A portfolio analysis of autism research funding in Australia, 2008–2017

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Abstract

Autism research funding across the world has disproportionately been invested in biological and genetic research, despite evidence that these topics are not prioritized by community members. We sought to determine whether a similar pattern was evident in Australia's autism research funding landscape between 2008 and 2017, by analysing the nation's portfolio of autism research investments. We also examined whether there was any change in this pattern of funding since the establishment in 2013 of the Cooperative Research Centre for Living with Autism (Autism CRC). Overall, Australian autism research funding during 2008–2017 followed a similar pattern to other countries, but shifted in the past five years. Further progress is required to bring research funding into line with community priorities.

A portfolio analysis of autism research funding in Australia, 2008–2017

In recent years, global investment in autism research has steadily increased (Krahn & Fenton, 2012; Office of Autism Research Coordination, 2019; Pellicano, Dinsmore, & Charman, 2014). This growth in research funding has prompted a number of investigations into the allocation of research funding across topic areas. In an early evaluation of autism research funding, Singh, Illes, Lazzeroni, and Hallmayer (2009) found that 65% of autism research grants awarded in the United States (US) between 1997 and 2006 went to basic science research, with 20% of grants funding translational research and just 15% invested in clinical research. Basic science was also a focus of autism research in Canada, where 44% of autism research funding awarded between 2000 and 2010 was invested in biomedical research (Krahn & Fenton, 2012). These early studies, however, were hindered by a lack of standardized criteria for determining autism research topic areas.

In 2008, the Interagency Autism Coordinating Committee (IACC) initiated a series of annual portfolio analyses, to track the distribution of autism research funding in the US (Office of Autism Research Coordination, n.d., 2011, 2012, 2016, 2017a, 2017b, 2019). These analyses have been guided by a series of research questions that correspond to key topics in autism research, proposed by the IACC in their Strategic Plan (IACC, 2009). In 2013, Pellicano, Dinsmore, and Charman undertook an analysis of autism research funding (for the period 2007–2011) in the United Kingdom (UK), guided by the IACC Strategic Plan research questions. This study was followed more recently by a comparison of autism research funding in 2016 across the US, UK, and Canada (Daniels & Warner, 2018). Consistent across all of these analyses is the finding that autism research funding is skewed towards biological and genetic research, with biological research funding accounting for between 18 and 64% of reported autism funding, and research into genetic 'risk' factors accounting for, on average, 20% of funding. In comparison, research into services for autistic

people and their families received, on average, only 6% of reported research funding, and lifespan issues received just 3% across analyses.

In a subsequent paper, