National Centre
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An Audit of Intellectual Disability Health Research Funding in Australia

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Conflicts of interest

PS is a consultant for the Australian Institute of Health and Welfare (AIHW) but the views expressed in this manuscript are those of the authors and do not necessarily reflect the views or policies or AIHW.

Acknowledgement of Country

We acknowledge the Traditional Custodians of Country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to elders both past and present. We pay our respects to all First Nations people with intellectual disability and acknowledge the higher prevalence of intellectual disability among First Nations peoples and the distinct challenges they face, along with the contributions they make to society.

National Centre of Excellence in Intellectual Disability Health

The establishment of the National Centre of Excellence in Intellectual Disability Health was in response to the significant health disadvantage experienced by people with intellectual disability. The Centre supports the delivery of the Australian government's National Roadmap for Improving the Health of People with Intellectual Disability.

The Centre builds on the work of 3DN and the Centre's nine Consortium organisations – First Peoples Disability Network, Council for Intellectual Disability, Down Syndrome Australia, The Kids Research Institute Australia, Queensland Centre of Excellence in Autism and Intellectual Disability Health, Queenslanders with Disability Network, Centre for Disability Studies and UNSW.

Our vision is that every person with intellectual disability in Australia gets high quality health care.

Our mission is to work together with people with intellectual disability to make their health as good as it can be.

Our values

- We support the leadership of people with intellectual disability in their own lives and in the Centre.
- We are leaders in accessible communication and other inclusive practices.
- We respect family members and other advocates.
- We include people from diverse backgrounds.
- We listen to each other and value all perspectives.
- We are honest and open.
- We are accountable to people with intellectual disability and each other for what we do.

Cover Artwork:

My Place Drummoyne, Clare Hooper, 2025

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Executive Summary

This audit provides a comprehensive overview of intellectual disability health research funding in Australia between 2019 and 2024. It maps the funding landscape across major national funders, identifies patterns in funded research activity and health categories, and examines the extent to which lived experience involvement was supported in grant guidelines.

Thirty-three grants that focused on intellectual disability health were identified, representing $20.3 million AUD in total funding. The majority of this investment came from the National Health and Medical Research Council (NHMRC) (69.5% of total funding) and the Medical Research Future Fund (MRFF) (26.5% of total funding). The 2021 NHMRC Targeted Call for Research (TCR) in intellectual disability health was the single largest scheme, which together with the 2024 MRFF TCR, demonstrates an important milestone in recognising and addressing intellectual disability health inequities, and presents a valuable opportunity to strengthen the research landscape.

Funding was concentrated in a limited number of health categories, with general health and congenital disorders accounting for over 84.0% of total funding. Critical areas such as mental health and oral health – despite being well-documented priorities (1) – were notably underfunded. Research activity was mostly focused on health and support services, followed by finding and diagnosing illness and consumer healthcare experiences. Less than 10.0% of funding was directed toward prevention and staying healthy, despite national evidence showing that a third of Australia’s disease burden is preventable (2).

Encouragingly, the audit found growing support for lived experience involvement in intellectual disability health funded research. Recent grant guidelines increasingly referenced a range of roles for people with lived experience in research and lived experience participation in decision-making about grant outcomes. However, inclusion remains inconsistent and often lacks transparency.

This audit highlights the need for more equitable, strategic, ongoing, and inclusive investment in intellectual disability health research. It provides a foundation for future audits and offers initial recommendations to strengthen intellectual disability health research. As Australia continues to build its intellectual disability health research ecosystem, there is a clear opportunity to ensure that future research is not only scientifically robust, but also inclusive, relevant, and impactful.

Introduction

Intellectual disability is a lifelong condition characterised by limitations in intellectual functioning and adaptive behaviours, affecting communication, self-care, learning, and social skills to varying degrees. In Australia, approximately 2% of the population have an intellectual disability, with an even higher prevalence among Aboriginal and Torres Strait Islander people (3, 4). A substantial body of evidence highlights pervasive and multifaceted health inequities for people with intellectual disability across the lifespan, reflecting systemic failures in access, quality, and responsiveness of care.

People with intellectual disability experience stark health inequalities. They die at a younger age compared to the general population, with elevated mortality rates (5) primarily due to respiratory disease, cancer, and cardiovascular conditions (5, 6). They are more likely to present to emergency departments and experience preventable hospitalisations, with higher associated costs and poorer outcomes (7, 8). On average, individuals with intellectual disability have 2.5 times more health problems, with some studies reporting over 11 comorbidities per person (9, 10), some of which are associated with the condition causing the intellectual disability. Common comorbidities include epilepsy, cardiovascular disease, respiratory and gastrointestinal disorders, and sensory impairments (11-13). Mental illness is also highly prevalent, affecting over half of this population, with psychiatric conditions occurring 2-3 times more frequently than in the general population (14-16), particularly in custodial settings. Preventative healthcare uptake, such as cancer screening and vaccinations, is markedly lower and contributes to high rates of modifiable conditions such as diabetes, hypertension, and obesity (7, 17, 18). Additionally, premature ageing and early onset frailty are common, leading to increased care needs, hospitalisation, and mortality (19, 20).

Building on extensive evidence of health inequities experienced by people with intellectual disability, it is critical to recognise the broader systemic context in which these disparities occur. Australia's *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* made an official finding of systemic neglect in health, highlighting long-standing institutional and structural failures (21). Its final report issued a series of recommendations related to disability health research, data, and capacity building (22). These align with Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities (Article 25 and 31), which affirm the right to health without discrimination and require governments to collect data to inform inclusive policy (23). They also support progress toward the Sustainable Development Goals, particularly those focused on health and reducing inequalities (24).

Recent national strategies reflect a growing commitment to inclusive and responsive health systems. Released in 2021, *The National Roadmap for Improving the Health of People with Intellectual Disability* (The Roadmap) outlines goals for service coordination, workforce capacity, and engagement with people with intellectual disability, their families and their support networks (1). Importantly, one of its short-term actions was to explore options for targeted national research that builds the evidence base on strategies to improve health outcomes for people with intellectual disability. Similarly, *Australia's Disability Strategy 2021-2031*, launched in December 2021, provides a cross-sector framework that emphasises the role of evidence and lived experience in shaping policy and service delivery (25). These strategies set a clear direction for inclusive health reform, highlighting the need for research that can support evidence-informed decisions and lasting change.

Health and medical research funders

National health and medical research funding in Australia plays a critical role in generating evidence to inform policy, improve health outcomes, and respond to both identified and emerging population health needs. This funding is primarily delivered through the National Health and Medical Research Council (NHMRC) and the Medical Research Future Fund (MRFF). The NHMRC is the main funder across all research types, with an average annual budget of $913.8 million between 2019 and 2024 (26). The MRFF, established in 2015 (27), focuses on translational research with an average annual budget of $592.2 million between 2019 and 2024 (28). **Table 1** lists key developments (i.e. strategies and frameworks) from Australian health and medical research funders released between 2019 and 2024.

Both NHMRC and MRFF have increasingly prioritised consumer and community involvement in research, recognising the importance of lived experience in shaping relevant and impactful research outcomes. Recent initiatives from the NHMRC include the release of its *Consumer and Community Involvement Toolkit* (29) and the ongoing review of its *Statement of Consumer and Community Involvement in Health Research*. Similarly, the MRFF has introduced Consumer Involvement Statements, piloted in 2023 and implemented across all grant opportunities from mid-2024 (30). These developments reflect a broader commitment to inclusive research practices and improved translation of research into policy and practice.

In addition to NHMRC and MRFF, other funders also contribute to Australia’s health and medical research landscape. The Australian Research Council (ARC), while not funding health and medical research directly, supports research in adjacent areas such as social supports, which intersect with health outcomes. Non-government funders, including philanthropic and private organisations, also play a role, often supporting mission-driven or community-led initiatives. The National Disability Research Partnership (NDRP), an initiative of Australia’s Disability Strategy, facilitates collaborative and inclusive disability research nationally including funding research done by and with people with disability (31). These additional sources of funding diversify the research ecosystem and help address gaps not covered by national schemes.

Table 1 Key developments from Australian Health and Medical Research Funders (2019 - 2024)

Year	Key development
2019	MRFF releases 1st 10-year Investment Plan (32)
2020	NHMRC Toolkit for Consumer and Community Involvement in Health and Medical Research released (33) National Disability Research Partnership (NDRP) established (34)
2021	Australian Medical Research and Innovation Strategy 2021 – 2026 (35)
2022	Review of NHMRC Statement on Consumer and Community Involvement in Research commences (36) Australian Medical Research and Innovation Priorities 2022 – 2024 (37) NDRP preliminary research agenda released (38)
2023	Consultations about improving alignment and coordination between the MRFF and NHMRC's funds conducted (39)
2024	NDRP research agenda released (38) NHMRC 2024 – 2027 health priorities released (40) MRFF Consumer Involvement Fact Sheet (30) Australian Medical Research and Innovation Priorities 2024 – 2026.

Research funding audits

Building on an understanding of who funds health and medical research and what they prioritise, the next step is to examine how these investments are assessed through audit processes. Research funding audits aim to identify gaps, guide investment, and ensure that research is focused on areas of greatest impact. Methods typically involve mapping funded research against structured classification frameworks, strategic priorities, and community-identified needs. Key examples of research funding audits include:

- **Cancer Australia**, which maps funding against national cancer priorities using the Common Scientific Outline to identify gaps and guide investment (41, 42).
- **Autism research audits in Australia**, the UK, and the US, which assessed alignment between funded research and community priorities using the Interagency Autism Coordinating Committee (IACC) strategic plan framework (43-45).
- **Disability research in Australia**, where funding patterns were analysed through the funding acknowledgement sections of peer-reviewed publications to understand investment sources (46).
- **UK and international audits** use the Health Research Classification System (HRCS), which categorises research by activity type and health focus, enabling consistent cross-sector comparisons (47-49).

The HRCS has been selected as the central framework for this audit because it is designed specifically to classify health and medical research by type of research activity and by health category (50). Since its development in 2004, the HRCS has been applied in large-scale UK audits (47-49, 51) and targeted analyses, including Australian eating disorder research (52), and across diverse domains including mental health (53), health systems (54), and global health investment (55). These applications demonstrate its flexibility for both broad and niche research portfolios.

Table 2 lists the 21 health categories and eight research activity types within the HRCS. The health categories provide a comprehensive framework for classifying all diseases, conditions and areas of health, with each category able to represent both disease and normal function. The HRCS health categories are based on the World Health Organisation (WHO) International Classification of Diseases (ICD) codes (56). The research activity types encompass the full spectrum of health-related research, from foundational science to applied studies focused on treatment, service delivery, and health system improvement (57). Together, these categories offer a structured and comprehensive approach to analysing the scope and focus of intellectual disability health research funding in Australia.

Table 2 Health Research Classification System (HRCS) health categories and research activities[1]

Health Categories

1. Blood
2. Cancer and tumours
3. Congenital disorders
4. Ear health
5. Eye health
6. Heart and blood vessel health
7. Infection
8. Inflammatory and immune system
9. Injuries and accidents
10. Mental health
11. Metabolic and endocrine
12. Musculoskeletal
13. Neurological
14. Oral and digestive health
15. Kidney and urinary health
16. Reproductive health and childbirth
17. Respiratory health
18. Skin
19. Stroke
20. General health and wellbeing
21. Unclear causes and other conditions

Research Activities

1. Basic research
2. Causes of diseases
3. Preventing illness and staying healthy
4. Finding and diagnosing illness
5. Making new treatments and medicines
6. Testing treatments in real life
7. Managing illnesses and health problems
8. Research on health and support services

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[1] For clarity and consistency, adapted plain language names based on the Health Research Classification System are used throughout this report. Full technical category names are available in Appendix B.

Aims of this audit

This audit examines research funding related to intellectual disability health in Australia between 2019 and 2024, and focuses on the following research questions:

- **Funding patterns:** How much research funding was provided, who provided it, and what health topics or research activities were funded?
- **Support of lived experience involvement:** To what extent do the grant guidelines associated with funded intellectual disability health research promote or require involvement of people with lived experience?
- **Inclusive decision-making:** To what extent do the grant guidelines associated with funded intellectual disability health research describe the inclusion of people with lived experience in decision-making processes about grant outcomes?

This audit uses the 2019 to 2024 period because it provides a strong foundation for future audits and matches how other organisations track research funding over time (e.g. through triennial reporting) (43, 44, 58). It spans two triennia, that include key developments in intellectual disability health and includes funding from MRFF, which is now a central part of the research funding landscape. Expectations around lived experience involvement have become clearer and more prominent recently, making this timeframe more relevant for assessing current expectations.

