Strategic Review of Health and Medical Research in Australia
Submission of Insights and Suggestions from
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(4 pages)

Executive summary:

1. We cannot rely on other countries to do the medical research we need to solve our health care and health economics problems.
2. The Australian government is the main financial beneficiary of medical research in this country, through reduced long-term care costs and increased productivity.
3. The Australian government needs to invest more in Australian medical research for its own good.
4. We need to be smarter in the way medical research is performed by integrating it with routine patient care responsibilities.

About Myself

I am a neurologist with a passion for acquiring and implementing the knowledge (evidence) we need to optimise each patient's chance of a favourable outcome. As a young doctor I recognised 'stroke' was just one devastating problem where such knowledge was rudimentary. I put aside the secure income of a clinical job (implementing current knowledge) to undertake a PhD and post-doctoral studies. It has been a very hard road because there is no ready path for specialised medical researchers. I persisted because I could see the extreme public health significance of my preliminary findings regarding stroke prevention. In my case, persistence led to the discovery that carotid surgery (or stenting) should no longer be performed to prevent stroke associated with clinically silent, atherosclerotic narrowing of the internal carotid artery origin [1]. This is contrary to current guidelines and routine practice which are based on out-dated randomised trial data acquired 2-3 decades ago. My results are robust, have been independently validated and are changing guidelines, policy, the literature and practice [2]. My work has been acknowledged by top national awards, including the Australian Society for Medical Research Award and National Association of Research Fellows Award. My experience has given me clear insight into the importance of a sustainable, effective Australian medical research industry and an appreciation of major handicaps imposed on Australian medical research and some ideas to overcome these. My insights and vision for a bright future for health services and medical research are summarised below.

Answers to Terms of Reference Key Questions

1. Why is it in Australia's interest to have a viable, internationally competitive health & medical research sector? It is <u>essential</u> that Australia has viable, internationally competitive health & medical research sector because we cannot rely on other countries to conduct the medical research we need to solve our medical problems. Quality medical research is difficult to perform in any country because of insufficient, independent resources. Relatively very little research is done in relation to the clinical and economic scale of heath related issues. The data we need to address an individual's particular health problems are often unavailable (the studies have not been done) or are of questionable applicability, whether or not the data was acquired overseas. The story of carotid artery disease management is an excellent example of how other countries can be incorrect in relevant guidelines, policy and research, resulting in significant patient morbidity and mortality and staggering economic waste [2]. Lack of diversity in research activity leads to 'monopolisation' which increases the chance of errors. An effective, sustainable *local* health care system requires an effective, sustainable *local* health & medical research sector.

2. How might health & medical research be best managed & funded in Australia?

Unlike corporate industry, the medical/health industry is more about saving than making money- saving money required for managing illness, caring for patients with disability and saving productivity money lost

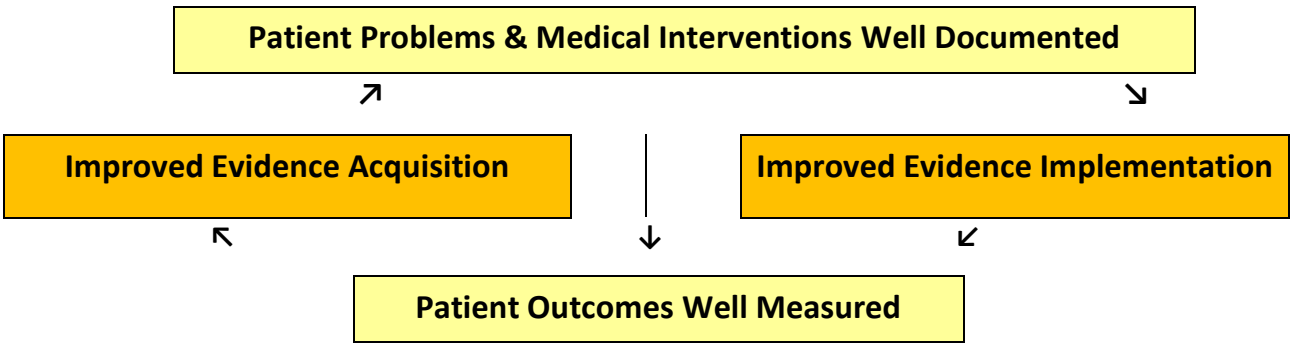
from illness and premature mortality. Therefore, the medical researcher does not usually benefit financially from his/her research to prevent and/or better manage illness (even though good health is priceless). Instead, the community benefits from improved health and more efficient use of resources. The government benefits most financially from a healthy population via reduced long-term care costs and increased productivity. Indeed, this is also in part why the pharmaceutical and 'device' industries are unable to viably fund much of the required medical research; most of the financial benefit flows to government rather than companies. Therefore, government funding of medical research is essential. Trouble is, the medical research industry is poorly understood. It is not recognised and supported as an industry in its own right. It is still heavily dependent on work done in 'spare time' and is rewarded by relatively few 'prizes'. Medical research in Australia has been chronically underfunded, making it obviously unattractive to new participants and wasteful of those who take it on- even if excellent in their achievements. Lack of funding causes lack of diversity and significant problems, including false criteria for real scientific research success.

