New South Wales

Special Commission of Inquiry into Healthcare Funding

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1. About Garvan

The Garvan Institute of Medical Research (Sydney) brings together world leading researchers and clinicians, collaborating locally and globally, to improve human health. From the individual patient with rare disease, to the many thousands affected by complex, widespread illness, we are pioneering discoveries across diseases that have the deepest impact on our community.

Through our key scientific strengths in data, genomics, cellular, translational and clinical science, and enabled by cutting-edge technology and world-class facilities, we aim to catalyse research from fundamental discovery to transformational impact.

Founded in 1963, Garvan's researchers have made significant breakthroughs for diseases including rare cancers and cancers of the breast, prostate and pancreas, immune deficiency and autoimmunity, COVID-19, diabetes and skeletal disease.

Today, Garvan's mission builds on those advances, harnessing all the information encoded in our genome, from DNA to complex organ systems, to better diagnose, treat, predict and prevent disease.

Patients, clinical trials and diverse population cohorts are at the centre of Garvan's research. We are focused on addressing the unmet needs of those living with disease – where better understanding, new treatments and more effective diagnosis can have the biggest impact for individuals and their families.

Garvan's research is funded through a crucial combination of peer-reviewed government grants and generous philanthropic investment from the community. With the support of our passionate Garvan family, our researchers strive, every day, to create a future where everyone lives longer, healthier lives.

Garvan is a founding member of the St Vincent's Sydney Health Innovation Precinct, Australia's oldest and most established partnership, located in the heart of Sydney. Our other Cornerstone Partners are St Vincent's Sydney Public and Private hospitals, St Vincent's Clinic, and the Victor Chang Cardiac Research Institute. Precinct partners share a vision to transform healthcare through Australia's closest research-clinical connections. Garvan is also affiliated with UNSW Sydney.

2. Context for this submission

Garvan welcomes the opportunity to provide expert perspectives to The Special Commission into Healthcare Funding, which is conducting a review of the funding of health services in NSW.

Garvan's core business is conducting medical research. Australian medical research delivers an outstanding return on investment to the Australian economy[1,2]; this relies on the effective translation of research from the laboratory into the clinic (effective treatments, tests, prevention approaches, and models of patient care).

For this reason, we have focused our response around the 'third space' between laboratory research and clinical practice. We discuss state-level interventions that we consider would be most impactful in bridging the divide between research and patient care.

Our response addresses two elements of the Special Commission's Terms of Reference:

> *B. The existing governance and accountability structure of NSW Health; and*
>
> *F. The current capacity and capability of the NSW Health workforce to meet the current needs of patients and staff, and its sustainability to meet future demands and deliver efficient, equitable and effective health services.*

We have organised our response into three overarching areas:

> *A. Clinician-scientists and clinical/research collaboration in NSW*
>
> *B. Building NSW leadership in clinical trials*
>
> *C. Empowering NSW government entities in health*

Within these three areas, we make a total of nine recommendations.

[1] Economic Impact of Medical Research in Australia. KPMG, 10/2018
[2] Why Basic Science Matters for Economic Growth. IMF blog, 06/10/2021

We note that our comments largely focus on the provision of **cancer** services in NSW. Cancer is one of several major disease foci for Garvan, and we have deep expertise across the full span of clinical services, clinical trials and medical research in the cancer space. We consider that many of the challenges and opportunities for NSW Health in the cancer space are also relevant to other disease areas.

In preparing our submission, we have consulted closely with representatives in key partner organisations, particularly St Vincent's Hospital Sydney (a member of St Vincent's Health Australia) who are co-located with Garvan on the St Vincent's Sydney Health Innovation Precinct in Darlinghurst. Garvan and SVH are working towards closer engagement in the translation of medical research into clinical practice; the challenges we have encountered in this endeavour inform aspects of our submission.

