez, E., … Uhlmansiek, M. (2021). Fostering global data sharing: highlighting the recommendations of the Research Data Alliance COVID-19 working group. *Wellcome Open Research*, *5*, 267. https://doi.org/10.12688/wellcomeopenres.16378.2

Austin, P. C., Mamdani, M. M., Juurlink, D. N., & Hux, J. E. (2006). Testing multiple statistical hypotheses resulted in spurious associations: a study of astrological signs and health. *Journal of Clinical Epidemiology*, *59*(9), 964–969. https://doi.org/10.1016/J.JCLINEPI.2006.01.012

Bakker, L., O'Malley, J., & Riley, D. (1999). *Risk of reconviction: Statistical models for predicting four types of re-offending* . Department of Corrections. https://www.corrections.govt.nz/__data/assets/pdf_file/0020/10667/roc.pdf

Ballantyne, A. (2019). Adjusting the focus: A public health ethics approach to data research. *Bioethics*, *33*(3). https://doi.org/10.1111/bioe.12551

Barlow, C. (1994). *Tikanga whakaaro: Key concepts in Māori culture*. Oxford University Press.

BBC Asia. (2020). *Covid-19: Singapore woman jailed for hiding meetings with male friend - BBC News*. https://www.bbc.com/news/world-asia-55579775

Bell Gully. (2021). *Offshoring New Zealand Government Data: A report prepared for Statistics New Zealand*. Statistics New Zealand. https://www.data.govt.nz/docs/report-offshoring-nz-govt-data/

Bellinger, G., Castro, D., & Mills, A. (2004). *Data, information, knowledge and wisdom*. http://www.systems-thinking.org/dikw/dikw.html

Benefits Review Committee v XXXX. (2017). NZSSAA 062.

Benjamin, R. (2013). *People's science: Bodies and rights on the stem cell frontier*. Stanford University Press.

Benjamin, R. (2019). Assessing risk, automating racism. *Science*, *366*(6464), 421–422. https://doi.org/10.1126/science.aaz3873

Berryman, M., Kerr, L., Macfarlane, A. H., Penetito, W., & Smith, G. H. (2016). *Summary of our education for Māori reports*. https://oag.parliament.nz/2016/education-for-maori-summary/docs/summary-education-for-maori.pdf

Bishop, R. (1995). *Collaborative Research Stories: Whakawhanaungatanga*. (Thesis, Doctor of Philosophy). University of Otago. Retrieved from http://hdl.handle.net/10523/531

Bishop, R. (2008). Te Kotahitanga: Kaupapa Māori in Mainstream Classrooms. In N. K. Denzin, Y. S. Lincoln, & L. Tuhiwai Smith (Eds.), *Handbook of Critical and Indigenous Methodologies* (pp. 439–458). SAGE.

Bishop, R. (2011). *Freeing ourselves* (Vol. 66). Springer Science & Business Media.

Blackstock, C. (2014). *An analysis of the ethical issues for Māori in predictive risk modelling to identify new-born children who are at high risk of future maltreatment*. First Nations Child and Family Caring Society of Canada. https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/research/predictive-modelling/ethical-issues-for-maori-blackstock-review.pdf

Blank, A., Cram, F., Dare, T., De, I., Smith, H. B., & Vaithianathan, R. (2015). *Ethical issues for Māori in predictive risk modelling to identify new-born children who are at high risk of future maltreatment*. Ministry of Social Development. https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/research/predictive-modelling/00-ethical-issues-for-maori-in-predictive-risk-modelling.pdf

Bochner, A. P. (2000). Criteria against ourselves. *Qualitative Inquiry*, *6*(2), 266–272.

Boisot, M., & Canals, A. (2004). Data, information and knowledge: have we got it right? *Journal of Evolutionary Economics*, *14*(1). https://doi.org/10.1007/s00191-003-0181-9

Bowen, G. A. (2009). Document Analysis as a Qualitative Research Method. *Qualitative Research Journal*, *9*(2). https://doi.org/10.3316/QRJ0902027

Brainbox Institute. (2020). *Research insights -Digital Council for Aotearoa: Trust and automated decision-making*. Digital Council for Aotearoa New Zealand. https://digitalcouncil.govt.nz/assets/Uploads/Brainbox-research-insights-automated-decision-making-2020.pdf

Bruhn, J. (2014). Identifying Useful Approaches to the Governance of Indigenous Data. *International Indigenous Policy Journal*, *5*(2). https://doi.org/10.18584/iipj.2014.5.2.5

Budzyn, A. (2019, April 30). *Data is the oil of the digital world. What if tech giants had to buy it from us?* https://www.weforum.org/agenda/2019/04/data-oil-digital-world-asset-tech-giants-buy-it/

Bull, J. (2020). Autoethnography and ethics: Sovereignty, Self-determination and Strategies. In L. George, J. Tauri, & L. T. A. o T. MacDonald (Eds.), *Indigenous Research Ethics: Claiming*

Research Sovereignty Beyond Deficit and the Colonial Legacy (pp. 83–94). Emerald Publishing Limited.

Burgess, H., & Painting, T. K. (2020). Onamata, anamata: A whakapapa perspective of Māori futurisms. In A.-M. Murtola & S. Walsh (Eds.), *Whose Futures?* (pp. 207–236). Economic and Social Research Aotearoa .

Burrell, H. (2021, May 5). *"Abject failure" in government websites' use of Facebook tracking*. Business Desk. https://businessdesk.co.nz/article/abject-failure-in-government-websites-use-of-facebook-tracking

Campbell, D., Boyle, L., Soakell-Ho, M., Hider, P., Wilson, L., Koea, J., Merry, A. F., Frampton, C., & Short, T. G. (2019). National risk prediction model for perioperative mortality in non-cardiac surgery. *British Journal of Surgery*, *106*(11), 1549–1557. https://doi.org/10.1002/bjs.11232

Carlson, N., Steinhauer, K., & Goyette, L. (2013). *Disinherited generations: Our struggle to reclaim Treaty rights as First Nations Women and their Descendants*. University of Alberta Press.

Carroll, S. R., Akee, R., Chung, P., Cormack, D., Kukutai, T., Lovett, R., Suina, M., & Rowe, R. K. (2021). Indigenous Peoples' Data During COVID-19: From External to Internal. *Frontiers in Sociology*, *6*, 70. https://doi.org/10.3389/FSOC.2021.617895/BIBTEX

Carter, B. (2009). Tick box for child? The ethical positioning of children as vulnerable, researchers as barbarians and reviewers as overly cautious. *International Journal of Nursing Studies*, *46*(6), 858–864. https://doi.org/10.1016/j.ijnurstu.2009.01.003

Cavino, H. M. (2019). "He would not listen to a woman": decolonizing gender through the power of pūrākau. In J.-A. Archibald, J. B. Lee-Morgan, & J. de Santolo (Eds.), *Decolonizing Research: Indigenous storywork as methodology* (pp. 95–106). Zed Books Ltd.

Chilisa, B. (2020). *Indigenous Research Methodologies* (2nd ed.). Sage.