Methodology

Search strategy

As in recent research funding audits (43, 44, 58), the first phase was to search for relevant grants awarded using Dimensions Database (https://www.dimensions.ai/). Dimensions is a comprehensive database that contains grants, publications, citations, alternative metrics, clinical trials, patents and policy documents. For awarded grants, Dimensions includes information such as the grant title, abstract, funder and location, funding period, grant number, start and end dates, awarded amount, lead research organisation and their location. The search terms used are listed in **Table 4** in *Appendix A - Search functions.* The search was limited to grants commencing between 2019 and 2024, with a listed location of Australia, and awarded by Australian funders. The Dimensions search returned a total of 99 grants, primarily funded by NHMRC or MRFF.

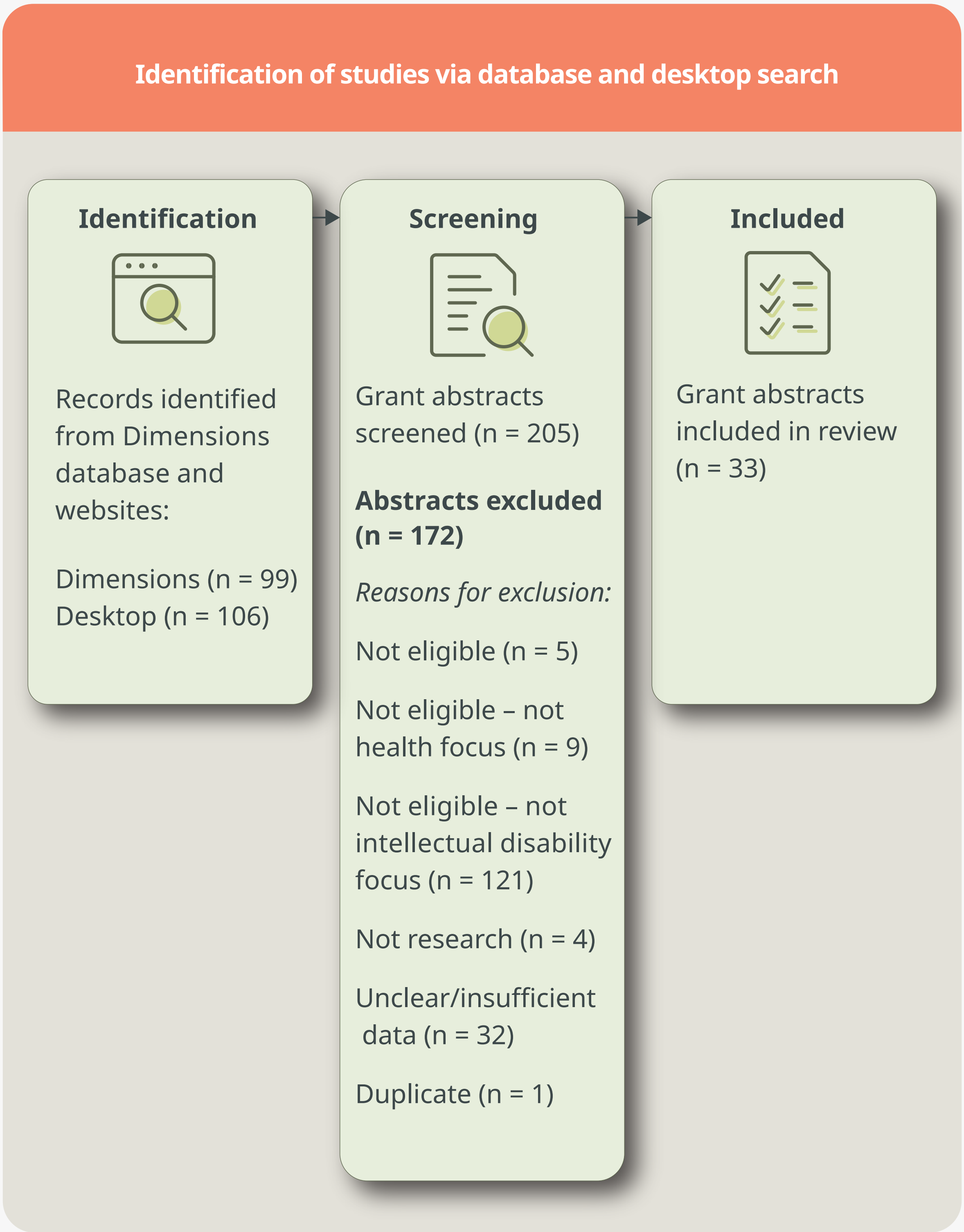
Next, a desktop search was conducted to capture grants awarded from other funding sources (i.e. University, NGO) which fund disability research across Australia (46). A full list of the organisations included in the desktop search is available in **Table 6** in *Appendix A - Search functions.* The desktop search returned 106 research grants. Three Australian non-government organisations were contacted directly to seek additional information about the awarded grants identified.

Together, these searches identified a total of 205 unique grants. Data extracted for all identified grants were compiled into a Microsoft Excel spreadsheet, where all key information (i.e. title, abstract, funder, start and end date, grant opportunity, lead research organisation and location) was organised to enable screening and coding.

Inclusion and exclusion of grants

The following criteria were applied to ensure that the audit captured research that directly addressed the health needs of people with intellectual disability. Awarded grants were eligible for inclusion if, based on their abstracts, they met the following criteria: (1) focused primarily on intellectual disability, (2) focused on health-related outcomes, services or interventions, or (3) funded research activities. Awarded grants were excluded if, based on their abstracts, they (1) were not health-related, (2) had a population focus broader than intellectual disability, (3) focused on health conditions that may co-occur with intellectual disability but did not explicitly identify intellectual disability as a central focus, (4) funded an activity not considered research, or (5) a grant abstract was not available for coding and analysis.

Two authors (AK and RC) reviewed all research grant abstracts independently in the Excel spreadsheet to determine eligibility. For a subset of randomly selected abstracts, RC conducted the eligibility assessment in collaboration with a lived experience project officer (please see *Appendix C - Eligibility and Coding Worksheet Template* for the co-designed template used throughout screening and coding). These abstracts had been adapted into plain language, and the assessment was guided by a shared understanding of the eligibility criteria. Following the independent reviews, AK and RC compared their eligibility decisions. Any discrepancies in eligibility were resolved through detailed discussion until consensus was reached. After assessment of eligibility and as shown in **Figure 1**, 172 grants were excluded from analyses, based on their abstracts, for the following reasons: grant not focused on intellectual disability (n = 121), grant not focused on health (n = 9), and insufficient information for analysis (n = 32). This resulted in a final set of 33 grants focused on intellectual disability health in Australia between 2019 and 2024 that proceeded to coding.



Identification of studies via database and desktop search

Identification

Records identified from Dimensions database and websites:

Dimensions (n = 99)
Desktop (n = 106)

Screening

Grant abstracts screened (n = 205)

Abstracts excluded (n = 172)

Reasons for exclusion:

Not eligible (n = 5)

Not eligible – not health focus (n = 9)

Not eligible – not intellectual disability focus (n = 121)

Not research (n = 4)

Unclear/insufficient data (n = 32)

Duplicate (n = 1)

Included

Grant abstracts included in review (n = 33)

Figure 1 Identification of grant abstracts flow chart

Coding of grant abstracts

Each eligible grant abstract was classified using the Health Research Classification System (HRCS) into one of 21 health categories and eight standard research activity types. To reflect the current Australian policy environment that emphasises the importance of consumer perspectives in health care (59), an additional research activity type named ‘Consumer Healthcare Experiences’ was developed. Therefore, each grant abstract was coded against the 21 HRCS health categories and against nine research activity types. Prior to coding, all health categories and research activity types were adapted into plain language with a lived experience project officer to enable the research team to work inclusively. The adapted versions of health categories and research activities are presented in *Appendix B - Adapted health categories and research activities* and are referred to from this point on.

Two authors (AK and RC) then reviewed all eligible research grant abstracts independently to code for health category and research activity type in the Excel spreadsheet. For a subset of randomly selected abstracts, RC completed coding in collaboration with a lived experience project officer. These abstracts had been adapted into plain language, and the coding was guided by a shared understanding of the coding dimensions. All coding was done referencing the health category and research activity types adapted into plain language. Following independent reviews, coding across both dimensions was then compared. Any discrepancies in coding were resolved through detailed discussion until consensus was reached.

Coding of grant guidelines for lived experience involvement

When the coding of grant abstracts was complete, the associated grant guidelines were retrieved via desktop search. Grant guidelines reflect the policy priorities of funding bodies, making them a valuable source for assessing the extent to which lived experience involvement was encouraged or required in funded research. These documents were reviewed to identify expectations for lived experience participation and their role in determining successful grant applications. To guide the coding process, the research team co-designed a set of codes based on key dimensions of lived experience involvement commonly referenced in funding policy and practice. For full definitions of codes and examples please see *Appendix D - Codes and definitions for lived experience involvement*. The codes were:

a. Lived experience involvement as a requirement of the grant
b. Lived experience involvement in assessment criteria
c. People with lived experience as investigators
d. People with lived experience as decision-makers
e. Support for researchers on lived experience involvement
f. Explicit budget advice for lived experience involvement

A total of 21 grant guidelines were retrieved, representing 25 of the 33 awarded grant abstracts (76.0%). Two authors (AK and RC) then reviewed all retrieved grant guidelines to independently to code for all elements of lived experience involvement in an Excel spreadsheet. For a subset of randomly chosen grant guidelines, RC completed coding in collaboration with a lived experience project officer. The relevant texts of these grant guidelines had been adapted into plain language, and the coding was guided by a shared understanding of the elements of lived experience involvement. Following independent reviews, coding across all elements was compared. Any discrepancies in coding were resolved through detailed discussion until consensus was reached.

Analyses

Descriptive analyses were conducted to examine patterns in research funding by HRCS categories, and to assess the inclusion of lived experience involvement within the grant guidelines of funded intellectual disability research. All monetary values are reported in Australian Dollars (AUD), and no adjustments for inflation were made. Funding amounts were extracted for each eligible grant.

For each HRCS health category and research activity type the following metrics were calculated:

- total funding amount (AUD)
- proportion of total funding (%)
- number of funded grants (n)
- proportion of total funded grants (%)

To assess funding distribution, the average funding per grant within categories was calculated by dividing the total awarded amount by the number of grants within each classification.

For each of the grant guidelines, lived experience involvement as a requirement of the grant was coded as yes, no, or encouraged. All others were coded as present or absent. Frequencies and percentages were calculated to describe how often each code appeared across the guidelines. To explore changes over time, these proportions were examined across two three-year periods, 2018-2020 and 2021-2023. This allowed identification of trends in how lived experience involvement was supported or encouraged in funding processes over time.

Results

Overall trends in research funding

This audit found that $20.3 million was provided to 33 intellectual disability health research grants that commenced between 2019 and 2024. The average funding per grant was just over $600,000. **Figure 2** shows the amount of funding and number of grants per year of the audit period. Across the six years of the audit, the greatest amount of funding was identified in 2023 with $6.2 million (30.4% of total audit funding) provided to seven grants (21.2% of total grants). **Figure 3** shows the distribution of research funding and grants by state or territory of the lead research organisation. Ordered by the total amount of funding the following was seen across states and territories:

- **New South Wales:** $11.9 million of funding (58.7%), 14 research grants (42.4%).
- **Victoria:** $5.0 million of funding (24.7%), 14 research grants (42.4%).
- **Western Australia:** $1.6 million of funding (8.0%), two research grants (6.1%).
- **Queensland:** $1.6 million of funding (7.9%), two research grants (6.1%).
- **South Australia:** $155,000 (0.8%), one research grant (3.0%).
- No research funding was awarded to grants led by research organisations in **Tasmania** or **Northern Territory**.

