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PHSS Data Ethics 13.02.2017

MARSDEN FUND

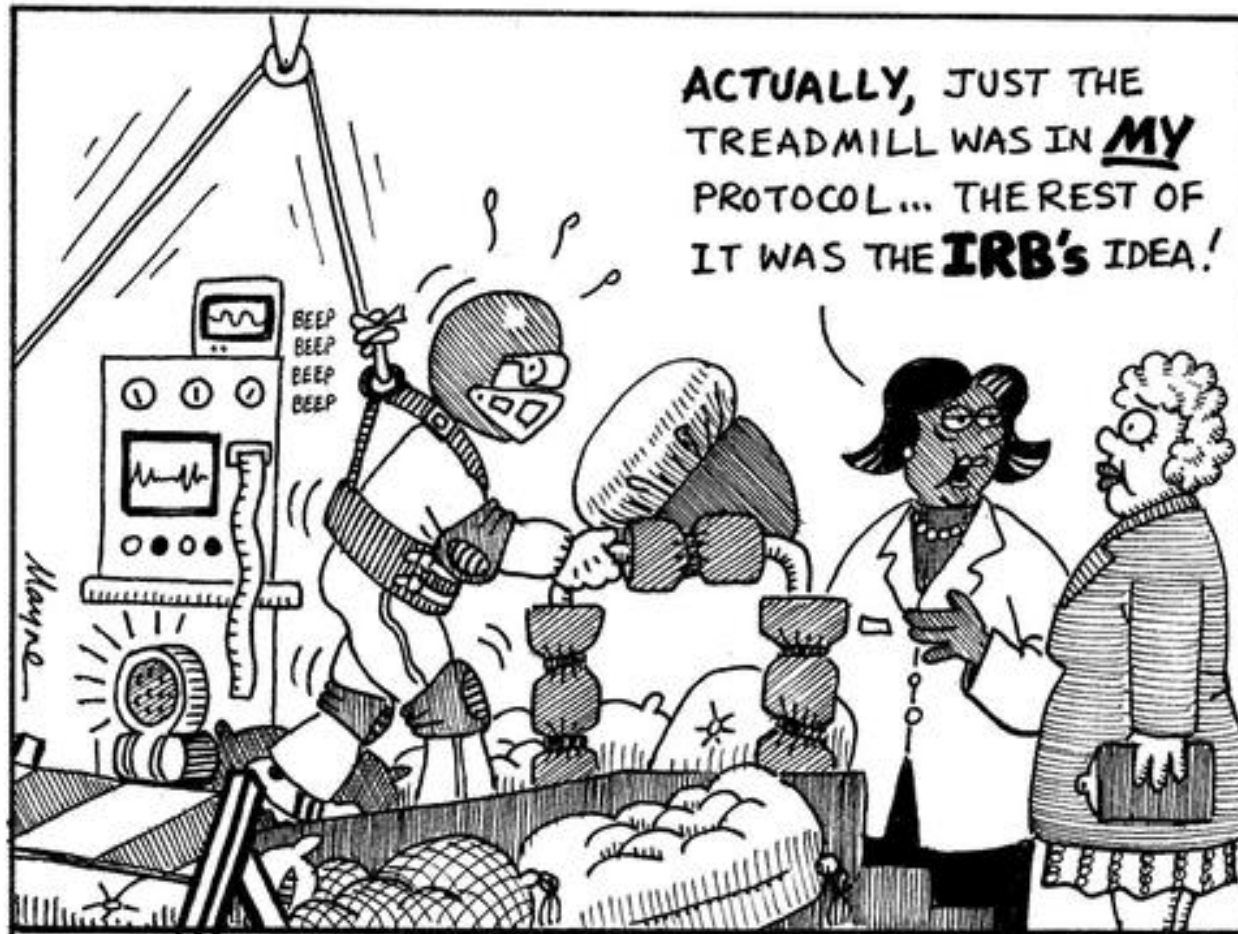
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NEW ZEALAND

HDEC Review of data studies



Health Information Privacy Code 1994



- ▶ Rule 11 Disclosure of health information
 - (2)(a) Disclosure for directly related purpose
 - ...within the **expectations** of the person
 - ...for example, **peer review and quality audit.**
 - 4(2)(c) that the information:
 - (iii) is to be used for research purposes (for which **approval by an ethics committee, if required,** has been given) and will not be published in a form that could reasonably be expected to identify the individual concerned

NEAC Observational Guidelines



- ▶ Paragraph 6.43: potentially identifiable data for research (without consent) :
- ▶ a) the procedures required to obtain consent
 - unnecessary anxiety
 - prejudice the scientific value of the study;
 - impossible in practice to obtain consent; AND
- ▶ b) there would be no disadvantage to the participants or their relatives or to any collectives involved; AND
- ▶ c) the public interest in the study outweighs the public interest in privacy.

Challenging cases



- ▶ Significant responsibility to promote “appropriate” use of public data
- ▶ Researchers want access to health data to identify potential participants for recruitment
- ▶ What is impractical? Does cost count?
- ▶ Journals increasingly require submission of raw data for future use

Under-review



- ▶ MOH is due to release the revised guidelines for targeted consultation in the next few months