Clarke, J. (2015). *Māori Participation and Representation: An Investigation into Māori reported experiences of Participation and Representation within the policy process post-MMP*

Coghlan, A. (2013, March 28). *Storm erupts over publishing of HeLa genome*. New Scientist. https://www.newscientist.com/article/dn23330-storm-erupts-over-publishing-of-hela-genome/

Confessore, N. (2018, April 4). *Cambridge Analytica and Facebook: The Scandal and the Fallout So Far - The New York Times*. NY Times. https://www.nytimes.com/2018/04/04/us/politics/cambridge-analytica-scandal-fallout.html

Cormack, D., Kukutai, T., & Cormack, C. (2020). Not One Byte More. In *Shouting Zeros and Ones: Digital Technology, Ethics and Policy in New Zealand* (pp. 71–83). Bridget Williams Books. https://doi.org/10.7810/9781988587387_4

Couldry, N., & Mejias, U. A. (2019). Data Colonialism: Rethinking Big Data's Relation to the Contemporary Subject. *Television & New Media*, *20*(4), 336–349. https://doi.org/10.1177/1527476418796632

Couldry, N., & Yu, J. (2018). *Deconstructing datafication's brave new world*. *20*(12), 4473–4491. https://doi.org/10.1177/1461444818775968

Coyne, I. (2010). Accessing children as research participants: examining the role of gatekeepers. *Child: Care, Health and Development*, *36*(4), 452–454. https://doi.org/10.1111/j.1365-2214.2009.01012.x

Dare, T. (2013). *Predictive risk modelling and child maltreatment: An ethical review.* Ministry of Social Development. https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/research/predictive-modelling/00-predicitve-risk-modelling-and-child-maltreatment-an-ethical-review.pdf

Davis, M. (2016). Data and the United Nations Declaration on the Rights of Indigenous Peoples. In T. Kukutai & J. Taylor (Eds.), *Indigenous Data Sovereignty: Toward an Agenda* (pp. 25–38). ANU Press. https://doi.org/10.22459/CAEPR38.11.2016

Davison, A., Beetham, J., Thomas, J., Harding, A., Ivory, V., & Bowie, C. (2015). *Public attitudes to data integration: Report prepared for Statistics New Zealand*. Statistics New Zealand

Desjardins, J. (2019). *How much data is generated each day?* https://www.weforum.org/agenda/2019/04/how-much-data-is-generated-each-day-cf4bddf29f

Digital Council For Aotearoa. (2020). *Our terms of reference | Digital Council for Aotearoa*. https://digitalcouncil.govt.nz/about-us/terms-of-reference/

Digital Council for Aotearoa New Zealand. (2020). *Towards trustworthy and trusted automated decision-making in Aotearoa*. Digital Council for Aotearoa New Zealand. https://digitalcouncil.govt.nz/assets/Uploads/FULL-REPORT-Towards-trustworthy-and-trusted-automated-decision-making-in-Aotearoa.pdf

Digital Inclusion Research Group [DIRG]. (2017). *Digital New Zealanders: The Pulse of our Nation: A report to MBIE and DIA*. https://www.mbie.govt.nz/dmsdocument/3228-digital-new-zealanders-the-pulse-of-our-nation-pdf

digital.govt.nz. (2021). *Digital Inclusion user insights - Māori*.

Durie, M. (2017). Kaupapa Māori: Indigenising New Zealand . In T. K. Hoskins & A. Jones (Eds.), *Critical conversation in kaupapa Māori* (pp. 1–10). Huia Publishers.

Edwards, J. (2018, April 3). *Facebook: What this is really about*. Privacy Commissioner Blog. https://www.privacy.org.nz/blog/facebook-what-this-is-really-about/

Enari, D., & Matapo, J. (2020). Pasifika education innovation during the COVID-19 pandemic. *MAI Journal*, *9*(4), 7–11. https://doi.org/10.20507/MAIJOURNAL.2020.9.4.2

Ermine, W., Sinclair, R., & Jeffery, B. (2004). *The ethics of research involving Indigenous peoples*. Indigenous Peoples' Health Research Centre.

Eubanks, V. (2018). *Automating Inequality: How high-tech tools profile, police and punish the poor*. St Martin's Press.

Evans, K. (2020). The River's Lizard Tail: Braiding Indigenous Knowledges with Geomorphology. *Eos*, *101*. https://doi.org/10.1029/2020EO148717

Fagan, K. (2002). "What about you?" Approaching the study of "Native literature. In R. Eigenbrod & J.-A. Episkenew (Eds.), *Creating community: A roundtable on Canadian Aboriginal Literature* (pp. 235–253). Theytus Books.

First Nations Information Governance Center. (2016). *The First Nations Principles of OCAP® - The First Nations Information Governance Centre*. https://fnigc.ca/ocap-training/

First Nations Information Governance Centre. (2016). Pathways to First Nations' data and information sovereignty. In T. Kukutai & J. Taylor (Eds.), *Indigenous Data Sovereignty: Toward an Agenda* (pp. 139–156). ANU Press.

Flyvbjerg, B. (2006). Five Misunderstandings About Case-Study Research. *Qualitative Inquiry*, *12*(2). https://doi.org/10.1177/1077800405284363

Frické, M. (2009). The knowledge pyramid: a critique of the DIKW hierarchy. *Journal of Information Science*, *35*(2). https://doi.org/10.1177/0165551508094050

Furlow, B. (2020, June 13). *A Hospital's Secret Coronavirus Policy Separated Native American Mothers From Their Newborns* . ProPublica. https://www.propublica.org/article/a-hospitals-secret-coronavirus-policy-separated-native-american-mothers-from-their-newborns

Furner, J. (2015). "Data": The data. In M. Kelly & J. Bielby (Eds.), *Information Cultures in the Digital Age* (pp. 287–306). Springer VS.

Gavaghan, C., Knott, A., MacLaurin, J., Zerilli, J., & Liddicoat, J. (2019). *Government use of artificial intelligence in New Zealand: Final report on phase 1 of the artificial intelligence and law in New Zealand project*. https://www.otago.ac.nz/caipp/otago711816.pdf

Gillham, B. (2000). *Case Study Research Methods*. Bloomsbury Publishing .

Gillingham, P. (2016). Predictive risk modelling and other adverse outcomes for service users: Inside the “black box” of machine learning. *British Journal of Social Work*, 1044–1058.

Gillingham, P. (2017). Predictive risk modelling to prevent child maltreatment: Insights and implications from Aotearoa/New Zealand. *Journal of Public Child Welfare*, *11*(2), 150–165. https://www-tandfonline-com.ezproxy.auckland.ac.nz/doi/pdf/10.1080/15548732.2016.1255697?needAccess=true

Gillon, A., West, K., & Ualesi, Y. (2020). Re-thinking Indigenous postgraduate whanaungatanga. *MAI Journal*, *9*(4), 25–29. https://doi.org/10.20507/MAIJOURNAL.2020.9.4.6

Global Indigenous Data Alliance [GIDA]. (2019). Oñati Indigenous Data Sovereignty (ID-SOV) Communique. In *Communique*.

Google. (2019, January 22). *Privacy policy*. https://policies.google.com/privacy

Gorrie, N. (2021, October 12). *Why vaccination presents an ethical dilemma for us, but remains the best way to keep our families safe - Nayuka Gorrie - IndigenousX*. IndigenousX. https://indigenousx.com.au/why-vaccination-presents-an-ethical-dilemma-for-us-but-remains-the-best-way-to-keep-our-families-safe/?fbclid=IwAR3GsRNpGEj5sd2jhQPcPJKoqIhMvMmEDEucCeA3EQ3opEnin5ye8vNT7I8

Goyette, L. (2013). Two strong women begin to tell a story. In N. Carlson & K. Steinhauaer (Eds.), *Disinherited generations: Our struggle to reclaim treaty rights for First Nations women and their descendants*. University of Alberta Press.

