

Leading the way with a health research repository

As an advocate of the growing movement towards open and free access to data and information, both in the publication arena, as well as other information initiatives such as those put forward by David Healey (RXisk.org) and Ben Goldacre (alltrials.net), I'd like to put forward a suggestion to New Zealand based on recent experiences. I'm a first-year PhD student, exploring the relationship between research practices, the research environment, and health equity.

Naturally, my first step in this process was to try and gain a picture of what research has occurred in New Zealand (generally, and more specifically clinically) over a specific time period and explore how that research was generated in terms of funding, participants, methodologies, etc.

My observations have been the following:

- Data is fragmented. Various bits of information are available from various sources, but no one source can be consulted to investigate health research activity in New Zealand.
- Data is not robust. Multiple sources consulted including both government and private organisation websites have shown to have errors in their records, some to the extent that an entire year's entries are mislabelled, some lists have omissions, double-ups, or incomplete entries.
- Data is not accessible in a user-friendly manner. While I recognise the sources accessed were not designed for my specific purposes, there are still issues in finding information. If I imagine, myself a public enquirer, professional, or researcher wanting to get information on a condition, then this task is not an easy one, if at all achievable.

A compulsory, centralised databank logging all health research from bench to bedside, including both qualitative and quantitative work would be an asset to New Zealand. We could lead the way with a “trial-registry” like system for all our health research. Each entry could have a simple entry “cover-page” (investigators/institution, title, start date, list of included supplements), plus compulsory supplementary documents, and the data set with data dictionary once completed.

Supplementary documents would include (where applicable): research protocol/study design, ethics application and outcome, data analysis plan, information sheet and consent form, Maori consultation, declaration of funding and conflicts of interest, log of adverse events (personal information redacted) and list of associated publications. This list is debatable and not exhaustive, but the idea would be to have a single source for research study information from inception to close.

This repository could be created in something as easy as D-Space (www.dspace.org, an open source repository application—so free) for example and administered ideally by the Ministry of Health. Records that are commercially sensitive could have

everything, but their cover page embargoed (some IT applications allow for this). Data-sets could be available on request rather than by default.

The benefits of creating this kind of repository are manifold:

- The PUBLIC have easy access to current research activity in New Zealand allowing them to know what is happening for a condition of interest, or follow-up on the outcomes of a trial they participated in.
- HEALTH PROFESSIONALS have a transparent view of research activity which is comprehensive, allowing them to look into particular conditions or search trials recruiting relevant to their patient(s).
- The GOVERNMENT have access to a complete picture of research activity – this enables better strategic planning, better audit, analysis of practice, targeting of funding, etc.
- The RESEARCH COMMUNITY has a complete record of their work in one place, which they can direct enquires to, reference in their publications, and they can also more easily access other's work to inform their own studies and combine data or learn from other's practices.

It would be hoped that such a repository would go some way to helping create a greater balance between collaboration and competition, where a collaborative environment could be seen as a more effective approach to limited funding.¹ It allows researchers to avoid unnecessary double-up or crossover of work (aside from replication studies), and identify areas that need more exploration more readily.

Objections regarding the conflict with publications, costs, and practicalities could all be worked out with discussion. For example, the repository does not negate the need for publication (publication still promotes results within the research community), but what it does do is offer transparency of all work whether published or not. An entry log tally of the use of individual entries in the repository could be added to research performance metrics and may represent an additional means of assessing impact.

The details of this recommendation need to be debated, but as a recommendation, a comprehensive, open access, research activity repository in New Zealand seems to offer many positives and would be world-leading.

I look forward to hearing the opinions of others on whether such a repository has merit or not.

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Reference:

1. Kitcher P. Science in a democratic society. Prometheus Books, 2011.