Dr Angela Ballantyne Angela.ballantyne@otago.ac.nz PHSS Data Ethics 13.02.2017



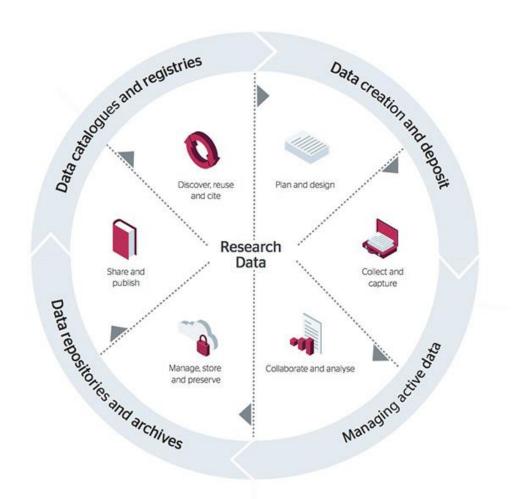
Te Whare Wánanga o Otâg NEW ZEALAND

Data life cycle



Data life cycle







- Which colour blue, ad size
- 71% self-censure on Facebook, writing comments they don't post
- Auto- versus active- sharing of "Facebook offers claimed"
- RCT of "political mobilization messages" delivered to 61 million users during the 2010 US congressional elections (Bond et al *Nature* 2012)

A/B testing Facebook

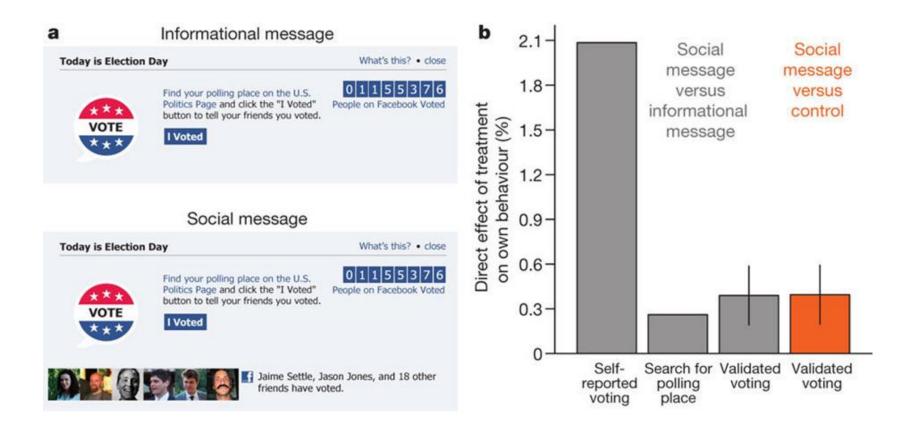
TE PŪTEA RANGAHAU Te Whare Wánanga o Otágo

MARSDEN FUND

A MARSDEN

UNIVERŠITY OTÃGO

NEW ZEALAND



Data



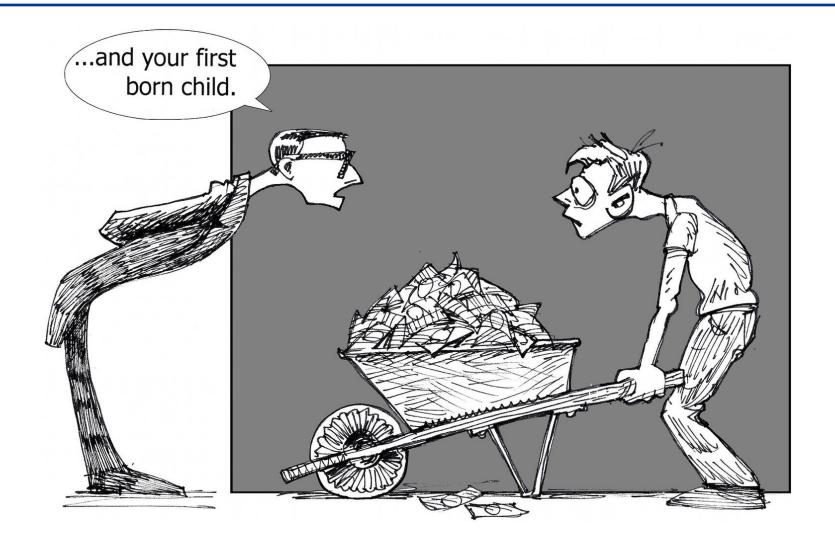






NEW ZEALAND

Data as a condition of publication





- "The International Committee of Medical Journal Editors (ICMJE) believes that there is an ethical obligation to responsibly share data generated by interventional clinical trials because participants have put themselves at risk. In a growing consensus, many funders around the world—foundations, government agencies, and industry—now mandate data sharing." (Taichman et al 2016 Lancet)
- As of 1 July 2018 manuscripts submitted to ICMJE journals that report the results of clinical trials must contain a data sharing statement.



Summary

- The experience IS the experiment
- Trade-off the more you protect privacy, the less utility you get from the data