Grimes, A., & White, D. (2019). Digital Inclusion and wellbeing in New Zealand: A report to Department of Internal Affairs. In *Motu Economic and Public Policy Research*.

Gulliver, P., Jonas, M., Fanslow, J., McIntosh, T., & Waayer, D. (2018). Surveys, social licence and the Integrated Data Infrastructure. *Aotearoa New Zealand Social Work*, *30*(3). https://doi.org/10.11157/anzswj-vol30iss3id481

Harcourt, D., & Conroy, H. (2011). Informed consent: Processes and procedures in seeking research partnerships with young children. In D. Harcourt, B. Perry, & T. Waller (Eds.), *Researching young children’s perspectives: Debating the ethics and dilemmas of educational research with children* (pp. 38–52). Routledge.

Harmon, A. (2010, April 22). Indian Tribe wins fight to limit research of its DNA. *New York Times*, A1-undefined. https://www.nytimes.com/2010/04/22/us/22dna.html

Hart, L. (2015, December 7). This is what it’s like to be a “bludger” in New Zealand. *Stuff*. https://www.stuff.co.nz/stuff-nation/12421335/This-is-what-its-like-to-be-a-bludger-in-New-Zealand

Health Research Council of New Zealand [HRC]. (2018). *The Health Research Council’s Annual Report 2018: For the year ended 30 June 2018*. https://www.hrc.govt.nz/sites/default/files/2019-09/Annual%20Report%202018.pdf

Henare, M. (1994). Human Labour as a Commodity - A Maori Ethical Response. *Labour, Employment and Work in New Zealand*. https://doi.org/10.26686/lew.v0i0.930

Henare, M. (2018). “Ko te hau tena o to taonga...”: The words of Ranapiri on the spirit of gift exchange and economy . *The Journal of the Polynesian Society*, *127*(4), 451–463.

Higgins, R., & Keane, B. (2013, September 5). *Language decline, 1900 to 1970s* . Te Ara Encyclopedia of New Zealand. https://teara.govt.nz/en/te-reo-maori-the-maori-language/page-4

Hirsch, D. D. (2014). The glass house effect: Big data, the new oil, and the power analogy. *Maine Law Review*, *66*(2), 373–395.

Hodder, I. (2013). The interpretation of documents and material culture. In N. K. Denzin & Y. S. Lincoln (Eds.), *SAGE Biographical Research* (pp. 171–188). SAGE Publications Ltd. https://doi.org/10.4135/9781446268537

Holvast, J. (2007). History of privacy. *The History of Information Security*, 737–769. https://doi.org/10.1016/B978-044451608-4/50028-6

Honderich, H. (2021, July 15). *Why Canada is mourning the deaths of hundreds of children - BBC News*. BBC News, Washington. https://www.bbc.com/news/world-us-canada-57325653

Hudson, M., Anderson, T., Dewes, T. K., Temara, P., Whaanga, H., & Roa, T. (2017). “He matapihi ki te mana raraunga” - Conceptualising big data through a Māori lens. In H. Whaanga, T. T. Keegan, & M. Apperley (Eds.), *He whare hangarau Māori - Language, Culture & Technology* (pp. 64–73). Te Pua Wānanga ki te Ao / Faculty of Māori and Indigenous Studies, the University of Waikato.

Hudson, M., Beaton, A., Milne, M., Port, W., Russell, K., Smith, B., Toki, V., Uerata, L., & Wilcox, P. (2016). *He Tangata kei tua: Guidelines for biobanking with Māori*. Te Mata Hautū Taketake - Māori & Indigenous Governance Centre University of Waikato.

Hudson, M., Milne, M., Reynolds, P., Russell, K., & Smith, B. (2010). *Te Ara Tika Guidelines for Māori research ethics: A framework for researchers and ethics committee members*. https://www.hrc.govt.nz/resources/te-ara-tika-guidelines-maori-research-ethics-0

Hudson, M., Russell, K., Uerata, L., Milne, M., Wilcox, P., Port, R. V., Smith, B., Toki, V., & Beaton, A. (2016). Te Mata Ira—Faces of the Gene: Developing a cultural foundation for biobanking and genomic research involving Māori. *AlterNative: An International Journal of Indigenous Peoples*, *12*(4). https://doi.org/10.20507/AlterNative.2016.12.4.1

Human Rights and Equal Opportunity Commission. (1997). *Bringing them Home: Report of the National Inquiry into the separation of Aboriginal and Torres Strait Islander Children from their Families.* https://humanrights.gov.au/our-work/bringing-them-home-report-1997

Irion, K. (2012). Government Cloud Computing and National Data Sovereignty. *Policy & Internet*, *4*(3–4). https://doi.org/10.1002/poi3.10

Ito, S. (1980). *The Medieval Translation of the Data of Euclid*. Tokyo University Press.

Jackson, M. (2020). What next? Decolonisation and the stories in the land. In B. Elkington, M. Jackson, R. Kiddle, O. R. Mercier, M. Ross, J. Smeaton, & A. Thomas (Eds.), *Imagining Decolonisation* (pp. 133–156). Bridget William Books.

Jackson, M. (2021, December 12). *Covid and the pandemic of colonisation*. E-Tangata. https://e-tangata.co.nz/comment-and-analysis/moana-jackson-covid-and-the-pandemic-of-colonisation/

Jones, C. (2019). Indigenous Law/stories: an approach to working with Māori law. In J.-A. Archibald, J. B. J. Lee-Morgan, & J. de Santolo (Eds.), *Decolonizing Research: Indigenous storywork as methodology* (pp. 120–136). Zed Books Ltd.

Jones, R. (2020, March 3). *Why equity for Māori must be prioritised during the COVID-19 response*. https://www.auckland.ac.nz/en/news/2020/03/20/equity-maori-prioritised-covid-19-response.html

Kamira, R. (2003). Kaitiakitanga: Introducing useful Indigenous concepts of governance. In E. Coiera, S. Chu, & C. Simpson (Eds.), *HIC 2003 RACGP12CC [combined conference]:Proceedings* (pp. 499–507). Health Informatics Society of Australia ; Royal Australian College of General Practitioners.

Keddell, E. (2014). Critical Social Policy The ethics of predictive risk modelling in the Aotearoa/New Zealand child welfare context: Child abuse prevention or neo-liberal tool? *Critical Social Policy*, *35*(1), 69–88. https://doi.org/10.1177/0261018314543224

Keddell, E. (2019). Algorithmic Justice in Child Protection: Statistical Fairness, Social Justice and the Implications for Practice. *Social Sciences 2019, Vol. 8, Page 281*, *8*(10), 303. https://doi.org/10.3390/SOCSCI8100281

Keddell, E., & Hyslop, I. (2019). Ethnic inequalities in child welfare: The role of practitioner risk perceptions. *Child & Family Social Work*, 1–12. https://doi.org/10.1111/cfs.12620

Kerr, F. (2021, September 1). *Covid-19: The hurt left by online racial hatred towards Pasifika people, who are already suffering*. Stuff. https://www.stuff.co.nz/national/health/coronavirus/300395625/covid19-the-hurt-left-by-online-racial-hatred-towards-pasifika-people-who-are-already-suffering

King, P., Cormack, D., McLeod, M., Harris, R., & Gurney, J. (2020, April 14). *COVID-19 and Māori health - when equity is more than a word*. https://sciblogs.co.nz/public-health-expert/2020/04/14/covid-19-and-maori-health-when-equity-is-more-than-a-word/

Kuehn, K. M. (2016). *The Post-Snowden Era: Mass Surveillance and Privacy in New Zealand*. Bridget Williams Books.