3. Summary of recommendations

Clinician-scientists and clinical/research collaboration in NSW	
1	Establish formal roles for "second specialties" held by clinicians that contribute to progressing healthcare delivery in Australia.
Building NSW leadership in clinical trials	
2	Introduce greater coordination of clinical trials across NSW.
3	Harmonise research governance and ethics approval across NSW.
4	Streamline ethics approvals for phase 2 trials.
5	Provide additional support to Human Research Ethics Committees.
6	Remove barriers to trial staff and participants engaging with multiple hospitals.
Empowering NSW government entities in health	
7	Empower OHMR/CINSW to establish data-informed clinical Centres of Excellence.
8	Build closer relationships between OHMR/CINSW and employment awards in health.
9	Advance PBS reform in NSW.

4. Clinician-scientists and clinical/research collaboration in NSW

Clinical medicine is increasingly shifting to a 'precision' model in which treatment is tailored to genetic or molecular features of an individual patient and their disease, rather than uniform therapy based on the patient's clinical diagnosis. This is a paradigm shift and an important step forward for the patient and the healthcare system.

Precision medicine used in the clinic is based on scientific research generated in the research laboratory. Moreover, the lag between research discovery and clinical use of precision medicine is shortening. It is therefore important that clinicians guiding delivery of precision medicine should have an understanding of the science behind the medicine, and research that seeks clinical impact should be conceptualised and conducted with input from clinicians. Bridging the research-clinical divide supports translatable research projects that are more likely to have tangible clinical impact, *and* supports research-informed clinical care that maximises clinical benefit and reduces cost of inappropriate tests and treatments.

4.1 Clinician-scientists

'Clinician-scientists' (practising clinicians who split their time between clinic and lab) are a foundational element of research/clinical collaboration. These individuals bring integrative capabilities, traversing the different knowledges and cultural norms of research and clinical practice in ways that can profoundly shape research programs to build new clinical treatments and approaches in the longer term, as well as tangibly improving patient care in the immediate term. Clinician-scientists are 'uniquely positioned to facilitate exchange between research and practice, and as such are deemed vital to the advancement of

medical practice'[3]; they are 'at the forefront of translating knowledge into health care while ensuring research agendas are relevant to health services and their patients'[4].

Despite the evident value of clinician-scientists, they remain scarce in Australia. We consider this is because of the substantial structural barriers and disincentives to conducting both research and clinical practice:

- First, clinicians in NSW are benchmarked and rewarded exclusively around direct patient care[5]. Key performance indices focus on patient outcomes (eg length-of-stay), clinical quality (eg infection rates) and operational outcomes (eg bed occupancy rate). There is therefore very little organisation-level incentive for clinicians to engage in research.
- Second, there are financial disincentives for clinicians to be research-active. A (0.2 FTE) clinical role for an experienced clinician seeing a moderate number of patients (level 4) draws a base salary of $59,080 with potential earnings of $88,620[6]. The equivalent time spent as an experienced postdoctoral researcher (SRO6) or Laboratory Head draws a salary that is only one third to one half of the clinical equivalent.

4.2 Researchers engaging with clinicians, and vice versa

There are substantial challenges for researchers in engaging with clinicians, even when the benefits of incorporating expert clinical perspectives to shape research are well understood. Researchers typically navigate frequent cycles of funding with very low acceptance rates – while large research projects involve dedicated networks of labs, with sufficient continuous funding to sustain skilled teams over years. In this context, researchers may feel it is difficult to access clinicians' time and attention. Conversely, access to scientists can be difficult too: scientific projects are highly complex and may appear difficult for 'outsider' clinicians to step into and add value.

4.3 Recommendation

To mitigate these substantial challenges, we see it as crucial that systems are put in place to support research/clinical collaborations and incentivise clinician-scientists.

Recommendation 1: Establish formal roles for "second specialties" held by clinicians that contribute to progressing health care delivery in Australia.

Currently, according to the NSW Health Staff Specialists (State) Award 2022[7], clinical, teaching, administrative, research, quality improvement and managerial duties are all 'important aspects of the Normal Duties of a staff specialist'. There is no incentive in the award for research productivity. An alternative approach (based on a model used in Canada[8]) is to formalise roles for a variety of clinicians within the industrial award, for instance (1) clinician-scientists, (2) clinician-educators, (3) clinician-administrators, (4) clinician (rural / regional) and (4) clinician-investigators, who have protected time dedicated to their 'second specialty' but are remunerated equally. This solution incorporates amendment of KPIs to recognise 'second specialty' achievements. Within research, this may include grants acquired; within education, this may include curriculum developments; within trials, this may include number of investigator-initiated and industry-sponsored trials opened and completed.

