



Submission to the Senate Community Affairs Legislation Committee;
Inquiry into the Medical Research Future Fund Bill 2015 and the
Medical Research Future Fund (Consequential Amendments) Bill 2015



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Senate Standing Committee on Community Affairs

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Dear Senators,

Re: Inquiry into the Medical Research Future Fund Bill 2015 and the Medical Research Future Fund (Consequential Amendments) Bill 2015

The Australian Clinical Trials Alliance (ACTA) is pleased to make the following submission to the Senate Community Affairs Legislation Committee regarding the Medical Research Future Fund Bill 2015 and the Medical Research Future Fund (Consequential Amendments) Bill 2015.

Our submission addresses:

- **ACTA's support for the Medical Research Future Fund**
- **Medical Research Future Fund Investment Strategy and Priorities**
- **Constitution of the Australian Medical Research Advisory Board**

Key background about ACTA

ACTA was established in 2014 as a national mechanism to support high-quality investigator-led clinical trials and clinical quality registries within the Australian healthcare system. The ACTA community represents more than 10,000 senior doctors, nurses, allied health professionals and career researchers around Australia.

ACTA's mission is to promote effective and cost-effective health care in Australia through investigator-initiated clinical trials that generate evidence to support decision-making by health practitioners, policymakers and consumers.

The ACTA community currently incorporates more than 60 clinical trials networks, clinical trial coordinating centres and clinical quality registries around Australia (see Appendix A). These groups cover a broad range of disease groups and clinical disciplines and extend well into regional – and in many cases, rural – healthcare facilitates in Australia. They are among Australia's most productive and high impact clinical researchers; responsible for establishing the effectiveness, and in some cases the harm, associated with numerous new and/or commonly used medical therapies through public-good clinical trials.

ACTA's support for the Medical Research Future Fund

New medical discoveries and medical innovation are the cornerstones of modern medicine, but it is only through investigator-led, public-good clinical trials (those conducted in the absence of commercial interest) and clinical quality registries that we can reliably monitor and independently compare the myriad of available healthcare treatments and services – old and new, inexpensive and costly - to provide reliable evidence about what works best, for whom, and at what cost to the health budget.

ACTA has previously expressed its strong support for the establishment of the Medical Research Future Fund and our belief that it is a truly transformative initiative for two key reasons:

- it recognises the critical need to invest in research that can **improve health outcomes and the productivity of the healthcare system** as the complexity and cost of providing world-class healthcare for Australians rapidly increases; and
- it addresses the fact that current mechanisms for funding such research – largely via the Medical Research Endowment Account administered by the National Health and Medical Research Council (NHMRC) or via the Australian Research Council (ARC) – do not adequately fund the level of **core national infrastructure** or **strategic, outcomes-driven research** that is required to equip our healthcare system for the clinical and fiscal challenges that lay ahead.

Medical Research Future Fund Investment Strategy and Priorities

As proposed, we believe the *Medical Research Future Fund Bill 2015* and the *Medical Research Future Fund (Consequential Amendments) Bill 2015* can provide the necessary and appropriate flexibility for Governments current and future to shape an investment strategy that will deliver maximum impact to improve the health and wealth of Australians. **However, doing so will require an appropriate balance of investment that supports both basic research and medical innovation, (from which advances in patient care can take decades) and public-good clinical trials and clinical quality registries that can substantially improve patient outcomes as well as the productivity of the healthcare system – to the benefit of all Australians, in the short-medium term.**

To this end, ACTA supports the requirement to establish the *Australian Medical Research and Innovation Strategy* and the *Australian Medical Research and Innovation Priorities* ('the Strategy and Priorities') as outlined in the *Supplementary Explanatory Memorandum*. In particular, we support the requirement for the Strategy and Priorities to take into account:

- *the **burden of disease** on the Australian community;*
- *how to deliver **practical benefits to as many Australians as possible** from medical research and innovation;*
- *how to ensure that financial assistance provided under this Act provides **the greatest value for all Australians;***
- *how to ensure that financial assistance provided under this Act complements and enhances other funding provided for medical research and medical innovation.*

Additionally, we suggest that the Bill should be amended to stipulate that development of the Strategy and Priorities by the Australian Medical Research Advisory Board includes a process of consultation with, and input from, consumers.

Constitution of the Australian Medical Research Advisory Board

The *Supplementary Explanatory Memorandum* outlines the establishment of the Australian Medical Research Advisory Board to provide guidance to the Health Minister on the Strategy and Priorities to be considered in determining the distribution of funds from the MRFF.

As proposed, the Advisory Board is to consist up to 8 members (including the CEO of the NHMRC) that *will collectively possess expertise in medical research, policy relating to health systems, management of health services, medical innovation, financing and investment, and commercialisation.*

ACTA is broadly supportive of the constitution of the Advisory Board, including the inclusion of the CEO, NHMRC as a member of the Board. However, in order for the MRFF to deliver, as envisaged, “*greater value and returns to the Australian people*” through the “*translation of medical research into health and economic benefits*”, **ACTA believes it is absolutely critical that the Advisory Board includes at least one person with expertise not only in medical research (a broad church that includes the laboratory-based basic sciences) but explicitly in clinical research (inc. health services research) and public-good clinical trials.**

This will require the expertise of a senior clinician researcher who understands the real-world process of generating high quality evidence *within the healthcare system*, and how evidence must be applied in policy terms so that actual improvements in health outcomes and health system productivity can be realised.