The medical research industry needs resuscitation with secure and adequate funding. It is well recognised that medical research saves the community and government much more money than the cost of the research [3]. My own discovery regarding stroke prevention came from very modest financial investment in research. However, billions of dollars will be saved around the world each year by no longer performing unnecessary invasive carotid procedures. Medical costs are rising for several reasons, including lack of research into how to best prevent and manage illness. So much more could be achieved by secure and adequate funding from government and philanthropic investment. Ultimately, countries will succeed on the strength of their scientific capacity. I believe that most problems regarding the present system of Australian medical research are symptomatic of chronic underfunding. The major problem is lack of support for salaries and other costs and career certainty due to scarcity of funding. NHMRC salaries do not cover base award rates or on-costs. About one in five NHMRC salary or project grant applications are successful, despite high or excellent applicant standards. Grant support lasts 1-5 years only. However, it takes decades to train skilled researchers and develop research capability. 'Break throughs' from medical research usually come from chipping away at problems over many years. Medical research needs uninterrupted support as an on-going activity. Specialised medical researchers need uninterrupted support of a lifelong career (once a researcher leaves research due to lack of funding, they are almost always lost to research forever). Yet the medical research funding model is a pyramid, with steady attrition and very little available at the top (for example, there are presently sufficient funds to support only half of NHMRC career development fellows transitioning to the next level). It is not the medical research system that needs fundamental change in Australia, it is the level of funding. The research industry needs a significant capital injection and secure and adequate ongoing 'future' funds, free from political whims.

3. What are the health & medical research strategic directions & priorities? How might we meet them?

Secure and adequate government funding for medical research is essential if we are to address current and future health and economic challenges in Australia. Further, we need to be smarter about the way medical research is conducted. Currently, medical research is very difficult and inefficient to perform. Medical research should be driven by patient need- clinically defined problems. Trouble is, medical 'evidence' is largely derived from a relatively very small number of dedicated 'studies'. The largest, most relevant source of medical evidence is the experience of patients managed routinely in every day practice. However, regrettably, information about routine-practice patients' diagnoses, interventions and outcomes is recorded in a relatively non-standardized way on paper, excluding it from systematic review and our evidence-base. Clinical research largely depends on separate efforts and resources, making it expensive and often inefficient by duplicating routine clinical activity. I recommend a key health and medical research strategic direction should be to organise routine medical practice to allow all willing clinicians and their patients to contribute to evidence base, making cost-effective, large-scale clinical research and a self-improving medical industry possible [5]. This can be achieved by changing to an electronic system that incorporates routine practice patient reporting responsibilities with research (data-base building, see Figure).

