PARTICIPATORY RESEARCH

WE NEED TO TALK ABOUT MAX

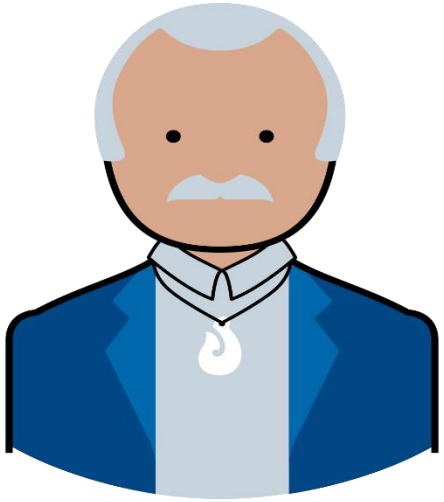
Otago University, Wellington PHSS
15th February 2019

Rochelle Style

Interactive session - Use clickers to vote

Max – Chart 1

- 80 year old male Māori (Ngāi Tahu) HIV+, T2 diabetes
- Critically unwell in ICU
- Blood tests (blood glucose - hypoglycemia) + multiple other tests and images - collected for the purposes of treating him
- Max's data submitted to the ANZICS database
- Minimum data set requirement - 105 variables - HIV status, diabetic status, glucose concentration values, patient identifier, residential postcode, "indigenous status" and a "statistical linkage key"



Source: https://www.healthcarehome.org.nz/patient-provider-stories

Max – Chart 2

- Max's data also added to a training data set for an AI tool (fictitious) – "*Diabins*"
- Predicts optimal way to avoid hypoglycaemia by determining when to start IV insulin. Conventionally: when blood glucose exceeds 10 mmol/l but evidence improved outcome starting treatment at 14 mmol/l.
- *Diabins* designed by a private AI company

Max – Chart 3

- Use of an iphone for rehab, trialling Medibank "*LiveBetter*" app
- Personal well-being coach, Liam, provides 'digital nudging', texting Max encouraging him to take " tiny, happy breaks". Max will learn to think more positively, deal with stress better, get better sleep …. "Right" healthy goal?
- *LiveBetter* + Fitbit allows GP to track all Max's health data.

Max – Chart 4

- Max is part of some exciting AI research which promises great benefit to future diabetic patients like him

BUT

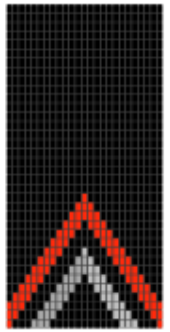
- Max has not consented to his data being included in the ICU database or the *Diabins* training dataset. He has no idea what happens to his data with the *LiveBetter* app – he doesn't know what he doesn't know. USA law.

- He is surprised there is an ICU database located outside NZ

Max – Chart 5

- Max is a Jehovah's Witness
- Very sensitive about HIV status
- If asked, or even told, about the ICU database or the *Diabins* training data, he would have objected to the inclusion of his data, even if anonymised. Similarly with *LiveBetter*.
- Concerned whether consideration given to principles of Māori data sovereignty and Te Ara Tika. Data is taonga.

Jehovah's Witnesses



TE MANA RARAUNGA
Māori Data Sovereignty Network

Challenges – ICU database

1. Should Max's consent have been sought before his identifiable data was included in the ICU database located offshore?

   A. Yes

   B. No

Challenges – ICU database

2. Assume Max's consent should have been sought, should it be:

   A. Opt-in consent

   B. Opt-out consent

Challenges - ICU database

3. Does Max have an obligation of reciprocity to allow his data to be used for research?

   A. Yes

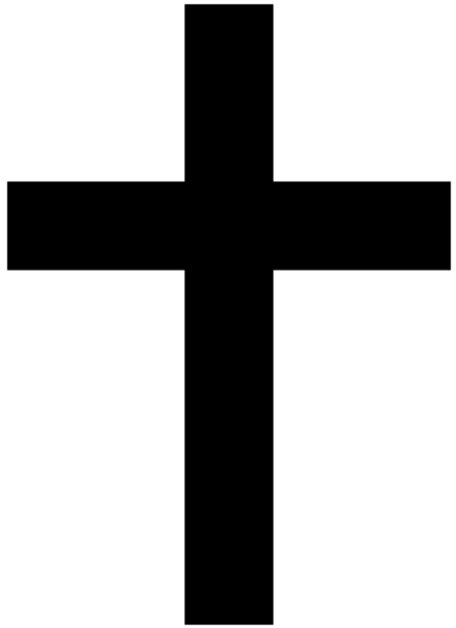
   B. No

Challenges – *Diabins*

4. Does it matter that Max's religious beliefs mean he objects to his blood being used for research purposes?

   A. Yes

   B. No



Challenges – *Diabins*

5. Do you think the potential public benefits of the *Diabins* research outweigh the private risks of harm to people like Max?

