

PARTICIPATORY RESEARCH

WE NEED TO TALK ABOUT MAX

Answers given to clicker
questions by attendees

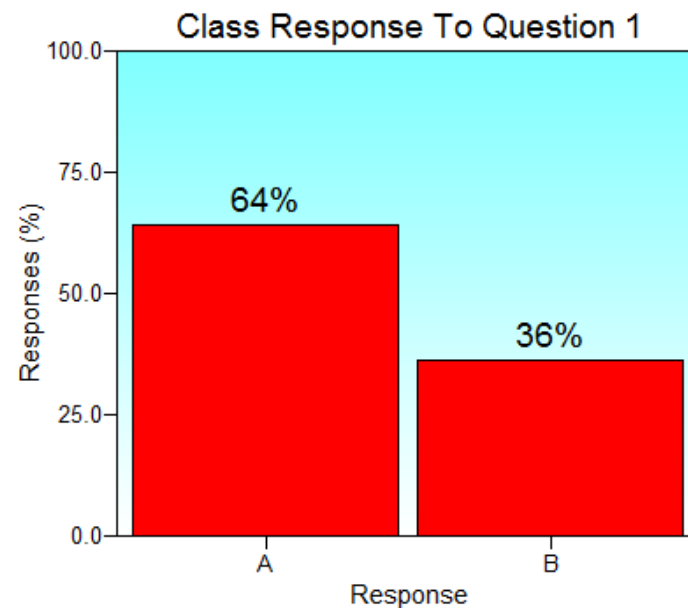
Otago University, Wellington PHSS
15th February 2019

