

Health Research Priority-Setting for New Zealand

A review of priority-setting approaches and proposed method for targeted consultation

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Executive Summary

The New Zealand Health Research Strategy 2017-2027 (the NZHRS) envisages that *'by 2027, New Zealand will have a world-leading health research and innovation system, that through excellent research, improves the health and wellbeing of all New Zealanders.'*¹ Strategic Priority 1, Action 1 of the NZHRS, sets out that to ensure New Zealand has a world-leading health system, an **inclusive and broad ranging** health research priority-setting process will be implemented.

This paper includes background information gathered through a literature review and contact with key health and health research agencies. It provides a body of knowledge to assist in the development of a fully-fledged, fit-for-purpose method for health research priority-setting for New Zealand. It covers:

- Planning and methods for priority-setting
- Examples of prioritisation in health research
- Examples of prioritisation in health delivery
- Case studies of health research priority-setting in practice
- An options analysis of the priority-setting models under consideration
- The proposed fit-for-purpose method, **fit-for-purpose for health research priority-setting for New Zealand**.

Several formal priority-setting methods were identified in the literature. However, no one method is consistently used. The Council on Health Research for Development (COHRED) advise that there is no single best method for priority-setting, suggesting those responsible should weigh methodological complexity against the goal of prioritisation, and resources available.

A fit-for-purpose method is proposed for setting national health research priorities, for New Zealand. The Health Research Council of New Zealand (HRC), in collaboration with the Ministry of Health and Ministry for Business, Innovation and Employment (MBIE), in proposing this process considered: A review of relevant literature; the New Zealand context; data from recent 'related' consultation processes; issues of good practice in priority-setting; and necessarily balancing time and resource constraints. The approach is intentionally pragmatic, incorporates the key stages of a robust prioritisation process, but is still manageable for the HRC to run within existing resources and timeframes.

The proposed method involves the development of broad research areas – termed 'Strategic Investment Areas' (SIAs) with specific knowledge gaps that sit underneath them – termed 'Themes'. Draft SIAs will be drawn up for consultation by a group of respected individuals - the SIA Development Group (SIA-DG). During consultation, Themes that might fit within each SIA will be gathered through public consultation. The SIA-DG will gain expert input during the development of Themes and review the consultation feedback to refine the SIAs and Themes, which would then be internationally reviewed. The final draft SIAs and Themes, will go back out for consultation to the health research community and broader science, technology and innovation sector.

¹ Ministry of Business, Innovation and Employment and the Ministry of Health (2017). New Zealand Health Research Strategy 2017-2027. Wellington, New Zealand: Ministry of Business, Innovation and Employment and the Ministry of Health. ISBN 978-1-98-851786-5

Table of Contents

Executive Summary	2
Table of Contents	3
List of Tables	4
List of Figures	4
List of Abbreviations	5
1.0 Introduction	6
2.0 Approaches to Prioritising Research	8
2.1 Planning and Methods for Priority-Setting.....	8
2.2 Priority-Setting Methods.....	9
2.3 Prioritisation in Health Research	11
2.4 Prioritisation in Health Service Delivery.....	17
2.5 Summary of Findings.....	19
3.0 Prioritising Health Research in New Zealand	21
3.1 Action One: Purpose Statement, NZHRS Guiding Principles & Outcomes Sought.....	21
3.2 Planning for Priority-Setting in Health Research in New Zealand.....	22
4.0 Options Analysis: Identifying a fit-for-purpose method	23
4.1 Options Analysis Objective and Process	23
4.2 Options Assessment of Priority-Setting Methods.....	23
4.3 Proposed Fit-For-Purpose Prioritisation Methodology	27
4.4 Option Assessment of Proposed Method.....	29
Appendix A: Health Research Priority-Setting Methods	33
Burden of Disease	33
Essential National Health Research (ENHR)	33
3D Combined Matrix Approach	34
Child Health and Nutrition Research Initiative (CHNRI)	35
James Lind Alliance.....	37
Delphi and Foresight Techniques	38
Evidence Gap Maps (EGMs).....	38
Appendix B: Appraisal of Strengths and Weaknesses of Priority-Setting Methods	40
Appendix C: Equity Lens for Research Priority-Setting	42
Appendix D: Priority-Setting in Practice	44
Appendix E: Full Options Assessment of Long List Prioritisation Methods	54

List of Tables

Table 1: Summarised Options Assessment of Priority-Setting Methods.....	24
Table 2: Description of Priority-Setting Methods and Features of Fit-For-Purpose Method	26

List of Figures

Figure 1: PHARMAC Factors for Consideration	18
Figure 2: Proposed Method for Health Research Priority-Setting for New Zealand	27
Figure 3: Example of a 3D CAM.....	35
Figure 4: JLA Priority-Setting Process	44
Figure 5: The CHNRI Process.....	50

List of Abbreviations

3IE	International Initiative for Impact Evaluation
3D CAM	3D Combined Matrix
A4R	Accountability for Reasonableness
AHMAC	Australian Health Ministers' Advisory Council
AMRAB	Australian Medical Research Advisory Board
CAG	Cochrane Airways Group
CHNRI	Child Health and Nutrition Research Initiative
CIHR	Canadian Institute for Health Research
COHRED	Council on Health Research for Development
COSTECH	Commission for Science and Technology (Tanzania)
DALE	Disability-Adjusted Life Expectancy
DALY	Disability-Adjusted Life Year
ENHR	Essential National Health Research
EU	European Union
HRB	Health Research Board (Ireland)
HRC	Health Research Council of New Zealand
JLA	James Lind Alliance
MBIE	Ministry of Business, Innovation and Employment
MCDM	Multi-Criteria Decision Making
MRC	Medical Research Council (United Kingdom)
MRFF	Medical Research Future Fund (Australia)
NEPAD	New Partnership for Africa's Development
NGO	Non-Governmental Organisation
NHMRC	National Health and Medical Research Council (Australia)
NHPA	National Health Priority Areas (Australia)
NHS	National Health Service (United Kingdom)
NICE	National Institute for Health and Care Evidence (United Kingdom)
NIHR	National Institute for Health Research (United Kingdom)
NSC	National Science Challenge
NSSI	National Statement of Science Investment
NZHRS	New Zealand Health Research Strategy 2017 – 2027
PCSF	Prostate Cancer Support Federation (United Kingdom)
PSA	Prostate-Specific Antigen
PSP	Priority-Setting Partnership
QALY	Quality-Adjusted Life Year
SAEI	Small Advanced Economies Initiative
SIA	Strategic Investment Area
SIA-DG	Strategic Investment Area Development Group
TCR	Targeted Calls for Research (Australia)
WHO	World Health Organisation

1.0 Introduction

The New Zealand Health Research Strategy (the NZHRS) 2017-2027 envisages that ‘by 2027, New Zealand will have a world-leading health research and innovation system, that through excellent research, improves the health and wellbeing of all New Zealanders.’²

The NZHRS sets out 10 actions to achieve this. The first action to be implemented, ‘**Action One: Prioritise investments through an inclusive priority-setting process**’ will identify health research priorities for New Zealand. The Health Research Council of New Zealand (the HRC) is to lead this process in collaboration with the Ministry of Health and Ministry of Business, Innovation and Employment (MBIE), ‘in line with the HRC’s role as the Government’s primary funder of health research and the strategic role recommended for the HRC in the 2015 strategic refresh’³ (for more information refer to Strategic Priority 1, Action 1 of the New Zealand Health Research Strategy).⁴

It is widely recognised that ‘health research is difficult to prioritise, there are many competing ideas for research, outcomes are inherently uncertain, and impact is hard to predict and measure.’⁵ Yet, challenges notwithstanding, rigorous and inclusive health research priorities do help balance the needs of stakeholders and underpin the health research system by guiding research expenditure; promoting science and innovation; stimulating research workforce development; and supporting negotiations with partners for targeted funding and longer-term research efforts.⁶

Unlike many other priority-setting exercises that focus on a specific health issue or system area (e.g. primary care), the NZHRS priority-setting process seeks to look across all health research and the health research ‘system’ to identify priorities. The outcome will advise the Minister of Health and the Minister of Science and Innovation on health research priorities for New Zealand, as well as form the basis of the HRC’s three-yearly Investment Plan and guide other areas of government-funded mission-led health research – such as the National Science Challenges (NSCs), health sector agency research and health research commissioned by government agencies.

The priority-setting process is to be **inclusive**. It will ‘involve consumers, researchers, health sector agencies, health practitioners, philanthropic bodies, iwi, Pacific peoples, community organisations, people with disabilities, and government agencies.’⁷

The NZHRS signals the need for **broad ranging** priorities, considering research that:

- helps to advance the priorities of the **New Zealand Health Strategy** and the NSSI⁸

² New Zealand Health Research Strategy 2017-2027.

³ Ibid., 11.

⁴ Ibid.

⁵ Rudan, I., Gibson, J., Kapiriri, L., Lansang, M. A., Hyder, A. A., Lawn, J., ... & Hess, S. Y. (2007). Setting priorities in global child health research investments: Assessment of principles and practice. *Croatian Medical Journal*, 48(5): 595-604, cited in Yoshida, S. (2016). Approaches, tools and methods used for setting priorities in health research in the 21st century. *Journal of Global Health*, 6(1). DOI: 10.7189/jogh.06.010507.

⁶ See https://healthresearchweb.org/en/national_priorities_for_health_research, a web-based, interactive platform aimed at improving health, equity and development through research.

⁷ New Zealand Health Research Strategy 2017-2027, p.12.

⁸ National Statement of Science Investment.

- improves **health outcomes** and addresses **burden of disease** – for example, in mental health
- improves understanding of the various **determinants of health**, including social, environmental and occupational factors
- will contribute to **health equity** across New Zealand’s diverse populations and communities
- achieves **health equity for Māori** and reflects the principles of He Korowai Oranga and Vision Mātauranga
- responds to **new and emerging threats** to health
- is an area where New Zealand has **international standing or leadership**
- has the potential to be disruptive and is **highly novel or innovative**
- **complements offshore research**, and
- is an area where **New Zealand has significant interest** such as Pacific health research.

At a high-level, the priority-setting process involves:

- describing the purpose of priority-setting and the outcomes sought from it
- designing an approach that engages partners and stakeholders and makes efficient use of existing information and is feasible within the available resources
- consulting and informing the health research community and broader health, and science, technology and innovation sectors on how health research priority-setting will be undertaken
- running a consultative priority-setting exercise.

This paper reports on the extensive literature review, method planning, options analysis for identifying an appropriate methodology and proposed process, as follows.

- Section 2: Approaches to Prioritising Research, provides an overview of how to plan for priority-setting, the factors for consideration, common priority-setting methods used in New Zealand and internationally, and examples of priority-setting in practice covering a range of case studies from health research, health service delivery and the public sector.
- Section 3: Prioritising Health Research in New Zealand, details the NZHRS guiding principles, purpose statement and outcomes sought from this priority-setting exercise.
- Section 4: Options Analysis outlines the systematic assessment of common priority-setting methodologies undertaken to enable development of a fit-for-purpose method and the proposed process to identify health research priorities for New Zealand.

The proposed method involves the development of broad research areas – termed ‘Strategic Investment Areas’ (SIAs) with specific knowledge gaps that sit underneath them – termed ‘Themes’. Draft SIAs will be drawn up for consultation by a group of respected individuals - the SIA Development Group (SIA-DG). During consultation, Themes that might potentially fit within each SIA will be gathered. The SIA-DG will gain expert input during the development of Themes and review the consultation feedback to refine the SIAs and Themes, which would then be internationally reviewed. The final draft SIAs and Themes, will go back out for consultation to the health research community and broader science, technology and innovation sector.

2.0 Approaches to Prioritising Research

To identify methods for priority-setting within the health research, health delivery and science, technology and innovation research systems, a literature review was completed, and key health research agencies have been contacted, internationally and in New Zealand, taking learnings from specific case studies.

2.1 Planning and Methods for Priority-Setting

Historically, a barrier to health research priority-setting has been a lack of rigorous and transparent planning and methods. To address this guidance has been developed by organisations such as the Council on Health Research for Development (COHRED)⁹ and best-practice findings published by initiatives like the Small Advanced Economies Initiative (SAEI)¹⁰ or as noted by some academics.¹¹

In 2010, COHRED developed a comprehensive priority-setting guidance document.¹² The guide notes that the most important steps in priority-setting are clearly defining both the *purpose* and *scope* of the priority-setting exercise and the *level of detail* needed in the research priorities: too broad and they fail to provide guidance; too detailed and they risk being too prescriptive.¹³ COHRED suggests the following key actions underpin the priority-setting process:

1. **Assessing the situation:** Take a snapshot of the current status of health research, including understanding of the current production, capacity and use of research for health, and the performance of the system
2. **Setting the scene:** Identify and engage partners, defining roles and responsibilities
3. **Choose the best method:** Choose a method best suited to the local context and need, combining methods and adapting for available data resources and local needs
4. **Planning for priority-setting:** Develop a detailed workplan, including financial resources, a budget and communications, evaluation and monitoring plans
5. **Defining the priorities and managing the process:** Implement the plan
6. **Making research for health priorities work:** Evaluate the process and set a clear process time and date for review of the national research priorities.

COHRED add, while health research priority-setting should ideally build on comprehensive nationwide data and analysis, gathering this depth of information may not be possible in the early stages. Therefore, priority-setting should be approached as a continuous, cyclical activity, improving over time and involving more individuals and more accurate data.

COHRED's recommendations are closely aligned with those of Glod, Duprel and Keenan (2009)¹⁴ who document through the case study of Luxembourg, five dilemmas that can arise during the priority-setting process.

⁹ <http://www.cohred.org/>.

¹⁰ Small Advanced Economies Initiative. (2015). *Discussion Paper: Prioritisation of Public Sector Research across the SAEI*.

¹¹ See Glod, F., Duprel, C., & Keenan, M. (2009). Foresight for science and technology priority setting in a small country: The case of Luxembourg. *Technology Analysis & Strategic Management*, 21(8), 933-951.

¹² Montorzi, G., de Haan, S., Ijsselmuiden, C. Council on Health Research for Development. 2010. Priority-setting for research for health: a management process for countries. ISBN 929226-039-1.

¹³ McGregor, S., Henderson, K.J., & Kaldor, M. (2014). How are health research priorities set in low and middle-income countries? A systematic review of published reports. *PLoS ONE*, 9(10): e108787. Doi:10.1371/journal.pone.0108787.

¹⁴ Glod, et al. (2009).

1. **Scope of the prioritisation:** That priority-setting *should* but often does not, include both thematic priorities (e.g. scientific fields, technology areas, industrial sectors, or issues) and structural priorities (e.g. funding mechanisms, research infrastructure, higher education, innovation initiatives, industry, system networking) priorities. Given their interdependence, thematic and structural priorities should not be considered in isolation.
2. **Institutional positioning of prioritisation:** Some organisations can feel they have no ownership over the process of prioritisation and can therefore be uncomfortable with the findings, which can lead to insufficient uptake or poor implementation.
3. **Granularity of areas to be prioritised:** At the national level, the granularity of priorities (the differences in scale and level of detail) can be problematic, namely due to the breadth of possible priorities. Ensuring the level of granularity is consistent across priorities can be difficult.
4. **Criteria for prioritisation:** The assessment criteria of priorities need to be pragmatic. Particularly detailed assessment criteria can make the process too demanding for participants or may mean they lack the necessary knowledge to be able to make an assessment. The **feasibility** of a given priority should form part of the assessment process.
5. **Who prioritises:** The prioritisation process should include not just researchers but also end-users. As it is not feasible to include all stakeholders within a system, participants who represent key stakeholder communities, and can act as advocates within these communities, should be chosen to participate.

When planning to undertake a priority-setting exercise, those running such processes should also be cognisant of the possibility of unintended or problematic effects of prioritisation – such as reduced funds for some areas, a lack of research infrastructure in certain parts of the system and increased pressure on other parts of the system, e.g. the need to access particular patient groups for research.

See section 3.2 of this paper for a discussion on how these factors are being managed in the planning for, and setting of, health research priorities for New Zealand, these factors are being managed.