We thank the Committee for the opportunity to make this submission on behalf of the investigator-led clinical trials and registries sector and would be pleased to provide further advice to assist the inquiry as required.

Professor John R. Zalcberg OAM
MB BS, PhD, FRACP, FRACMA FAHMS, FAICD

on behalf of the Australian Clinical Trials Alliance

14 July 2015

Appendix A.

Members of the ACTA Community

1. Australasian Child and Adolescent Obesity Research Network (ACAORN)
2. Australasian College for Emergency Medicine Clinical Trials Group (ACEM Clinical Trials Group)
3. Australasian Consortium of Centres for Clinical Cognitive Research (AC4R)
4. Australasian Gastro-Intestinal Trials Group (AGITG)
5. Australasian Kidney Trials Network (AKTN)
6. Australasian Lung Cancer Trials Group (ALTG)
7. Australasian Radiopharmaceutical Trials Network (ARTnet)
8. Australasian Sarcoma Study Group (ASSG)
9. Australasian Sleep Trials Network (ASTN)
10. Australasian Society for Infectious Diseases Clinical Research Network (ASID CRN)
11. Australasian Stroke Trials Network (ASTN)
12. Australia & New Zealand Breast Cancer Trials Group (ANZBCTG)
13. Australia & New Zealand Neonatal Network (ANZNN)
14. Australia & New Zealand Society of Cardiac & Thoracic Surgeons (ANZSCTS) National Cardiac Surgery Database
15. Australia New Zealand Gynaecological Oncology Group (ANZGOG)
16. Australian & New Zealand Children's Haematology/Oncology Group (ANZCHOG)
17. Australian & New Zealand College of Anaesthetists Clinical Trials Network (ANZCA CTN)
18. Australian & New Zealand Intensive Care Society Centre for Outcomes & Resource Evaluation (ANZICS CORE)
19. Australian & New Zealand Intensive Care Society Clinical Trials Group (ANZICS CTG)
20. Australian & New Zealand Melanoma Trials Group (ANZMTG)
21. Australian & New Zealand Musculoskeletal Clinical Trials Group (ANZMUSC)
22. Australian & New Zealand Urogenital & Prostate Cancer Trials Group (ANZUP)
23. Australian Epilepsy Clinical Trials Network (AECTN)
24. Australian Motor Neuron Disease Registry (AMNDR)
25. Australian Neuromuscular Network (ANN)
26. Australian Orthopaedic Association National Joint Replacement Register (AOANJRR)
27. Australian Paediatric Research Network (APRN)
28. Australian Primary Care Research Network (APCRen)
29. Australian Research Centre for Health of Women & Babies, Robinson Institute.
30. Bi-national Colorectal Cancer Audit (BCCA)
31. Burns Service of Western Australia
32. Centre for Anaesthesia & Cognitive Function
33. Centre for Biostatistics & Clinical Trials (BaCT)
34. Cooperative Trials Group for Neuro-Oncology (COGNO)
35. Multiple Sclerosis Research Australia Clinical Trials Network (MSRACTN)
36. Neuroscience Trials Australia (NTA)
37. NHMRC Clinical Trials Centre (NHMRC CTC)
38. NSW Better Treatments 4 Kids (BT4K)
39. Orygen Youth Health Research Centre
40. Paediatric Research in Emergency Departments International Collaborative (PREDICT)
41. Paediatric Trials Network Australia (PTNA)
42. Palliative Care Clinical Studies Collaborative (PaCCSC)
43. Perinatal Society of Australia & New Zealand IMPACT Collaboration
44. Primary Care Collaborative Cancer Clinical Trials Group (PC4)
45. Prostate Cancer Clinical Quality Registry
46. Psycho-oncology Co-operative Research Group (PoCoG)
47. Queensland Centre for Mental Health Research
48. Queensland Clinical Trials & Biostatistics Centre
49. School of Public Health & Preventative Medicine, Monash University
50. South Australian Health & Medical Research Institute (SAHMRI)
51. Spinal Cord Injury Network (SCIN)
52. The ASPREE Study Group
53. The George Institute for Global Health
54. Therapeutic and Vaccine Research Program (TVRP), The Kirby Institute for Infection and immunity in Society
55. Trans-Tasman Radiation Oncology Group (TROG)
56. Transfusion Research Outcomes Collaborative (TORC)
57. Type 1 Diabetes Clinical Research Network (T1DCRN)
58. Victorian Ambulance Cardiac Arrest Registry
59. Victorian Cardiac Outcomes Registry (VCOR)
60. Victorian Cervical Cytology Registry (VCCR)
61. Victorian State Trauma Outcomes and Monitoring Registry (VSTORM)