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

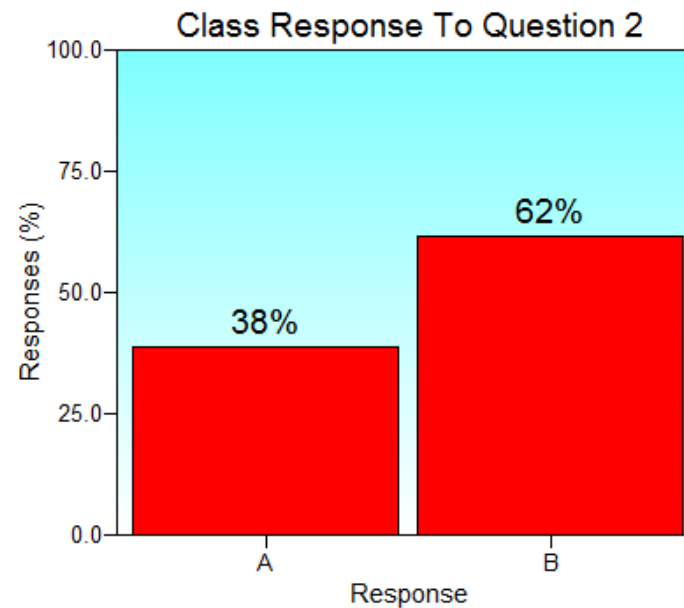


Challenges – ICU database

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

A. Opt-in consent

B. Opt-out consent

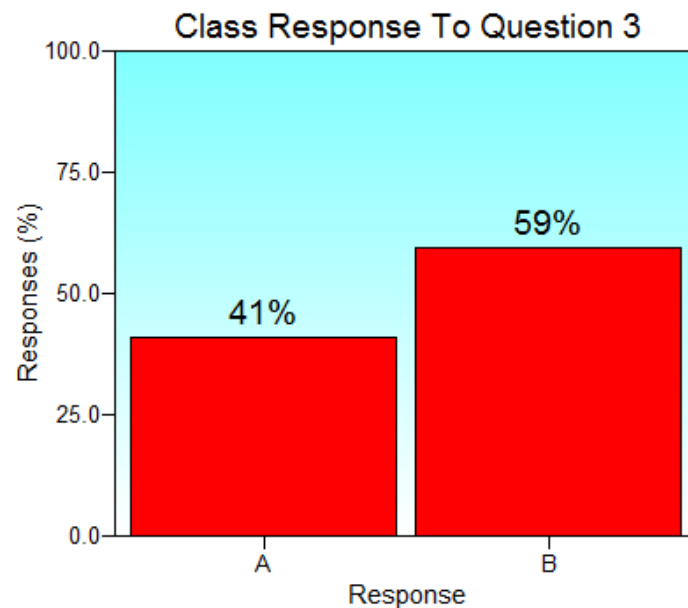


Challenges - ICU database

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

A. Yes

B. No

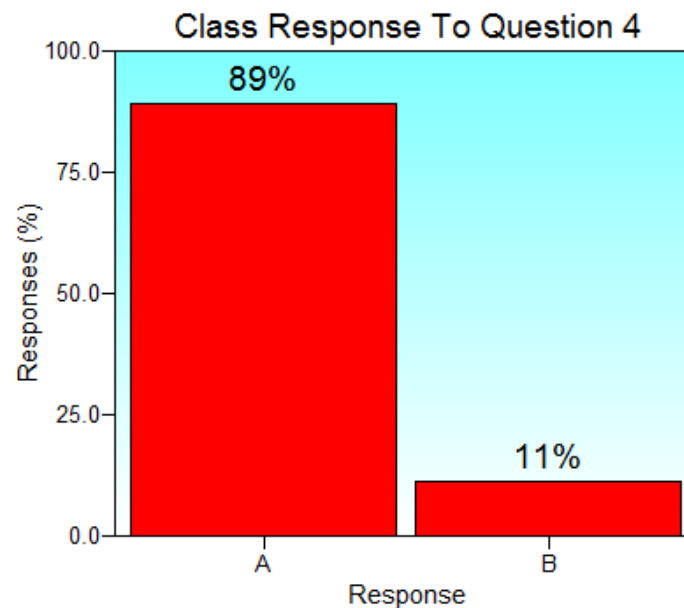


Challenges – *Diabins*

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