(Figure) Revolutionary Model for a Self-Improving Health System



This is not about existing government initiatives to transfer to 'electronic records', which currently focus on immediate patient care duties. Such initiatives are not designed for my proposed research activity and quality improvement. For instance, scanning poorly legible/illegible, hand-written, non-standardized records will not allow systematic review and generation of quality data. The system required needs to be designed with substantial input from the research and clinician community. I propose a Revolutionary new registry system [5] for hospital outpatient clinics where each medical specialty develops and utilizes an industry standard, web-based, electronic 'super' registry/database which allows communication between specialties. Routine patient information should be recorded only in the registry (via a user-friendly interface) by relevant staff as direct type or 'pasted in' by receptionists using clinician-dictated text. Fundamental data collected and terminology should be standardized using multi-disciplinary consultation, allowing comparison of diagnoses, risk factors, interventions and outcomes. Each specialty super-registry will generate standardized hardcopy/electronic medical reports and store accumulating prospective data. This will be a novel and invaluable tool for medical research. Existing registries, used in some clinics, collect data overlapping with routinely collected information and are additional work to routine duties. Each super-registry will incorporate these registries, avoiding duplication. The aim is one registry/specialist.

Research-nurses should be employed to facilitate the self-improving health system in several ways. Firstly, research nurses should save specialist time by entering routine clinical information, prior to physician review, allowing specialists more time for complex aspects. Secondly, research-nurses should help ensure data quality and completeness. Thirdly, research nurses can complete the 'research loop' by helping to track experience of individual patients through the health care system to measure outcomes of particular interest. Then we can start to measure outcome rates for known, specific interventions, such as the rate of stroke in patients given current optimal medical (non-invasive) intervention alone, or the rate of stroke or bleeding in patients given new classes of antithrombotic drugs for atrial fibrillation. Ancillary developments are being made in the transfer to electronic medical records that facilitate my proposals. These include government initiatives such as the Personally Controlled Electronic Health Record (PCEHR) System, the National Healthcare Identifiers for individuals, healthcare providers and healthcare organisations, as well as the National Authentication Service for standardizing clinical terminology and facilitating methods of health information communication (like specialist letters discharge summaries and electronic referrals) [6]. My proposals for integrating routine medical record keeping with fundamental research capacity are novel and complementary these initiatives, providing immediate, serious research capacity to improve best-evidence and facilitate its implementation (translation) (see below).

4. How can we optimise translation of health and medical research into better health & wellbeing?

As patients survive longer with complex, multidisciplinary medical conditions, it becomes increasingly difficult to keep pace with current best evidence and to implement (translate) it. The super-registries, described above, will also provide a cost-effective, user friendly mechanism to ensure current best evidence for optimizing patient outcomes is implemented (see Figure). Inventions given according to individual patient diagnoses will be examinable. Therefore, adherence to current best evidence (defined by consensus among participating clinicians) will be measurable. In addition, the system will facilitate implementation of

current best evidence by built-in alerts for outlier parameters, guides to current best practice diagnosis and management and links to pharmaceutical information.

Summary of Benefits from the Revolution Registry System [5]

i. **Save specialist time** in managing clinic patients via more easily accessible patient files, support staff, registry prompts for best care and avoiding effort duplication in satisfying multiple registries.
ii. **Help ensure best practice** (defined by participant consensus using current best evidence/guidelines) is delivered via registry prompts and systematic outcome measurement.
iii. **Improve best practice** care by providing a cost-effective way for all consenting patients and clinicians to contribute to the evidence-base required to improve patient outcomes.
iv. **Improve communication** among health-care providers (consistent, more prompt reports).
v. **Save clinician-researcher time and other resources** by integrating fundamental research with routine care. An efficient way to identify and follow-up patients of interest, making the next study of carotid disease (for example) easier, cheaper and less reliant on grant or industry funding.
vi. **A model** for outpatient and inpatient hospital service (data from discharge letters) and all medical specialties.
vii. **The capacity for large-scale collaborative research** as not seen before. A means to study populations in real time as medical practice evolves (rather than study tiny samples occasionally) and a means to better research rare conditions.
viii. **Improved patient outcomes** via better acquisition and implementation of best evidence.
ix. **Better directed health-care and research dollars** via improved efficacy.
x. **A self-perpetuating revolution** for improvement in medical practice and research

References

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I am more than happy to discuss these issues further.
Yours sincerely,
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