Kuehn, K. M., & Salter, L. (2020). Assessing Digital Threats to Democracy, and Workable Solutions: A Review of the Recent Literature. *International Journal of Communication*, *14*(2020), 2589–2610. http://ijoc.org.

Kukutai, T., Clark, V., Mika, J., Muru-Lanning, M., Pouwhare, R., Sterling, R., Teague, V., Watts, D., & Cassim, S. (2021). The COVID 19 domestic vaccine pass: Implications for Māori. *National Institute of Demographic and Economic Analysis*. https://mro.massey.ac.nz/handle/10179/16804

Kukutai, T., & Cormack, D. (2019). Mana motuhake ā-raraunga: datafication and social science research in Aotearoa. *Kōtuitui: New Zealand Journal of Social Sciences Online*, *14*(2). https://doi.org/10.1080/1177083X.2019.1648304

Kukutai, T., McIntosh, T., Boulton, A., Durie, M., Foster, M., Hutchings, J., Mark-Shadbolt, M., Moewaka Barnes, H., Moko-Mead, T. T., Paine, S.-J., Pitama, S., & Ruru, J. (2021). *Te Pūtahitanga: A Tiriti-led science-policy approach for Aotearoa New Zealand.* http://www.maramatanga.co.nz/sites/default/files/CB_TePutahitanga_A4_2021_inner_Digital_final.pdf

Kukutai, T., & Taylor, J. (2016). Data Sovereignty for Indigenous Peoples: Current practice and future needs. In T. Kukutai & J. Taylor (Eds.), *Indigenous Data Sovereignty: Toward an Agenda* (pp. 1–22). ANU Press.

Kukutai, T., & Walter, M. (2019). Indigenous Statistics. *Handbook of Research Methods in Health Social Sciences*, 1691–1706. https://doi.org/10.1007/978-981-10-5251-4_40

Kukutai, T., & Walter, M. (2021). Indigenous Data Sovereignty: Implications for Data Journalism. In L. Bounegru & J. Gray (Eds.), *The Data Journalism Handbook: Towards a Critical Data*

Practice (pp. 65–73). Amsterdam University Press. https://doi.org/10.5117/9789462989511_ch09

Lawson-Te Aho, K., & Liu, J. H. (2010). Indigenous suicide and colonization: The legacy of violence and the necessity of self-determination. *International Journal of Conflict and Violence*, *4*(1), 124–133.

Lee-Morgan, J. B. J. (2019). Pūrākau from the inside-out: Regenerating stories for cultural sustainability. In J.-A. Archibald, J. B. J. Lee-Morgan, & J. de Santolo (Eds.), *Decolonizing Research: Indigenous storywork as methodology* (pp. 151–166). Zed Books Ltd.

Levi-Strauss, C. (1987). *Introduction to the work of Marcel Mauss*. Routledge.

Lincoln University. (2020). *Human Ethics Committee Policy*. Lincoln University.

Lindgren, S., & Holmström, J. (2020). Social Science Perspective on Artificial Intelligence. *Journal of Digital Social Research*, *2*(3). https://doi.org/10.33621/jdsr.v2i3.65

Lovett, R., Lee, V., Kukutai, T., Cormack, D., Rainie, S. C., & Walker, J. (2019). Good data practices for Indigenous data sovereignty and governance. In A. Daly, S. K. Devitt, & M. Mann (Eds.), *Theory on Demand #29: Good Data* (pp. 27–36). Institute of Network Cultures .

Lupton, D. (2016). Digital health technologies and digital data: New Ways of monitoring, measuring and commodifying human bodies. In F. X. Olleros & M. Zhegu (Eds.), *Research Handbook on Digital Transformations* (pp. 85–102). Edward Elgar Publishers.

Macfarlane, A. H., Duckworth, F., & Macfarlane, S. (2020). Static or Changing? Revealing Patterns of Cultural Influences on the Discourses of Research Ethics. In L. Georege, J. Tauri, & L. T. A. o T. MacDonald (Eds.), *Indigenous Research Ethics: Claiming Research Sovereignty Beyond Deficit and the Colonial Legacy*. Emerald Publishing Limited. https://doi.org/10.1108/S2398-601820200000006013

Mahuika, N. (2019). A Brief History of Whakapapa: Māori Approaches to Genealogy. *Genealogy*, *3*(2). https://doi.org/10.3390/genealogy3020032

Maiam nayri Wingara. (2017). *Indigenous Data Sovereignty Communique*.

Manuirirangi, K., & Jarman, J. (2021). The Taranaki COVID-19 response from a Māori perspective: lessons for mainstream health providers in Aotearoa New Zealand. *The New Zealand Medical Journal (Online)*, *134*(1533), 122–124.

Markham, A. N. (2013). Undermining 'data': A critical examination of a core term in scientific inquiry. *First Monday*, *18*(10). https://doi.org/10.5210/fm.v18i10.4868

Mascheroni, G. (2020). Datafied childhoods: Contextualising datafication in everyday life. *Current Sociology Review*, *68*(6), 798–813. https://doi.org/10.1177/0011392118807534

Massey University. (2017). *Code of ethical conduct fore research, teaching and evaluations involving human participants*. Massey University .

McAllister, T. G., Kidman, J., Rowley, O., Theodore, R. F., Maniapoto, N., Raukawa Te Kura Mäori, N., Zealand, N., & Arawa, T. (n.d.). *Why isn't my professor Māori? A snapshot of the academic workforce in New Zealand universities*. https://doi.org/10.20507/MAIJournal.2019.8.2.10

McCormack, F. (2011). Rāhui: A blunting of teeth. *Journal of Polynesian Society*, *120*(1), 43–55.

McGowan, H. (2019, May 3). The dehumanising reality of life on a benefit in New Zealand . *The Spinoff*. https://www.newshub.co.nz/home/new-zealand/2019/05/the-dehumanising-reality-of-life-on-a-benefit-in-new-zealand.html

McLeod, M., Gurney, J., Harris, R., Cormack, D., & King, P. (2020). COVID-19: we must not forget about Indigenous health and equity. *Australian and New Zealand Journal of Public Health*, *44*(4). https://doi.org/10.1111/1753-6405.13015

McMahon, R., LaHache, T., & Whiteduck, T. (2015). Digital Data Management as Indigenous Resurgence in Kahnawà:ke. *International Indigenous Policy Journal*, *6*(3). https://doi.org/10.18584/iipj.2015.6.3.6

Mead, H. M. (2003). *Tikanga Māori: Living by Māori Values*. Huia Publishers.

Meyns, C. (2020). 'Data' in the Royal Society's *Philosophical Transactions* , 1665–1886. *Notes and Records: The Royal Society Journal of the History of Science*, *74*(3). https://doi.org/10.1098/rsnr.2019.0024

Microsoft. (2019, March). *Microsoft Privacy Statement*. https://privacy.microsoft.com/en-ca/privacystatement

Mika, C. T. (2017). The uncertain kaupapa of kaupapa Māori. In T. K. Hoskins & A. Jones (Eds.), *Critical conversation in kaupapa Māori* (pp. 119–132). Huia Publishers.