A. Yes

B. No

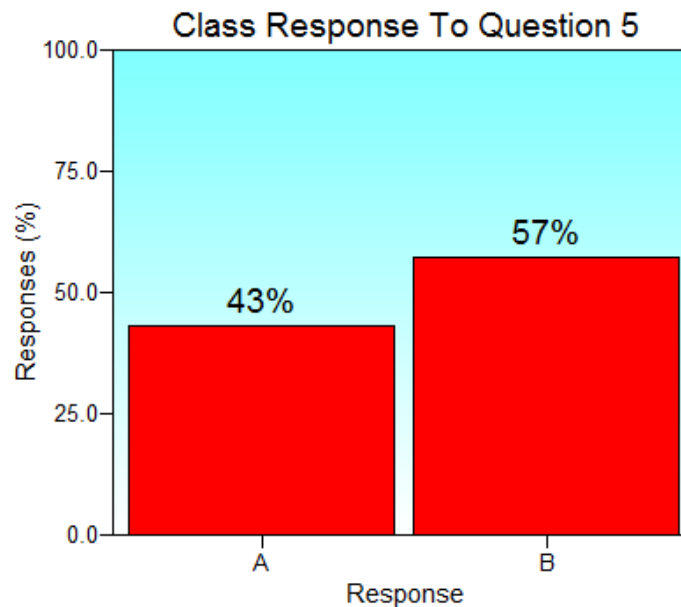


Challenges – *Diabins*

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

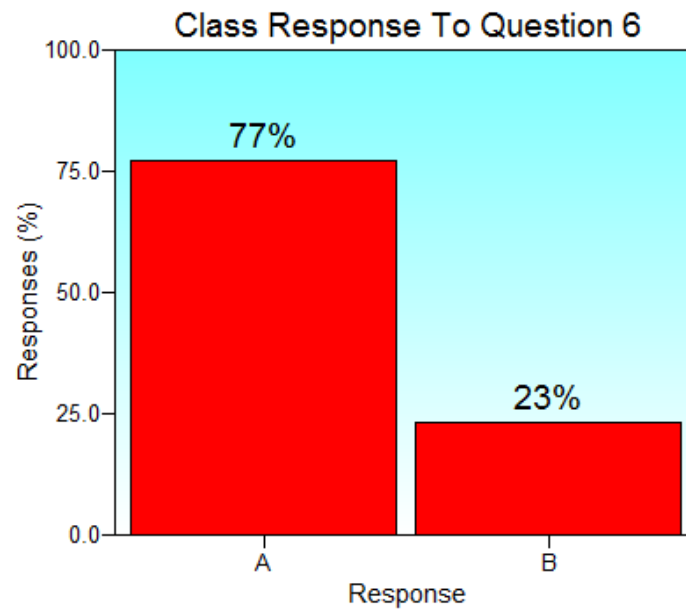


Challenges - *Diabins*

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

A. Yes

B. No

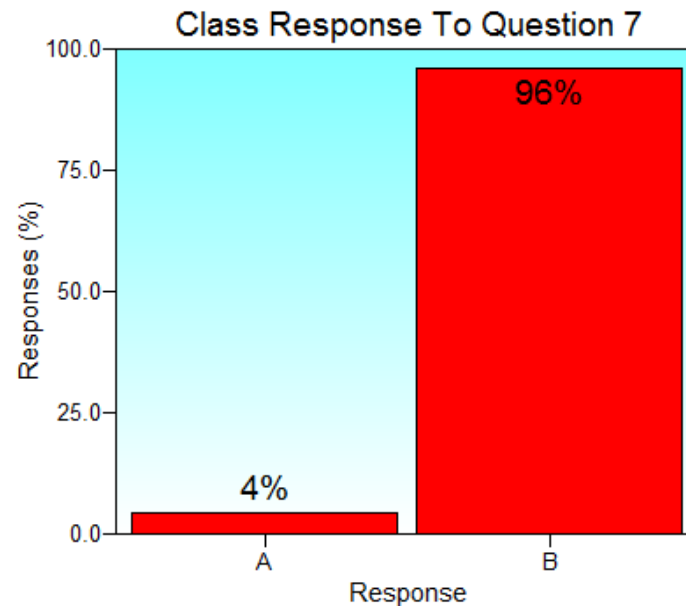


Challenges - General

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

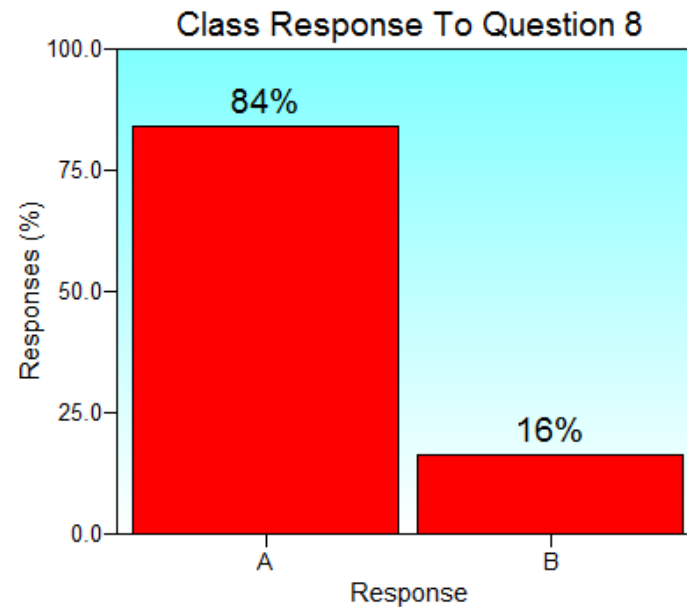