2.2 Priority-Setting Methods

The literature review elucidated that there are two broad approaches to setting priorities for health research,¹⁵ namely:

- The use of technical analyses, which relies on quantifiable epidemiological, clinical, financial or other data, and
- The use of interpretive assessments, which rely on consensus views of informed participants.

¹⁵ Kaplan, W., Wirtz, V. J., Teeuwiss-Mantel, A., Stolk, P., Duthey, B., & Laing, R. (2013). *Priority medicines for Europe and the World: 2013 update*. World Health Organisation. ISBN 978-92-4-150575-8.

There are several formal prioritisation methodologies cited in literature. This includes:

1. Burden of Disease Approach¹⁶
2. Essential National Health Research (ENHR) Approach¹⁷
3. 3D Combined Matrix (3D CAM)¹⁸
4. Child Health and Nutrition Research Initiative Approach (CHNRI)¹⁹
5. James Lind Alliance Method (JLA)²⁰
6. Delphi and other foresight techniques²¹
7. Evidence Gap Maps²²

See **Appendix A** for information on each and **Appendix B** for an appraisal of their strengths and weaknesses.

Other more informal methodologies typically include: Literature reviews, qualitative data collection through interviews and focus groups, prioritisation through a workshop or further consultation with stakeholders. In recognition of the need to ensure that equity is a core component of priority-setting, irrespective of the method chosen, the Cochrane Collaboration (2013) has recently developed an equity lens to help introduce a more equity-oriented approach toward priority-setting.²³ The lens provides a systematic approach to prioritising topics with a potential for impact on reducing inequity in health, both in terms of the process undertaken to set priorities and the outcomes of the process itself. The equity lens can be applied prospectively or retrospectively²⁴ (see **Appendix C** for more detail on the equity lens guidelines and **Section 4.4** for its application to setting health research priorities for New Zealand).

No one method is consistently used. Two recent reviews of approaches, tools and methods used to prioritise health research provide interesting insight into the uptake of the various methods. For example, Yoshida (2016)²⁵ identified 165 studies that set health research priorities, only 60% used a defined method. The CHNRI approach was most common (26%), followed by the Delphi method (24%), James Lind Alliance method (8%), and the CAM method (2%). Forty percent of studies did not use a defined method but listed combinations of expert panel interviews, focus group discussions, literature reviews and questionnaires.

McGregor, Henderson and Kaldor (2014)²⁶ similarly reported on 126 priority-setting initiatives with the most common approach to prioritisation being a workshop or conference without any

¹⁶ Montorzi, et al. (2010).

¹⁷ Ibid.

¹⁸ Gaffar, A., Collins, T., Matlin, S.A. & S, Olifson. (2009). *The 3D Combined Approach Matrix: An Improved Tool for Setting Priorities in Research for Health*. Geneva, Switzerland: Global Forum for Health Research. ISBN 978-2-940401-19-2.

¹⁹ Rudan, I., Gibson, J. L., Ameratunga, S., Arifeen, S. E., Bhutta, Z. A., Black, M., ... & Chan, K. Y. (2008). Setting priorities in global child health research investments: Guidelines for implementation of CHNRI method. *Croatian Medical Journal*, 49(6): 720-733. Retrieved from <https://hrcak.srce.hr/35106>

²⁰ Lophatananon, A., Tyndale-Biscoe, S., Malcolm, E., Rippon, H. J., Holmes, K., Firkins, L. A., ... & Muir, K. R. (2011). The James Lind Alliance approach to priority setting for prostate cancer research: An integrative methodology based on patient and clinician participation. *British Journal of Urology International*, 108(7): pp.1040-1043.

²¹ Montorzi, et al. (2010).

²² <http://www.3ieimpact.org/en/evaluation/evidence-gap-maps/>

²³ Nasser, M., Ueffing, E., Welch, V., & Tugwell, P. (2013a). An equity lens can ensure an equity-oriented approach to agenda setting and priority setting of Cochrane Reviews. *Journal of Clinical Epidemiology*, 66(5): 511-521. DOI: <https://doi.org/10.1016/j.jclinepi.2012.11.013>

²⁴ Ibid.

²⁵ Yoshida, S. (2016).

²⁶ McGregor, et al. (2014).

explicit specification of an established method (24%), followed by CHNRI (18%) and a stepwise process including a literature review, in-depth interviews and consultation (18%). The number of research priorities identified ranged from 5 to 588. In terms of granularity of priorities, 42% resulted in specific research topics, 35% in broad research areas, and 23% in specific questions. The application of criteria to determine research priorities was used in 67% of reports.

Across both reviews, **most priority-setting exercises employed a non-standard methodology**. Yoshida (2016)²⁷ comments that ‘with the development of new priority-setting tools and methods which have a well-defined structure, – such as the CHNRI method, James Lind Alliance Method and Combined Approach Matrix – it is likely that the Delphi method and non-replicable consultation processes will gradually be replaced by these emerging tools, which offer more transparency’ (and notes this is broadly confirmed in the results of their review).

Appendix D presents a series of case studies of priority-setting in practice including the James Lind Alliance Prostate Priority-Setting Partnership (PSP) in the United Kingdom; national level priority-setting in Tanzania, a low to medium income country; priority-setting for vulnerable populations; priority-setting by systematic review, and disease level international priority-setting by the World Health Organisation (WHO) to set mental health priorities.

2.3 Prioritisation in Health Research

The need for health research priority-setting has long been recognised. As far back as 1990, a report by COHRED noted that:

‘too often priorities for public health sector research and development investments are determined with little concern for the magnitude of the problem to be addressed, for the extent to which scientific judgement supports the possibility that new products and initiatives will be more cost-effective than available alternatives, or for ongoing efforts elsewhere.’²⁸

In recent years, health research priority-setting has become increasingly common. Between 2001 and 2014 an average of 12 prioritisation exercises were initiated each year with a peak of 34 published prioritisation exercises in 2014.²⁹

Generally, priority-setting has been more rigorous and detailed in low-to-medium income countries. This is possibly due to the efforts of COHRED whose role as a global non-profit is to maximise the potential of research and innovation to deliver sustainable health and development solutions to people living in low and middle-income countries. Likewise, the WHO - Global Forum for Health Research³⁰ has used priority-setting to help direct investment into areas of greatest need, to highlight gaps in international health knowledge to improve health equity and for vulnerable population groups.

²⁷ Yoshida, S. (2016).

²⁸ Commission on Health Research for Development, Health Research (COHRED). (1990) *Essential Link to Equity in Development*. New York, United States: Oxford University Press cited in Gaffar, et al. (2009).

²⁹ Yoshida (2016).

³⁰ See Viereger, R. F. (2010). *Health research prioritization at WHO: An overview of methodology and high-level analysis of WHO led health research priority setting exercises*. Geneva, Switzerland: Department of Public Health, Innovation and Intellectual Property, World Health Organization **and** Kaplan, et al. (2013).

As part of this review, the following organisations were contacted (or a web-based search of their strategic objectives and priority-setting was undertaken), and an overview of their priority-setting processes and / or outcomes follows:

- National Health and Medical Research Council (NHMRC) - Australia
- Medical Research Council (MRC) – United Kingdom
- National Institute for Health Research (NIHR) – United Kingdom
- Health Research Board (HRB) – Ireland
- Canadian Institutes for Health Research (CIHR)
- National Science Challenges (NSCs) – New Zealand.

National Health and Medical Research Council (Australia):^{31 32} The National Health and Medical Research Council Act requires the CEO to identify major national health issues likely to arise. These are identified on a three-yearly basis when Council and Principal Committee appointments are made, so members are able to advise on the health issues to be included. There is no formal method for this prioritisation process and priorities are implemented through targeted funding, policies or guidelines.

The primary NHRMC priority-driven funding mechanism is Targeted Calls for Research (TCRs) to address a specific research question or knowledge gap. Areas for investigation can be put forward by the NHRMC Council or Principal Committees, and more recently, by the Australian Health Ministers' Advisory Council (AHMAC), or professional and community groups via an online portal. The NHMRC has established a Prioritisation Committee to advise on proposed topics and usually runs 2-3 TCRs per year, allocating \$3-5 million per topic.

In consultation with Council, the NHMRC has identified the following major health issues:

- create stronger pathways to capture the economic value of research discoveries
- improve the health of Aboriginal and Torres Strait Islander peoples
- harness the power of new technologies to improve health care
- prepare for rapid and unpredictable change
- develop and promote robust frameworks to support evidence-based decision-making
- address the social, environmental and community dimensions of health, and
- strengthen the quality of evidence from research.

Of note, is that, while the NHMRC calls the above list health priorities, they are a combination of health (or thematic) priorities and priorities related to research infrastructure, translation and quality (or structural priorities).³³

Further, the NHMRC allocated funding is *reported* against the Department of Health, National Health Priority Areas (NHPA), but is not awarded based on the NHPAs. The NHPAs were established in response to the WHO 'Global Strategy Health for All by the Year 2000'.³⁴ The NHPAs are: Cancer control; cardiovascular health; injury prevention and control; mental health; diabetes mellitus; asthma; arthritis and musculoskeletal conditions; obesity; and dementia.

³¹ See NHMRC Corporate Plan 2016-17 available from <https://www.nhmrc.gov.au/guidelines-publications/nh171>

³² Information supplied directly by the NHMRC.

³³ For discussion on thematic and structural priorities see Section 2.1 of this paper or Glod, et al. (2009).

³⁴ Global strategy for health for all by the year 2000: 1981, World Health Organization, Geneva.

In addition to the NHMRC's funds, the \$20 billion Medical Research Future Fund (MRFF)³⁵ was established in 2016 by the Department of Health. The MRFF has an Australian Medical Research Advisory Board (AMRAB), but funds are administered by the Australian Government. The fund was established as a 'top-down priority-driven approach'³⁶ intended to complement existing funds. The Australian Medical Research and Innovation Strategy 2016-2021³⁷ and Australian Medical Research and Innovation Priorities 2016-2018³⁸ were set by public consultation and are periodically refreshed. Consultation consisted of two phases, with a third planned. Phase one determined the strategy via written submissions. Phase two, determined themes and priorities by public forum, roundtables and a national webinar³⁹. The priority areas set for 2016-2018 include: Strategic and international horizons; Data and infrastructure; Health services and systems; Capacity and collaboration; Trials and translation and Commercialisation.⁴⁰

Medical Research Council (United Kingdom):⁴¹ The MRC's Strategic Plan 2014-19 specifies the following health research priorities as those most likely to deliver improved health outcomes:

- resilience, repair and replacement: natural protection; tissue disease and degeneration; mental health and wellbeing; repair and replacement, and
- living a long and healthy life: molecular datasets and disease; life course perspective; lifestyles affecting health; environment and health.

The MRC was contacted for information about their priority-setting process but did not respond.

National Institute for Health Research (United Kingdom):⁴² The NIHR states it is committed to maximising the potential impact of research by answering the right questions, delivering research efficiently and publishing the results in full in an accessible and unbiased report. For the NIHR, the 'right questions' means ensuring that those research questions being investigated are those most important to patients, the public, and clinicians, and address a genuine gap in knowledge.

The NIHR work with a range of partners, including patients and the public, researchers, Government, health authorities, charities and the James Lind Alliance (JLA) to identify research priorities. Together they consider:

- research priorities set by Government. In response to the 2015 Nurse Review, the National Health Service (NHS) recently identified Areas of Research Interest,⁴³ which

³⁵ <http://www.health.gov.au/internet/main/publishing.nsf/Content/mrff>

³⁶ [http://health.gov.au/internet/main/publishing.nsf/Content/mrff/\\$FILE/MRFF%202016%20Consultations%20presentation.pdf](http://health.gov.au/internet/main/publishing.nsf/Content/mrff/$FILE/MRFF%202016%20Consultations%20presentation.pdf)

³⁷ [http://health.gov.au/internet/main/publishing.nsf/Content/mrff/\\$FILE/Australian%20Medical%20Research%20and%20Innovation%20Strategy%202016.pdf](http://health.gov.au/internet/main/publishing.nsf/Content/mrff/$FILE/Australian%20Medical%20Research%20and%20Innovation%20Strategy%202016.pdf)

³⁸ [http://health.gov.au/internet/main/publishing.nsf/Content/mrff/\\$FILE/Australian%20Medical%20Research%20and%20Innovation%20Priorities%202016.pdf](http://health.gov.au/internet/main/publishing.nsf/Content/mrff/$FILE/Australian%20Medical%20Research%20and%20Innovation%20Priorities%202016.pdf)

³⁹ [http://health.gov.au/internet/main/publishing.nsf/Content/mrff/\\$FILE/MRFF%202016%20Consultations%20presentation.pdf](http://health.gov.au/internet/main/publishing.nsf/Content/mrff/$FILE/MRFF%202016%20Consultations%20presentation.pdf)

⁴⁰ For a full list of the priority areas and specific themes see: [http://health.gov.au/internet/main/publishing.nsf/Content/mrff/\\$FILE/Australian%20Medical%20Research%20and%20Innovation%20Priorities%202016.pdf](http://health.gov.au/internet/main/publishing.nsf/Content/mrff/$FILE/Australian%20Medical%20Research%20and%20Innovation%20Priorities%202016.pdf)

⁴¹ <https://www.mrc.ac.uk/publications/browse/strategic-plan-2014-19/>

⁴² <https://www.nihr.ac.uk/partnering-with-us/identifying-research-priorities/>

⁴³ For more information see <https://www.nihr.ac.uk/research-and-impact/research-priorities/areas-of-research-interests.htm>

recommended that Government sets out the most important departmental research questions;

- research recommendations from high quality research and guidelines including, reviews from the Cochrane Library and the National Institute for Health and Care Evidence (NICE) published guidelines;
- the views of patients, carers and clinicians on those treatment uncertainties agreed as the most important for research. James Lind Alliance PSP are set up to address any misalignment between what researchers want to research, and the practical information that is needed day-to-day by patients and health professionals, and
- the views of key stakeholders who know what research and evidence they need such as NHS, public health community and NIHR, including NIHR Horizon Scanning Centre, Royal Colleges and other health professional and policy making groups, and charities.

Health Research Board (Ireland):⁴⁴ The HRB does not typically ring-fence funding for disease areas in its bottom-up schemes but is open to funding any disease area put forward, once the proposal is deemed of high quality by an international peer review panel. However, the HRB does, de facto, prioritise some areas of research, although the path to prioritisation is not prescribed and is often opportunistic in nature, rather than carefully considered as part of an overall plan. Several examples are listed below:

- the original calls for the establishment of Health Research Centres, where themes were specified in the call documents, and developed in collaboration with the Department of Health;
- a mapping exercise of the national population health sciences and health services in 2010 identified significant capacity issues and prompted the HRB to invest in a PhD scholars programme;
- a cross-border initiative (with Northern Ireland) was formed over 10 years ago, which resulted in the formation of an all-Ireland cancer clinical trials network that the HRB continues to fund, and
- the HRB's Applied Partnership Awards and Research Collaborative in Quality and Patient Safety require co-funding from health services. Therefore, it is their service delivery priorities that drive the topics of individual projects.

Specific priorities for research with a direct commercial impact were set through a national level prioritisation exercise in 2011. From a health perspective, the focus was on medical devices, connected health and therapeutics. The HRB noted that the lack of clearly defined health research priorities at the time caused difficulties in ensuring that the commercialisation priorities remained visible.

Canadian Institute for Health Research (Canada)⁴⁵: The CIHR has a programme of priority-driven health research that provides funding to researchers for ethically sound, emergent and targeted research that responds to the changing health needs and priorities of Canadians. The goal of this programme is to advance health knowledge and its application, in specific areas of

⁴⁴ Information supplied directly by the HRB. Also see Health Research Board, Department of Health and Children. (2010). *The Identification of Research Priorities for Therapy Professions in Ireland*. Dublin, Ireland: Health Research Board, Department of Health and Children **and** Research Prioritisation Project Steering Group (2011). *Report of the Research Prioritisation Steering Group*. Dublin, Ireland: Forfás.

⁴⁵ <http://cihr-irsc.gc.ca/e/49658.html#s2.2>

research identified by CIHR in consultation with other government departments, partners and stakeholders, to improve health systems and/or improve health outcomes in these priority areas.