Million, D. (2013). *Therapeutic Nations: Healing in an Age of Indigenous Human Rights by Dian Million*. University of Arizona Press. https://www.goodreads.com/book/show/17738670-therapeutic-nations

Milne, M. (2020). Iwi response to COVID-19 shows power of Maori-led health care. *Kai Tiaki: Nursing New Zealand*, *26*(5), 12–14.

Ministry of Health. (2015). *Tatau Kahukura Māori Health Chart Book 2015* (3rd ed.). Ministry of Health.

Social Security Act 2018, (2021) (testimony of Ministry of Social Development [MSD]).

Mittelstadt, B. D., & Floridi, L. (2016). The Ethics of Big Data: Current and Foreseeable Issues in Biomedical Contexts. *Science and Engineering Ethics*, *22*(2). https://doi.org/10.1007/s11948-015-9652-2

Moewaka Barnes, H., Gunn, T. R., Moewaka Barnes, A., Muriwai, E., Wetherell, M., & McCreanor, T. (2017). Feeling and spirit: developing an indigenous wairua approach to research. *Qualitative Research*, *17*(3), 313–325. https://doi.org/10.1177/1468794117696031

Naepi, S., Mcallister, T. G., Thomsen, P., Leenen-Young, M., Walker, L. A., Mcallister, A. L., Theodore, R., Kidman, J., & Suaalii, T. (2019). The Pakaru “Pipeline”: Māori and Pasifika Pathways within the Academy. *New Zealand Annual Review of Education*, *24*, 142–159. https://doi.org/10.26686/nzaroe.v24i0.6338

New Zealand Human Rights Commission. (2018). *Privacy, Data and Technology: Human Rights Challenges in the Digital Age.* https://www.hrc.co.nz/our-work/privacy-data-and-technology/

ngaituhoe.iwi.nz. (2019, August 23). *Protection for Tuhoe tamariki* . Iwi News. https://www.ngaituhoe.iwi.nz/Protection-for-Tuhoe-tamariki

Ngapuhi Iwi. (2020). *Tai Tokerau Community Borders*. https://dev.ngapuhi.iwi.nz/wp-content/uploads/2020/03/ZA20-COVID-flyer.pdf

Ngomo, A. (2019, December). *Can biased people create unbiased algorithms*. https://towardsdatascience.com/can-biased-people-create-unbiased-algorithms-a01813e0473a

Nielson. (2021). *Te Kaikiri me te Whakatoihara i Aotearoa i te Urutā COVID-19: He aro ki ngā hapori Hāina, Āhia hoki. Racism and Xenophobia Experiences in Aotearoa New Zealand during COVID-19: A focus on Chinese and Asian Communities*. http://communityresearch.org.nz/research/te-kaikiri-me-te-whakatoihara-i-aotearoa-i-te-uruta-covid-19-he-aro-ki-nga-hapori-haina-ahia-hoki-racism-and-xenophobia-experiences-in-aotearoa-new-zealand-during-covid-19-a-focus-on-chinese-and/

Nightingale, M. (2020, August 19). *Beneficiary claims privacy breached in fraud investigation, argues admissibility of documents*. NZ Herald Online. https://www.nzherald.co.nz/nz/beneficiary-claims-privacy-breached-in-fraud-investigation-argues-admissibility-of-documents/5Y7M7HPYHZVKX47DYGTZRL5WPI/

Noble, S. U. (2018). *Algorithms of Oppression: How Search Engines Reinforce Racism*. New York University Press.

NZ Council for Civil Liberties. (2021, June 23). *Media Release: NZ Government enabling Facebook spying on New Zealanders*. https://nzccl.org.nz/media-release-nz-government-enabling-facebook-spying-new-zealanders/

nzRISK. (2020). *Clinical decision making informed by science*. https://nzrisk.com/#calculate

Office of the Privacy Commissioner [OCP]. (2019a). *Inquiry into the Ministry of Social Development's Exercise of Section 11 (Social Security Act 1964) and Compliance with the Code of Conduct Report by the Privacy Commissioner pursuant to section 13(1)(m) of the Privacy Act 1993*. https://www.privacy.org.nz/publications/commissioner-inquiries/inquiry-into-msd-exercise-of-section-11-social-security-act-1964-and-compliance-with-the-code-of-conduct/

Office of the Privacy Commissioner [OCP]. (2019b). *MSD fraud investigations "intrusive, excessive and inconsistent with legal requirements" - Privacy Commissioner*. https://www.privacy.org.nz/publications/statements-media-releases/msd-fraud-investigations-privacy-commissioner/

Office of the Privacy Commissioner [OCP]. (2020). *Privacy, Covid-19 and the "Serious Threat to Public Health" exception*. https://www.privacy.org.nz/blog/privacy-covid-19-and-the-serious-threat-to-public-health-exception/#_ftn1

O'Neill, C. (2016). *Weapons of Math Destruction: How Big Data Increases Inequality and Threatens Democracy*. CROWN.

Oranga Tamariki. (2021, February). *Care and protection statistics*. https://www.orangatamariki.govt.nz/about-us/reports-and-releases/quarterly-report/care-and-protection-statistics/

Papilloud, C. (2018). Marcel Mauss, the Gift and Relational Sociology. In F. Dépelteau (Ed.), *The Palgrave Handbook of Relational Sociology* (pp. 663–675). Springer International Publishing. https://doi.org/10.1007/978-3-319-66005-9_33

Parkins, D. (2017). The world's most valuable resource is no longer oil, but data. *The Economist*.

Penk, S. (2010). Thinking about privacy. In S. Penk, R. Tobin, & W. J. Brookbanks (Eds.), *Privacy Law in New Zealand*. Thomson Reuters.

Peterson, Z. N. J., Gondree, M., & Beverly, R. (2011). A position paper on data sovereignty: the importance of geolocating data in the cloud. *HotCloud'11: Proceedings of the 3rd USENIX Conference on Hot Topics in Cloud Computing*, 1–9.

Pickering-Martin, E. (2020, August 23). *Rumours, racism, and privilige*. E-Tangata. https://e-tangata.co.nz/comment-and-analysis/rumours-racism-and-privilege/

Pickering-Martin, E. (2021, August 29). *Here we go again: Covid and racism*. E-Tangata. https://e-tangata.co.nz/comment-and-analysis/here-we-go-again-covid-and-racism/

Pihama, L., Campbell, D., & Greensill, H. (2019). Whānau storytelling as Indigenous Pedagogy: tiakina te pā harakeke. In J.-A. Archibald, J. B. J. Lee-Morgan, & J. de Santolo (Eds.), *Decolonizing Research: Indigenous storywork as methodology* (pp. 137–150). Zed Books Ltd.

Pihama, L., & Lipsham, M. (2020). Noho Haumaru: Reflecting on Māori approaches to staying safe during Covid-19 in Aotearoa (New Zealand). *Journal of Indigenous Social Development*, *9*(3), 92–101.

Quince, K. (2010). Maori concepts and privacy. In S. Penk & R. Tobin (Eds.), *Privacy law in New Zealand* (First, pp. 27–48). Brookers Ltd.