Challenges - *Diabins*

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

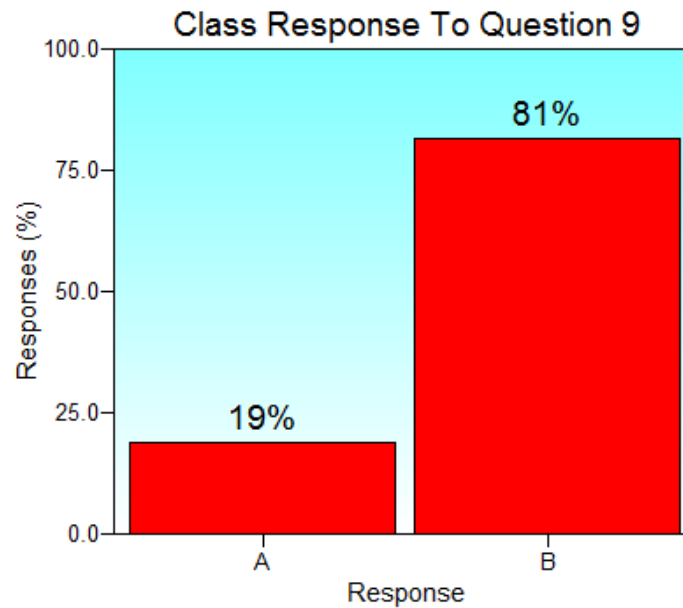


Challenges - *Livebetter*

9. Is it OK for Max to be digitally nudged into healthier behaviour without his knowledge or consent?

A. Yes

B. No

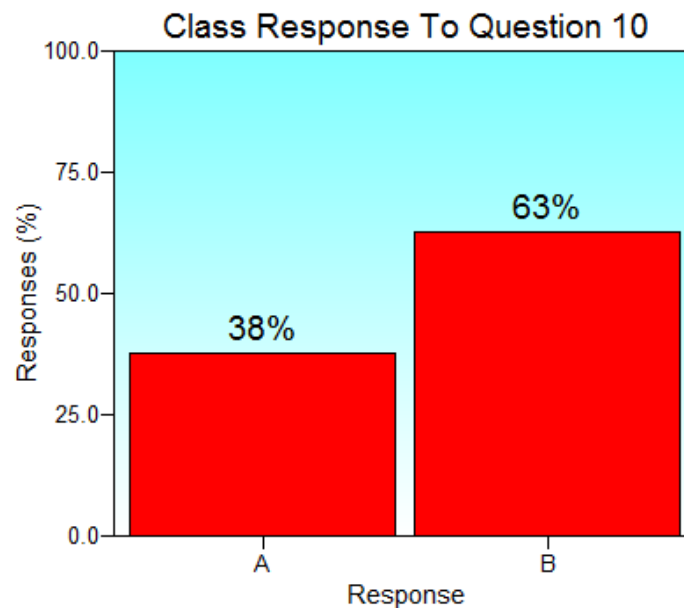


Challenges - *Livebetter*

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

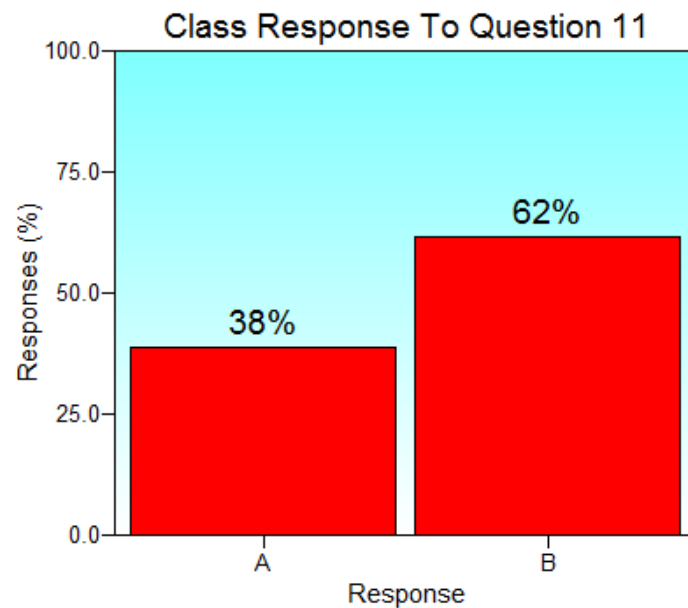


Challenges - General