Health research priorities support the CIHR's Strategic Plan *'Health Research Roadmap II: Capturing Innovation to Produce Better Health and Health Care for Canadians.'*⁴⁶ For the CIHR's Priority-Driven Research Programme, a multi-pronged approach is applied when identifying research priorities. These can generally be classified as top-down and bottom-up approaches, described below.

- **Top-down:** Driven by priorities defined and set out by the Canadian Federal Government. The CIHR aligns with Federal Directives indicating priority areas for Government and works in collaboration with stakeholders to increase research capacity and outputs in these areas. The CIHR also consults with the Deputy Ministers of Health of Canada's provinces and territories to seek the opinion of these key policy makers on their research needs and health care priorities.
- **Bottom-up:** Two key bottom-up sources for priorities are used by the CIHR: a) knowledge of the opportunities, needs and gaps within CIHR Institutes enable the CIHR to capture and identify gaps and opportunities; b) The CIHR performs periodic environmental scans focusing on broad health topics such as, Canadian patient-indicated priorities, systematic review of research foresight/trend articles etc. to inform potential future CIHR organisational priorities and activities.

Using the collective input of the sources listed above, CIHR staff and leadership (scientific and executive management) embarked on an exercise to outline the directions that CIHR will pursue that best support its corporate mandate, strategy and objectives. This exercise typically involves the assessment of the nature, scope and niches within the proposed areas of interest and is guided by a set of principles that enable the implementation of CIHR's strategic plan.

National Science Challenges (New Zealand):⁴⁷ In late 2012, consultation was undertaken by MBIE, to determine areas where Government should focus a portion of its mission-led research investment to solve 'the most important issues for New Zealand that can be addressed by science.'⁴⁸ Consultation engaged the public through the 'Great New Zealand Science Project' television and online ad campaign and workshops were held nationally with the science and research sector. Submissions received from 138 members of the public and 223 members of the science and research community.⁴⁹

In 2013, a Peak Panel was formed to assess the submissions and devise Challenges that met the Minister of Science and Innovation's Challenge characteristics and selection criteria. Each Challenge was to be characterised as:⁵⁰

1. Having strong, virtual governance across researchers and institutions

⁴⁶ <http://www.cihir-irsc.gc.ca/e/48964.html>

⁴⁷ <http://www.mbie.govt.nz/info-services/science-innovation/national-science-challenges>

⁴⁸ See Report of the National Science Challenges Panel (2013, p.3) available from: <http://www.mbie.govt.nz/info-services/science-innovation/national-science-challenges/documents-image-library/key-documents/Peak-Panel-report.pdf>

⁴⁹ Ibid.

⁵⁰ For a detailed outline of the NSC characteristics see: National Science Challenge Features and Selection Criteria available from: <http://www.mbie.govt.nz/info-services/science-innovation/national-science-challenges/documents-image-library/key-documents/NSC-Features-and-Selection-Criteria-1.pdf>

2. Being multi-disciplinary and involve collaboration
3. Having more granular and inter-related research themes and research components to provide steps to achieving the Challenge
4. Utilising expertise across the science sector
5. Being linked to international research activity
6. Involving collaboration between researchers and end-users
7. Including existing research.

Challenges were selected on the basis of:⁵¹

- Having a high-level goal that would have an enduring public benefit
- Public consensus that the Challenge would address a national scale issue of public opportunity or importance
- Requiring scientific research to solve it
- Having the scientific capability and capacity to solve it
- External motivation and linkages for the research to be implemented to achieve the Challenge.

The Peak Panel was appointed by the Minister of Science and Innovation and chaired by the Prime Minister's Chief Science Advisor. The panel met four times to assess consultation feedback, determine the specificity of a Challenge, long list possible topics, and to refine topics based on the selection criteria and need for a Challenge to be science led, with not all areas of science suited to the Challenge framework. The Peak Panel recommended Challenges to Cabinet who further refined the selection. A total of 11 Challenges were established:

- A Better Start - E Tipu e Rea
- Healthier Lives - He Oranga Hauora
- Ageing Well - Kia eke kairangi ki te taikaumātuatanga
- High-Value Nutrition - Ko Ngā Kai Whai Painga
- Building Better Homes, Towns and Cities - Ko ngā wā kāinga hei whakamāhorahora
- New Zealand's Biological Heritage - Ngā Koiora Tuku Iho
- Our Land and Water - Toitū te Whenua, Toiora te Wai
- Resilience to Nature's Challenges - Kia manawaroa - Ngā Ākina o Te Ao Tūroa
- Sustainable Seas - Ko ngā moana whakauka
- The Deep South - Te Kōmata o Te Tonga
- Science for Technological Innovation - Kia kotahi mai - Te Ao Pūtaiao me Te Ao Hangarau

Government has allocated to the Challenges \$326 million of additional funding over 10 years, with some Challenges receiving additional funding through contestable contracts. The NSCs are currently undergoing a mid-way review. The process to determine the NSCs received widespread comment from the science and research sectors. The consultation process was regarded as very participatory and extensive, especially given the high public involvement. However, there has been some criticism with regard to the transparency of the Peak Panel. Consultation feedback and the decision-making process of which were only retrospectively made public.

⁵¹ For a detailed outline of the NSC selection criteria see: National Science Challenge Features and Selection Criteria available from: <http://www.mbie.govt.nz/info-services/science-innovation/national-science-challenges/documents-image-library/key-documents/NSC-Features-and-Selection-Criteria-1.pdf>

2.4 Prioritisation in Health Service Delivery

Priority-setting is common in the context health service delivery where effective resource allocation is crucial for maximising health outcomes. Therefore, the experiences of the health service delivery sector provide a useful basis for thinking about how to set health research priorities, for New Zealand.⁵² The following section offers a short description of two decision-making or prioritisation models in health service delivery:

- Accountability for Reasonableness (A4R) framework, and
- Multi-Criteria Decision Making (MCDM) models.

In New Zealand, MCDMs have been used by PHARMAC, Ministry of Health, and the Social Investment Fund to guide health and social investment. The HRC contacted PHARMAC and the Ministry of Health who have previously employed versions of these decision-making models, for comment on their experiences as presented below.

The A4R framework is 'based on the principle that stakeholders often justifiably disagree about the importance of specific social values in setting priorities, but they are more likely to accept priorities that are the outcome of a fair process.'^{53,54} A4R aims to set ground rules for decision making which ensure that decisions will be considered fair, reasonable, and legitimate even by those who may be adversely affected using the following four conditions:⁵⁵

- It must be **relevant** to the local context as determined by accepted criteria;
- Its eventual decisions – and the reasons behind them – must be **publicised**;
- It must include **appeal mechanisms** for challenging, revising, and reversing decisions, and
- Its leaders must be able to **drive delivery** on the above three conditions.

MCDM is an umbrella term describing priority-setting methods with multiple criteria to help individuals and groups explore decisions. Such methods are used in a range of contexts, including healthcare, and aim to help decision-makers process and systematically evaluate information to select between options.⁵⁶

Both approaches have specific weaknesses: 'A4R has been criticised for being largely theoretical and not providing guidance on the identification and operationalisation of values [...] whereas, MCDM is criticised for being technocratic and lacking a deliberative component that involves

⁵² See Campbell, S. (2010). Deliberative priority-setting – A CIHR KT Module available from <http://www.cihrrisc.gc.ca/e/43533.html#s18>

⁵³ Baltussen, R., Jansen, M. P. M., Bijlmakers, L., Grutters, J., Kluytmans, A., Reuzel, R. P., ... & van der Wilt, G. J. (2017). Value assessment frameworks for HTA agencies: The organization of evidence-informed deliberative processes. *Value in Health*, 20(2): 256-260. <https://doi.org/10.1016/j.jval.2016.11.019>

⁵⁴ Accountability for Reasonableness was developed by Norman Daniels. For more information see: Daniels, N. (1999). Decisions about access to health care and accountability for reasonableness. *Journal of Urban Health*, 76(2): 176-191.

⁵⁵ Kieslich, K., & Littlejohns, P. (2015). Does accountability for reasonableness work? A protocol for a mixed methods study using an audit tool to evaluate the decision-making of clinical commissioning groups in England. *BMJ Open*, 5(7): DOI:10.1136/bmjopen-2015-007908.

⁵⁶ For further information see: Thokala, P., Devlin, N., Marsh, K., Baltussen, R., Boysen, M., Kalo, Z., ... & Ijzerman, M. (2016). Multiple criteria decision analysis for health care decision making - an introduction: Report 1 of the ISPOR MCDA Emerging Good Practices Task Force. *Value in Health*, 19(1): 1-13. <https://doi.org/10.1016/j.jval.2015.12.003> and Marsh, K., Ijzerman, M., Thokala, P., Baltussen, R., Boysen, M., Kaló, Z., ... & Devlin, N. (2016). Multiple criteria decision analysis for health care decision making – emerging good practices: Report 2 of the ISPOR MCDA Emerging Good Practices Task Force. *Value in Health*, 19(2): 125-137. <https://doi.org/10.1016/j.jval.2015.12.016>

stakeholders.⁵⁷ Recently there has been a move towards a model termed ‘evidence-informed deliberative processes’ which appears aimed towards combining the strengths of A4R and MCDM⁵⁸. Evidence-informed deliberative processes allow stakeholders to participate in the identification of ‘values’ (the key attribute of the A4R framework) which are assessed based on the collection of evidence and rational decision-making (the core competency of the MCDM model)⁵⁹. The process does not usually achieve consensus on the outcomes but enhances legitimacy through the opportunity for stakeholder involvement.

PHARMAC: In 2014, PHARMAC developed a refreshed set of decision-making criteria for investments in pharmaceuticals. The change was driven by a need to be less ‘black box’ regarding investment decisions. PHARMAC invested considerable effort in consulting on the development of the new decision-making process inviting both written submissions and holding community forums. The intent was to enable stakeholders to help ‘shape the way PHARMAC makes decisions’⁶⁰ to be able to build trust in the decision-making process.

Based on stakeholder consultation, PHARMAC developed a set of ‘Factors for Consideration’ (See Figure 1: PHARMAC Factors for Consideration, below). Each factor is a criterion in PHARMAC’s decision making model. PHARMAC has deliberately decided not to introduce scoring or weighting of each factor, instead the focus is on providing detailed consistent information on a factor for each pharmaceutical option and involving the ‘right’ people in the decision-making process.

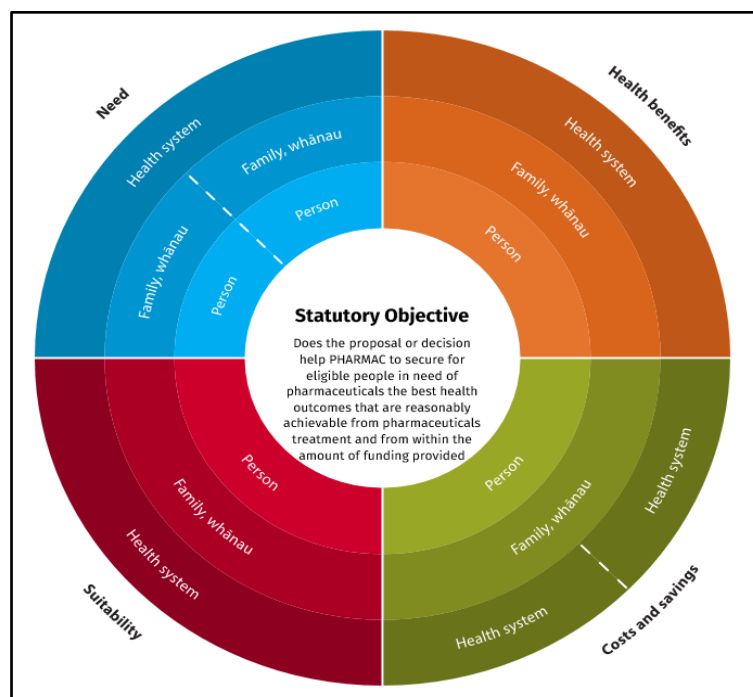


Figure 1: PHARMAC Factors for Consideration⁶¹

⁵⁷ Baltussen, et al. (2017).

⁵⁸ Baltussen, R., Jansen, M. P., Mikkelsen, E., Tromp, N., Hontelez, J., Bijlmakers, L., & Van der Wilt, G. J. (2016). Priority setting for universal health coverage: We need evidence-informed deliberative processes, not just more evidence on cost-effectiveness. *International Journal of Health Policy and Management*, 5(11): 615. DOI: 10.15171/ijhpm.2016.83

⁵⁹ Baltussen, et al. (2017).

⁶⁰ For further information on PHARMAC’S consultation process see: <https://www.pharmac.govt.nz/assets/consultation-2013-05-17-decision-criteria-review.pdf>

⁶¹ Source: <https://www.pharmac.govt.nz/medicines/how-medicines-are-funded/factors-for-consideration/>

To enable consistent assessment of each new pharmaceutical option, PHARMAC requires new options to be presented in a prescribed proposal format. Proposals from drug companies and others are first put to a clinical review committee and, if the proposal is supported by this committee, they are then developed (usually internally by PHARMAC) into an assessment dossier that includes a full cost-utility analysis. Each option is then discussed at a PHARMAC prioritisation meeting.

The PHARMAC drug prioritisation meeting is open to all staff, with a quorum of 20-30 people in key roles. Various pre-meetings prior to the formal prioritisation meeting ensure that any technical questions have been addressed. Prioritisation meetings typically involve comparing 5-10 new drug options with a ranked list of 30-40 existing priorities. A portfolio manager presents each new option and the option is discussed in terms of the set topics defined by the factors for consideration. During the prioritisation meeting, the Chair aims to ensure that all voices are heard, and discussion is directed towards producing consensus-based decisions. Discussion and decisions are carefully recorded both in terms of decisions made and the reasons for the decision.

Ministry of Health – 1000Minds: In New Zealand, as elsewhere, insufficient capacity necessitates the prioritisation of patients for elective surgery. Since 2004, using 1000Minds software, the Ministry of Health has led projects to create and validate new points systems for elective services. 1000Minds is a MCDM tool which contains three main elements: Alternatives, decision-making criteria, and weights. The validity of the prioritisation system is established by examining the face validity of the relative importance (weighting) of the criteria implied by the system and comparing the ranking of patient case descriptions from the prioritisation system with clinicians’ consensus intuitive rankings.

2.5 Summary of Findings

Key learnings taken from the review of priority-setting approaches indicate, **there is no commonly accepted form or structure for producing health research priorities**, leading COHRED to advise in 2010, **there is no single best method for priority-setting**.⁶² The method for, and process of, priority-setting should largely be driven by **weighing the complexity of methods against what is to be achieved, and what resources are available**.⁶³

There are however, generally agreed *approaches* to priority-setting⁶⁴ defined by their use of either:

- technical analyses, which relies on quantifiable epidemiological, clinical, financial or other data, or
- interpretive assessments, which rely on consensus views of informed participants.

To further support the development of prioritisation methodologies, there is also a growing body of literature that signals the importance of addressing issues around the **scope** and **purpose** of priority-setting exercises, in advance of the selection and implementation of a method. As discussed in Section 2.1, COHRED and Glod, et al. (2009) put forward comparable frameworks for how this is best achieved and is a critical outcome of this review.

⁶² The SAEI also suggest a ‘mixed methods’ approach. See Small Advanced Economies Initiative. (2015) for discussion.

⁶³ Montorzi, et al. (2010).

⁶⁴ Kaplan, et al. (2013).

The case studies and examples of priority-setting in practice provided in Sections 2.2 to 2.4 and Appendix D, demonstrate that the uptake of methodologies, formal or otherwise, is not consistent. Whilst those health agencies contacted and identified through an environmental scan document their process in detail, it is not often attributable to a formal methodology. This serves to affirm that internationally, the use of non-standard methodologies may not be best practice, but it is certainly *common practice*. This is not without validity as each case study highlights the need for a priority-setting method that is locally responsive and flexible enough to respond to any 'dilemmas'⁶⁵ that can arise throughout the process. This is in keeping with the A4R decision-making framework which highlights the need for decisions to be relevant to the local context in order to ensure their legitimacy and be able to drive their delivery.