5. Building NSW leadership in clinical trials

Clinical trials are essential to the development of new tests, treatments or clinical approaches that have been identified through the research process. Trials allow researchers to test interventions in individuals and determine safety, side-effects and efficacy (alone or in combination, and in different patient populations). Importantly, later-stage clinical trials are also themselves a clinical intervention, providing patients with access to cutting-edge interventions that would not otherwise be available.

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[3] De Groot E, Baggen Y, Moolenaar N, et al. (2021). Clinician-scientists in-and-between research and practice: how social identity shapes brokerage. *Minerva: A Review of Science, Learning and Policy*; 59:123.

[4] Eley DS, O'Leary SP, Young A, Buttrum P (2020). Is Australia's clinician scientist capacity appropriate for addressing the next pandemic? *Journal of the Australian Healthcare & Hospitals Association*

[5] https://www.health.nsw.gov.au/careers/conditions/Awards/staff-specialists-award.pdf. Accessed 21/11/2023

[6] NSW Health Information Bulletin IB2023_037 – Staff Specialist (State) Award Salary Increases. Publication date 04/09/2023. Accessed 24/11/2023

[7] https://www.health.nsw.gov.au/careers/conditions/Awards/staff-specialists-award.pdf. Accessed 21/11/2023

[8] See https://deptmedicine.utoronto.ca/academic-position-descriptions for an example. Accessed 24/11/2023

Trials necessarily operate in the space of previously untested interventions on participants, including patients, and are therefore subject to crucial logistical, ethical and governance requirements that are designed to inform participants and safeguard their health and personal information. Without effective oversight and coordination, these requirements can become highly unwieldy, slowing the introduction of new therapeutic approaches into health care, and limiting timely access to new therapies.

Challenges associated with streamlining clinical trial provision are shared by health care systems around making NSW an attractive location for clinical trials.

5.1 Ongoing challenges for clinical trials in NSW

Our comments focus on cancer care. As a whole, cancer clinical trials are initiated and coordinated in an *ad hoc* manner, often with co-located hospitals competing for the same patient population. Moreover, ethics and governance processes for clinical trials are highly fragmented, for example:

- Multiple HREC submission platforms are in simultaneous use across public and private hospital sites and across the country, adding complexity and discouraging multi-centre and multi-state trials. Further, there is often no ability to share information across platforms, forcing the laborious manual submission of human ethics applications across multiple platforms and formats.
- Ethics review of trials beyond phase 1 remains cumbersome. Unlike phase 1 trials (conducted by Bellberry Ltd, see below), phase 2 and 3 trials in NSW require review by a hospital HREC committee, which meets once per month, is staffed by volunteer clinicians and lay-members, and has limited monthly capacity, which impacts turnaround times.

5.2 Increasing coordination of clinical trials at NSW and federal level

We acknowledge that oversight and coordination of clinical trials is improving. Supported by NSW Health entities (NSW Health – Office for Health & Medical Research (OHMR), Clinical Trials NSW, Cancer Institute NSW (CINSW)), state-level coordination of trials is improving:

- A state-wide clinical trial management software package (Clinical Conductor) launched September 2023
- The NSW Early Stage Clinical Trials Alliance (NECTA[9]; co-funded by OHMR and CINSW and based at the Garvan Institute) acts together with Clinical Trials NSW[10] to advocate for NSW on the global stage in cancer as well as coordinating the movement of patients between NSW hospitals to access the most appropriate trials through a central email (trials@necta.org.au) and phone (1800-PHASE1).
- Commencing in 2019, Bellberry Ltd[11] manages and streamlines scientific and ethical review of early phase clinical trials involving adults that are conducted at NSW Public Health Organisation (PHO) sites. This initiative was established through the NSW Health Early Phase Clinical Trial Scheme[12].
- Public LHDs in NSW use a unified platform for Human Research Ethics Committee (HREC) applications (Research Ethics and Governance Information System; REGIS[13]), reducing repetition.