Quince, K. (2020, August). *Can algorithms make decisions about our lives in an unbiased fashion?* Dominion Post. https://www.stuff.co.nz/dominion-post/comment/columnists/122364803/can-algorithms-make-decisions-about-our-lives-in-an-unbiased-fashion

Rainie, S. C., Kukutai, T., Walter, M., Figueroa-Rodríguez, O. L., Walker, J., & Axelsson, P. (2019). Indigenous data sovereignty. In T. Davies, S. B. Walker, M. Rubinstein, & F. Perini (Eds.), *The State of Open Data: Histories and Horizons* (Issue September, pp. 300–319). African Minds and the International Development Research Centre (IDRC). https://researchcommons.waikato.ac.nz/handle/10289/12918

Rainie, S. C., Rodriguez-Lonebear, D., & Martinez, A. (2017). *Policy brief: Indigenous data sovereignty in the United States* . Native Nations Institute, University of Arizona.

Rameka, L. (2016). Kia whakatōmuri te haere whakamua: ‘I walk backwards into the future with my eyes fixed on my past.’ *Contemporary Issues in Early Childhood*, *17*(4). https://doi.org/10.1177/1463949116677923

Rapley, T. (2007). Exploring documents. In *Doing Conversation, Discourse and Document Analysis*. SAGE Publications Ltd. https://doi.org/10.4135/9781849208901.n9

Rauika Māngai. (2020). *A Guide to Vision Mātauranga: Lessons from Māori voices in the New Zealand Science Sector*. http://www.maramatanga.co.nz/sites/default/files/Rauika%20Ma%CC%84ngai_A%20Guide%20to%20Vision%20Ma%CC%84tauranga_FINAL.pdf

Rendgen, S. (2018, June 20). *What do we mean by "data"?* https://idalab.de/blog/data-science/what-do-we-mean-by-data

Rewi, L.-D. N. K., & Hastle, J. L. (2021). Community resilience demonstrated through a Te Ao Māori (Ngāti Manawa) lens: The Rahui. *Aotearoa New Zealand Social Work*, *33*(4), 65–76.

RNZ. (2020a, March 29). *Coronavirus: First death in New Zealand from Covid-19*. https://www.rnz.co.nz/news/national/412864/coronavirus-first-death-in-new-zealand-from-covid-19

RNZ. (2020b, September 16). *Man dies from Covid-19 in Waikato Hospital, one new case at border*. https://www.rnz.co.nz/news/national/426184/man-dies-from-covid-19-in-waikato-hospital-one-new-case-at-border

RNZ. (2021, September 19). *Three new cases in Waikato connected to remand prisoner | RNZ News*. https://www.rnz.co.nz/news/national/451839/three-new-cases-in-waikato-connected-to-remand-prisoner

Rodriguez-Lonebear, D. (2016). Building a data revolution in Indian Country. In T. Kukutai & J. Taylor (Eds.), *Indigenous Data Sovereignty: Toward an Agenda* (pp. 253–272). ANU Press.

Rosenberg, D. (2013). Data before the fact. In L. Gitelman (Ed.), *"Raw Data" is an oxymoron* (pp. 15–40). MIT Press.

Rowley, J. (2002). Using case studies in research. *Management Research News*, *25*(1), 16–27.

Roy, M., Hansen, P., Sullivan, T., Ombler, F., Kiore, M., Stapleton, A., & Carr, C. (2021). Rapid Development of a Tool for Prioritizing Patients with Coronavirus Disease 2019 for Intensive Care. *Critical Care Explorations*, *3*(3), e0368. https://doi.org/10.1097/CCE.0000000000000368

Royal, T. A. C. (2007). *Hineahuone and Tāne – Papatūānuku – the land – Te Ara Encyclopedia of New Zealand*. Te Ara - the Encyclopedia of New Zealand. https://teara.govt.nz/en/artwork/11431/hineahuone-and-tane

Ruru, J. (2009). *The Legal Voice of Māori in Freshwater Governance A Literature Review*.

Ruru, J., & Wheen, N. (2016). Providing for rāhui in the law of Aotearoa New Zealand. In T. Bambridge (Ed.), *The Rahui: Legal pluralism in Polynesian traditional management of resources and territories* (pp. 195–210). ANU Press.

Sahlins, M. (1997). The Spirit of the Cift. In A. D. Schrifft (Ed.), *The logic of the gift: Toward an ethic of generosity* (pp. 70–100). Routledge.

Salmond, A. (1999). Maori and modernity: Ruatara’s Dying. In A. Cohen (Ed.), *Signifying Identities: Anthropological perspectives on boundaries and contested identities* (pp. 37–58). Routledge.

Salmond, A., Brierley, G., & Hikuroa, D. (2019). Let the Rivers Speak: thinking about waterways in Aotearoa New Zealand. *Policy Quarterly*, *15*(3), 45–54. https://ojs.victoria.ac.nz/pq/article/view/5687/4996

Samasoni, S. (2021, August 30). *Pasifika community feels “battered and bruised” by communication blunders*. Stuff. https://www.stuff.co.nz/opinion/300394463/pasifika-community-feels-battered-and-bruised-by-communication-blunders

Sato, M. (2021, January 5). *Singapore’s police now have access to contact tracing data | MIT Technology Review*. https://www.technologyreview.com/2021/01/05/1015734/singapore-contact-tracing-police-data-covid/

Seed-Pihama, J. (2019). Naming our names and telling our stories. In J.-A. Archibald, J. B. J. Lee-Morgan, & J. de Santolo (Eds.), *Decolonizing Research: Indigenous storywork as methodology* (pp. 107–119). Zed Books Ltd.

Sium, A., & Ritskes, E. (2013). Speaking truth to power: Indigenous storytelling as an act of living resistance. *Decolonization: Indigeneity, Education & Society*, *2*(1), I–X.

Skloot, R. (2011). *The immortal life of Henrietta Lacks*. Random House Inc.

Smith, G. H. (2017). Kaupapa Māori Theory: Indigenous transforming of education. In T. K. Hoskins & A. Jones (Eds.), *Critical conversation in kaupapa Māori* (pp. 79–94). Huia Publishers.

Smith, G. H., & Tuhiwai Smith, L. (2018). Doing Indigenous Work: Decolonizing and Transforming the Academy. In *Handbook of Indigenous Education*. Springer Singapore. https://doi.org/10.1007/978-981-10-1839-8_69-1

Smith, Graham. H. (1992). Tane-nui-a-rangi’s Legacy: Popping up the sky: Kaupapa Maori as Resistance and Intervention. *NZARE/AARE Joint Conference*.

Snipp, C. M. (2016). What does data sovereignty imply: What does it look like? In T. Kukutai & J. Taylor (Eds.), *Indigenous Data Sovereignty: Toward an Agenda* (pp. 39–56). ANU Press.

Solove, D. J. (2009). *Understanding Privacy*. Harvard University Press.

Sporle, A., Hudson, M., & West, K. (2021). Indigenous data and policy in Aotearoa New Zealand. In M. Walter, T. Kukutai, S. R. Carroll, & D. Rodriguez-Lonebear (Eds.), *Indigenous Data Sovereignty and Policy* (pp. 62–80). Routledge.