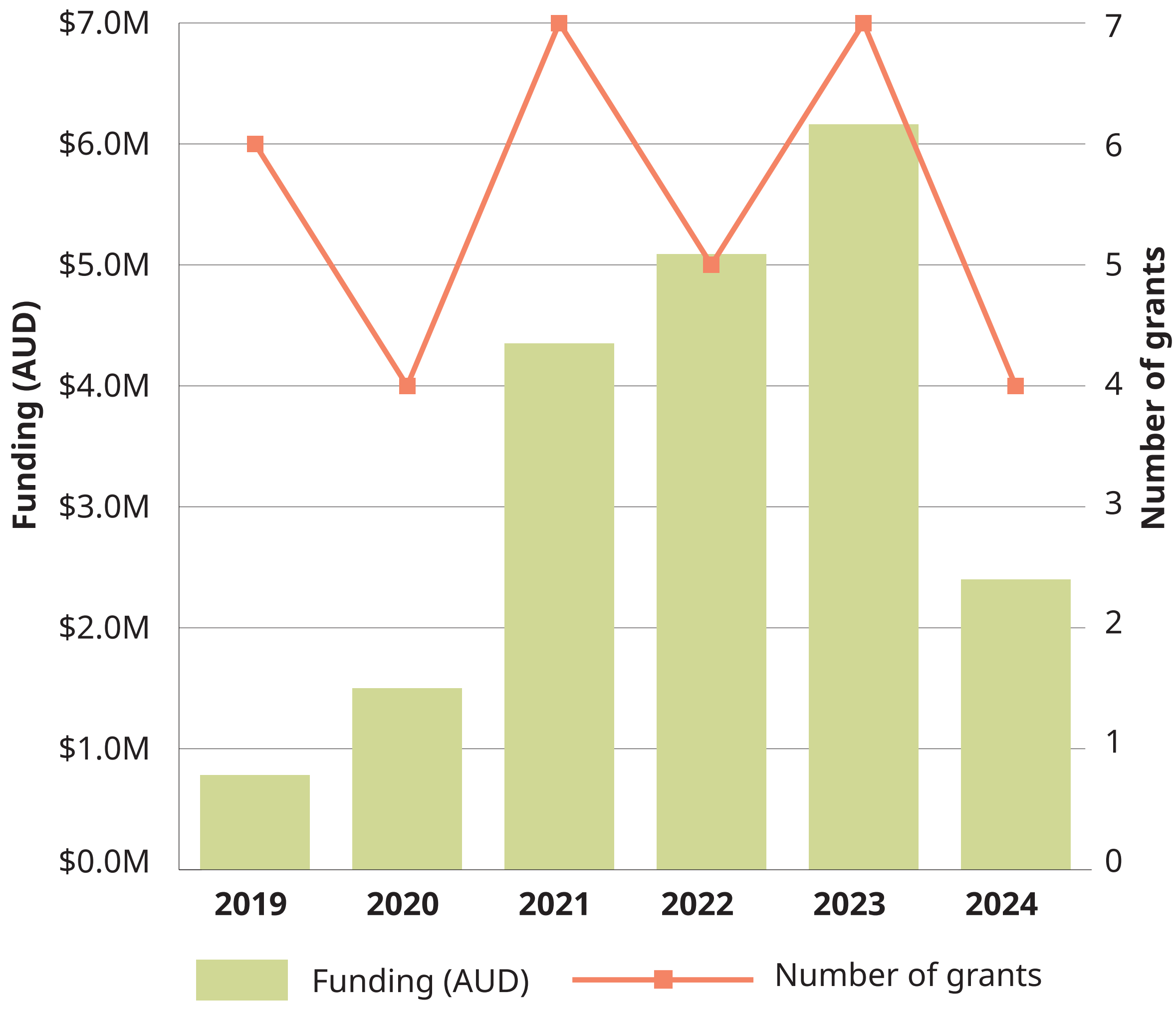


Figure 2 Total research funding (AUD) and number of research grants, 2019-2024

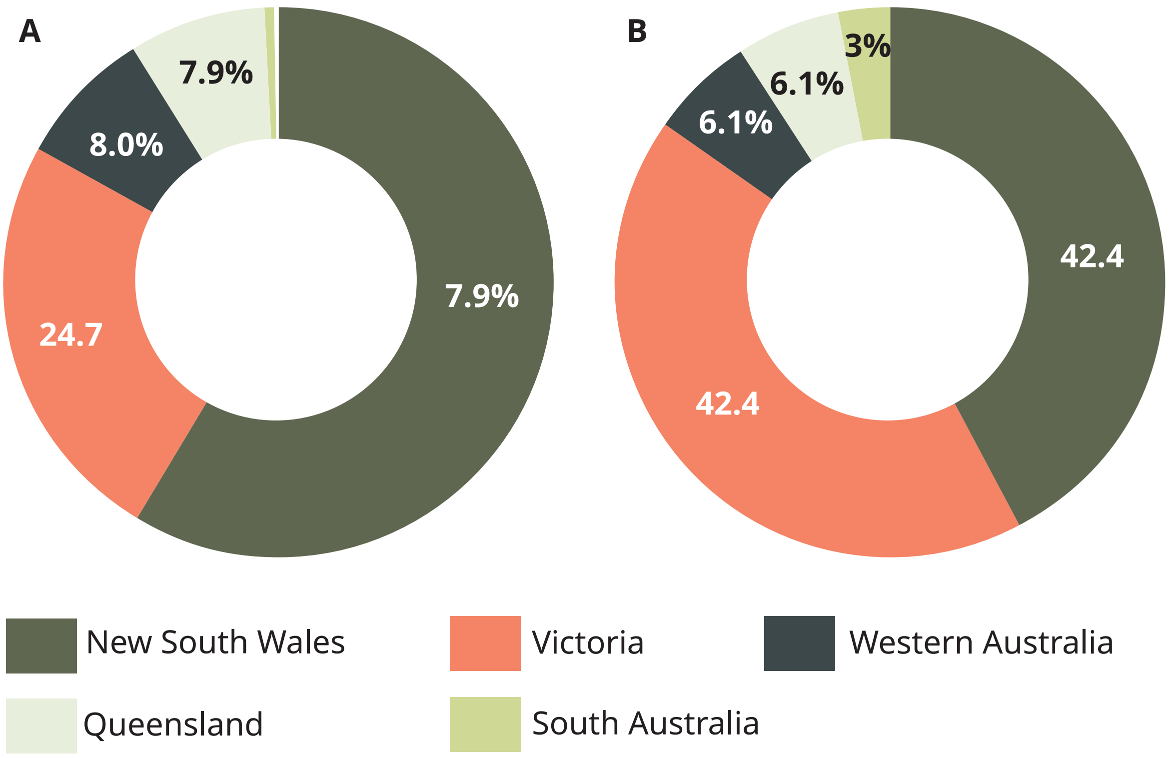


Figure 3 Distribution of (A) total research funding and (B) number of grants by state or territory of lead research organisation, 2019-2024

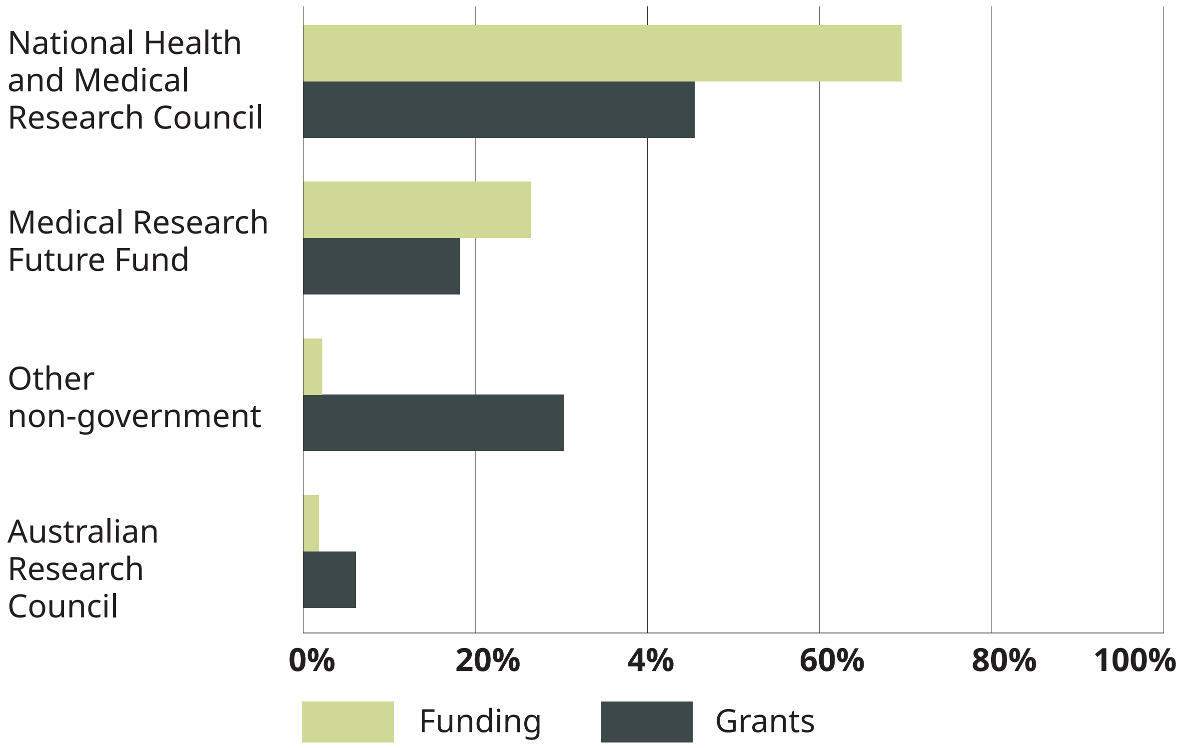


Figure 4 Percentage of research funding (AUD) and research grants by funder, 2019-2024

Figure 4 shows the proportion of funding and grants by funder over the audit period. The major funders, total funding amounts, number of grants, and notable grant schemes or opportunities were as follows:

- **NHMRC**: $14.1 million of total funding (69.5%), 15 research grants (45.5% of all grants).
    - **Broad grant schemes:** Targeted Calls for Research (i.e. any TCR regardless of year) were the largest schemes ($6.8 million, 33.6% of total audit funding); NHMRC Ideas Grants from any year were the 3rd largest scheme ($2.7 million, 13.1% of total audit funding).
    - **Individual grant opportunity:** 2021 NHMRC Targeted Call for Research – Improving Health of People with Intellectual Disability was the largest funder ($5.4 million, 26.6% of total funding); 2021 NHMRC Investigator Grants were the 2nd largest funder ($2.4 million, 11.7% of total funding).
- **MRFF:** $5.4 million of total funding (26.5%), six research grants (18.2% of all grants).
    - **Broad grant scheme:** MRFF Genomics Health Futures Mission was the 2nd largest scheme ($2.8 million, 13.7% of total funding).
    - **Individual grant opportunity:** the 2022 MRFF Genomics Health Futures grant opportunity was the 3rd largest funder ($2.3 million, 11.3% of total funding).
- **Other non-government:** $456,000 of total funding (2.2%), 10 research grants (30.3% of all grants).
- **ARC:** $362,000 of total funding (1.8%), two research grants (6.1% of all grants).

Research funding by HRCS health category

Research grants during the 2019 to 2024 period were coded to six of the 21 HRCS health categories. These health categories and example grants were:

- General health (e.g. grants to find out about gaps in health care, or identifying barriers and facilitators to meeting health needs)
- Congenital disorders (e.g. Rett syndrome, Prader-Willi syndrome)
- Neurological (e.g. study brain tissue)
- Cancer and tumours (e.g. cervical cancer)
- Mental health
- Oral and digestive health

The 15 health categories without coded research grants were:

- Blood
- Heart health
- Ear health
- Eye health
- Infection
- Inflammation and immune system
- Injuries and accidents
- Metabolic and endocrine
- Musculoskeletal
- Kidney and urinary health
- Reproductive health and childbirth
- Respiratory health
- Skin
- Stroke
- Unclear causes or other conditions

Figure 5 shows the distribution of research funding and grants by health category between 2019 and 2024. Most of the funding was directed toward grants coded to **general health** and **congenital disorders**, which together accounted for 84.3% of total funding. The highest average funding per grant was for those coded to **cancer and tumours** at $1.4 million per grant and the lowest average funding per grant funding was for those coded to **oral and digestive health** with $37,5000 per grant. The total funding and number of grants coded to each health category were as follows:

- **General health:** $11.9 million of total funding (58.5%) across 19 grants (57.6%).
- **Congenital disorders:** $5.2 million of total funding (25.8%) for seven grants (21.2%).
- **Cancer and tumours:** $1.4 million of total funding (7.1%) for one grant (3.0%).
- **Mental health:** $1.1 million (5.3%) for three grants (9.1%).
- **Neurological health:** $600,000 of total funding (2.9%) for one grant (3.0%).
- **Oral and digestive health:** $75,000 (<1.0%) for two grants (6.1%).