⁶⁵ Glod, et al. (2009)

3.0 Prioritising Health Research in New Zealand

The principles outlined below have been developed to ensure that the prioritisation approach selected for New Zealand health research is fit-for-purpose. The HRC Council and the NZHRS Steering Group have indicated their support for a priority-setting process that upholds the NZHRS Guiding Principles and realises the Action One, statement of purpose and outcomes sought. The purpose statement and outcomes sought from the NZHRS Strategic Priority 1, Action 1, were developed in collaboration with the Ministry of Health and MBIE, with input and approval from the NZHRS Steering Group and HRC Council.

3.1 Action One: Purpose Statement, NZHRS Guiding Principles & Outcomes Sought

What follows is a **purpose statement** for health research priority-setting for New Zealand:

The purpose of setting health research priorities for New Zealand is to signal to the health research community, and indeed all stakeholders who are involved in or might benefit from health research, where there are opportunities for research to help address the current and future needs of New Zealanders and where New Zealand can add most value to, and benefit from, the international health research effort.

The priority-setting approach will be guided by the principles set out in the NZHRS. To meet the guiding principles the priority-setting process must:

- support **research excellence** by providing clear stable signals to the health research community and embracing and valuing all fit-for-purpose research approaches and methodologies that may be applied to health research.
- provide **transparency**, both in terms of the process by which priorities are identified and supported, and by providing a forum for all research stakeholders to share their knowledge about where research is most needed.
- enable and support **partnership with Māori** by partnering to identify the health and wellbeing needs of Māori communities and providing opportunities for Māori to harness their own knowledge and innovations to improve the lives of their communities.
- take a **collaborative approach** both in how research priorities are identified and by enabling collaboration through articulating knowledge needs and research opportunities around which collaborations can form.

A successful priority-setting method should be developed to meet the following outcomes. To:

- Identify the most **important knowledge needs** of health research stakeholders;
- Identify where knowledge is needed to achieve **health equity**;
- Identify where knowledge is needed to tackle **new and emerging threats to health**;
- Identify where New Zealand is best able to contribute to, and benefit from **participation in the international health research effort**;
- Enhance **health research systems** and infrastructure;
- Reflect the principles of **He Korowai Oranga and Vision Mātauranga**;
- **Advance priorities set** through Government and other strategies;
- **Enhance economic outcomes** for New Zealand, and
- Support development of New Zealand's **health research workforce**.

3.2 Planning for Priority-Setting in Health Research in New Zealand

Substantial consideration has been given to mitigating the potential risk of Glod, et al.'s (2009) 'five dilemmas'⁶⁶ arising when setting health research priorities for New Zealand, specifically:

- **Scope of the prioritisation:** The scope has largely been established by the NZHRS which calls for national and *broad ranging priorities*,⁶⁷ and will follow the international literature on priority-setting, which recommends that consideration needs to be given to both thematic and structural priorities. This means, our task is to look across all of health research and the health research system to identify where investment will achieve the greatest benefit.
- **Institutional positioning of prioritisation:** The NZHRS specifies the priorities will form the basis of the HRC's three-yearly investment plan and guide other areas of Government-funded, mission-led research such as the National Science Challenges, health sector agency research and health research commissioned by government agencies. The Government will develop new approaches for co-investment with the not-for-profit sector on the agreed priorities. The inclusive priority-setting process also provides the opportunity to build consensus among partners and stakeholders, so they are in a position to meaningfully respond to the priorities.
- **Granularity:** There is tension between being overly prescriptive in identifying priorities and undermining the ability of science to creatively solve problems and identify opportunities not yet conceived of, *versus* coming up with areas that are so broad that they fail to identify the important knowledge and evidence gaps that will make a tangible difference to the health of New Zealanders. The proposed approach is an attempt to capture both the creative ability of science to advance health and wellbeing, as well as the opportunity to identify important knowledge needs and evidence gaps, by providing for different levels of 'granularity' under the umbrella of each priority identified.
- **Criteria for prioritisation:** Most approaches to prioritisation require a mechanism where the importance of areas can be decided relative to each other to support decision-making. Criteria developed by the CHNRI for this purpose includes such considerations as: Answerability, deliverability, impact on disease burden and equity. Additional considerations could include an assessment of the level of existing relevant research in the area; the time taken for research to have an impact on burden of disease and equity; and whether the research capacity exists to respond with high-quality research on this issue.
- **Who prioritises:** The NZHRS has set that the process 'will be inclusive, involving consumers, researchers, health sector agencies, health practitioners, philanthropic bodies, iwi, Pacific peoples, community organisations, disabled people and government agencies.'⁶⁸ However, other very important issues to consider regarding 'who prioritises' include, who should participate in prioritising? How can the breadth of insight from across the health research and science, technology and innovation sectors be adequately captured? Can participants be considered representative of their communities? When and at what level in the process should various partners and stakeholders be engaged? Is there a way to ensure that the inputs from competing single-interest groups are balanced and taken into account? Who makes the final decisions? With respect to final decision making, this rests with the HRC Council and the NZHRS Steering Group, who will approve the priorities identified (ratified) through the process.

⁶⁶ Refer to Section 2.1 of this paper for an outline of the 'five dilemmas'.

⁶⁷ For more information see Section 1.0 of this report or Strategic Priority 1, Action 1 of the New Zealand Health Research Strategy.

⁶⁸ Ibid., 12.

4.0 Options Analysis: Identifying a fit-for-purpose method

4.1 Options Analysis Objective and Process

A process to appraise formal priority-setting approaches was undertaken, to assess if any were **fit-for-purpose for health research priority-setting** for New Zealand. The approaches assessed include:

- Burden of Disease Approach⁶⁹
- Essential National Health Research (ENHR) Approach⁷⁰
- 3D Combined Matrix (3D CAM)⁷¹
- Child Health and Nutrition Research Initiative Approach (CHNRI)⁷²
- James Lind Alliance Method (JLA)⁷³
- Delphi and other foresight techniques⁷⁴
- Evidence Gap Maps⁷⁵

The MCDM model presented in Section 2.4 has not be included in the options assessment, as given the defined scope of the prioritisation exercises run by PHARMAC and the Ministry of Health, the decision-making model is not appropriate to be operationalised at the national level.

As these priority-setting approaches have predominantly been applied in international contexts, the evaluation process sought to determine the feasibility and acceptability of adapting such an approach, for the New Zealand context. The appraisal process involved assessing the 7 established models against 5 broad domains, with a total of 28 individual criteria.⁷⁶ Each priority-setting method must:

1. Meet the **NZHRS guiding principles**;
2. Meet the **purpose statement** of priority-setting for health research;⁷⁷
3. Meet the **outcomes sought** by setting health research priorities for New Zealand;
4. Meet the **Accountability for Reasonableness (A4R)** principles, and
5. Be feasible within the **allocated resources and time constraints**.

4.2 Options Assessment of Priority-Setting Methods

Table 1: Summarised Options Assessment of Priority-Setting Methods (see over page), illustrates the performance of each priority-setting approach against the five overarching assessment criteria (see Appendix E for an appraisal against all 28 evaluation criteria and the relative strengths and weaknesses of each). A satisfactory score on each domain, or 'tick', means that a method met 50% or more of the individual criteria.

⁶⁹ Montorzi, et al. (2010).

⁷⁰ Ibid.

⁷¹ Gaffar, et al. (2009).

⁷² Rudan, et al. (2008).

⁷³ Lophatananon, et al. (2011).

⁷⁴ Montorzi, et al. (2010).

⁷⁵ <http://www.3ieimpact.org/en/evaluation/evidence-gap-maps/>

⁷⁶ See Appendix E for the full 28 assessment criteria and an evaluation of each of method.

⁷⁷ The purpose statement and outcomes sought from the NZHRS Strategic Priority 1, Action 1, were developed in collaboration with the Ministry of Health and MBIE, with input and approval from the NZHRS Steering Group and HRC Council.

The options assessment process is not designed to critique the overall validity of each model, rather it assesses its suitability for the New Zealand context, and scope of the priority-setting exercise. In other words, the relative poor performance of some methods refers only to its likelihood of being able to achieve the best outcome for New Zealand. Table 1 demonstrates that each method has relative strengths and weaknesses, with most priority-setting methods falling short of meeting the NZHRS Guiding Principles, A4R framework and resourcing constraints.

Priority-Setting Method	Assessment Criteria				
	NZHRS Guiding Principles	Action One: Purpose Statement	Action One: Outcomes Sought	A4R	Resourcing
Burden of Disease	✗	✗	✗	✗	✓
Essential National Health Research (ENHR)	✓	✓	✓	✗	✗
3D Combined Matrix (3D CAM)	✓	✓	✓	✗	✓
Child Health and Nutrition Research Initiative (CHNRI)	✗	✓	✓	✗	✓
James Lind Alliance (JLA)	✗	✓	✓	✗	✗
DELPHI and Foresight Techniques	✗	✗	✗	✗	✓
Evidence Gap Maps (EGM)	✗	✓	✓	✓	✗

Table 1: Summarised Options Assessment of Priority-Setting Methods

The options assessment affirms the literature review finding that there is no single best method for priority-setting. Based on this analysis, the HRC Council and NZHRS Steering Group supported the development of a **fit-for-purpose method** that incorporates the **best features of several methodologies and key stages of a robust prioritisation process, meets the options analysis evaluation criteria**, but is **intentionally pragmatic**, making it **manageable** for the HRC, Ministry of Health and MBIE to run, for partners and stakeholders to participate in and to achieve the best outcome for New Zealand. Table 2: Description of Priority-Setting Methods and Features of Fit-For-Purpose Method, (see over page), outlines which aspects of each method have been included in the proposed fit-for-purpose method.

The primary **weakness** of the approaches assessed was their ability to meet the **A4R principles** of sound decision-making⁷⁸, particularly in relation to the **publishing of decisions and appeals mechanism**. Without effective and clearly defined processes for publication and appeal, this could potentially become a risk for the institutional positioning of prioritisation and make it difficult to drive delivery on the outcomes. The fit-for-purpose method proposed⁷⁹ has an explicit approach to publishing outcomes at each phase of development and an in-built appeals mechanism, making it not only more fit-for-purpose and locally responsive, but increases the transparency and perceived fairness of the process, thereby strengthening the acceptability and robustness of the approach from the perspective of partners and stakeholders. Further, where the A4R principles have been criticised as largely theoretical and not providing guidance on the identification and operationalisation of values, as the evaluation criteria is directed by the NZHRS Guiding Principles, this is expected to mitigate against any such concerns.

⁷⁸ See Table 1: Summarised Options Assessment of Priority-Setting Methods (previous page), for more information.

⁷⁹ See Figure 2: Proposed Method for Health Research Priority-Setting for New Zealand (page 26), for more information.

The method ►	Burden of Disease (BoD)	Essential National Health Research (ENHR)	3D Combined Matrix (3D CAM)	Child Health & Nutrition Research Initiative (CHNRI)	James Lind Alliance (JLA)	Delphi and other foresight techniques (DF)	Evidence Gap Maps (EGM)
Description of method ►	Evidence-based approach, relating research to burden of disease, determinants & cost-effectiveness. Requires sophisticated health info systems & statistical expertise.	Working groups of stakeholders determine priorities. Consider areas which are amenable to research, research already underway, & links to existing strategies.	Creates systematic framework of information, along 3 dimensions, public health, institutional & equity. Identifies gaps in knowledge and facilitates comparisons between sectors.	Research ideas identified by stakeholders & ranked against: Answerability; equity; impact on burden; deliverability; effectiveness.	Identifies questions & uncertainties most important to patients, their carers, & clinicians. Intensive data gathering & analysis to develop very specific questions.	Covers a number of tools, all focused on forecasting, scenario creation & 'visioning' by experts.	Maps systematic reviews & impact evaluations. Focused on quality of existing evidence for policy-makers & practitioners. Highlights absolute gaps & synthesis gaps.
What does not fit the criteria? ►	Purely data driven. No feasibility criteria. No stakeholder involvement. No way to incorporate opportunities, innovation or Māori and Pacific issues & frameworks.	Working groups as sole input, too resource intensive & limits inclusivity of consultation.	Very detailed – suited to narrow areas of interest. Logistically difficult & time-consuming. No repeatable or systematic component to identify & score research priorities.	Solely an 'investments-based' philosophy, no face-to-face meetings – not appropriate for Māori & Pacific input.	Suitable for detailed analyses within specific diseases – not broad areas. Unclear criteria for selection, mix of participants may skew information base. Resource intensive to identify & verify uncertainties.	Looks only at possible future scenarios, not current issues, opportunities or burden of disease. Relies solely on expert opinion.	New & unproven method. Too risky to use this approach for a national-level prioritisation exercise.
What fits the NZHRS prioritisation model ►	Evidence-based approach – relating research to burden of disease, determinants, & cost-effectiveness	Working Groups to enhance reach of online consultation supported by additional advisors in areas where specific expertise is needed.	Identify gaps in knowledge, involve a broad range of stakeholders, & include equity as a lens across all areas. Make comparisons of input across sectors.	Inclusion of specific criteria to review research options against, rather than simply creating a list.	A focus on knowledge gaps rather than priorities. Provision of data to support expert decision-making. Ranking of priorities.	Future scanning for emerging threats, potential risks & opportunities – involving national & international experts.	Use of synthesised data (systematic reviews) where possible. Identification of areas where systematic reviews are needed.

Table 2: Description of Priority-Setting Methods and Features of Fit-For-Purpose Method

4.3 Proposed Fit-For-Purpose Prioritisation Methodology

The elements identified in Table 2 (see previous page), as fitting with the New Zealand scope and context, have been formulated in the fit-for-purpose method proposed below. In developing this approach, central consideration was given to the role of Te Tiriti o Waitangi and Māori as partners with the Crown; New Zealand as a Pacific nation and significant interest in Pacific health research; and the wider context of the rationale and impetus for prioritisation, with stakeholders anticipating this process following on from the development and launch of the NZHRS in 2017. In the past five years, there has also been related strategies and consultations that have taken place, including the New Zealand Health Strategy in 2016 and NSCs in 2013.