Stanley, E. (2016). The road to hell: State violence against children in postwar New Zealand. In *Performance Enhancement and Health* (Issues 3–4). Auckland University Press. https://doi.org/10.1016/J.PEH.2016.05.001

Stats NZ. (2018a). *Algorithm Assessment Report*. https://data.govt.nz/use-data/analyse-data/government-algorithm-transparency

Stats NZ. (2018b). *Data in the IDI: September 2018*. http://archive.stats.govt.nz/browse_for_stats/snapshots-of-nz/integrated-data-infrastructure/idi-data.aspx

Stats NZ. (2018c). *How we keep IDI and LBD data safe*. http://archive.stats.govt.nz/browse_for_stats/snapshots-of-nz/integrated-data-infrastructure/keep-data-safe.aspx#safes

Stats NZ. (2020a). *Guidelines 2020 Ngā Tikanga Paihere: a framework guiding ethical and culturally appropriate data use*. www.stats.govt.nz

Stats NZ. (2020b). *Integrated Data Infrastructure*. https://www.stats.govt.nz/integrated-data/integrated-data-infrastructure/

Stats NZ. (2020c, July). *Algorithm Charter for Aotearoa New Zealand*. https://data.govt.nz/toolkit/data-ethics/government-algorithm-transparency-and-accountability/algorithm-charter/

Stats NZ. (2020d, November 30). *Integrated Data Infrastructure | Stats NZ*. https://www.stats.govt.nz/integrated-data/integrated-data-infrastructure/

Stats NZ, & Data Iwi Leaders Group. (2019). *Mana Ōrite Relationship Agreement* . https://www.stats.govt.nz/about-us/what-we-do/mana-orite-relationship-agreement/

Stewart, G. (2017). The 'Hau' of Research: Mauss Meets Kaupapa Māori. *Journal of World Philosophies*, *2*(1), 1–11. https://doi.org/10.2979/jourworlphil.2.1.01

Steyn, N., Binny, R. N., Hannah, K., Hendy, S. C., James, A., Lustig, A., Ridings, K., Plank, M. J., & Sporle, A. (2021). *Māori and Pacific people in New Zealand have a higher risk of hospitalisation for COVID-19*. *134*, 1538. www.nzma.org.nz/journal

Taisbak, C. M. (2003). *Dedomena: Euclid's data, or, the importance of being given*. Museum Tusculanum Press.

Taiuru, K. (2018, December 19). *Data is a Taonga. A customary Māori perspective* . https://www.taiuru.maori.nz/data-is-a-taonga/

Talamaivao, N., Harris, R., Cormack, D., Paine, S.-J., & King, P. (2020). Racism and health in Aotearoa New Zealand: a systematic review of quantitative studies. *New Zealand Medical Journal*, *133*(1521), 55–68. www.nzma.org.nz/journal

Tauri, J. (2014). Resisting Condescending Research Ethics in Aotearoa New Zealand. *AlterNative: An International Journal of Indigenous Peoples*, *10*(2). https://doi.org/10.1177/117718011401000204

Tauri, J. (2018). Research ethics, informed consent and the disempowerment of First Nation peoples. *Research Ethics*, *14*(3). https://doi.org/10.1177/1747016117739935

te Mana Raraunga. (2016). *Te Mana Raraunga - Māori Data Sovereignty Network Charter*.

Te Mana Raraunga. (2018). *Māori data sovereignty principles*. https://www.temanararaunga.maori.nz/new-page-2

Te One, A., & Clifford, C. (2021). Tino Rangatiratanga and Well-being: Māori Self Determination in the Face of Covid-19. *Frontiers in Sociology*, *6*. https://doi.org/10.3389/fsoc.2021.613340

Te Puni Kōkiri. (2006). *Te Kotahitanga o te Whakahaere Rawa: Māori and Council Engagement under the Resource Management Act 1991*.

Te Rito, J. S. (2007). Whakapapa: A framework for understanding Identity. *MAI Review*, *2007*(2), 1–10.

Te Taura Whiri i te Reo Māori. (n.d.). *1900 | Tātai Kōrero* . Retrieved December 17, 2021, from https://www.tetaurawhiri.govt.nz/en/te-reo-maori/history/1900-tatai-korero/

Teräs, M., Suoranta, J., Teräs, H., & Curcher, M. (2020). Post-Covid-19 Education and Education Technology “Solutionism”: a Seller’s Market. *Postdigital Science and Education*, *2*, 863–878. https://doi.org/10.1007/s42438-020-00164-x

Thaker, J. (2021). *Aotearoa New Zealand Public Responses to COVID-19: March 2021*.

The Truth and Reconciliation Commission of Canada. (2015). *Honouring the Truth, Reconciling for the Future: Summary of the Final Report of the Truth and Reconciliation Commission of Canada*. https://irsi.ubc.ca/sites/default/files/inline-files/Executive_Summary_English_Web.pdf

The University of Auckland. (2020). *Taumata Teitei: Vision 2030 and Strategic Plan 2025*. https://cdn.auckland.ac.nz/assets/auckland/about-us/the-university/official-publications/strategic-plan/2021-2030/taumata-teitei-vision-2030-and-strategic-plan-2025.pdf

Thompson, D. (1987). The hau of the gift in its cultural context. *Pacific Studies*, *11*(1), 63–79.

Tomas, N. (2006). *Key concepts of tikanga Maori (Maori custom law) and their use as regulators of human relationships to natural resources in Tai Tokerau, past and present*.

Tuck, E. (2009). Suspending Damage: A Letter to Communities. *Harvard Educational Review*, *79*(3), 409–427.

Tuhiwai Smith, L. (1999). *Decolonizing Methodologies: Research and Indigenous Peoples* (First). Zed Books Ltd.

Tuhiwai Smith, L. (2012). *Decolonizing Methodologies: Research and Indigenous Peoples* (Second). Zed Books Ltd.

Tuhiwai Smith, L. (2021). *Decolonizing Methodologies*. Zed Books. https://doi.org/10.5040/9781350225282

Tuhiwai-Smith, L. (2020). A story about the time we had a global pandemic and how it affected my life and work as a critical Indigenous scholar. In B. Hokowhitu, A. Moreton-Robinson, L. Tuhiwai-Smith, C. Andersen, & S. Larkin (Eds.), *Routledge Handbook of Critical Indigenous Studies* (pp. 365–377). Routledge. https://doi.org/10.4324/9780429440229-32

University of Canterbury. (2020). *Human Ethics Policy - Research Involving Human Participants* . University of Canterbury.

University of Otago. (2020). *Human Ethics Committees*. https://www.otago.ac.nz/council/committees/committees/HumanEthicsCommittees.html#guidelines_ethical

Vaithianathan, R., Maloney, T., Jiang, N., de Haan, I., Dale, C., Fellow, R., Putnam-Hornstein, E., Professor, A., & Dare, T. (2012). *Vulnerable Children: Can administrative data be used to identify children at risk of adverse outcomes*.

Vaithianathan, R., Maloney, T., Putnam-Hornstein, E., & Jiang, N. (2013). Children in the Public Benefit System at Risk of Maltreatment Identification Via Predictive Modeling. *American Journal of Preventive Medicine*, *45*(3), 354–359. https://doi.org/10.1016/j.amepre.2013.04.022

Verrall, A. (2020). *Rapid Audit of Contact Tracing for Covid-19 in New Zealand*. Ministry of Health.

Victoria University of Wellington. (2018). *Human Ethics Guidelines*. Victoria University of Wellington.

Villarroel, N., Davidson, E., Pereyra-Zamora, P., Krasnik, A., & Bhopal, R. S. (2019). Heterogeneity/granularity in ethnicity classifications project: the need for refining assessment of health status. *European Journal of Public Health*, *29*(2), 260–266. https://doi.org/10.1093/EURPUB/CKY191

Waitangi Tribunal. (1986). *The Waitangi Tribunal on The Te Reo Maori Claim: WAI 11*. www.waitangitribunal.govt.nz

Waitangi Tribunal. (1999). *The Wananga Capital Establishment Report - WAI718*.