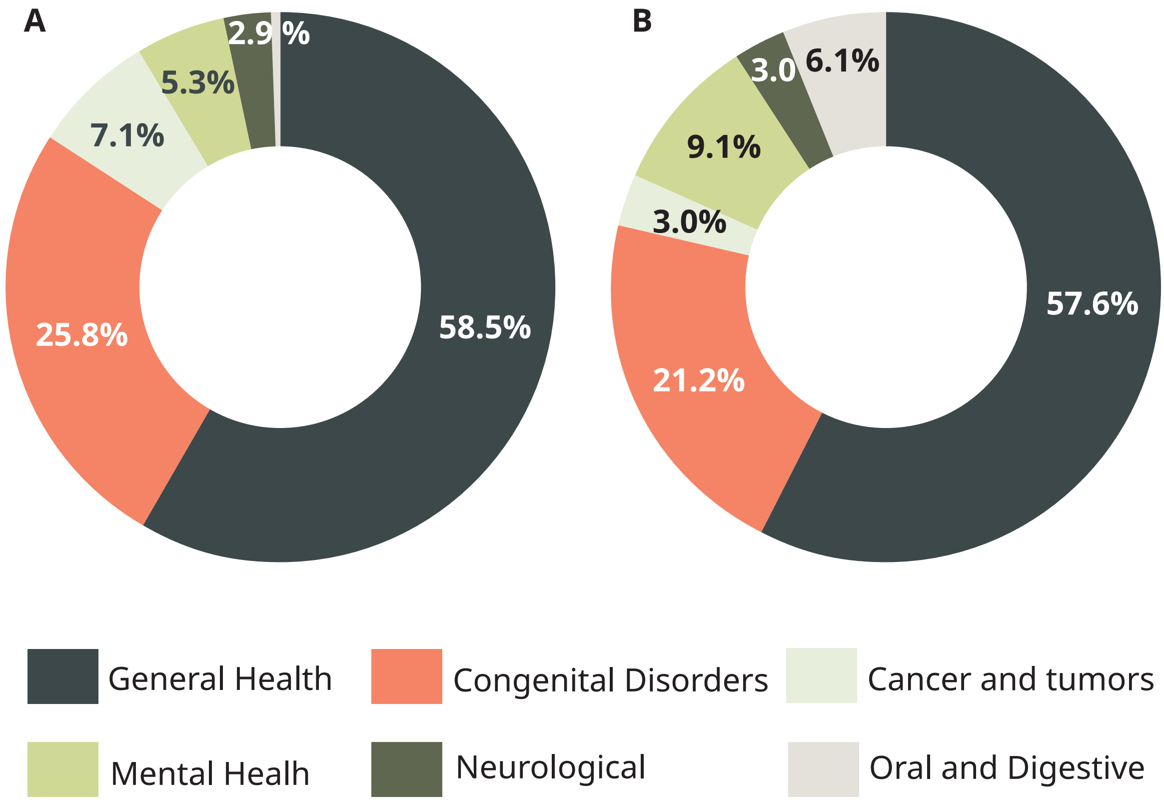


Figure 5 Proportion of **(A)** total research funding and **(B)** number of grants by HRCS health category, 2019-2024

Figure 6 shows the distribution of research funding by funder and health category in the period 2019 to 2024. These results show that:

- **NHMRC** was the primary source of funding for research on general health and cancer and tumours.
    - General health received the largest share of **NHMRC** funding ($10.2 million; 50.0% of total funding).
- Research coded to **general health** was supported by all four funder groups.
- Research coded to **cancer and tumours** was funded only by NHMRC.
- Research coded to **oral and digestive health** was funded only by other non-government sources.

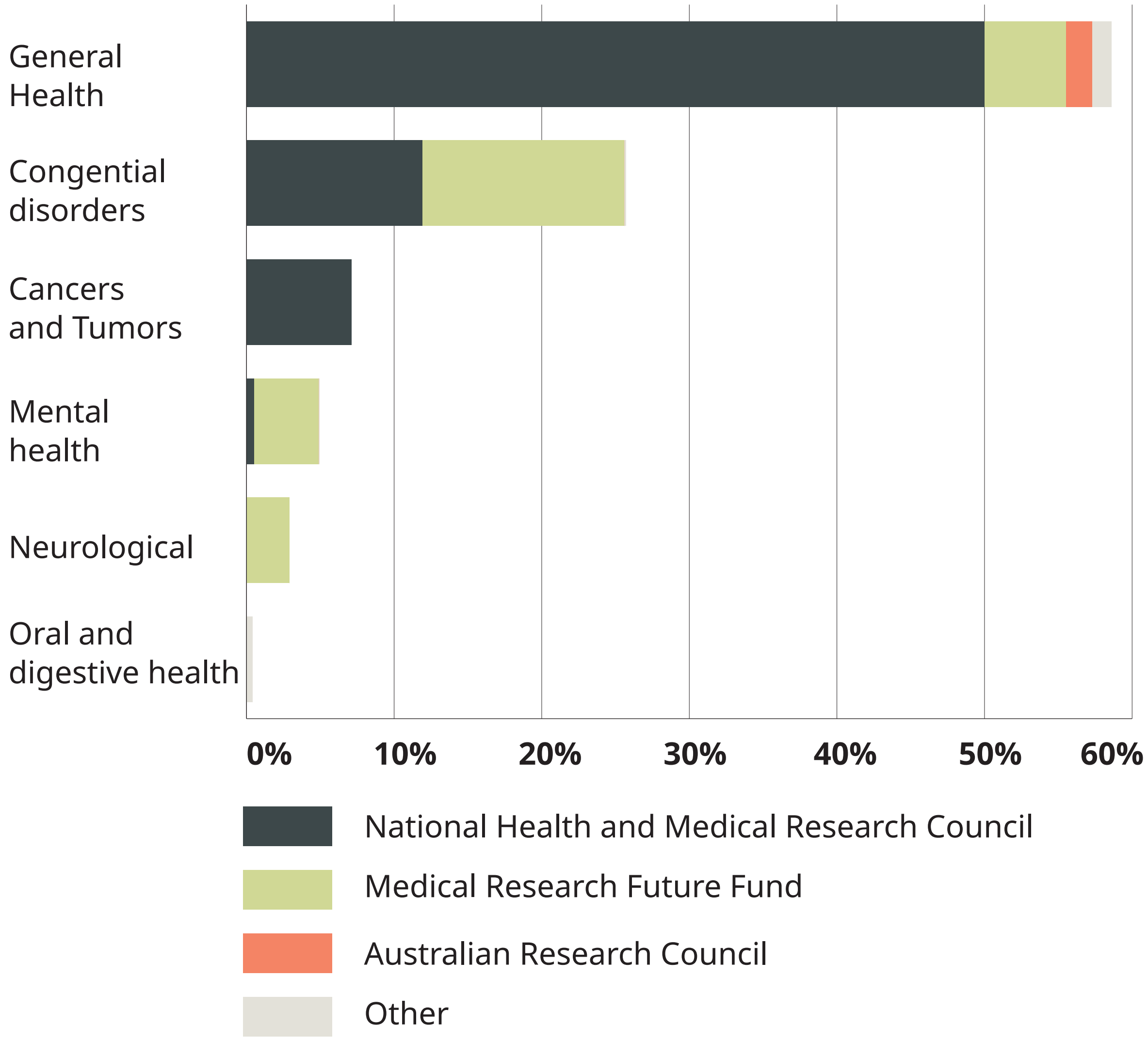


Figure 6 Percentage of total research funding (AUD) across HRCS health categories by funder, 2019-2024

Research funding by research activity type

The research grants funded and started between 2019 and 2024 were coded to all nine research activity types. **Figure 7** shows the percentage of funding and grants by type of research activity during the audit period. The highest percentage of total funding and grants was for those coded to **research on health and support services**. The highest average funding per grant was for those coded to **finding and diagnosing illness** with an average of $1.3 million per grant, and the lowest average funding per grant was for those coded to **basic research** at $272,000. The total funding amounts and number of grants by research activity were as follows:

- **Research on health and support services:** $6.5 million (32.0% of total funding) across 10 research grants (30.3%).
- **Finding and diagnosing illness:** $5.1 million (25.1% of total funding) for four research grants (12.1%).
- **Consumer healthcare experiences:** $2.6 million (12.8%) for five research grants (15.2%).
- **Preventing illness and staying healthy:** $1.6 million (7.9%) across two research grants (6.1%).
- **Causes of diseases:** $1.3 million (6.2%%) for four research grants (12.1%).
- **Basic research:** $1.1 million (5.4%) for four research grants (12.1%).
- **Testing treatments in real life:** $880,000 (4.4% of total funding) for one research grant (3.0%).
- **Managing illnesses and health problems:** $650,000 (3.2% of total funding) across two research grants (6.1%).
- **Making new treatments and medicines:** $600,000 (2.9%) for one research grant (3.0%).

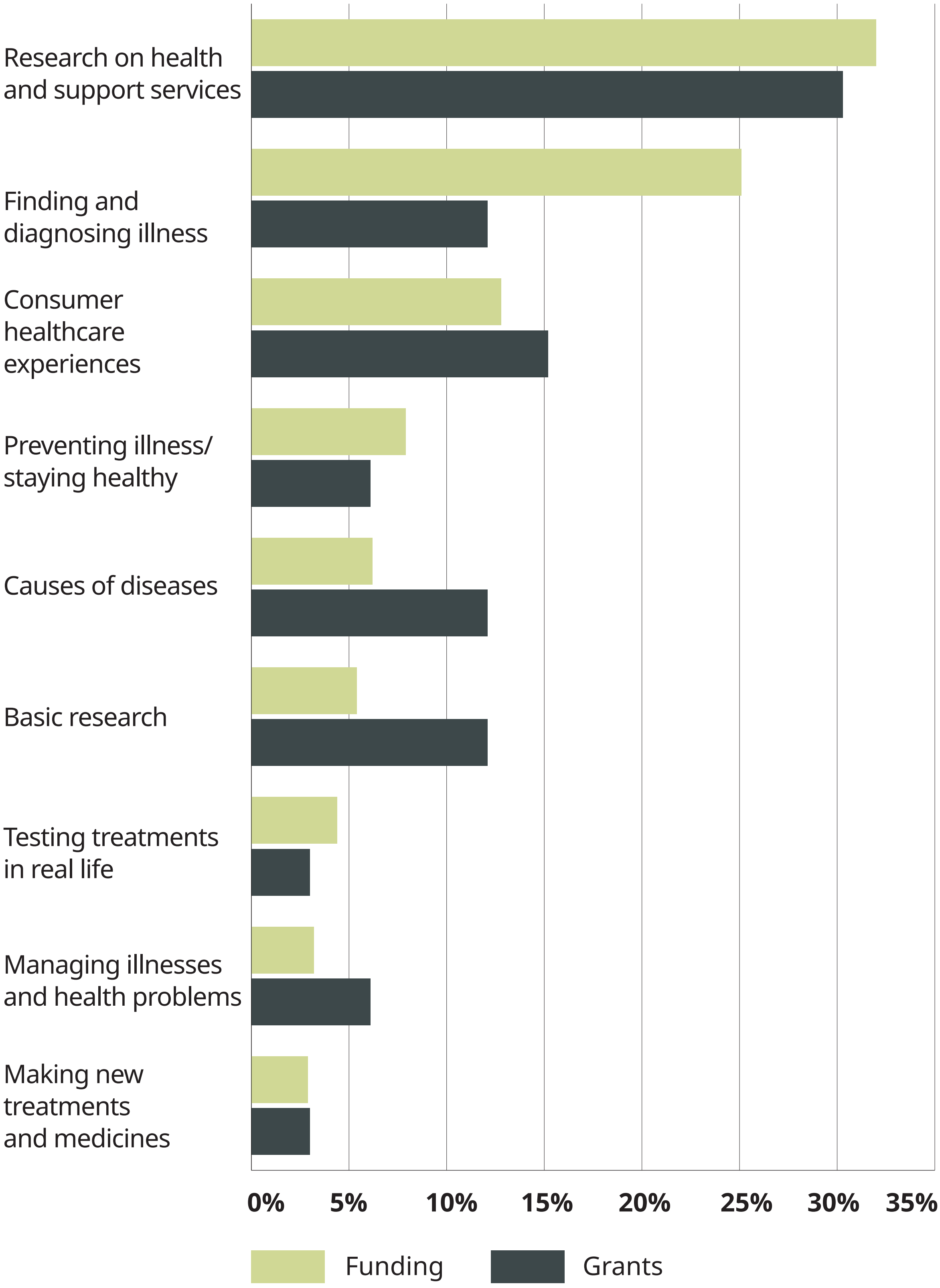


Figure 7 Percentage of total research funding and grants by research activity type, 2019-2024

Figure 8 shows the distribution of funding by HRCS research activity type and funder in the period 2019 to 2024. For six of the nine research activity types, NHMRC was the primary funder of grants. The largest proportions of funding from the NHMRC were for research coded to:

- **Research on health and support services:** $5.2 million (25.4% of funding audit total).
- **Finding and diagnosing illness:** $2.7 million (13.3% of funding audit total).
- **Consumer healthcare experiences:** $2.4 million (11.6% of funding audit total).

The NHMRC did not fund research coded to a) testing treatments in real life, b) making new treatments and medicines, or c) managing illnesses and health problems.

The largest proportions of MRFF funding were for grants coded to:

- **Finding and diagnosing illness:** $2.3 million (11.3% of funding audit total).
- **Research on health and support services:** $1.1 million (5.5% of funding audit total).
- **Testing treatments in real life:** $880,000 (4.4% of funding audit total).

The MRFF did not fund research coded to a) basic research, b) causes of diseases, c) preventing illness and staying healthy, and d) consumer healthcare experiences.