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

A. Yes

B. No

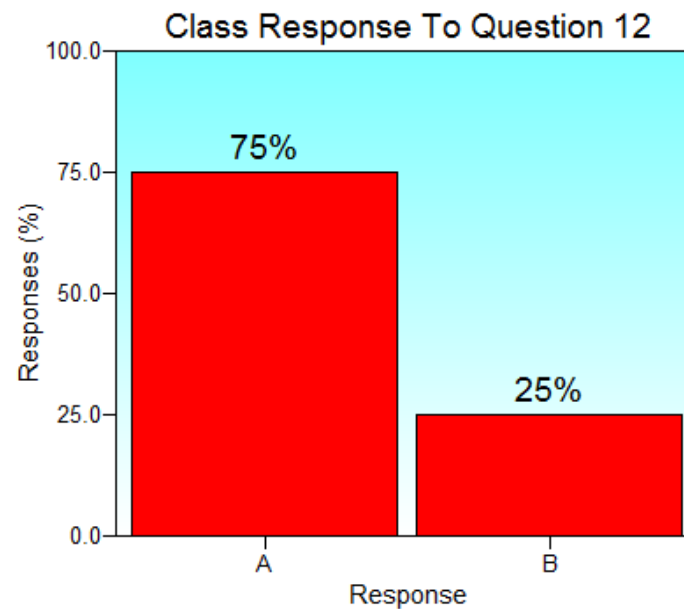


Challenges - General

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

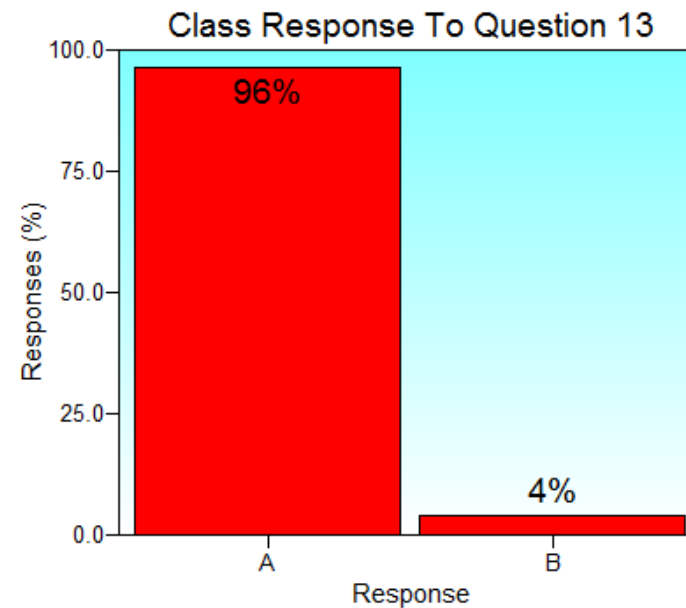


Challenges - Explainable AI (XAI)

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

A. Yes

B. No

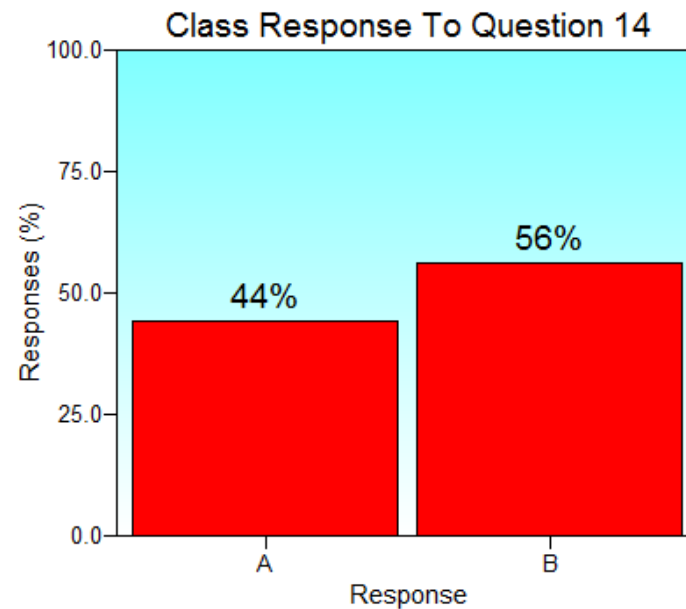


Challenges - XAI

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

