

Cut the crap – it’s personal!

Rudy bin Mahli, AUT

Slide 1

Cancer, diabetes, and stroke are 3 of Aotearoa’s top 10 causes of death by diseases in 2017 ¹. With a population of just 4.7 million, 24 Kiwis per day will experience stroke, 63 per day will be told “**You have cancer**” ². And currently, 240,000 are suffering from diabetes. It is an unfortunate fact that most of us know loved ones who suffer from these diseases ³.

Coincidentally, these killer diseases are popular research areas for AUT postgraduate students, which is a good thing. Right? Globally, billions of dollars are spent every year in order to discover the cures, and AUT postgraduate students have contributed to this crusade when their research, carried out as part of a thesis, uncovers findings that might be vital to the discovery of such cures.

By embargoing their theses, however, and thus making these discoveries inaccessible, the students contradict the objective of finding a cure. Therefore, authorising embargo of AUT theses on cancer, diabetes, and stroke, must stop, and as librarians, we must make this a personal objective.

Reference:

^{1, 2, 3} <http://www.healthdata.org/new-zealand>

Slide 2

Tēnā koutou, tēnā koutou, tēnā tatou katoa.

My name is Rudy, and I add content into the Tuwhera Theses and dissertation collection. My presentation is about the current practice, by Faculties, of offering students the option to embargo their thesis, even the ones that researched cancer, diabetes and stroke.

The embargo period applied on such valuable theses usually runs between 2 to 3 years. Regrettably, embargo extensions are also common.

The most popular reasons for embargoing theses are; students wanting to publish their discovery, and students wanting to patent their discovery.

Quickly take note of the embargo period again before we continue ⁴.

Reference:

⁴ <https://tuwhera.aut.ac.nz/>

Slide 3

These are a sample of abstracts of embargoed theses. These abstracts mention research-proven potentials for either cure, or, relief from disease symptoms. With such potentials, the objective to cure, care, or even inform the public are lost behind an embargo.

For your information, all these theses were approved for an embargo period of between 2-3 years ⁵. One of them is funded by the Health Research Council of New Zealand ⁶, whose contract includes the term;

“Promoting and disseminating the results of health research in ways that will be **most effective** in encouraging their contribution to health science, health policy and health care delivery.” ⁶

Again, quickly take note of the embargo period mentioned before we continue.

Reference:

⁵ <http://hdl.handle.net/10292/11053> (24-months, IP and publication)

⁵ <http://hdl.handle.net/10292/11943> (36-months, IP and publication)

⁵ <http://hdl.handle.net/10292/10771> (36-months, IP and publication)

⁵ <http://hdl.handle.net/10292/10989> (36-months, IP and publication)

⁶ <http://www.hrc.govt.nz/sites/default/files/HRC%20Research%20Contract%202018.pdf>

Slide 4

Can anyone guess the average number of years it takes to put a drug to market, from the moment a discovery is made? 12 years. ⁷

Can anyone guess the average number of drugs that made it all the way to human testing? 5. ⁷

Lastly, can anyone guess the number of drugs approved? 1. ⁷

Reference:

⁷ <https://www.medicinenet.com/script/main/art.asp?articlekey=9877>

⁷ <https://www.pharmaceutical-journal.com/publications/tomorrows-pharmacist/drug-development-the-journey-of-a-medicine-from-lab-to-shelf/20068196.article?firstPass=false>



N.B. ⁷ & ⁸ The figures are based on the US Food and Drugs Administration (FDA) statistics, and not New Zealand's. Until today, the US is still the leading country that spent money and hours in drug development. Also, there is no similar data from Aotearoa.

Slide 5

Factoring these odds, what are the implications for someone embargoing for 36 months? What are the chances of a quick patent, or commercial drug approval? Most importantly, what are the implications for the patients if that process is slowed further?

As Librarians, we can stop this nonsense, and work on how to make theses on cancer, stroke, and diabetes publicly accessible, instantly. In the spirit of AUT values ⁹ of tika, pono, and aroha, I believe we can give hope to the sufferers by carrying out actions such as:

- Advise Faculties to stop offering students thesis embargo option, especially for theses on cancer, stroke, and diabetes;
- Convince the Ethics committee on the importance of having the discoveries publicly, AND instantly, available;
- Inform government funders of the research they're sponsoring and advise them to insist that discoveries are quickly open to all.

In addition to the values, these actions should also fit in with an AUT Directions to 2025 theme; to share our discoveries and developments in ways that allow them to be widely used.

We have 6 years to 2025. We have discovered the challenge. It's time for action!

Reference:

⁹ https://www.aut.ac.nz/_data/assets/pdf_file/0019/119503/aut-directions-4pg-010917-v11.pdf