Waitangi Tribunal. (2005). *The Offender Assessment Policies Report - WAI 1024*. https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_68001752/Offender%20Assessment%20Policies.pdf

Waitangi Tribunal. (2011). *Ko Aotearoa Tēnei: A Report into Claims Concerning New Zealand Law and Policy Affecting Māori Culture and Identity - WAI 262*.

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

Waitangi Tribunal. (2021a). *He pā Harakeke, He rito whakakīkīnga whāruarua: Oranga Tamariki Urgent Inquiry (Report no. WAI 2915)*.

Waitangi Tribunal. (2021b). *The Report on the Comprehensive and Progressive Agreement for Trans-Pacific Partnership - WAI 2522*. www.waitangitribunal.govt.nz

Walker, R. (2016). Reclaiming Māori Education. In J. Hutchings & J. Lee (Eds.), *Decolonisation in Aotearoa: Education, research and practice* (pp. 19–38). New Zealand Council for Educational Research.

Walling, J., Small-Rodriguez, D., & Kukutai, T. (2009). Tallying tribes: Waikato-Tainui in the census and iwi register. *Social Policy Journal of New Zealand* , *36*, 2–15.

Walter, M. (2016). Data politics and Indigenous representation in Australian Statistics. In T. Kukutai & J. Taylor (Eds.), *Indigenous Data Sovereignty: Toward an Agenda* (pp. 79–98). ANU Press.

Walter, M. (2018). The voice of indigenous data: Beyond the markers of disadvantage. *Griffith Review*, *60*, 256–263. https://search.informit.org/doi/10.3316/INFORMIT.586241932732209

Walter, M., & Carroll, S. R. (2021). Indigenous Data Sovereignty. governance and the link to Indigenous Policy. In M. Walter, T. Kukutai, S. R. Carroll, & D. Rodriguez-Lonebear (Eds.), *Indigenous Data Sovereignty and Policy* (pp. 1–21). Routledge.

Walter, M., Kukutai, T., & Russo, S. C. (2021). Indigenous Data Sovereignty . In D. N. Berger, N. Bulanin, L. García-Alix, M. W. Jensen, S. Leth, E. A. Madsen, D. Mamo, A. Parellada, G.

Rose, S. Thorsell, & K. Wessendorf (Eds.), *The Indigenous World 2021* (35th ed., pp. 692–702). The International Work Group for Indigenous Affairs.

Walter, M., Lovett, R., Bodkin Andrews, G., & Lee, V. (2018). *Indigenous Data Sovereignty Briefing Paper 1*.

Walter, M., Lovett, R., Maher, B., Williamson, B., Prehn, J., Bodkin-Andrews, G., & Lee, V. (2021). Indigenous Data Sovereignty in the Era of Big Data and Open Data. *Australian Journal of Social Issues*, *56*(2), 143–156. https://doi.org/10.1002/AJS4.141

Weiner, A. B. (1985). inalienable wealth. *American Ethnologist*, *12*(2). https://doi.org/10.1525/ae.1985.12.2.02a00020

Weisberger, M. (2021, July 14). *Remains of more than 1,000 Indigenous children found at former residential schools in Canada | Live Science*. Live Science. https://www.livescience.com/childrens-graves-residential-schools-canada.html

Welfare Expert Advisory Group [WEAG]. (2019). *Whakamana Tāngata: Restoring Dignity to Social Security in New Zealand*. http://www.weag.govt.nz/assets/documents/WEAG-report/aed960c3ce/WEAG-Report.pdf

Welfare Justice. (2010). *Welfare Justice in New Zealand: What we heard*. http://www.weag.govt.nz/weag-report/whakamana-tangata/listening-to-new-zealanders-what-we-heard/

West, K., Hudson, M., & Kukutai, T. (2020). Data ethics and data governance from a Māori world view. In L. George, J. Tauri, & L. T. A. o T. MacDonald (Eds.), *Indigenous Research Ethics: Claiming Research Sovereignty Beyond Deficit and the Colonial Legacy* (pp. 67–82). Emerald Publishing Limited.

West, K., Wilson, D., Thompson, A., & Hudson, M. (2020). *Māori Perspectives on Trust and Automated Decision Making (Report for the Digital Council)*.

West-McGruer, K. (2016). *Ethical constraints in research: A kaupapa Māori critique*.

West-McGruer, K. (2020). There’s ‘consent’ and then there’s consent: Mobilising Māori and Indigenous research ethics to problematise the western biomedical model. *Journal of Sociology*, *56*(2). https://doi.org/10.1177/1440783319893523

Whiteduck, M. (2013). “But it’s our story. Read it”: Stories my Grandfather told me and writing for continuance . *Decolonization: Indigeneity, Education & Society*, *2*(1), 72–92.

Whitehead, B., Andrews, D., Shah, A., & Maidment, G. (2014). Assessing the environmental impact of data centres part 1: Background, energy use and metrics. *Building and Environment*, *82*, 151–159. https://doi.org/10.1016/j.buildenv.2014.08.021

Williams, J. (2016). *He Araroa tenei ki te timatanga: This is a long journey to our beginning*. Ngā Pae o te Māramatanga. http://mediacentre.maramatanga.ac.nz/content/justice-joe-williams

Wilson, S. (2008). *Research is Ceremony: Indigenous Research Methods*. Fernwood Publishing.

Xia, L. (2021, December 15). *New Zealand's youngest confirmed Covid-19 death is a person in their 30s | Stuff.co.nz*. https://www.stuff.co.nz/national/health/coronavirus/127295922/new-zealands-youngest-confirmed-covid19-death-is-a-person-in-their-30s

Yap, M., & Yu, E. (2016). Data sovereignty for the Yawuru in Western Australia . In T. Kukutai & J. Taylor (Eds.), *Indigenous Data Sovereignty: Toward an Agenda* (pp. 233–252). ANU Press.

Yates, S. (2012, October 2). Battle against beneficiary bashing. *Stuff*. http://www.stuff.co.nz/national/politics/7759711/Battle-against-beneficiary-bashing

Yin, R. K. (2003). *Case study research: Design and methods* (Third). SAGE.

Yunkaporta, T. (2019). *Sand talk: How Indigenous thinking can save the world*. The Text Publishing Company.

Zhang, X., Pérez-Stable, E. J., Bourne, P. E., Peprah, E., Duru, O. K., Breen, N., Berrigan, D., Wood, F., Jackson, J. S., Wong, D. W. S., & Denny, J. (2017). Big Data Science: Opportunities and Challenges to Address Minority Health and Health Disparities in the 21st Century. *Ethnicity & Disease*, *27*(2). https://doi.org/10.18865/ed.27.2.95

Zins, C. (2007). Conceptual approaches for defining data, information, and knowledge. *Journal of the American Society for Information Science and Technology*, *58*(4). https://doi.org/10.1002/asi.20508

Zuboff, S. (2019). *The age of surveillance capitalism: The fight for a human future at the frontier of power*. Profile Books Ltd.

Zuckerberg, M. (2018). *Zuckerberg statement on Facebooks response to Cambridge Analytica*. https://www.facebook.com/zuck/posts/10104712037900071