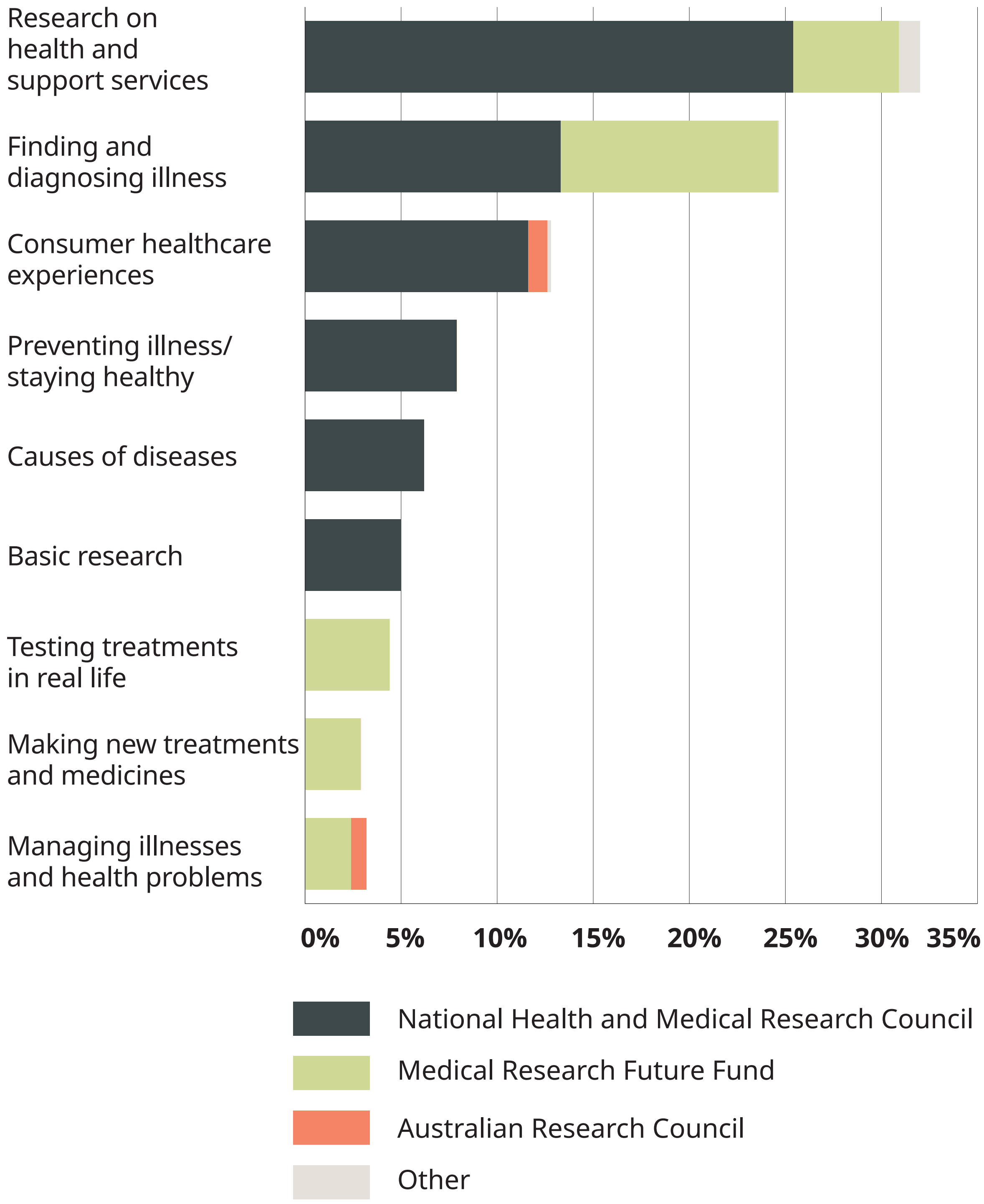


Figure 8 Percentage of total research funding (AUD) across research activity types by funder, 2019-2024

Research funding to health categories by research activity type

This section presents the interaction between HRCS health categories and research activity types for grants funded and started between 2019 and 2024. Grants coded to **general health** had the greatest variation of research activities within a health category with six of the nine research activities represented. Grants coded to **basic research** and **finding and diagnosing illness** had the greatest variation within a research activity with three health categories represented. **Table 3** lists the top 10 health category and research activity coding interactions by total funding. Notable interactions include:

- Grants coded to **general health** and **research on health and support services** represented the largest proportion of funding ($6.4 million, 31.8% of total) and number of grants (nine projects, 27.3% of total).
- Only two combinations had an average funding per grant above $1.0 million, and these were:
  - > Grants coded to **congenital disorders** and **finding and diagnosing illness**.
  - > Grants coded to **cancer and tumours** and **finding and diagnosing illness**.
- Research coded to **congenital disorders** and **finding and diagnosing illness** had the largest average funding per grant at $1.8 million.

Table 3 Health category and research activity coding interactions by total funding, 2019-2024

Rank	HRCS health – research activity codes	Funding (% of total)
1	General health – research on health and support services	$6.4M (31.8%)
2	Congenital disorders – finding and diagnosing illness	$3.6M (17.6%)
3	General health – consumer healthcare experiences	$2.6M (12.7%)
4	General health – preventing illness and staying healthy	$1.6M (7.9%)
5	Cancer and tumours – finding and diagnosing illness	$1.4M (7.1%)
6	Congenital disorders – causes of diseases	$1.2M (5.7%)
7	General health – basic research	$0.97M (4.8%)
8	Mental health – testing treatments in real life	$0.88M (4.4%)
9	Neurological – making new treatments and medicines	$0.60M (2.9%)
10	Congenital disorders – managing illnesses and health problems	$0.49M (2.4%)

Support for co-design and lived experience decision-making in grant guidelines

Of the 33 research grants identified above, 21 grant guidelines were available for further analysis which covered 25 (76.0%) of the awarded research grants. In this section, the data is presented in two three-year blocks to enable comparison over time. Grant guidelines retrieved were not evenly distributed between these periods with 38.1% from the first triennia (2018-2020) and 61.9% from the second triennia (2021-2023).

Figure 9 shows the percentage of grant guidelines that were coded as supporting each of the elements for lived experience involvement in research and decision making in 2018-2020 compared to 2021-2023. For funded intellectual disability health research, the results show growth in lived experience involvement in research and decision-making:

- Most grant guidelines either **required** or **encouraged lived experience involvement** in the research proposal (76.2% of all grant opportunities over time).
  - 19.0% of all grant opportunities **required** lived experience involvement and these were all within the 2021-2023 period.
- Just over half of all grant guidelines were coded positively for lived experience involvement listed explicitly within the **assessment criteria** (52.4% of all grant opportunities over time).
  - 38.1% of these opportunities were in the 2021-2023 period.
- 19.0% of all grant guidelines provided **explicit budget guidance** about including the costs of supporting the involvement of people with lived experience in research, and all of these were within the 2021-2023 period. 71.5% of all grant guidelines referenced **support for researchers** about lived experience involvement in research (i.e. additional training, guidelines).
- Only 4.8% of all grant guidelines had explicit references to **people with lived experience as investigators** in research, and all of these were within the 2021-2023 period.
- 28.6% of all grant guidelines explicitly named **people with lived experience as part of the decision-making process** for the grant opportunity, and these were all within the 2021-2023 period.

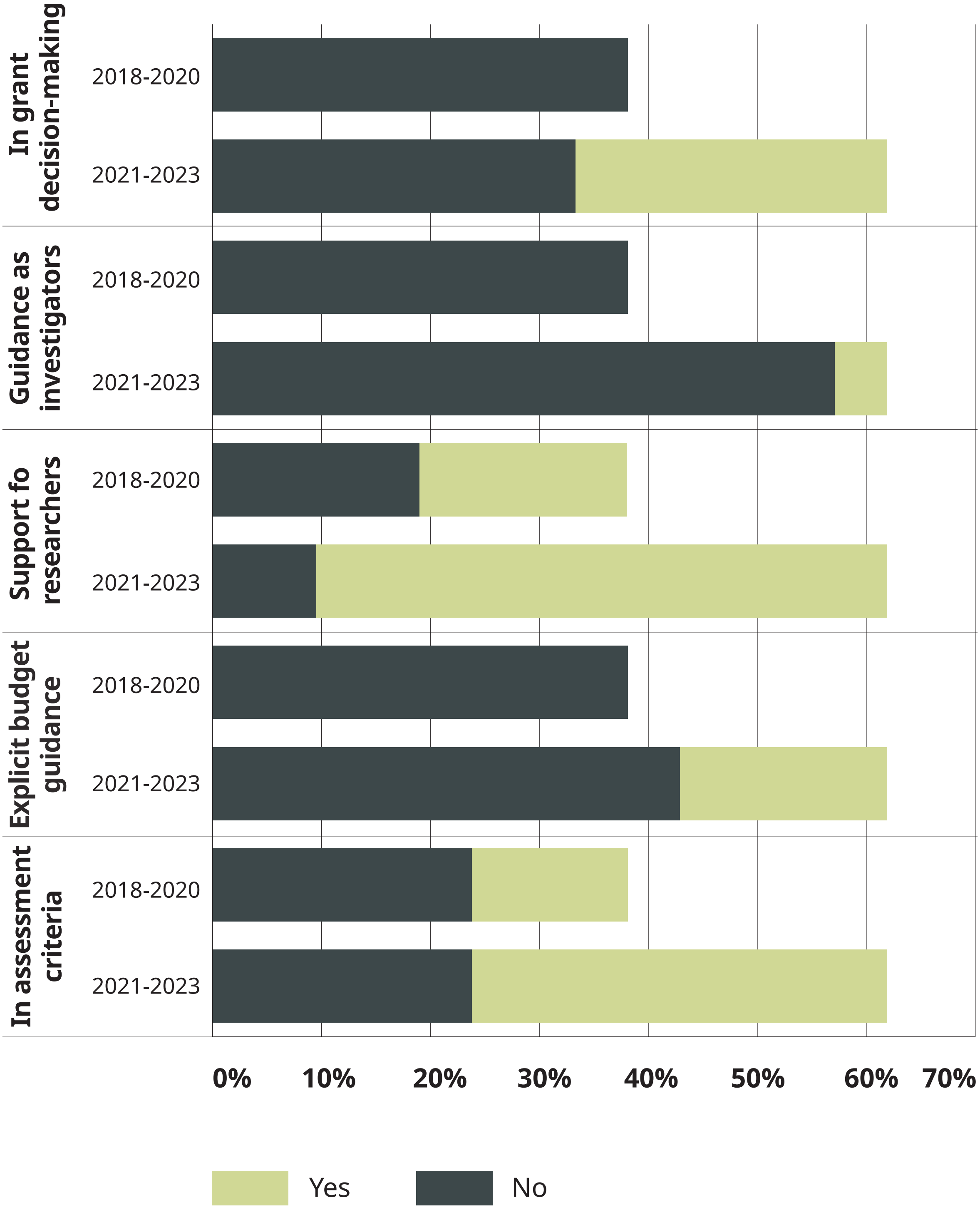


Figure 9 Proportion of funded intellectual disability health research grant guidelines supporting lived experience involvement, 2018-2020 and 2021-2023

Discussion

This audit is important because it offers a data driven view of how intellectual disability health research has been funded in Australia over a recent six-year period. By mapping research funding patterns, research activity types, and lived experience involvement, the audit supports efforts to align research investment with population health needs, policy priorities, and lived experience. The findings indicate that while some targeted investments have been made, overall research funding for intellectual disability health remains small relative to the magnitude of need.

What was funded, by whom, and in what areas?

This audit identified 33 intellectual disability health research grants funded between 2019 and 2024, accounting for a total investment of $20.3 million or an average of $3.4 million per year. Of this total, $14.1 million of funding was from NHMRC and $5.4 million from MRFF. The level of investment identified in this audit represents approximately 0.3% of NHMRC's total funding (26) and approximately 0.2% of MRFF's total funding (28), demonstrating significant underinvestment relative to population need and disease burden. The dominance of these two funders is appropriate given their role as Australia's major health and medical research funders and is consistent with other Australian research audits in disability (46), autism (44), and eating disorders (52). In the audit period, NHMRC awarded 4,525 new grants (60), thus the 15 grants identified here represent 0.3% of all new NHMRC grants. This audit identified six MRFF-funded grants which is inconsistent with the 2024 MRFF performance indicator report that found only one grant had people with intellectual disability as the priority population for their research (61). It is possible that other MRFF grants were reported against the broader priority population of *"people with a disability, including people with intellectual disability"*, making it difficult to readily track research related to people with intellectual disability.