   A. Yes

   B. No

Challenges - *Diabins*

6. Does it matter that *Diabins* is privately developed?

A. Yes

B. No

Challenges - General

7. If it does matter, is there a social licence in New Zealand to use identifiable health information, without consent, to do private research for commercial gain?

   A. Yes

   B. No

Challenges - *Diabins*

8. Are you concerned that the predictive accuracy of the *Diabins* dataset might be biased because of a lack of data about elderly Māori males ?

   A. Yes

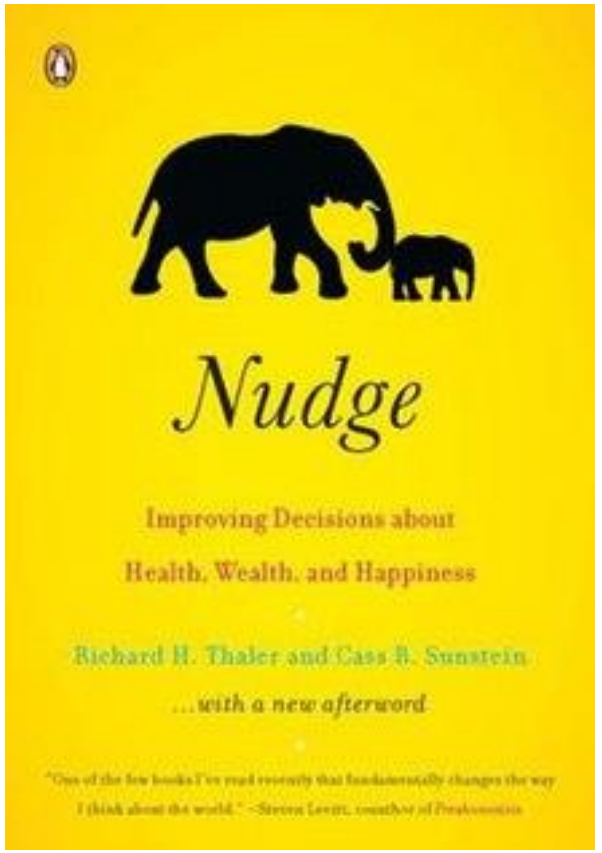
   B. No

Challenges - *Livebetter*

9. Is it OK for Max to be digitally nudged into healthier behaviour with out his knowledge or consent?

   A. Yes

   B. No



Challenges - *Livebetter*

10. Is it OK for Max's *Livebetter* data to be used for research when he doesn't understand that's happening, despite it being in the privacy policy?

    A. Yes

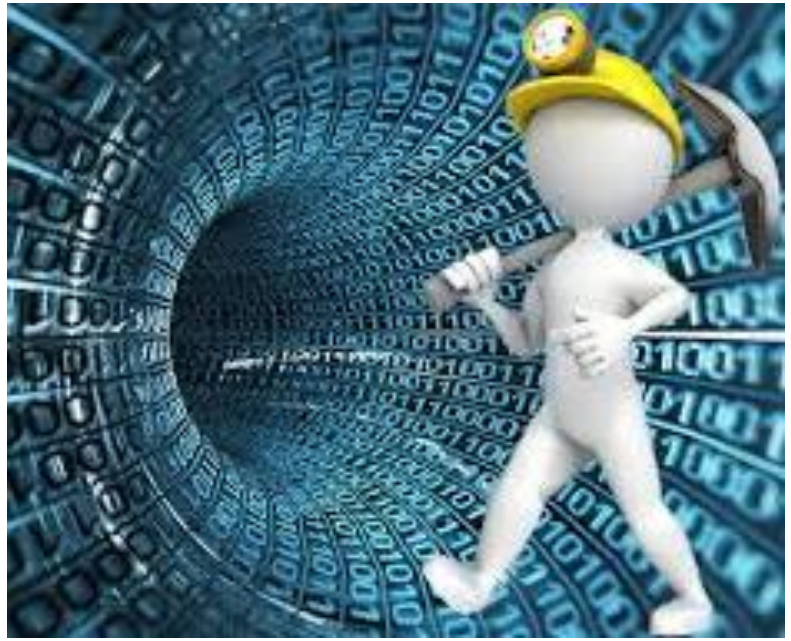
    B. No

Challenges - General

11. Should individuals own all of their data and have complete control over its use?

    A. Yes

    B. No



Data mine-ing

Challenges - General

12. Should we discard notions of individual data ownership and focus on data rights which allow for the balancing of benefits and harms?