Coordination of trials at federal level is also improving:

- The National One Stop Shop[14] (a national cross-jurisdictional platform for health-related human research) is under development. This initiative includes a 'National Clinical Trials Front Door'. The goal of the initiative is to 'eliminate long-standing challenges with duplication delays, navigation and fragmentation'[15] that result from differing state-level processes in clinical trials ethics and governance and other aspects of medical research.

[9] http://www.necta.org.au/ Accessed 21/11/2023
[10] https://www.medicalresearch.nsw.gov.au/clinicaltrialsnsw/ Accessed 21/11/2023
[11] https://bellberry.com.au/ Accessed 21/11/2023
[12] https://www.medicalresearch.nsw.gov.au/early-phase-clinical-trials-2/ Accessed 21/11/2023
[13] https://regis.health.nsw.gov.au/ Accessed 21/11/2023
[14] https://www.safetyandquality.gov.au/our-work/health-and-human-research/national-one-stop-shop-national-platform-health-related-human-research Accessed 21/11/2023
[15] Ibid.

5.3 Recommendations

We see considerable opportunities for NSW Health to refine the model for clinical trial provision across the state and provide best-practice national leadership that attracts commercial clinical trials to NSW.

Recommendation 2: Introduce greater coordination of clinical trials across NSW

We recommend that NSW Health builds on existing infrastructure currently used by NECTA (see 5.1 above) to co-ordinate clinical trials across the state. This could involve (1) further formalising the NECTA infrastructure to facilitate the identification of trials for patients in need from around NSW; and (2) assistance with the ongoing work of NECTA in promotion and facilitation of clinical trials across NSW beyond the work done to date such as the annual Drug Development Meeting[16], educational activities and regular NECTA podcast (Dangerous Ideas in Drug Development[17]). This increased coordination and oversight would limit duplication and overlap. We additionally recommend a change to the model of clinical trial coordination and management, such that clinical trial coordinators are employees of NSW Health rather than a particular LHD.

Recommendation 3: Harmonise research governance and ethics approval across NSW

We recommend:

- Removing the current requirement for governance approval at individual trial sites (e.g. by establishing a centralised governance regulator).
- Creating a unified platform for HREC application submission across public/private and states and territories.
- Supporting a smooth and supported roll-out of the National One Stop Shop, by providing trained staff at trial sites to help implement the platform after launch, and establishing a real-time support team of programme developers to provide guidance and correct programming errors.

Recommendation 4: Streamline ethics approvals for phase 2 trials

We recommend expanding the mandate of private companies, such as Bellberry Ltd, to include ethics review of phase 2 clinical trials in addition to phase 1 trials.

Recommendation 5: Provide additional support to Human Research Ethics Committees

We note that in our model (see Recommendation 6), hospital HREC committees no longer have responsibility for phase 2 trials, allowing them to focus on review of larger phase 3 trials. We further recommend remuneration for members of hospital HREC committees, and the provision of additional human resources for NSW hospital research offices, to expedite the large volume of regulatory negotiations required in the current system.

The poor quality of many HREC applications leads to substantial increase in workload, both for HREC committees and for the researcher seeking ethics approval. We therefore recommend provision of additional formal training for researchers, to guide investigators through the process of protocol preparation, governance, contract and sponsorship structure and other requirements including drug shipment procedures.

Recommendation 6: Remove barriers to trial staff and participants engaging with multiple hospitals

Many trials have touchpoints across multiple LHDs, yet it can be highly challenging to navigate inter-LHD relationships to deliver trials. We recommend a suite of approaches to support engagement of multiple LHDs across a single trial. The proposed changes will disproportionately improve access to trials for patients in rural and regional areas.

- Introduce a 'Research Passport' as a single screening process accepted across all public hospitals, eliminating new police and Working With Children (WWC) checks for trial researchers across each hospital site
- Remove inter-LHD restrictions on transfer and dispensing of medicines, and introduce inter-LHD service agreements for non-trial specific care in clinical trial. Together, these initiatives would make it possible for research participants in decentralised clinical trials – particularly regional and rural patients – to receive treatments and care within their local health facility.