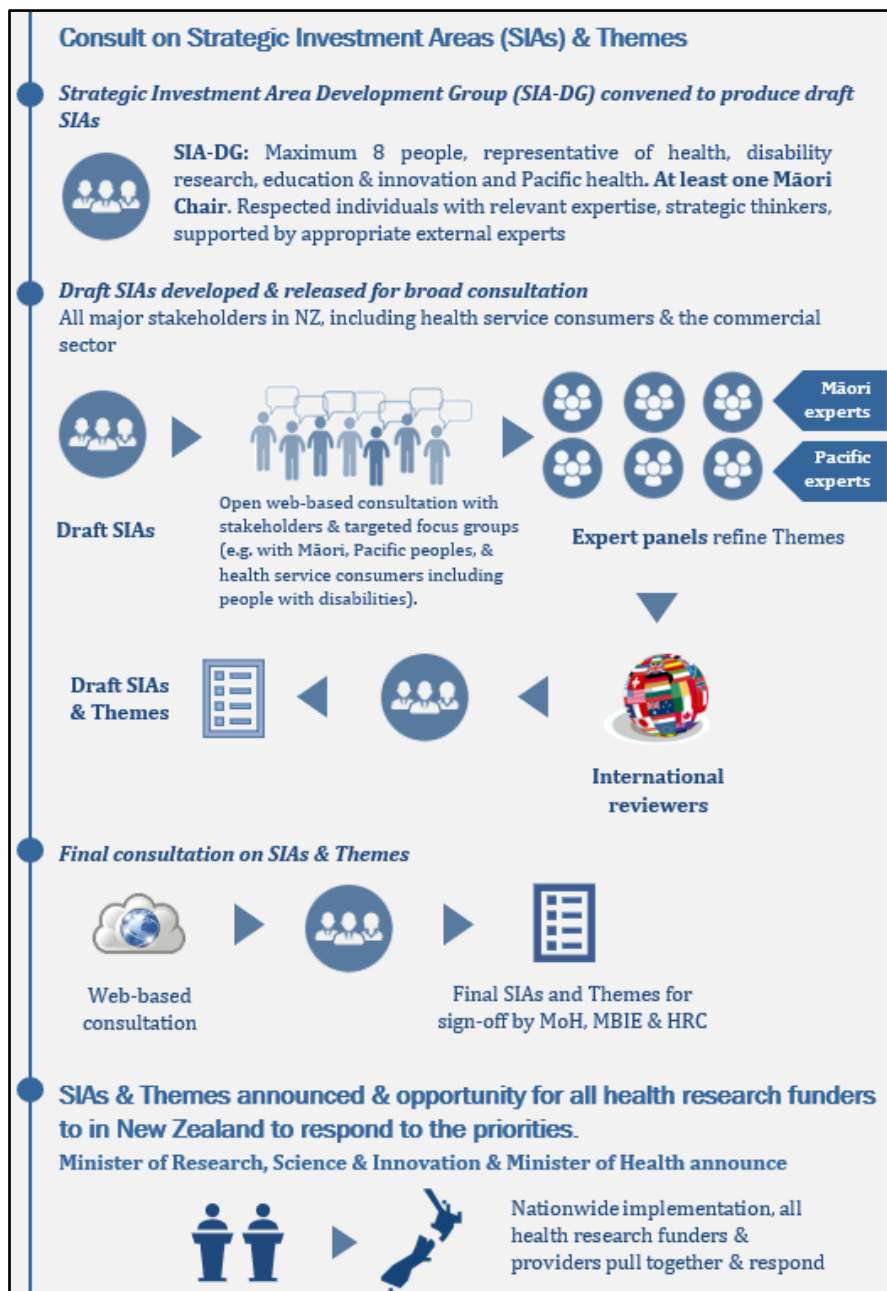


Figure 2: Proposed Method for Health Research Priority-Setting for New Zealand

As detailed in Table 2, the proposed fit-for-purpose priority-setting method builds on the strengths of well-established formal methodologies, with a greater focus on the A4R sound decision-making principles to ensure that it is fit-for-purpose in a New Zealand context. Those aspects of each model that fit with the NZHRS prioritisation include:

- a **Burden of Disease** and evidence-based approach will be included as part of the background information supplied to the SIA-DG to be able to effectively draft SIAs.
- the convening of experts or representative stakeholders is a commonly accepted and proven component of several formal methodologies including the **ENHR, CNHRI, JLA, and Delphi and foresight techniques approaches**, with subject matter expert working groups (either pre-existing or specially assembled) to be convened for the refinement of Themes to enhance the reach of consultation.
- as the **3D Combined Matrix** employs, an equity lens will be applied to the processes and outcomes of the prioritisation process.
- as adapted from the **CHNRI** method, during consultation submitters will be asked to assess the SIAs and Themes on specific criteria to review research options against, rather than simply creating a list.
- like the **James Lind Alliance**, there will be a focus on knowledge gaps as identified by a broad range of stakeholders and refined by expert decision-making groups.
- **Delphi and other foresight techniques** emphasis the need to have an emphasis on future scanning and international peer review and comment, included in the proposed method to ensure that New Zealand's health priorities serve the needs of future New Zealanders, is an area where New Zealand has international standing or leadership and complements offshore research.
- like the **Evidence Gap Map** method, where possible, systematic reviews will be used as part of the evidence base for drafting SIAs and Themes.
- in keeping with the **A4R principles**, all stages of the process, consultation feedback and decisions reached by the SIA-DG, NZHRS Steering Group and HRC Council will be published online with an appeals mechanism outlined.

In addition, the HRC has taken into account how a fit-for-purpose method considers:

- **The stability of signals:** There is tension between identifying priorities that are enduring and will provide stable signals to the research community, versus having a framework that allows for new or emerging knowledge needs and opportunities to be pursued. The proposed method aims to identify a priority framework that is stable but not stagnant. Due to the potential to incorporate granularity within priority areas, there should be enough flexibility inherent to respond to new and emerging opportunities and evidence gaps.
- **Terminology:** A preliminary decision has been made to frame 'priorities' as 'strategic investment areas' for the following reasons. It is arguably more constructive to talk about areas that require strategic investment. The word 'priority' has become problematic and tends to have a limited interpretation in some sectors (drawing a focus to diagnostic conditions as the sole consideration). It also allows a focus on targeting areas that require strategic investment, rather than identifying 'x' as a priority, which correspondingly determines that 'y' is not. The term 'strategic investment areas' also signals that not all priorities are health issue or theme based. Some priorities are structural and require investment at the systems, infrastructure or personnel level.

- **Resources available:** Resource, budget and timeline constraints have been key considerations in framing the approach. The premise has been to approach this as efficiently and effectively as possible, making best use of all existing data and information sources (including the unique data resource gained through the strategy consultation).

4.4 Option Assessment of Proposed Method

The detailed option assessment of the preferred priority-setting method (shown below), demonstrates it has the potential to meet the NZHRS Guiding Principles, Action One purpose statement and outcomes sought, A4R principles and resourcing constraints. On this basis, it has the support of the NZHRS Working Group and Steering Group, and HRC Council, to be put forward for consultation.

NZHRS Guiding Principles	
Support research excellence	The identification of SIAs will provide stable signals and the focus on identifying knowledge needs will mitigate the risk that the priorities focus on specifying the approach that should be taken to addressing knowledge gaps.
Provide transparency	The approach taken to developing SIAs and Themes, particularly communication of the prioritisation method to health research partners and stakeholders, publication of the decision-making process, and the provision of an appeals process will provide transparency as to how priorities are set.
Enable and support partnership with Māori	The consultation process and the make-up of the SIA-DG will provide opportunities for partnership with Māori. Māori health research stakeholders will also be engaged during the targeted consultation on the method to ensure opportunities for partnership are maximised.
Take a collaborative approach	The approach taken, particularly the consultation work, the specified method for analysing consultation feedback to ensure it can be best used by the SIA-DG and providing opportunities for feedback and appeal ensure a collaborative approach. The identification and articulation of research themes provides opportunities around which on-going collaborations can form.
Action One: Purpose Statement	
To signal to the health research community, and indeed all stakeholders who are involved in or might benefit from health research, where there are opportunities for research to help address the current and future needs of New Zealanders and where New Zealand can add most value to, and benefit from, the international health research effort.	<p>The scope as defined in the NZHRS that the priorities set are national priorities, along with the broad and inclusive consultation process to develop said priorities, means that the outcome will be stable signals for all those in health research community or who benefit from health research.</p> <p>The use of existing data, provision of data on the future state and engagement of experts, partners and stakeholders throughout the health research system, means the method will be able to address the current and future needs of New Zealanders.</p> <p>Data on existing research strengths, collaborations and international funding opportunities will be made available, health researchers and end-users with expertise or knowledge of New Zealand research will assist in identifying areas where international participation is particularly important and would be particularly beneficial, and international peer reviewers will provide overseas context and expert overview.</p>
Action One: Outcomes Sought	
Identify the most important needs of health research stakeholders	The combination of broad consultation, expert input, international peer review and New Zealand specific data, will enable the identification of areas of greatest need.

Identify where knowledge is needed to achieve health equity	Provision of equity data, inclusive consultation as well as engagement of experts in health equity in the SIA Development Group, will ensure knowledge needs to achieve health equity are identified and incorporated.
Identify where knowledge is needed to tackle new and emerging threats	Provision of data on the future state (e.g. demographic trends, emerging health issues, emerging technology etc.) as well as engagement of experts in these areas will ensure these knowledge needs are identified and incorporated.
Identify where New Zealand is best able to contribute to, and benefit from participation in the international health research effort	Data on existing research strengths, collaborations and international funding opportunities will be made available, and health researchers with expertise or knowledge of New Zealand research will assist in identifying areas where international participation is particularly important and would be particularly beneficial, as well as international peer review for context.
Health research systems and infrastructure are enhanced	The SIAs will include both thematic and structural priorities which will enhance and strengthen the health and science and innovation systems in New Zealand. The consideration of thematic and structural themes in tandem is also expected to enhance the feasibility of implementing the priorities.
Reflect the principles of He Korowai Oranga and Vision Mātauranga are reflected	These principles will be integrated during development of SIAs and Themes and are inherent to the NZHRS Guiding Principle of enabling and supporting partnership with Māori.
Advance priorities set through Government and other strategies	Alignment with Government strategies will be actively considered during development of SIAs and Themes. Stakeholders involved in key Government strategies such as the implementation of the National Science Challenges, will also be able to participate in the consultation process to drive greater alignment.
Enhance economic outcomes for New Zealand	To develop the SIAs data, information and expert opinion will be provided on New Zealand's current strengths, challenges and opportunities to better support and capitalise upon the economic outcomes and commercial potential of NZs investment in health research.
Support development of New Zealand's health research workforce	The method supports identification of important structural priorities, of which the health research workforce is likely the most important enabler.
A4R Principles	
Must be relevant to the local context as determined by accepted criteria	The method is intended to meet the New Zealand specific purpose statement and outcomes sought and fit with the national scope of prioritisation. SIA-DG members will be relevant to the local context.
Eventual decisions – and the reasons behind them – must be publicised	The communications plan will ensure prioritisation methods and decisions are fully documented and communicated throughout the process.
It must include appeal mechanisms for challenging, revising, and reversing decisions	The consultation process provides multiple opportunities for feedback from partners and stakeholders and an opportunity to appeal the SIAs and Themes.
Its leaders must be able to enforce the above three conditions.	The implementation mechanisms for the NZHRS provides a means of enforcement.
Resourcing	
The consultation process to identify health research priorities for New Zealand needs to be undertaken with the HRC's existing operational budget and available FTE.	<p>The proposed methodology is designed to make the most efficient use of existing information gained through the extensive consultation process undertaken to develop the NZHRS.</p> <p>A primarily web-based consultation, supplemented by key focus group is the most resource and time efficient approach.</p>

The additional step of applying an equity lens to the proposed method has been carried out, using the criteria set out by the Cochrane Collaboration.⁸⁰ The equity lens applies to both the prioritisation **process** and **outcomes**, across broad domains each of which will be discussed below (see Appendix C for the specific questions that sit within the domains):

- **Different stakeholders who might be affected by the prioritisation are involved in the process:** The processed method intends on targeting our partners and stakeholders for participation in the consultation process to ensure that it is as broad and inclusive as possible, as set out by not only the equity lens, but in the NZHRS itself. The open, online consultation process also ensures that **all** partners and stakeholders can be part of the process. There is the option to collect some demographic data on participants to capture who has participated, such as age, gender, location and occupation or role in the health research system.
- **Prioritisation process and outcomes explicitly aim to reduce inequity:** The selection criteria for Themes within each SIA specifies there must be a demonstrable impact on reducing inequity.
- **All stakeholders can understand the tools being used to implement, disseminate and communicate the priorities:** The online consultation process, although it widens the opportunity for all stakeholders to be included, will only be in English which may limit who can participate. The website used for consultation complies with the New Zealand Government Web Usability Standards 1.2 and Web Accessibility Standard 1.0 and aims to comply with the World Wide Web Consortium's Web Accessibility Initiative. There will be provision for some focus groups for important population groups and end-users. The consultation documents, both online and offline will be accessible to the lay person.
- **A situational analysis is conducted that considers differences in prevalence, severity, urgency of the health problems and differences in the impact of interventions, by different population groups:** There is scope to ensure the SIA-DG and expert groups contributing to the development of Themes to consider such analysis.
- **Considers health problems as experienced by disadvantaged compared with privileged populations:** Equity and burden of disease will form part of the development of SIAs and themes, through guidance provided to the SIA-DG and the evidence and background information provided to develop drafts SIAs for consultation.
- **Considers the impact of any changes made to policy or health care:** The priority-setting process is being led by the HRC, in collaboration with the Ministry of Health and MBIE, but the resultant priorities will guide other areas of government-funded mission-led health research such as the NSCs, health sector agency research and health research commissioned by government agencies, with each government and health sector agency to determine how to respond to, and implement, the health research priorities once set. This makes it difficult to assess what, if any changes to policy or health care will be made and their impact on equity.
- **Manages the varying values and preferences across different stakeholders:** This is the most difficult measure of equity to achieve. The guiding principles of the NZHRS provides some direction as to the values to be upheld throughout the process and the A4R decision-making framework provide the basis for balancing the needs of diverse partners and stakeholders.

⁸⁰ Nasser, et al. (2013a).

- **Stakeholders are provided with the opportunity to give feedback and appeal the outcome:** The targeted consultation on the method enables key partners and stakeholders to provide feedback on and appeal the process. The consultation on the drafts SIAs and Themes enables the public to participate and as set out by the A4R decision-making framework, all decisions can be appealed.

Appendix A: Health Research Priority-Setting Methods

Burden of Disease⁸¹

The Burden of Disease approach relates research to burden of disease and determinants, cost-effectiveness, and financial flows. It was developed in 1996 by the WHO Ad Hoc Committee on Health Research Relating to Future Intervention Options.

It is useful for comparing population groups, tracking population health over time, measuring the effects of morbidity on overall health, and informing priorities for research on health service delivery and research and development (R&D) in the health system. However, it requires sophisticated health information systems and high levels of statistical expertise.

The steps in the Burden of Disease approach are:

- Magnitude (disease burden): Measure the disease burden as years of healthy life lost due to premature mortality, morbidity or disability using DALY⁸²s, QALYs⁸³ or DALE⁸⁴.
- Determinants (risk factors): Analyse the factors responsible for the persistence of the burden, such as lack of knowledge about the condition, lack of tools, failure to use existing tools, or factors outside the health domain.
- Knowledge: Assess the current knowledge base to solve the health problem and evaluate the applicability of solutions, including the cost and effectiveness of existing interventions.
- Cost effectiveness: Assess the promise of the R&D effort and examine if future research developments would reduce costs, thus allowing interventions to be applied to wider population segments. Cost-effectiveness is measured in terms of DALYs saved for a given cost.
- Resources: Calculate the present level of investment into research for specific diseases and/or determinants.

Essential National Health Research (ENHR)⁸⁵

The ENHR technique is suitable for guiding resource allocation for health research to the areas of highest priority. It is particularly useful to address the issues of equity and social justice and to direct attention to the most vulnerable groups in a population. It is an approach used if reliable data is not available. It encourages a multidisciplinary and cross-sectorial approach as it involves all those with a stake in health research. The steps in the ENHR approach are:

- Holding a national conference or workshop on Essential National Health Research, with participation from communities, researchers, health programme managers and policy makers.
- Formation of a task force with wide representation to refine the research agenda.
- Formation of an inter-sectorial and multidisciplinary working group (could be appointed by the Ministry of Health or other relevant institution).

⁸¹ Montorzi, et al. (2010).

⁸² Disability-Adjusted Life Year.

⁸³ Quality-Adjusted Life Year.

⁸⁴ Disability-Adjusted Life Expectancy.

⁸⁵ Montorzi, et al. (2010).

- A small group (could be University based) is then tasked to develop and propose processes for priority-setting.
- A larger group of participants is involved in the actual priority-setting process.

3D Combined Matrix Approach

In 1999, the Global Forum for Health Research developed a research priority-setting tool called the Combined Matrix Approach (CAM). The rationale for CAM was to bring together a large range of factors, along different dimensions, into a single analytical tool. Since its development, CAM has been successfully applied to set research priorities for diseases, conditions and programmes at global, regional and national levels.⁸⁶ The point of departure was the five-step methodology developed by the WHO (burden of disease approach described above). This links burden of disease with determinants, level of knowledge in relation to interventions, cost-effectiveness and financial flows.

The first version of CAM comprised two dimensions, adding an institutional dimension to the public health dimension (which is the same as the Burden of Disease method). The tool has now been further refined into a 3D CAM. This version includes an equity dimension. 3D CAM has three equally important pillars:

- Process – the process of selecting priorities is a continuous and cyclical activity that involves many stakeholders. The key is to make the process as objective and participatory as possible and define priorities that are responsive to local needs.
- Tools – instruments that enable the collection, organisation and analysis of information needed to help set priorities.
- Context – priority-setting is a value-laden and political process which is undertaken to assess health research needs in a social, economic and cultural context which needs to be taken into consideration.

3D CAM involves consideration of factors along three dimensions (see Figure 3: Example of a 3D CAM, over page):

- Public Health – five elements, magnitude of problem, determinants, level of knowledge in relation to intervention, cost-effectiveness of interventions, and present level of investments/resources.
- Institutional – individual, household, community, health sector, other sectors, governance.
- Equity – not yet fully elucidated but typically questions addressed are, equivalence of burden across societal groups, the income, assets, access to resources by race, social class, geography, religion and gender. Which factors are responsible for differences across groups, do diseases affect groups differently, is sufficient knowledge available to focus interventions on disadvantaged groups.