    A. Yes

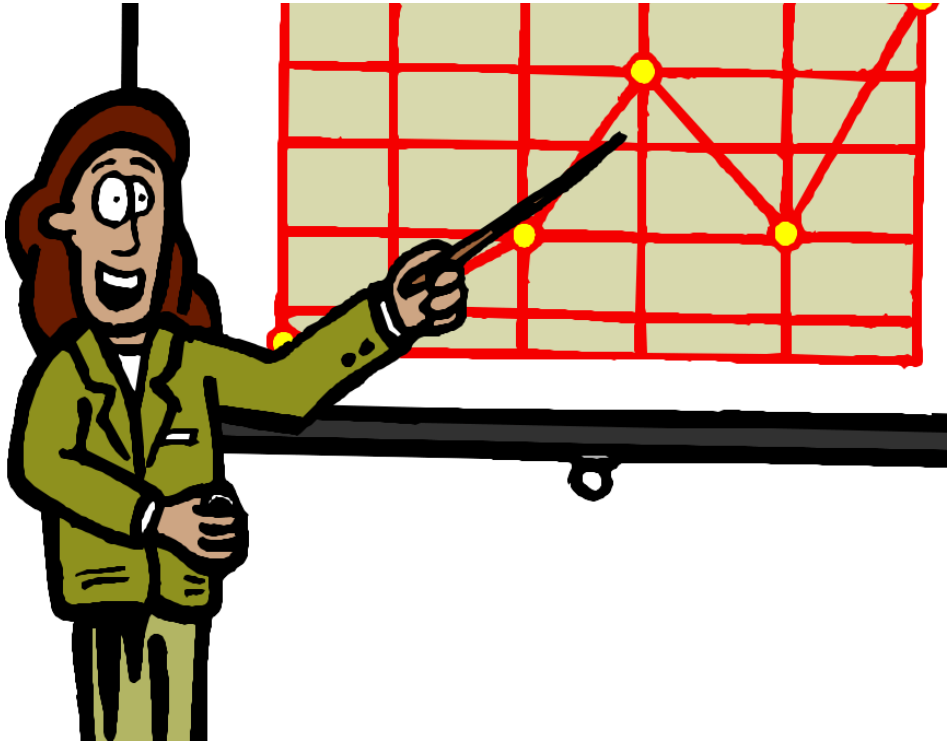
    B. No

Challenges - Explainable AI (XAI)

13. Should Max be given an explanation of the ICU database and *Diabins*?

A. Yes

B. No



Challenges - XAI

14. Is it enough that Max believes the models are reliable and doesn't receive an explanation?

    A. Yes

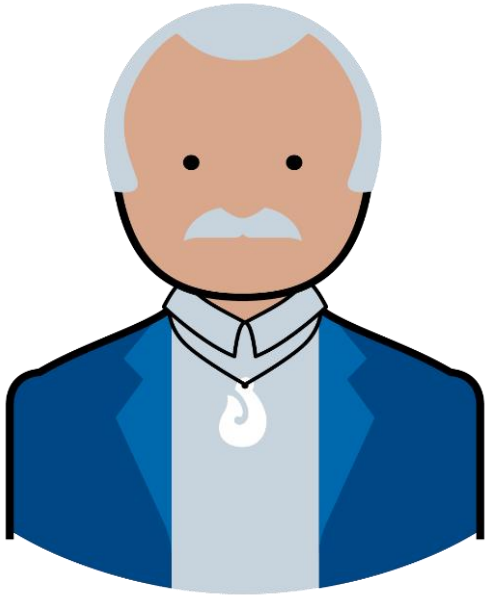
    B. No

Challenges – Trust

15. Should there be an independent body which oversees data use in New Zealand ?

A. Yes

B. No



“The challenge will be to ensure that innovation in AI is developed and used in a ways that are transparent, that address societal needs, and that are consistent with public values.”

(Hugh Whittall, Director of the Nuffield Council on Bioethics)