[16] www.drugdevelopment.com.au

[17] https://podcasts.apple.com/au/podcast/dangerous-ideas-in-drug-development/id1698040978

6. Empowering NSW government entities in health

NSW is fortunate to have several state agencies that capably advance aspects of the state's overarching health and medical research agenda. At Garvan, we deal particularly closely with:

- the NSW Health Office of Health & Medical Research (OHMR), which focuses on 'providing researchers, clinicians, managers and policy makers with the tools they need to translate research into innovative policy and practice to create healthier communities'[18] and
- Cancer Institute NSW (CINSW), a pillar organisation of NSW Health, providing the strategic direction for cancer control in NSW, including the NSW Cancer Plan 2022-2027[19].

Garvan strongly supports the ongoing existence of OHMR and CINSW, and considers their work to be vital to health outcomes in NSW.

We consider that OHMR has made excellent progress in promoting coordination and networking across the state, including in research, clinical trials collaborations (such as funding NECTA, see 5.1 above), and high need areas such as mental health. Likewise, CINSW has made significant progress in advancing strategic initiatives in NSW, such as progress in cancer screening, prevention and education, support of research and innovation, facilitating clinical trials, and collection and analysis of data and statistics.

There are a number of areas in which we consider the existing capabilities, scope and areas of focus across OHMR and CINSW could be strengthened, to better facilitate world-leading healthcare in NSW.

Recommendation 7: Empower OHMR/CINSW data-informed Centres of Excellence

In the cancer context, CINSW collects extensive data about surgical numbers and outcomes at each NSW hospital site (including readmission rates, complications etc). However, at present, CINSW has limited agency to act on these data, including in matters related to the volume–outcome relationship in cancer care[20]. State Government could use CINSW-collected information to provide leadership for establishment of 'Centres of Excellence' for specialty procedures, such as types of surgery that have complex peri-operative care requirements or medical oncology for rare cancers; in these scenarios, volume equates to quality and better outcomes, such that focusing funds and expertise within specific Centres of Excellence would therefore likely cost less and provide better outcomes for patients.

Recommendation 8: Build closer relationships between OHMR/CINSW and employment awards in health

OHMR and CINSW have key roles in shaping strategy. In the context of cancer, this includes strategy around the NSW clinical workforce in cancer (NSW Cancer Plan Priority 4.5: Build the capability of the cancer control workforce to engage and participate in cancer research, including clinical research[21]). This work could include the shaping of new types of roles that traverse research and clinic (see Recommendation 1, above). Despite this, these agencies have only limited engagement with the industrial mechanisms governing working conditions in health care (which are managed by the Industrial Relations Commission of NSW); this hampers the ability of OHMR and CINSW to advance their agendas.

Recommendation 9: Advance PBS reform in NSW

Unlike in other Australian states, the PBS reform package (Public Hospitals Pharmaceutical Reform Agreement) has not been enacted between the NSW government and the Federal government[22]. We recommend that these negotiations are progressed. Enactment of the reform package will allow administration of PBS-listed medications to inpatients, and avoid premature patient discharges which often lead to early re-admissions, added emergency bed occupancy and added cost.

7. Conclusion

Garvan has welcomed the opportunity to share our perspectives and recommendations with The Special Commission into Healthcare Funding. We have recommended a suite of state-level initiatives (Recommendations 1-6) that together would support the translation of medical research into new treatments, tests, policies and practice. Additionally, we have voiced support for OHMR and CINSW and suggested actionable areas of focus for these entities going forward (Recommendations 7-9).

[18] – accessed 21/11/2023

[19] Cancer Institute NSW. NSW Cancer Plan 2022–2027. Sydney: Cancer Institute NSW, 2022.

[20] Watson DI, Bright T (2022). Measuring the quality of surgical care in Australia, Med J Aust 217. doi: 10.5694/mja2.51684

[21] Cancer Institute NSW. NSW Cancer Plan 2022–2027. Sydney: Cancer Institute NSW, 2022.

[22] https://shpa.org.au/publicassets/89e22a0e-37b5-ec11-9100-00505696223b/shpa_submission_to_review_of_pra_mar2022.pdf Accessed 24/11/2023.