This audit also showed that the single largest scheme was the 2021 NHMRC TCR for Improving Health of People with Intellectual Disability (26.6% of total funding). It is important to note that the 2024 MRFF TCR for Improving Health Outcomes for People with Intellectual Disability fell outside of the audit period and had up to $20 million of funding available. This level of investment is the equivalent of almost all (98.5%) of the total funding identified in this audit, which further illustrates the relative importance of TCRs as funders of intellectual disability health research. Notably, even if the 2024 MRFF TCR funding was within the timeframe of the current audit and the revised MRFF funding total in this audit was $25.4 million, this would still only represent approximately 0.7% of MRFFs total funding awarded (28). NHMRC frames TCRs as a one-time request for grant applications to address a specific health issue where there is a significant research knowledge gap or unmet need (62), so together the 2021 and 2024 TCRs suggest growing momentum in recognising and addressing intellectual disability health inequities, and present a valuable opportunity to strengthen the research landscape.

This audit revealed that research coded to general health represented the majority of funding ($11.9 million, 58.5%) and grants (n = 19, 57.6%). This represents research where the aim of the grant was not condition or health issue specific. In UK-wide research audits, funding coded to general health is consistently the highest proportion by health category but remains stable over time at approximately 25% of total funding (47). Research coded to congenital disorders was the next most common health category by funding ($5.2 million, 25.8%) and grants (n = 7, 21.2%) in this audit. This includes grants focused on specific syndromes such as Rett syndrome, Prader-Willi syndrome, and Angelman syndrome – all of which have a relatively high prevalence of intellectual disability.

In contrast, mental health and oral health – two areas with well-documented disparities for people with intellectual disability that are specifically discussed in the Roadmap (1) – were among the least funded health categories. Research coded to oral and digestive health represented approximately $75,000 in total funding (<1.0%) despite being specified in the Roadmap as a potential targeted research area (1). Fortunately, the 2024 MRFF TCR specified oral health research as one of the priority streams. Similarly, despite being a national health priority between 2015 and 2024, mental health had only $1.1 million (5.3%) invested in intellectual disability-specific mental health research. This represents less than 0.2% of the total NHMRC funding for mental health research and just over 1.3% of the $84 million of research funded through the MRFF Million Minds Mental Health Research Mission within the audit period (28). Notably, the NDRP Research Agenda, co-designed with people with disability, specifies mental health within four of the nine topics in the health and wellbeing research area (38), highlighting a broader recognition of the importance of mental health for people with disability, including those with intellectual disability.

For research activity type, the largest proportion of funding and grants were coded to research on health and support services (32.0% of total funding, 30.3% of total grants). This includes grants with core aims to develop new models of care, better understand why there are gaps in health care, and examine use of health care services. This focus may reflect recognition of the persistent barriers people with intellectual disability face in navigating mainstream health systems and the need for structural reform to promote equity and inclusion. In contrast, less than 10% of funding and grants were coded to preventing illness and staying healthy (7.9% of total funding, 6.1% of total grants). This is an important research activity with recent Australian evidence estimating over one-third of the total burden of disease in Australia could have been prevented (2). The pattern in this audit is consistent with a broader lack of government spending towards prevention and health promotion (63). Interestingly, UK health research audits show prevention research has grown from 2.5% to 7.1% of total funding over the last 20 years but at this level is still the 2nd lowest research activity type by proportion (47).

In summary, this audit shows that while there has been some targeted investment between 2019 and 2024, the overall level of research funding remains disproportionately low relative to population need and disease burden. The majority of funding was concentrated in general health and congenital disorders – both important areas for people with intellectual disability – but other critical health categories such as mental health and oral health were notably underfunded, despite strong evidence of inequity and strategic prioritisation. The dominance of NHMRC and MRFF as funders is consistent with other national audits, and the 2021 NHMRC TCR stands out as a key driver of investment.

To what extent was co-design supported in grant guidelines?

This audit found growing support for co-design and lived experience involvement in the grant guidelines associated with funded intellectual disability health research. Three codes that were only seen in the most recent triennia, 2019-2023, were a) lived experience involvement as a requirement of applications (19.0% of total), b) explicit budget guidance about supporting the involvement of people with lived experience in research (19.0% of total), and c) explicit information about people with lived experience as investigators (4.8% of total).

Further evidence of increasing lived experience involvement is provided by the 2024 MRFF performance indicator report, which showed that 82.7% of MRFF funded projects involved consumers in research (61). The most common types of involvement were a) consumer organisations as project partners or advisory groups (61.7% of projects), b) consumers in priority setting and co-design of study (59.1% of projects), and c) consumers in project governance (46.7% of projects) (61). However, consistent with the limited mentions of consumers as investigators noted in this audit, only 0.2% of MRFF projects included consumer investigators (61).

While the NHMRC does not currently publish comparable data on consumer involvement in funded research, a recent report for the review of the *Statement of Consumer and Community Involvement in Health and Medical Research* offers insight into sector expectations. Overall, 93% of responses agreed that the involvement of consumers should be an expectation of research (64). Importantly, 76% of responses agreed that funders should mandate the involvement of consumers in research they fund and the key reasons for a mandated approach included improved research quality and driving cultural change (64).

Together, these findings suggest a move toward embedding lived experience involvement in research funding frameworks, particularly throughout MRFF initiatives. However, there remains room for growth in integrating lived experience voices more broadly across the research ecosystem and increasing lived experience involvement is a pathway to ensuring that people with intellectual disability are actively and fairly included in research.

To what extent were people with lived experience included in decision-making of funded intellectual disability health research?

This audit found that 28.6% of the grant guidelines associated with funded intellectual disability health research explicitly listed consumers as part of the decision-making process for grants and these were all in the most recent triennium (2021-2023). This suggests a recent shift by funders towards greater lived experience involvement in decision-making.

Consistent with this observation, many funders note the benefits of including consumers in the peer review process. NHMRC notes the involvement of consumers in the peer review of grant applications includes benefits like enhanced relevance and impact, improved transparency and communication, reducing bias and encouraging innovation (65) while also noting that a good level of reading and technical expertise is required. NHMRC has consumer and community peer reviewers involved in formal scoring for TCRs and will expand this to the Clinical Trials and Cohort Studies grant scheme from 2025 (29). NHMRC also seeks feedback from consumer and community representatives to assess whether the process is inclusive of all consumer and community members (66).

Despite these developments, there remains a lack of publicly available data on the experiences and extent of lived experience involvement in decision-making processes. The NHMRC sector report showed that only 40% of responses supported research funders involving consumers and community members in their own processes (i.e. reviewing funding applications, setting priorities, identifying research topics, designing and developing programs) (64), suggesting there is significant room for growth in the inclusion of people with lived experience in the internal decision-making frameworks of funding bodies.

While lived experience involvement in decision-making is gaining traction across funding bodies, transparency and consistency in how people with lived experience are engaged - and how their contributions are valued – remain areas for improvement. For intellectual disability health research, strengthening lived experience involvement in decision-making is essential to ensure that people with intellectual disability are not only represented but actively shaping the research that affects their lives.

Limitations

This audit has several limitations that should be considered when interpreting its findings. First, the use of the Health Research Classification System (HRCS) to code health categories and research activities provided a structured and replicable framework, but it may not reflect community-led or co-designed research priorities in intellectual disability health. Future audits should categorise awarded grants using the co-designed national research priorities in intellectual disability health, currently being led by the National Centre of Excellence in Intellectual Disability Health.

Next, this audit only included grants where intellectual disability was the main focus. As a result, it may have excluded some research where people with intellectual disability were part of a broader group of priority populations within a grant (e.g. an MRFF grant relevant to multiple priority populations). This was done to align with the aims of the current audit, but future audits may benefit from developing a method to fairly represent such grants.

Third, this audit was unable to provide detailed insights about the subgroups within intellectual disability, such as people with intellectual disability who are ageing or from culturally and linguistically diverse backgrounds. This is because of the limited granularity available in publicly accessible grant abstracts. Other audits that have been able to present this level of detail have examined published outputs (46). Future audits should consider leveraging Dimensions to retrieve the linked outputs for individual grants.

Moreover, this audit provided limited information on the research teams delivering the work represented here. Data on location was limited to the lead research organisation. Future audits may wish to expand this to the location of research organisations within the research team or seek information from Chief Investigators about partner organisations on grants. This information would identify and acknowledge the important role of partners in research. Last, this audit was limited to Australian funders which may not provide a complete picture of funding to intellectual disability health research in Australia. Future audits should consider mapping international funders for comparison.

Recommendations

Intellectual disability health research is shaped by a complex ecosystem involving funders, researchers and institutions, policymakers, sector leaders, and people with lived experience. Funding decisions shape not only which topics are supported, but also the conditions under which research is developed, who is involved, and how findings are translated into practice. Thus, the actions within the recommendations below span multiple stages of the research lifecycle and multiple stakeholders. The following recommendations suggest initial actions directly supported by the audit findings, recognising that they form part of a broader, ongoing effort to transform intellectual disability health research.

1. Prioritise people with intellectual disability in health and medical research

The lack of recognition of intellectual disability health in research leads to fragmented investment, missed opportunities to build a coherent evidence base, and limited visibility in performance reporting and strategic planning. Recognising intellectual disability health as a distinct priority is essential to ensure it is strategically positioned, systematically tracked, and consistently funded across the research ecosystem.

Funders

- Include intellectual disability as a distinct category in funder reporting systems and strategic plans to enable tracking of investment and alignment with population needs.

Policymakers

- Strengthen accountability by encouraging funders to report on intellectual disability health research as a distinct category.

Researchers and Institutions

- Use precise language in grant applications and publications to distinguish intellectual disability from broader disability categories, ensuring visibility.
- Disseminate findings in accessible formats (e.g. Easy Read, plain language summaries) to ensure visibility of intellectual disability health research among policymakers, funders, and lived experience communities and to support its recognition as a strategic priority.

Sector Leaders

- Track alignment between research funding and community-identified needs.
- Publish insights to inform funders, researchers, and policymakers.

2. Reform the funding landscape to support equitable investment

This audit found low overall funding in intellectual disability health research that was unevenly distributed across health areas. Critical areas such as mental health, oral health, and preventative health were underfunded. Additionally, there was a high reliance on one-off Targeted Calls for Research, compared to recurring, established funding schemes. This fragmented and inconsistent investment limits the development of a coherent evidence base, undermines efforts to address health inequities, and fails to support long-term capacity building in intellectual disability health research.

Funders

- Prioritise underfunded health areas with high need in intellectual disability health research (e.g. mental health, oral health, preventive health).

Policymakers

- Ensure national strategies (e.g. Roadmap) include measurable targets for research investment in intellectual disability health.
- Hold system to account when targets are not being met.

Researchers and Institutions

- Develop proposals that address underfunded health areas and align with community-identified intellectual disability health research priorities.
- Build interdisciplinary teams to address complex health needs.

Sector Leaders

- Advocate for alignment between research funding and community needs.
- Track funding trends and gaps in intellectual disability health research.
- Translate audit findings into actionable insights for funders, policymakers, and researchers.

3. Improve transparency and accountability in inclusion

Within the context of awarded intellectual disability health grants, this audit showed that lived experience involvement is increasingly encouraged but remains inconsistently applied, poorly tracked, and rarely required. The lack of transparency and accountability may lead to tokenistic inclusion where lived experience involvement is superficial or symbolic, limited visibility of how lived experience shapes research outcomes, and missed opportunities to build trust, relevance, and impact. Improving transparency and accountability is essential to a) ensuring lived experience involvement is meaningful, not performative, b) supporting inclusive research ecosystems that reflect lived experience, and c) enabling evaluation and continuous improvement in intellectual disability health research.

Funders

- Include people with intellectual disability in peer review and decision-making processes.
- Seek feedback from people with intellectual disability involved in peer review and in funded research grants.
- Use this feedback to refine funding processes and support structures.
- Provide tailored resources (e.g. Easy Read toolkits) to support inclusive practices specific to intellectual disability.
- Structure funding opportunities to allow sufficient time and flexibility for inclusive practices.
- Publish reports on lived experience involvement metrics, including roles, formats, and outcomes.

Policymakers

- Encourage public reporting by funders on lived experience involvement in health and medical research, including metrics on inclusion, decision-making, and lived experience leadership – with attention to priority populations such as people with intellectual disability.

Researchers and Institutions

- Partner with people with intellectual disability from the earliest stages of research design.
- Use accessible formats and inclusive methods to support meaningful involvement.
- Describe lived experience involvement clearly in grant applications, ethics submissions, and final reports – including roles, contributions, and supports provided.

Sector Leaders

- Amplify lived experience in priority-setting, evaluation, and advocacy – ensuring people with intellectual disability are central to shaping the research agenda.

Conclusion and Future Directions

This audit provides a valuable overview of intellectual disability health research funding in Australia between 2019 and 2024. It highlights targeted investments and increasing support for lived experience involvement, while also identifying opportunities for improvement in how research funding aligns with population health needs.

People with intellectual disability experience significant health disparities across the lifespan, and research plays a vital role in addressing these inequities. The findings of this audit suggest that while intellectual disability health has received some dedicated funding, overall investment remains relatively low compared to the scale of need. Certain health areas were notably underrepresented, despite being well-documented priorities in both evidence and policy (i.e. mental health, oral health, prevention and staying healthy).