The 3D CAM is highly time consuming and it is important to pick which aspects are truly needed. It enables a detailed review of specific health issues but would require considerable investment to gain broad coverage across a health research system.

⁸⁶ Gaffar, et al. (2009).

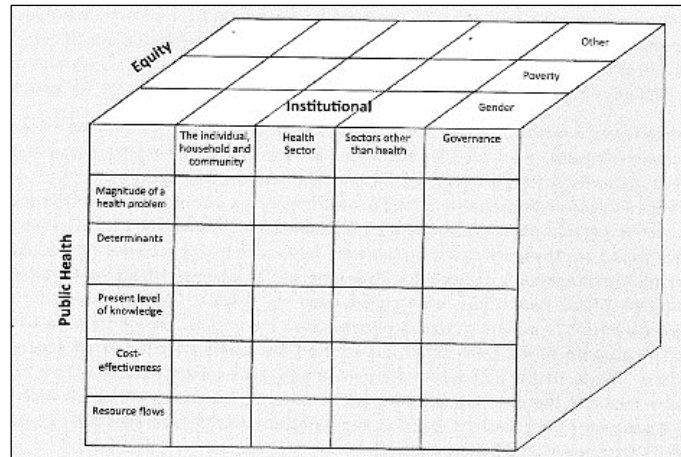


Figure 3: Example of a 3D CAM

The 3D CAM approach is usually applied in workshops. The 3D matrix is completed in layers beginning with public health and institutional dimensions. The best available information and references to key sources is provided to participants. Emphasis is placed on entering available information and data into the cells of the matrix. Where no information is available it can indicate a research gap or priority. Once this phase is complete, participants are asked to repeat the exercise considering stratified data for different groups to identify equity priorities.

Child Health and Nutrition Research Initiative (CHNRI)⁸⁷

In 2007, CHNRI (as an initiative of the Global Forum for Health Research) published the first version of its method for priority-setting. The method is intended for use by international agencies, large research funding donors and national governments and policy makers. Recent reviews show that CHNRI method has become the dominant method for setting health research priorities in the past decade.

The key principle of CHNRI is that all health research should have a common goal of reducing burden of disease and disability and improving health. Reductions in disease burden resulting from research are considered ‘profits’ by the model. Investments in health research are considered investment in ‘options’ with potential for profit and associated risk. The key value of CHNRI to funders lies in its ability to transparently lay out the potential profits and risks associated with investing in many competing research ideas by drawing on collective knowledge.

The CHNRI method has practical advantages. It is relatively low cost and low burden because it is undertaken over the internet. Possible flaws with the CHNRI approach are that it does not provide participants with a review of evidence and the process does not have any formal interaction between participants, such as feedback of views or facilitated meetings. However, these omissions are deliberate as the approach was specifically designed to avoid biases arising from providing evidence reviews or allowing interactions between participants.

The first step in the CHNRI method is for a small group of process managers (who represent ‘investors’ in health research) to specify the context and their risk preferences. Context and risk

⁸⁷ Rudan, I. (2016). Setting health research priorities using the CHNRI method: IV. Key conceptual advances. *Journal of Global Health*, 6(1). DOI: 10.7189/jogh.06.010501.

preference are used to specify criteria for assessing competing research options. The five components of context specified within the method are: population of interest; disease, disability and death burden; geographic limits; time scale; and preferred style of investing. Core CHNRI criteria derived from context and risk information are answerability, deliverability, impact on disease burden and equity⁸⁸. However, the number and composition of criteria can be changed to meet the needs of the specified context and risk. Example criteria include:

- The issue is likely to be a high priority for at least 3-5 years
- There is not a large stock of existing relevant research in the area
- The research capacity exists to respond with high-quality research on this issue
- Decision makers would be able to use research results on this issue
- The research would potentially have high impact relative to cost.⁸⁹

The next stage of the CHNRI method is to identify a large set of within scope research options or questions. To provide a systematic approach, research questions are divided into the following four categories:

- **Description research:** Any proposed health research that would allow researchers to assess the burden of health problems in the population of interest and understand its determinants (i.e. risk factors)
- **Delivery research:** All research questions that allow researchers to optimise health status of the population using means that are already available. This is typically achieved through implementation research, operations research and/or health policy and systems research.
- **Development research:** Research focused on improving interventions that already exist, but could be made more effective, affordable or sustainable.
- **Discovery research:** Research questions that could lead to innovation, i.e. generation of new knowledge to develop entirely new health interventions.

Within each of the above areas research options/questions of different 'depth' can be posed:

- Very broad *research avenues* (which correspond to research fields);
- More specific *research options* (which correspond to a typical research program of about 5-years duration), and
- Very specific *research questions* (which correspond to a title of a typical research paper).

Based on this framework, a very large number of proposed research ideas can be systematically assembled and prepared for prioritisation against the specified criteria. Next, a consensus development exercise is undertaken. Opinions from many international experts are collected via email. Experts are only required to say whether each research idea is likely, or not, to meet the priority-setting criteria. Feedback on the collective opinion can be returned to participants but there is no need to develop a consensus, because a quantitative analysis of the received input turns the information obtained from each expert into a 'collective result' which would belong to every single participant, but no single participant would have a chance of influencing any

⁸⁸ Rudan, et al. (2008).

⁸⁹ Council on Health Research for Development (COHRED). (2006). *Priority Setting for Health Research: Toward a management process for low and middle income countries (Working Paper 1)*. Geneva, Switzerland: COHRED. ISBN 92 – 9226-008-1

substantial portion of it. This limits the potential of individual personal biases to substantially influence the outcome of the prioritisation exercise.

James Lind Alliance⁹⁰

The James Lind Alliance (JLA) is an independent organisation funded by the National Institute for Health Research and Medical Research Council UK. It was established in 2004 to encourage patients, carers and clinicians to work together to identify and prioritise shared healthcare uncertainties, arguing that research should identify and address the questions and uncertainties that are of most practical importance to patients, their carers, and clinicians

The organisation's role is to provide a platform for an independent and integrated approach to determining both patient's and clinician's views on setting the research agenda. The JLA has an established methodology that aims to incorporate aspects of both quantitative and qualitative approaches.

The process starts when a disease-focused public or professional group⁹¹ approaches JLA and proposes a PSP. A steering group is then created to administer the prioritisation process. Each PSP steering group has an Information Specialist who can review and analyse data collected, review existing evidence and formulate potential research questions and a Project Coordinator. The PSP, led by the steering group, undertake the following process which normally takes 12-18 months to complete:

Stage 1: Gathering the Uncertainties

While the approach was originally intended to gather treatment uncertainties, it is recognised that many PSPs now extend their scope and include other health care interventions like prevention, diagnosis, rehabilitation, care and service organisation and delivery.

The aim is to harvest as many non-overlapping uncertainties as possible from a representative group of participating organisations and individuals. Uncertainties are gathered using a form consisting of two parts, the first requesting general information about the respondent and the second requesting details of treatment uncertainties which are questions about the effects of diagnosis, treatment and prognosis that cannot be answered through a relevant and reliable systematic review⁹². A survey of research recommendations from NICE and Cochrane Systematic Reviews can also be undertaken.

Stage 2: Consultation Process to Refine Uncertainties

The steering group then refine the list of 'raw uncertainties' into 'collated indicative uncertainties' which are clear, addressable by research and understandable to all. Uncertainties that can already be answered, are currently being answered, or that cannot be addressed by research are removed.

⁹⁰ Lophatananon, et al. (2011).

⁹¹ PSPs do not typically involve pharmaceutical companies and non-clinical researchers.

⁹² The JLA guidebook notes that many PSPs define uncertainties more broadly and other evidence checking methods may be required in these cases.

Stage 3: Verification of True Uncertainties

The refined uncertainties list is further reviewed against existing literature to ensure that the refined questions have not been reliably addressed by previous research.

Stage 4: First Ranking Exercise: Quantitative Method

Uncertainties are then sent to affiliated partners who identify their top ten (and rank them). Ranking scores of all partners are used to produce an overall sum score for each uncertainty (some normalisation of scores can occur at this stage). The top scoring uncertainties are then taken to a priority-setting workshop.

Stage 5: Priority-Setting Workshop: Qualitative Method

All partners attend a workshop where uncertainties are discussed, and an iterative prioritisation process is undertaken. At the end of the process a 'top 10' list of priorities is obtained.

Delphi and Foresight Techniques

A common feature of all the tools described to date is that they use and build on past and current data on health status and a health situation in a country rather than looking at future problems for which research is needed. The application of foresight methodologies brings a useful perspective to more traditional priority-setting methods⁹³.

Foresight Techniques:

- **Visioning:** Creates a rich picture of possible futures based on a creative approach.
- **Scenario Creation:** Builds scenarios from an assessment of how trends and drivers might influence the present to create the future. It helps identify the unexpected, both potential challenges and opportunities. Steps: decide the question, identify drivers, rank drivers, decide axes for scenarios, draft scenarios, test scenarios, consider implications of scenarios.
- **Delphi:** A systematic interactive forecasting method which uses a panel of experts who answer questionnaires in two or more rounds. After each round, a facilitator provides an anonymous summary of experts' forecasts and the reasons they have provided for their judgements. Experts are encouraged to revise their answers after considering the views of other panel members. Finally, the process is stopped after a pre-defined stop criterion and the mean or median scores of the final round determine the results.

Evidence Gap Maps (EGMs)

EGMs are a relatively recent approach to consolidating what is known, and not known, in a sector or sub-sector by mapping completed and ongoing systematic reviews and impact evaluations.⁹⁴ They enable policy makers and practitioners to explore the findings and quality of existing evidence identify key "gaps" where little or no evidence from impact evaluations and systematic reviews is available and where future research should be focused.

EGMs are structured around a matrix designed to reflect the relevant interventions and outcomes associated with a sector. When populated with available studies and reviews, the 'map' highlights

⁹³ Council on Health Research for Development (COHRED). (2006).

⁹⁴ <http://www.3ieimpact.org/en/evaluation/evidence-gap-maps/>

'absolute gaps', where few or no impact evaluations exist. It also highlights 'synthesis gaps', where there are impact evaluations but no recent systematic review.

The International Initiative for Impact Evaluation (3IE) develops maps by drawing on the principles and methodologies developed for systematic and transparent evidence reviews. 3IE EGMs include consultation with relevant decision makers and other key stakeholders, often in the form of an informal advisory group. 3IE consults them at the beginning of the mapping to discuss the scope, questions and framework and to review draft findings at the end of the mapping.

Appendix B: Appraisal of Strengths and Weaknesses of Priority-Setting Methods

Methods	Strengths	Weaknesses	Conclusion
Burden of Disease Approach	An evidence-based approach, particularly useful for comparing population groups, tracking population health over time, measuring the effects of morbidity on overall health, and informing priorities for research on health service delivery and R&D in the health system.	<ul style="list-style-type: none"> • Requires sophisticated health information systems • Requires high levels of statistical expertise • Data driven approach that does not engage stakeholders • Does not identify those areas that are amenable to research • Does not identify those areas already being researched • Does not identify priority areas linked to existing strategies. 	Useful method to provide data and information but not sufficient to identify priorities without additional information.
Essential National Health Research (ENHR) Approach	Stakeholders are engaged in setting priorities through working groups. This enables stakeholders to consider issues such as areas amenable to research, research already underway and links to existing strategies.	<ul style="list-style-type: none"> • Limited number of stakeholders can be engaged through working groups unless many are held • Significant workload to support working groups who need to be provided with an evidence-based situational analysis to support identification of priorities • There is little guidance on criteria against which to review possible priorities, which can lead to vague criteria and a lack of transparency. 	ENHR is a relatively old method developed by the Commission on Health Research for Development in 1990. Subsequent methods provide better information on developing systematic criteria and trading off options.
Child Health and Nutrition Research Initiative Approach (CHNRI)	<p>CHNRI's greatest advantage is the use of an independent ranking system against the pre-defined criteria to prioritise the research ideas. Research ideas are generated by stakeholders and evaluated against the following criteria:</p> <ol style="list-style-type: none"> 1. Answerability 2. Equity 3. Impact on burden 4. Deliverability 5. Effectiveness <p>It is less costly than other methods as it does not require multiple workshops.</p>	<ul style="list-style-type: none"> • Potentially represents collective opinion of the limited group of people who were included in the process • Does not provide participants with a review of evidence which means that involving those with genuine expertise only is critical • The process does not have any formal interaction between participants, such as feedback of views or facilitated meetings. However, these omissions are deliberate, and the approach was specifically designed to avoid biases. 	<p>Components of CHNRI, particularly the use of clearly defined criteria against which to consider research options are useful and should be considered for use when developing a method.</p> <p>Using the 'investments based' philosophy and no face-to-face meetings is unlikely to have face validity in the New Zealand context and may not be appropriate for specific groups such as Māori and Pacific.</p>

Methods	Strengths	Weaknesses	Conclusion
3D Combined Matrix (3D CAM)	<p>A comprehensive method including measuring disease burden, analysing determinants, identifying present level of knowledge, evaluating cost and effectiveness, and present resource flows.</p> <p>3D CAM creates a systematic framework of information, identifies gaps in knowledge, facilitates comparisons between sectors, involves broad range of stakeholders and includes equity.</p>	<ul style="list-style-type: none"> • Very detailed analysis more suited to specific diseases or narrower areas of interest • Difficult and time-consuming as involves multi-stage discussion • Does not provide an algorithm to establish and score research priorities therefore is neither repeatable nor systematic. 	<p>3D CAM is a useful method for detailed analysis but not suited to a broader review of national health research priorities. Some of the measures used (e.g. present level of knowledge) should be considered for use when developing a method.</p>
James Lind Alliance (JLA) Method	<p>Is based on the principle that research should identify and address the questions and uncertainties that are of most practical importance to patients, their careers and clinicians.</p> <p>The method uses a mixture of data gathering, quantitative and qualitative analysis to create research priorities in areas of treatment uncertainty.</p>	<ul style="list-style-type: none"> • Is intended to undertake very detailed disease specific analyses • Time consuming to identify and verify uncertainties • Selection of criteria not clear • Disproportionate mix of participants may skew information base. 	<p>The concept of identifying what is 'not known' should be considered for use when developing a method.</p> <p>The provision of data to support expert decision making should be included in our method.</p> <p>The concept of ranking priorities may be too difficult to achieve due to the broad nature of priorities and the resources involved.</p>
Delphi and other foresight techniques	<p>Takes a future focused approach.</p>	<ul style="list-style-type: none"> • Does not provide methodology for identifying participants • Lack of criteria transparency • Potential for low response rate due to multiple iterations • Is time-consuming • Potential for investigators and facilitators to bias opinions. 	<p>The principle of considering future need should be considered for use when developing a method.</p>
Evidence Gap Maps	<p>Evidence Gap Maps consolidate what is and is not known, in a sector or sub-sector by mapping completed and ongoing systematic reviews and impact evaluation. They enable policy makers and practitioners to explore the findings and quality of existing evidence, identify key 'gaps' where little or no evidence from impact evaluations and systematic reviews is available and where future research should be focused.</p>	<ul style="list-style-type: none"> • Relatively unproven • More suited to detailed analyses (e.g. specific diseases or health delivery issues). 	<p>Relatively new and unproven method. Too risky to use this approach for a national-level prioritisation exercise.</p>

Appendix C: Equity Lens for Research Priority-Setting⁹⁵

1. Are different stakeholders who might be affected by the choice of research (review) topics, involved in the prioritisation process (different age, sex, sexual orientation, disability, ethnicity, and religion, place of residence, occupation, education, socioeconomic status, and social capital groups)? In which steps are they involved?
2. Does the prioritisation project consider reducing inequity as part of its objectives?
3. Are the selected methods and tools to identify prioritise, implement, disseminate, and communicate research topics understandable, transparent and relevant for different stakeholders (different age, sex, sexual orientation, disability, ethnicity, religion, place of residence, occupation, education, socioeconomic status, and social capital groups)?
4. Are specific strategies considered to minimise the barriers to reach disadvantaged or less accessible populations?
5. In the stage of situation analysis (evaluating the current health research coverage, identifying gaps, evaluating healthcare needs, etc.), does the analysis consider the differences in the prevalence, severity and urgency of health problems along with potential differences in the impact or value of the health care interventions assessed across different subgroups (age, sex, sexual orientation, disability, ethnicity, religion, place of residence, occupation, education, socioeconomic status)?
6. Do the criteria for prioritisation consider the potential differences in the severity and urgency of health problems in disadvantaged populations or less accessible groups as opposed to the health problems in privileged populations?
7. Do the criteria for prioritisation consider the potential differences in the impact of a health care intervention in disadvantaged populations as opposed to the health problems in privileged populations?
8. Do the criteria for prioritisation consider that different population groups might have different values and preferences?
9. Are different stakeholders' groups (representing age, sex, sexual orientation, disability, ethnicity, and religion, place of residence, occupation, education, socioeconomic status, and social capital groups) provided with an opportunity to provide feedback and appeal the process and results of the prioritisation process?
10. Did the prioritisation result in more research topics that are relevant to disadvantaged groups?
11. Did the dissemination and implementation strategy increase the likelihood that funders and research institutes become aware of the prioritised research topics and consider them as part of their research agenda or strategic planning?
12. Did the dissemination and implementation strategy increase the likelihood that the prioritised research topics that are relevant to disadvantaged groups get funded and conducted?

⁹⁵ Nasser, et al. (2013a).

13. Did the dissemination and implementation strategy increase the likelihood that researchers who work with disadvantaged groups conduct or get involved in the prioritised research projects?
14. Did the dissemination and implementation strategy increase the likelihood that disadvantaged groups or decision makers or practitioners who work with disadvantaged groups get involved in the prioritised research topics?
15. Does the dissemination and implementation strategy increase the likelihood that policy makers and decisions makers who work with disadvantaged groups use the result of the prioritised research topics?
16. Did the results of the prioritised research topics changed policies, legislation or clinical practice in favour of disadvantaged groups?
17. Did the appeal and enforcement strategy increase the likelihood that disadvantaged groups or decision makers, researchers and practitioners who work with disadvantaged group had provided feedback and comments on the prioritisation process or results?

Appendix D: Priority-Setting in Practice

James Lind Alliance (JLA) – Prostate Priority-Setting Partnership (PSP)^{96,97}

The aim of the Prostate Cancer PSP was to identify patient, carer and clinician shared priorities for research into the treatment of prostate cancer. To coordinate the activities of this PSP, a steering group was formed consisting of members of the JLA, Prostate Action, the Prostate Cancer Support Federation (PCSF) and the Prostate Cancer Charity. The steering group worked together to approach patients with prostate cancer and clinicians to become affiliates. The group followed the JLA priority-setting process (see Figure 1: JLA Priority-Setting Process over page).

Uncertainties were harvested by requesting respondents provide their unanswered questions about prostate cancer, which were questions about diagnosis, treatment or prognosis that cannot be answered through a reliable systematic review. Questions harvested were combined with a survey of current research recommendations from NICE and Cochrane Systematic Reviews. In total, 391 treatment uncertainties were harvested.

Uncertainties were refined by the PSP steering committee to produce collated indicative questions which were clear, discrete, addressable by research and understandable by all. Following this, the number of identified uncertainties was 134.

Uncertainties were verified through review against existing literature to ensure that they had not been addressed. This review suggested all 134 uncertainties were unaddressed or not adequately addressed by existing research.

Uncertainties were prioritised through a workshop which used an adapted Delphi method exercise, involving extensive discussion within groups and an iterative prioritisation process. The workshop aimed to identify the shared top 10 prostate cancer uncertainties.

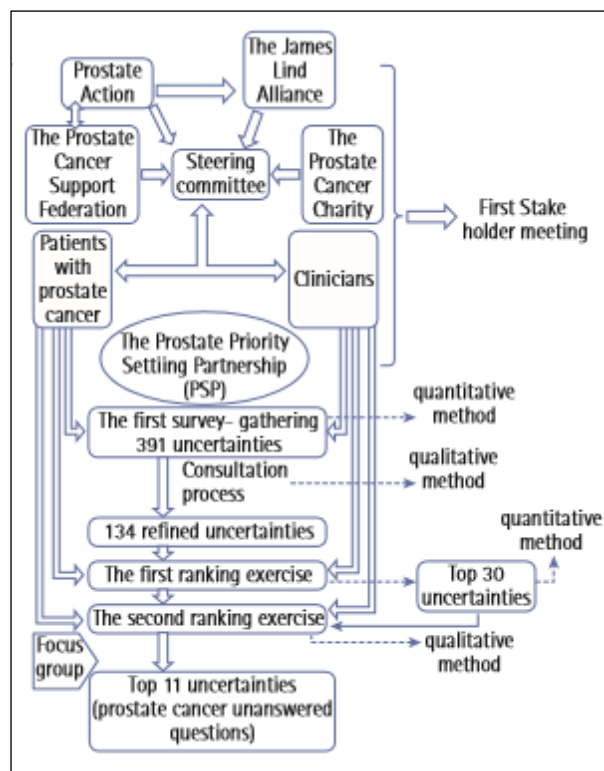


Figure 4: JLA Priority-Setting Process

⁹⁶ James Lind Alliance is an independent research organisation funded by the NIHR and the MRC UK.

⁹⁷ Lophatanon, et al. (2011).

The results: James Lind: Prostate Cancer Top 10 Research Priorities

1. How can overtreatment for prostate cancer be prevented by identifying and excluding the treatment of harmless tumours? (Tigers & Pussycats)
2. Is there a genetic marker for prostate cancer that would be both more sensitive and more specific than Prostate-Specific Antigen (PSA) serum level?
3. What can be done to delay or prevent the onset of hormone-independent prostate cancer?
4. Are there any dietary measures that can prevent prostate cancer or slow its progression?
5. Does serial PSA measurement in patients with prostate cancer accurately monitor disease progression?
6. Would prostate cancer screening targeted at high risk groups, i.e. those with positive family history, and ethnic minorities with higher rates, improve the outcomes of treatment in these groups?
7. Does active surveillance work for treatment of prostate cancer?

The following priorities were ranked joint 8th at the workshop:

- Do variations in GP awareness of prostate cancer affect outcomes?
- What is the effectiveness of new treatments for prostate cancer such as high intensity focused ultrasound and cryotherapy?
- Is there a vaccine that can prevent prostate cancer?
- Are there any non-intrusive diagnostic tests that will identify patients with aggressive prostate cancer whilst not identifying harmless cancers? (Tigers and Pussycats).

National Priority-Setting Across Sectors - Tanzania

Health research priority-setting at a national level, particularly in low to medium income countries, is aimed at directing limited resources to areas of greatest need and impact. Recent national level priority-setting by Tanzania provides a useful example.⁹⁸

Tanzania's Commission for Science and Technology (COSTECH) partnered with COHRED and the New Partnership for Africa's Development (NEPAD)⁹⁹ Agency to implement the first cross-sectorial nationwide research priority-setting effort in Tanzania.¹⁰⁰ The first stage in the priority-setting process was to identify a method. The key decision points in choosing a method were:

- The process should be carried out within a short timeframe.
- It should involve all sectors.
- Consensus building among stakeholders was given high importance.
- The process should be expert driven (due to limited financial resources to undertake an analysis of research conducted in the past).
- The research agenda should be set for a period of 3-5 years (with a mid-term review to accommodate emerging priority issues).

⁹⁸ de Haan, S., Kingamkono, R., Tindamanyire, N., Mshinda, H., Makandi, H., Tibazarwa, F., ... & Montorzi, G. (2015). Setting research priorities across science, technology, and health sectors: The Tanzania experience. *Health Research Policy and Systems*, 13(1): 14. DOI: <https://doi.org/10.1186/s12961-015-0002-2>

⁹⁹ <http://www.nepad.org/>.

¹⁰⁰ This process was broader than, but included, health research.

Based on the context within Tanzania, the team opted for defining priorities through consultative expert workshops that would be guided by a clear process, criteria and ranking framework. The workshops included broad attendance, and the aim was to obtain good representation across the relevant institutions, government bodies, research institutions and non-governmental organisations (NGOs).

The following criteria were applied at different stages in the priority-setting process:

1. **Appropriateness** (e.g. ethical, availability of pre-existing data, culturally accepted etc.)
2. **Relevance** (e.g. equity focus and community concern/demand, problem size, contribution to national objectives).
3. **Feasibility** (e.g. capacity of the system to support the research, financial and human resources available, the cultural/political environment).
4. **Impact of research outcome** (e.g. opportunity to implement, use of research results, link of research to policy decisions, overall reduction of the problem, including cost).
5. **Opportunity to strengthen collaboration with partners** (e.g. presence of capable partners, available infrastructure and resources, possibility of collaboration, possibility of greater research outcome with partner involvement).

Workshops were run over three days:

- Day One focused on providing participants with an overview of current research, major research areas, questions to be addressed, research collaborations and available resources. Any data available from information systems demonstrating the degree of current problems was used. Day One resulted in a list of (max 50) outstanding problems and questions as well as a list of (max 50) research areas presented.
- Day Two focused on identifying research topics important to decision makers and researchers. Participants received copies of the lists produced on Day One. They were then divided into small groups representing various institutions of a sub-sector. The small groups were tasked with identifying areas from the list that are already researched and that did not need further research. Following the exclusion task, the small groups were given a task to list a maximum of 20 priority research areas using some of the criteria listed above.
- Day Three focused on rating and ranking research priorities. Participants first received training on performing individual and group rating activities. Each participant was then asked to conduct individual rating of the research area identified using the criteria listed above. Results were then compiled in a group score sheet, per research area which was used for ranking of research priorities for each sub-sector.

Using the method outlined above, 800 research priorities were identified across 42 sub-sectors. An expert group then assessed the alignment of priorities with government strategies, identified overlaps, removed any priorities that were not research focused reducing the number of priorities to 140.

The key lessons learned from this national level priority-setting exercise are outlined in a paper by de Haan, et al. (2015), summarised below as:

- The need to include broad representation of all stakeholder groups, so that each group's voice contributes the priorities identified through the process

- Ensure a systematic, transparent process and do not lose sight of the fundamental questions: Whose voices are heard, whose views prevail and, thus, whose interests are advanced
- Guarantee relevance by periodic review and updating.

The authors also noted that a broad cross-sectorial priority-setting process, such as the Tanzanian example, inevitably leads to a broad research agenda that has the value of providing strategic guidance. However, under this umbrella, more specific research agendas are required at the sector level for management purposes.

The Results: Tanzanian Health Research Priorities	
<ul style="list-style-type: none"> • Communicable diseases • Reproductive and maternal health • Health systems • Newborn and child health • Food and nutrition • Noncommunicable diseases • Climate change and environmental health • Indigenous knowledge • Product development and commercialisation 	<ul style="list-style-type: none"> • Food and medicine safety • Traditional and alternative medicine • Bioinformatics and information technology • Socio-cultural determinants of health • Injuries • Occupational health • Violence • Substance abuse • Oral health • Geriatrics and elderly health care

Priority-Setting for Vulnerable Populations¹⁰¹

Tomlinson, et al. (2009) note that ‘International evidence shows that people with disabilities have many unmet health and rehabilitation needs, face barriers in accessing mainstream health-care services, and can consequently have poor health.’¹⁰² To best use scarce research funds to the benefit of people with disabilities, one research team used the CHNRI method to identify priorities.¹⁰³ The method involved the following steps:

- Five domains of research questions were developed and cross-referenced with the convention on the Rights of Persons with Disabilities and the International Classification of Functioning: Disability and Health.¹⁰⁴
- Research questions across each domain were gathered by convening international experts and using a snowballing approach to identify further researchers and activists with disabilities, to participate in the process. A total of 82 experts contributed generating a list of 348 proposed research questions.
- The initial list of research questions was refined to 83 knowledge needs, once overlap had been eliminated.
- The expert working group ranked the 83 research questions based on CHNRI’s assessment criteria and included whether a research question was likely to:
 - Be answerable
 - Be applicable

¹⁰¹ Tomlinson, M., Swartz, L., Officer, A., Chan, K. Y., Rudan, I., & Saxena, S. (2009). Research priorities for health of people with disabilities: An expert opinion exercise. *The Lancet*, 374(9704): 1857-1862. DOI: [https://doi.org/10.1016/S0140-6736\(09\)61910-3](https://doi.org/10.1016/S0140-6736(09)61910-3)

¹⁰² Ibid, 1857.

¹⁰³ A range of academic institutions were involved in this work in conjunction with World Health Organisation staff.

¹⁰⁴ Tomlinson, et al., (2009), 1858.

- Be potential sensitivity
- Obtain support
- Have a predicted effect on equity
- Each research question was attributed a score based on the ranking exercise. A score indicating level of agreement was also calculated.

The research question which scored the highest (i.e. **were most likely to be** answerable by research, applicable, were not potentially sensitive, obtain support and make a positive impact on equity), was about 'identification of barriers that people with disabilities have in accessing health services at different levels'¹⁰⁵ and how such barriers could be removed. Other knowledge gaps that scored highly included:

- Health systems and policies in developed countries
- Sustainable rehabilitation in middle and low-income countries
- Early detection and referral in primary health-care services
- Strategies for including mental and physical rehabilitation services in health care and delivery
- Service provision in rural areas.

Research questions which scored the lowest related to treatment specific knowledge needs, for example:

- The physiological factors that enable assistive technology use
- The accessing of physiotherapy for people with spinal injuries
- How to reduce drug side effects for neurological impairments
- Diagnostic rates of sexually transmitted disease among those who have a physical or sensory impairment and are sexually active, compared with those who are sexually active and not disabled.

Those research questions which achieved a low score or ranking, may have been due to the criteria used or how they were applied. In other words, they may have been considered potentially sensitive or that they were unlikely to obtain support, rather than being assessed as unimportant knowledge needs.

¹⁰⁵ Ibid., 1858.

Priority-Setting for Cochrane Reviews

The general structure of the Cochrane Collaboration has been set up to facilitate the involvement of clinicians and patients in developing high-quality evidence through a rigorous process. However, the Cochrane Collaboration recognises the need for a more accountable and systematic approach to selecting research questions for systematic reviews.¹⁰⁶

To this end, the Cochrane Agenda and Priority-Setting Methods Group has been established. The group aims to fill the gap in research priority-setting and support researchers in selecting and prioritising topics for reviews. This group works closely with the James Lind Alliance.

The Cochrane Airways Group (CAG) comments that historically, review topics have been proposed by authors. This has left groups with a collection of systematic reviews that have evolved over time, rather than a carefully planned and curated collection of reviews.

CAG have now undertaken a pragmatic and transparent prioritisation exercise and identified 25 to 35 high-priority review updates. They used the following prioritisation process:

1. Understanding patient uncertainties about asthma: CAG used the 267 treatment uncertainties and the top 10 priority questions identified by James Lind Alliance.
2. Uncertainties and priorities were reviewed identifying those covered by existing reviews and where new reviews or updates were required.
3. The need for updating a review was judged using a Bazian decision support tool that assessed whether existing reviews were likely to change based on the number of participants found in new eligible studies. This was supported by a survey of the CAG editorial board.
4. CAG now maintain a horizon-scanning based list of possible new review titles. This is used to inform decisions about unsolicited review proposals together with priorities identified through the JLA.

¹⁰⁶ Nasser, M., Welch, V., Ueffing, E., Crowe, S., Oliver, S., & Carlo, R. (2013b). Evidence in agenda setting: New directions for the Cochrane Collaboration. *Journal of Clinical Epidemiology*, 66(5): 469-471. DOI: <http://dx.doi.org/10.1016/j.jclinepi.2012.08.006>

International Priority-setting for a Specific Health Issue – Mental Health

The WHO used the CHNRI method to identify mental health research priorities.¹⁰⁷ The team invited a group of mental health experts (the Lancet Mental Health group) to form a technical working group.

Technical working group members generated a list of research questions by research domain. They proposed a total of 290 questions which were synthesised into a final 55 questions.

Research investment options were then scored according to the 5 criteria recommended by CHNRI (see Figure 5: The CHNRI Process, right). Scoring, was performed by 24 members of the working group.