Encouragingly, the audit also found signs of growing support for lived experience involvement. Recent grant guidelines increasingly referenced lived experience involvement across a range of research elements, including participation in decision-making. These developments reflect a broader shift toward embedding lived experience in research processes and ensuring that research is responsive to the communities it serves.

As Australia continues to build its intellectual disability health research ecosystem, including through the development of co-designed national research priorities, there is an opportunity to strengthen alignment between funding, policy, and lived experience. Doing so will help ensure that future research is not only scientifically robust but also inclusive, relevant, and impactful for people with intellectual disability.

Beyond the scope of this audit, strengthening intellectual disability health research requires change across the broader research ecosystem. Advocacy can help ensure ethics committees and institutional review boards recognise intellectual disability health as an important area of focus, and that inclusive research practices are supported from the outset. Building a sustainable and impactful research workforce may involve targeted mentoring, upskilling, and salary support for emerging researchers, including those with lived experience and those working in underrepresented areas. This could also include tailored pathways for researchers with intellectual disability, such as accessible training, mentorship, and leadership opportunities. Researchers and institutions may benefit from practical guidance on inclusive research methods, including co-design, accessible communication, and ethical engagement. While these actions are not directly measurable within the audit, they are important considerations for creating a research environment that is equitable, strategic, and truly reflective of the needs and strengths of people with intellectual disability.

Appendix A – Search functions

Table 4 Search string for database search

(intellectual disabilit*) OR (developmental disabilit*) OR (“down syndrome”) OR (“fragile X syndrome”) OR (“cerebral palsy”) OR (“prader-willi syndrome”) OR (“Rett syndrome”) OR (“Angelman syndrome”) OR (“williams syndrome”) OR (rare genetic syndrome*) OR (neurodevelop* disorder*).

Table 5 Desktop search functions

Within organisation websites, search terms used: *“Intellectual disability”, “research”, “funding”, ‘grant”.*

Grant recipients | Cerebral Palsy Alliance

Research - Fragile X Association of Australia

Prader-Willi Research Foundation of Australia

Research - Angelman Syndrome Association Australia

Search terms within annual reports (years 2019-2024): *“intellectual disability”, “research”, “funding”, ‘grant”.*

Table 6 Funding sources explored in desktop search

Universities: Australian Catholic University, Avondale University, Bond University, Charles Darwin University, Charles Sturt University, CQ University, Curtin University, Deakin University, Edith Cowan University, Federation University, Flinders University, Griffith University, James Cook University, Latrobe University, Macquarie University, Monash University, Murdoch University, Queensland University of Technology, Royal Melbourne Institute of Technology, Swinburne University, The Australian National University, The University of Adelaide, The University of Canberra, The University of Melbourne, The University of Newcastle, The University of Queensland, The University of Sydney, The University of Western Australia, University of New South Wales, University of Technology Sydney.
Other non-government funding sources: Apex Foundation, auDA Foundation, Cerebral Palsy Alliance Research Foundation, Clem Jones Foundation, Collier Charitable Fund, Deafness Foundation of Australia, Dementia Research Foundation Australia, Ear Science Institute, Endeavour Foundation, Foundation for Children, (now renamed Pride Foundation Australia), Geelong Community Foundation, Jack Brockhoff Foundation, Lord Mayor's Charitable Foundation, Lorenzo and Pamela Galli Charitable Trust, Mater Foundation, Mind Australia, Minderoo Foundation, MJD Foundation, Multiple Sclerosis Research Australia, MND Research Institute, Movember Foundation, National Heart Foundation of Australia, National Stroke Foundation, Perth Children's Hospital Foundation, Pierce Armstrong Foundation, Pratt Foundation, Repat Foundation, Roger Montgomery Family Trust, Royal Children's Hospital Foundation, RSL Queensland, Select Foundation, Sidney Myer Fund, Simons Foundation, Sydney Medical Foundation, The University of Melbourne Humanities Foundation Board, Victorian Health Promotion Foundation, WA Foundation for Deaf Children, Western Australian Nurses Memorial Charitable Trust

Appendix B – Adapted health categories and research activities

Table 7 Plain language definitions of health categories and research activity types

Health categories	
Blood	This is about problems with the blood, like diseases that affect how blood cells work, not having enough red blood cells (called anemia), or issues with blood clotting (like when blood clots in the wrong places). It also looks at how blood cells and platelets normally develop and work in the body.
Cancer and tumours	This is about all kinds of growths in the body, including non-cancerous ones (benign), ones that could become cancer (possibly malignant), and cancer itself (malignant).
Congenital disorders	This is about conditions people are born with that cause physical differences or health problems, like Down’s syndrome or cystic fibrosis.
Heart and blood vessel health	This is about problems with the heart and blood vessels, like when the heart doesn’t work right. It also looks at how blood moves through the body, including the special system that helps fight sickness. It shows how the heart and blood vessels should normally work.

Health categories	
Ear health	This is about hearing problems, like deafness, and how the ears normally grow and work. It looks at how our ears help us hear and what happens when they don't work correctly.
Eye health	This is about problems with the eyes, like vision problems or eye diseases. It also looks at how the eyes normally grow and work so we can see.
Infection	Is the research about infections, like diseases caused by germs, viruses, or other harmful things? Like cold & flu, malaria.
Inflammation and immune system	This is about when the body gets too angry and hurts itself, like in arthritis or allergies. It also looks at how the body's defence system (the immune system) grows and works to keep us healthy.
Injuries and accidents	This includes broken bones, poisoning, and burns as well as other injuries.
Mental health	This is about things like: • feeling very sad (depression) • worry or fear (anxiety) • problems with eating • struggles with learning • difficulties regulating behaviour
Metabolic and endocrine	This is about conditions that affect how the body uses food for energy and how the body's hormones and glands work.
Musculoskeletal	This is about conditions that affect bones and muscles. It also includes how bones and muscles normally grow and work.

Health categories	
Neurological	This is about conditions that affect the brain and nerves like: • memory loss (dementia) • shaking or stiff muscles (Parkinson’s disease) • brain problems (epilepsy) It also includes learning about how the brain and nerves usually work.
Oral and digestive health	This is about problems with the mouth, teeth, and stomach. It also includes how the mouth and digestive system normally grow and work.
Kidney and urinary health	This is about problems with the kidneys, bladder, and private parts. It also includes how the kidneys and urinary system normally grow and work in boys and girls.
Reproductive health and childbirth	This is about topics like: • having babies • getting pregnant • birth control It also includes things like pregnancy, periods, and taking care of mums and babies before and after birth.
Respiratory health	This is about conditions that affect breathing like asthma and chest infections. It also includes how the lungs and breathing system grow and work.
Skin	This is about conditions that affect the skin like rashes or infections. It also includes how skin normally grows and works.
Stroke	Stroke is when the brain can’t get the right amount of blood because of a clot or bleeding episode and that makes it stop working the way it should.

Health categories	
General health and wellbeing	This will be used for research that looks at all kinds of health problems or how to stay healthy overall. It covers research that isn't focused on one specific illness or condition.
Unclear causes and other conditions	This is about problems that doctors don't fully understand yet, like chronic fatigue syndrome. It is also about research that doesn't fit into general health categories or conditions with clear causes.

Research activity categories		
Basic research	This is the research that helps us understand: • the reasons why people get sick • how diseases grow • how to find if the disease is there • how to treat or manage them It's like building a foundation to understand health problems better.	Is the research about how healthy bodies work and not about diseases or treatments?
Causes of diseases	This is about figuring out: • what causes people to get sick • what makes them more likely to get a disease • how diseases start or grow It's like finding out what things make us more at risk for getting sick.	Is the research about finding out what causes diseases and health problems?

Research activity categories		
Preventing illness and staying healthy	This research focuses on ways to stop diseases or health problems before they start and helping people stay healthy and feel good. It's about learning how to keep ourselves from getting sick and how to stay happy and well.	Is the research about stopping diseases before they start and helping people stay healthy?
Finding and diagnosing illness	This research is about: • finding ways to detect diseases early • figure out what is causing diseases • working out how diseases will progress It includes creating tools and tests to help doctors understand what's wrong and how to treat it.	Is the research trying to make new tests to help doctors find or predict diseases?
Making new treatments and medicines	This research is about finding and making new treatments or medicines to help people feel better. Researchers may test these treatments in labs or in animals before they are used by real patients	Is the research about making new treatments or medicines?

Research activity categories		
Testing treatments in real life	This research is about testing treatments or medicines on real people and in real places to see how well they work in hospitals, communities, or other places. It helps make sure the treatments are safe and work for everyone.	Is the research about testing new treatments or medicines with patients in real-life settings?
Managing illnesses and health problems	This research is about working out the best ways to take care of people who are sick or have health problems. It looks at what each person needs to feel better and how to manage their condition in the best way.	Is the research about how to take care of people with diseases or health problems?
Research on health and support services	This research looks at how doctors, nurses, and other helpers provide care to people who are sick or need support. It also studies how to make healthcare services better and how to measure if they work well.	Is the research about how health and social care are given to people and how they work?
Consumer healthcare experiences	This research focuses on the experiences of people with an intellectual disability and their families with the health system. Including barriers to accessing appropriate care (e.g. communication, attitudinal issues, etc.)	Is the research about how people with intellectual disabilities and their families experience healthcare?

Appendix C - Eligibility and Coding Worksheet Template

Worksheet for Research Funding Audit Project

This worksheet has two parts:

- Information to read about the research projects
- Space to write about what groups the project belongs in

The research project

This is the information we have found about the research project:

Name of the research project	
Name of organisation doing the research	
Name of funder	
Year the research started	
Summary about the research project	

Putting the project into groups

These are the groups we think the research project belongs to:

Is the research project mainly about health?	**YES**	☐
	NO	☐
Is the research project mainly about people with intellectual disability?	**YES**	☐
	NO	☐

If you have said yes to the two questions above then this research **project is included** in our project.

If you have **said no** to any of the questions above then the research project is not included in our project and you can **stop here**.

What health problem is the research about?

Where is the research being done?

What type of research is being done?

Who does the research focus on?

Who is included in the research?

Appendix D - Codes and definitions for lived experience involvement

Table 8 Lived experience involvement in research code definitions and examples

Code	Definition	Example
Lived experience involvement guidance	Whether the guidelines explicitly stated that consumer involvement was mandatory or encouraged.	"Research must be done by and with people with disability"
Lived experience involvement assessment criteria	Whether consumer involvement in the proposed research was a part of scoring grant applications.	"Selection criteria…… genuine involvement of people with disability and/or families in all aspects of the project."
Explicit budget guidance on lived experience involvement	Whether the guideline provided direction on allocating funds to support consumer participation.	"Payment for….co-researchers (people with disability engaged in the research as researcher) and their supports."
Explicit guidance on people with lived experience as investigators	Whether the guideline explicitly acknowledged consumers as eligible or appropriate members of the research team.	

Code	Definition	Example
Support for researchers on lived experience involvement	Whether the guidelines included additional information to support researchers (e.g. reference to guideline or toolkit, webinars or training).	“Guidance on consumer consultation is outlined in the…”
People with lived experience named as part of grant decision making	Whether consumers were named in the review or selection process for successful grants.	“Expert assessors, including consumer representatives, will score your application…”

Appendix E - Data tables

Table 9 Total research funding (AUD) by state of lead research organisation, 2019-2024

Start year	State of research organisation					
	NSW	VIC	WA	QLD	SA	Total (%)
2019		**$703K** (3.5%)	**$75K** (<1.0%)			**$778K** (3.8%)
		5 (15.2%)	**1** (3.0%)			**6** (18.2%)
2020	**$512K** (2.5%)	**$883K** (4.4%)		**$100K** (<1.0%)		**$1.5M** (7.4%)
	2 (6.1%)	**1** (3.0%)		**1** (3.0%)		**4** (12.1%)
2021	**$3.1M** (15.1%)	**$1.1M** (5.6%)			**$155K** (0.8%)	**$4.3M** (21.4%)
	3 (9.1%)	**3** (9.1%)			**1** (3.0%)	**7** (21.2%)
2022	**$4.3M** (21.2%)	**$792K** (3.9%)				**$5.1M** (25.1%)
	4 (12.1%)	**1** (3.0%)				**5** (15.2%)

Start year	State of research organisation					
	NSW	VIC	WA	QLD	SA	Total (%)
2023	**$2.9M** (14.3%)	**$231K** (1.1%)	**$1.5M** (7.6%)	**$1.5M** (7.4%)		**$6.2M** (30.4%)
	2 (6.1%)	**3** (9.1%)	**1** (3.0%)	**1** (3.0%)		**7** (21.2%)
2024	**$1.1M** (5.6%)	**$1.3M** (6.3%)				**$2.4M** (11.9%)
	3 (9.1%)	**1** (3.0%)				**4** (12.1%)
Grand total	**$11.9M** (58.7%)	**$5.0M** (24.7%)	**$1.6M** (8.0%)	**$1.6M** (7.9%)	**$155K** (0.8%)	**$20.3M** (100%)
	14 (42.4%)	**14** (42.4%)	**2** (6.1%)	**2** (6.1%)	**1** (3.0%)	**33** (100%)

Denotes number of grants

Table 10 Total research funding (AUD) by funder, 2019-2024

Start year	Funder				
	NHMRC	MRFF	ARC	Other	Total (%)
2019	**$564K** (2.8%)			**$214K** (1.1%)	**$778K** (3.8%)
	1 (3.0%)			**5** (15.2%)	**6** (18.2%)
2020		**$1.4M** (6.8%)		**$125K** (<1%)	**$1.5M** (7.4%)
		2 (5.9%)		**2** (6.1%)	**4** (12.1%)
2021	**$3.9M** (19.1%)	**$109K** (<1%)	**$362K** (1.8%)		**$4.3M** (21.4%)
	4 (12.1%)	**1** (2.9%)	**2** (5.9%)		**7** (21.2%)
2022	**$5M** (24.8%)			**$67K** (<1%)	**$5.1M** (25.1%)
	4 (12.1%)			**1** (3.0%)	**5** (15.2%)
2023	**$3.2M** (16.0%)	**$2.9M** (14.3%)		**$25K** (<1%)	**$6.2M** (30.4%)
	4 (12.1%)	**2** (5.9%)		**1** (3.0%)	**7** (21.2%)

Start year	Funder				
	NHMRC	MRFF	ARC	Other	Total (%)
2024	**$1.4M** (6.8%)	**$997K** (4.9%)		**$25K** (<1%)	**$2.4M** (11.9%)
	2 (6.1%)	**1** (2.9%)		**1** (3.0%)	**4** (12.1%)
Grand total	**$14.1M** (69.5%)	**$5.4M** (26.5%)	**$362K** (1.8%)	**$456K** (2.2%)	**$20.3M** (100%)
	15 (45.5%)	**6** (18.2%)	**2** (6.1%)	**10** (30.3%)	**33** (100%)

	Denotes number of grants

Table 11 Total research funding (AUD) by health category, 2019-2024

Health category	Year						
	2019	2020	2021	2022	2023	2024	Total (%)
General health	**$0.1M** (0.7%)	**$25K** (<1.0%)	**$3.8M** (18.6%)	**$3.7M** (18.1%)	**$3.2M** (15.5%)	**$1.1M** (5.6%)	**$11.9M** (58.5%)
	3 (9.1%)	**1** (3.0%)	**5** (15.2%)	**4** (12.1%)	**3** (9.1%)	**3** (9.1%)	19 (57.6%)
Congenital disorders	**$589K** (2.9%)	**$487K** (2.4%)	**$585K** (2.9%)		**$2.3M** (11.3%)	**$1.3M** (6.3%)	$5.2M (25.8%)
	2 (6.1%)	**1** (3.0%)	**2** (6.1%)		**1** (3.0%)	**1** (3.0%)	7 (21.2%)
Cancer and tumours				**$1.4M** (7.1%)			$1.4M (7.1%)
				1 (3.0%)			1 (3.0%)
Mental health		**$984K** (4.8%)			**$94K** (<1.0%)		$1.1M (5.3%)
		2 (6.1%)			**1** (3.0%)		3 (9.1%)

Health category	Year						
	2019	2020	2021	2022	2023	2024	Total (%)
Neurological					**$596K** (2.9%)		$600K (2.9%)
					1 (3.0%)		1 (3.0%)
Oral & digestive health	**$50K** (<1.0%)				**$25K** (<1.0%)		$75K (<1.0%)
	1 (3.0%)				**1** (3.0%)		2 (6.1%)
Grand total	**$778K** (3.8%)	**$1.5M** (7.4%)	**$4.3M** (21.4%)	**$5.1M** (25.1%)	**$6.2M** (30.4%)	**$2.4M** (11.9%)	**$20.3M** (100%)
	6 (18.2%)	**4** (12.1%)	**7** (21.2%)	**5** (15.2%)	**7** (21.2%)	**4** (12.1%)	**33** (100%)

Denotes number of grants

Table 12 Total research funding (AUD) by health category and funder

Health category	Funder				
	NHMRC	MRFF	ARC	Other	Total (%)
General health	$10.2M (50%)	$1.1M (5.5%)	$360K (1.8%)	$260M (1.3%)	**$11.9M (58.5%)**
	9 (27.3%)	2 (6.1%)	2 (6.1%)	6 (18.2%)	**19** (57.6%)
Congenital disorders	$2.4M (11.9%)	$2.8M (13.7%)		$30K (<1%)	**$5.2M** (25.8%)
	4 (12.1%)	2 (6.1%)		1 (3.0%)	**7** (21.2%)
Cancer and tumours	$1.4M (7.1%)				**$1.4M** (7.1%)
	1 (3.0%)				**1** (3.0%)
Mental health	$90K (<1%)	$880K (4.4%)		$100K (<1%)	**$1.1M** (5.3%)
	1 (3.0%)	1 (3.0%)		1 (3.0%)	**3** (9.1%)
Neurological		$600K (2.9%)			**$600K** (2.9%)
		1 (3.0%)			**1** (3.0%)

Health category	Funder				
	NHMRC	MRFF	ARC	Other	Total (%)
Oral & digestive health				**$80K** (<1%)	**$80K** (<1.0%)
				2 (6.1%)	**2** (6.1%)
Grand total	**$14.1M** (69.5%)	**$5.4M** (26.5%)	**$360K** (1.8%)	**$460K** (2.2%)	**$20.3M** (100%)
	15 (45.5%)	**6** (18.2%)	**2** (6.1%)	**10** (30.3%)	**33** (100%)

▨	Denotes number of grants

Table 13 Total research funding (AUD) by type of research activity, 2019-2024

Research activity	Year						
	2019	2020	2021	2022	2023	2024	Total (%)
Research on health and support services	$140K (<1%)	$30K (<1%)	$2.5M (12.2%)	$1.3M (6.5%)	$1.5M (7.6%)	$1M (4.9%)	**$6.5M** (32.0%)
	3 (9.1%)	1 (3%)	2 (6.1%)	2 (6.1%)	1 (3%)	1 (3%)	**10** (30.3%)
Finding and diagnosing illness		$100K (<1%)		$1.4M (7.1%)	$2.3M (11.3%)	$1.3M (6.3%)	**$5.1M** (25.1%)
		1 (3%)		1 (3%)	1 (3%)	1 (3%)	**4** 12.1%)
Consumer healthcare experiences			$210K (1%)	$2.4M (11.6%)	$30K (<1%)	$30K (<1%)	**$2.6M** (12.8%)
			1 (3%)	2 (6.1%)	1 (3%)	1 3%)	**5** (15.2%)
Preventing illness/ staying healthy					$1.5M (7.4%)	$100K (<1%)	**$1.6M** (7.9%)
					1 (3%)	1 (3%)	**2** (6.1%)
Causes of diseases	$560K (2.8%)		$580K (2.9%)		$110K (<1%)		**$1.3M** (6.2%)
	1 (3%)		2 (6.1%)		1 (3%)		**4** (12.1%)

Research activity	Year						Total (%)
	2019	2020	2021	2022	2023	2024	
Basic research	$100K (<1%)		$900K (4.5%)		$100K (<1%)		**$1.1M** (5.4%)
	2 (6.1%)		1 (3%)		1 (3%)		**4** (12.1%)
Testing treatments in real life		$880K (4.4%)					**$880K** (4.4%)
		1 (3%)					**1** (3.0%)
Managing illness and health problems		$490K (2.4%)	$160K (<1%)				**$650K** (3.2%)
		1 (3%)	1 (3%)				**2** (6.1%)
Making new treatments and medicines					$600K (2.9%)		**$600K** (2.9%)
					1 (3%)		**1** (3.0%)
Grand total	$780K (3.8%)	$1.5M (7.4%)	$4.4M (21.4%)	$5.1M (25.1%)	$6.2M (30.4%)	$2.4M (11.9%)	**$20.3M**
	6 (18.2%)	4 (12.1%)	7 (21.2%)	5 (15.2%)	7 (21.2%)	4 (12.1%)	**3** (100%)

Denotes number of grants

Table 14 Total research funding (AUD) by type of research activity and funder

Research activity	**Funder**				
	NHMRC	**MRFF**	**ARC**	**Other**	**Total (%)**
Research on health and support services	$5.2M (25.4%)	$1.1M (5.5%)		$230K (1.1%)	**$6.5M** (32.0%)
	3 (9.1%)	2 (6.1%)		5 (15.2%)	**10** (30.3%)
Finding and diagnosing illness	$2.7M (13.3%)	$2.3M (11.3%)		$10K (<1%)	**$5.1M** (25.1%)
	2 (6.1%)	1 (3%)		1 (3%)	**4** (12.1%)
Consumer healthcare experiences	$2.4M (11.6%)		$210K (1.8%)	$50K (<1%)	**$2.6M** (12.8%)
	2 (6.1%)		1 (3%)	2 (6.1%)	**5** (15.2%)
Preventing illness & staying healthy	$1.6M (7.9%)				**$1.6M** (7.9%)
	2 (6.1%)				**2** (6.1%)
Causes of diseases	$1.3M (6.2%)				**$1.3M** (6.2%)
	4 (12.1%)				**4** (12.1%)

Research activity	Funder				
	NHMRC	MRFF	ARC	Other	Total (%)
Basic research	$1M (5%)			$70K (<1%)	**$1.1M** (5.4%)
	2 (6.1%)			**2** (6.1%)	**4** (12.1%)
Testing treatments in real life		$880K (4.4%)			**$880K** (4.4%)
		1 (3%)			**1** (3%)
Managing illness and health problems		$490K (2.4%)	$160K (<1%)		**$640K** (3.2%)
		1 (3%)	**1** (3%)		**2** (6.1%)
Making new treatments and medicines		$600K (2.9%)			**$600K** (2.9%)
		1 (3%)			**1** (3%)
Grand total	$14.1M (69.5%)	$5.4M (26.5%)	$360K (1.8%)	$460K (2.2%)	**$20.3M** (100%)
	15 (45.5%)	**6** (18.2%)	**2** (6.1%)	**10** (30.3%)	**33** (100%)

Denotes number of grants

Table 15 Total research funding (AUD) by health category and type of research activity

Research activity	Health problem						
	Oral and digestive health	Mental health	Cancer and tumors	Congenital disorders	General health	Neurological	Grand total
Research on health and support services	$50K (<1%)				$6.4M (31.8%)		**$6.5M** (32%)
	1 (3%)				9 (27.3%)		**10** (30.3%)
Finding and diagnosing illness		$100K (<1%)	$1.4M (7.1%)	$3.6M (17.6%)			**$5.1M** (25.1%)
		1 (2.9%)	1 (2.9%)	2 (5.9%)			**4** (12.1%)
Consumer healthcare experiences	$30K (<1%)				$2.6M (12.7%)		**$2.6M** (12.8%)
	1 (3%)				4 (12.1%)		**5** (15.2%)

Research activity	Health problem						
	Oral and digestive health	Mental health	Cancer and tumors	Congenital disorders	General health	Neurological	Grand total
Preventing illness/ staying healthy					$1.6M (7.9%)		**$1.6** (7.9%)
					2 (6.1%)		**2** (6.1%)
Causes of diseases				$1.2M (5.7%)	$110K (<1%)		**$1.3M** (6.2%)
				3 (9.1%)	1 (3%)		**4** (12.1%)
Basic research		$90K (<1%)		$30K (<1%)	$970K (4.8%)		**$1.1M** (5.4%)
		1 (3%)		1 (3%)	2 (6.1%)		**4** (12.1%)

Research activity	Health problem						
	Oral and digestive health	Mental health	Cancer and tumors	Congenital disorders	General health	Neurological	Grand total
Testing treatments in real life		$880K (4.4%)					**$880K** (4.4%)
		1 (3%)					**1** (3%)
Managing illnesses and health problems				$490K (2.4%)	$160K (<1%)		**$640K** (3.2%)
				1 (3%)	1 (3%)		**2** (6.1%)
Making new treatments and medicines						$600K (2.9%)	**$600K** (2.9%)
						1 (3%)	**1** (3%)

Research activity	Health problem						
	Oral and digestive health	Mental health	Cancer and tumors	Congenital disorders	General health	Neurological	Grand total
Grand total	**$80K** (<1%)	**$1.1M** (5.3%)	**$1.4M** (7.1%)	**$5.2M** (25.8%)	**$11.9M** (58.5%)	**$600K** (<1%)	**$20.3M** (100%)
	2 (5.9%)	**3** (9.1%)	**1** (3%)	**7** (21.2%)	**19** (57.6%)	**1** (3%)	**33**

▨ Denotes number of grants

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