Collective scores represented a robust measure of the view of the expert group that the option would satisfy the given criterion. To ensure wider involvement, opinions were also collected from a larger reference group.

Weights were derived for the five criterion and average expert agreement was computed for each scored investment option.

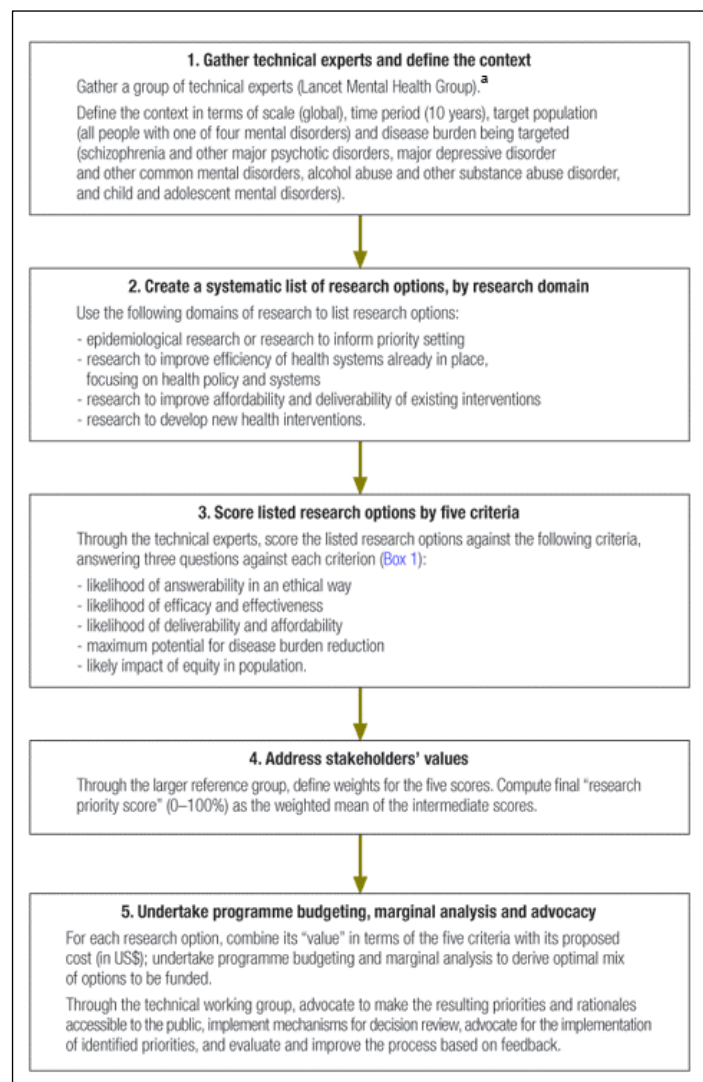


Figure 5: The CHNRI Process

¹⁰⁷ Tomlinson, M., Rudan, I., Shekhar, S., Swartz, L., Tsai, A. C., & Patel, V. (2009). Setting research priorities for mental health. *Bulletin of the World Health Organization*, 87: 438-446. DOI: 10.2471/BLT.08.054353

Priority-Setting for the Development of Priority Medicines¹⁰⁸

The 2013 Report '*Priority Medicines for Europe and the World*' provides a public-health based medicines development agenda based on a systematic methodology for priority-setting. The report analyses pharmaceutical innovation from a global public health perspective, based on principles of equity and efficiency.

The following method was applied to identify pharmaceutical gaps and to create a public health-based research agenda for the European Union (EU):

1. Review of demographic factors (e.g. life expectancy, age distribution) for countries in Europe and the world;
2. Ranking exercise using burden of disease information to generate two lists: One list of the major diseases and conditions which account for most the DALY¹⁰⁹ burden and a second counterpart list for the total mortality burden. Conditions not amenable to pharmaceutical treatment (e.g. injury) were removed;
3. Additional criteria were applied to generate additions to the lists of diseases and conditions. These included: Health-related projections and trends, risk factors, and social solidarity. This enables inclusion of rare diseases, for example, which may otherwise be excluded based on burden of disease measures;
4. A primary list was then created by combining DALY and mortality lists, removing any duplicate conditions, and adding new ones based on the three additional approaches;
5. A series of background papers on each condition were commissioned (in-depth reviews). The Cochrane Database of Systematic Reviews was also used to identify whether the pharmaceutical interventions available to treat these diseases were efficacious. The purpose of the review was to determine whether a pharmacotherapeutic treatment gap existed in any of the selected conditions, and
6. Those conditions with identified pharmaceutical gaps were added to the final list.

Using this method, pharmaceutical gaps were established for the diseases and risk factors identified. A gap exists for a disease or condition when: Pharmaceutical treatments for the condition will soon become ineffective (e.g. due to resistance), the delivery mechanism or formulation is not appropriate for the target patient group, or when an effective medicine either does not exist or is not sufficiently effective.

¹⁰⁸ Kaplan, et al. (2013).

¹⁰⁹ Disability-Adjusted Life Year.

Small Advanced Economies Initiative (SAEI)¹¹⁰

The SAEI, consisting of Denmark, Finland, Ireland, Israel, Singapore and New Zealand, have collaborated to analyse how countries of similar population and size, have prioritised funding and resources in the science, technology and innovation sectors. The paper sets out issues that can affect smaller countries such as, a greater need for international collaboration and partnering with nearby economies, retaining knowledge and skills, and developing research strengths.¹¹¹ The SAEI also identifies prioritisation may occur as an intermittent, regular or continuous process, by making new funding available or establishing new research institutes, or the reallocation of existing funds.

Like COHRED and Glod, et al. (2009), the SAEI highlight the need to mitigate potential risks to ensure effective prioritisation. The SAEI identify risks relating to the framework and processes used to prioritise, namely:

- A lack of buy-in from committees and policymakers to implement priorities;
- Lobbying to influence the process or outcomes;
- Short term needs dominating longer term needs, and
- Priorities being too granular or not granular enough, with the resultant priorities being too rigid or superficial.

The SAEI examined:

- **RESEARCH2020** (Denmark): A refresh of RESEARCH2015 which developed a catalogue of Denmark's science, technology and innovation research needs, to guide investment decisions. As a refresh, the process drew on existing consultation and horizon scan materials, on mapped current needs against those identified by RESEARCH2015, and identified more granular needs from dialogue with stakeholders.
- **National Research Prioritisation Exercise** (Ireland): In 2012, Ireland sought to identify 10-20 priorities that had market potential, were area where Ireland has research strength, required public research and development intervention, and represented a strategic challenge of national or global significance. To determine the priorities, Thematic Working Groups (TWG) were convened with sector-wide representation to propose research themes. Stakeholder engagement events were hosted to get feedback on the TWG themes. All information was assessed by a Steering Group who drafted a report and recommendations to the Government on those to be taken forward. A total of 14 priorities were selected.¹¹² An implementation plan, 'champion' and monitoring group assessed progress of priority implementation.
- **Finnsight2015** (Finland): In 2005, Finnsight2015 used a foresighting technique to assess the value of the science and technology sector to Finland, over the next 10-20 years. The assessment process involved over 120 experts from all parts of the sector, divided into 10 panels, each covering a different thematic area of research. In response to the foresighting process, 6 Strategic Centres for Science, Technology and Innovation

¹¹⁰ Small Advanced Economies Initiative. (2015). *Discussion Paper: Prioritisation of Public Sector Research across the SAEI*.

¹¹¹ For a full discussion see Small Advanced Economies Initiative. (2015).

¹¹² For more information on the priorities see National Research Prioritisation Exercise: First Progress Report (2014) available from: <https://dbe.gov.ie/en/Publications/Publication-files/Forf%C3%A1s/National-Research-Prioritisation-Exercise-First-Progress-Report.pdf>

(SHOK) platforms in the form of public-private partnerships were set up to ‘meet the needs of industry and society.’¹¹³

- **Research, Innovation and Enterprise 2020 (RIE2020) Strategy** (Singapore): THE RIE2020 was a refresh of RIE2015, a strategy that identifies five yearly priorities (since its establishment in 1995) for investment in science and technology. RIE2020 has the aim of ‘Transforming Singapore into a Smart Nation.’¹¹⁴ The RIE cover both thematic and structural priorities and is run by the National Research Foundation in collaboration with Government agencies, prepared before the budget as it applies to all Government funding.
- **National Science Challenges** (New Zealand): As discussed in Section 2.3 ‘Prioritisation in Health Research’ of this paper, the NSCs were aimed at focussing a portion of the Government’s mission-led research investment to solve ‘the most important issues for New Zealand that can be addressed by science.’¹¹⁵

¹¹³ Ibid, 14.

¹¹⁴ For more information see: <https://www.nrf.gov.sg/rie2020>

¹¹⁵ See Report of the National Science Challenges Panel (2013, p.3) available from: <http://www.mbie.govt.nz/info-services/science-innovation/national-science-challenges/documents-image-library/key-documents/Peak-Panel-report.pdf>

Appendix E: Full Options Assessment of Long List Prioritisation Methods

		Method						
		Burden of Disease	Essential National Health Research (ENHR)	3D Combined Matrix (3D CAM)	Child Health and Nutrition Research Initiative (CHNRI)	James Lind Alliance (JLA)	Delphi and Foresight Techniques	Evidence Gap Maps
NZHRG Guiding Principles	Research Excellence	✓	✓	✓	✓	✓	✓	✓
	Transparency	✓	✗	✓	✗	✗	✗	✗
	Partnership with Māori	✗	✓	✓	✗	✓	✗	✗
	Collaboration for Impact	✗	✓	✓	✗	✗	✗	✗
Purpose Statement	Provide signals for all stakeholders	✓	✓	✓	✓	✓	✗	✓
	Identify current & future needs	✗	✓	✓	✓	✓	✗	✓
	Identify where NZ can add value internationally	✗	✓	✓	✓	✓	✗	✓
	Identify where NZ can benefit from internationally	✗	✓	✓	✓	✓	✗	✓
Outcomes Sought	Identify the most important knowledge needs	✗	✓	✓	✓	✓	✗	✓
	Identify where knowledge is needed to achieve health equity	✗	✓	✓	✗	✗	✗	✓
	Identify where knowledge is needed to tackle new and emerging threats to health	✗	✓	✓	✓	✗	✓	✓
	Identify where NZ is best able to contribute to, and benefit from participation in the international health research	✗	✓	✓	✓	✓	✗	✓
	Enhance health research systems and infrastructure	✓	✓	✓	✓	✗	✗	✗
	Reflect the principles of He Korowai Oranga and Vision Mātauranga	✗	✓	✓	✗	✓	✗	✗
	Advance priorities set through Government and other strategies	✓	✓	✓	✗	✓	✗	✓
	Enhance economic outcomes for NZ	✓	✓	✓	✓	✓	✗	✓
	Support development of NZ's health research workforce	✓	✓	✓	✓	✓	✓	✓
A4R	Local Context	✗	✓	✓	✗	✓	✓	✓
	Decision Published	✗	✗	✗	✗	✗	✗	✓
	Appeals mechanism	✗	✗	✗	✗	✗	✗	✓
	Able to drive delivery	✗	✗	✓	✗	✓	✗	✗
Resourcing	Timeframe	✓	✗	✓	✓	✗	✓	✗
	Available Budget	✓	✗	✗	✓	✗	✓	✗
	Utilises existing evidence & NZHRG consultation data	✓	✓	✓	✓	✓	✗	✓
Additional Evaluation Criteria	Cultural appropriateness of prioritisation process	✗	✓	✓	✗	✗	✗	✗
	Acceptability of process	✗	✗	✓	✗	✗	✗	✗
	Feasibility of implementing priorities	✓	✗	✗	✓	✗	✓	✗
	Priorities stable but not stagnant	✓	✗	✗	✓	✗	✓	✗

Method	Comments
Burden of Disease	<p>The HRC anticipate that the resources exist to be able to carry out the Burden of Disease approach however, when assessed against the agreed evaluation criteria, the scope of the prioritisation would be too narrow to be able to set national health research priorities. On this basis, it was proposed that rather than be a standalone method, New Zealand's burden of disease data should form part of any preferred method to efficiently use existing resources.</p> <p>In a relative assessment of the strengths and weaknesses of the method, although the method is transparent and would fit within the resourcing constraints, there is limited opportunity for collaboration or partnership with Māori, meaning it falls down the A4R criteria of relevancy to the local context and being able to drive delivery.</p>
Essential National Health Research (ENHR)	<p>As Action 1 of the NZHRS is intended to build on the consultation data gathered as part of the NZHRS's development, the adoption of the ENHR approach would necessitate some duplication of process, such as the hosting of a national conference or workshops, which were conducted as part of the nationwide NZHRS consultation. An ENHR approach is also very resource heavy and would not be achievable within the identified resources constraints or timeframe. The resource intensive nature of this method would also put those priorities identified as risk of stagnation as the process could not easily be repeated or priorities refreshed.</p> <p>The ENHR approach also fails to meet the NZHRS Guiding Principle of transparency as the process for selecting a working group and defining the priorities is highly subjective and with the process less transparent to those not included. This would it difficult to secure buy-in from stakeholders and drive delivery of the priorities.</p>
3D Combine Matrix (3D CAM)	<p>Although the 3D CAM approach meets the priority-setting purpose statement, outcomes sought and NZHRS Guiding Principles, it faces resourcing constraints. To gather and convert existing data into the prerequisite format would be costly and highly time consuming. There is also some concern that some data sources such as the cost-effectiveness and financial flows would be difficult to obtain, if even in existence. Further, although the 3D CAM has been successfully applied to setting priorities at the global, regional and national level, this has been at the disease, condition or programme level and its ability to set priorities across the health research system remains unproven.</p>
Child Health and Nutrition Research Initiative (CHNRI)	<p>The CHNRI approach is largely not fit-for-purpose as it is centred around convening international experts which means it does not meet the need to be inclusive, for collaboration, partnership with Māori or transparency, as set out by the NZHRS guiding principles. This means the CHNRI approach does not meet the criteria for relevancy to the local context, is not culturally appropriate and would not have acceptability within the wider health research system and stakeholders making delivery of the resultant priorities difficult. Nor does the CHNRI approach give a review of evidence to experts, instead relying on their existing knowledge. CHNRI method may be more appropriate for Phase Two: Development of themes.</p> <p>A relative strength of the method is that is not resource intensive conducted largely online making it achievable within budget and time constraints. However, as a primarily online only methodology, it is unlikely to have validity in the New Zealand context and may not be appropriate for specific groups such as Māori and Pacific peoples.</p>
James Lind Alliance (JLA)	<p>The James Lind Alliance method does not meet the evaluation criteria primarily on the basis that it is predominantly clinically focussed and therefore not culturally appropriate. The clinical focus means it would be adept at generating specific research questions to answer or prioritise through funding partnerships, however, it ignores the social, cultural and other determinants of health. The JLA also falls down on some of the NZHRS Guiding Principles such as being transparent and collaborative as it only convenes professionals and stakeholders on certain issues. Due to this siloed approach the acceptability of this method is at the national level, is anticipated to be low.</p> <p>The long timeframe associated with the JLA approach means there is some risk priorities would become stagnant as they are not easily refreshed.</p>
Delphi and Foresight Techniques	<p>There is insufficient information available to adequately assess if the Delphi method and other foresight techniques would be fit-for-purpose. Based on the information available, the approach fails to meet any of the NZHRS Guiding Principles or the priority-setting purpose statement. This is because it centres on convening experts and unless able to be included within the expert group, there is limited opportunity for inclusive engagement, collaboration and partnership with Māori or other stakeholders.</p> <p>A relative strength of this method is that it can take be administered largely online and it is a future focused approach.</p>
Evidence Gap Maps (EGM)	<p>The EGM method is by comparison a relatively unproven method. In a New Zealand context is it expected to be difficult to carry out as it relies on systematic reviews and impact evaluations that likely do not exist. The reviews would have to be generated before the EGM could be produced meaning that there would not be sufficient resources to complete it. The production and analysis of any such reviews is not expected to meet the NZHRS Guiding Principles of collaboration and partnership with Māori. Consequently, the overall acceptability and cultural appropriateness of the method is low. This would make it difficult to drive delivery on any priorities identified.</p>

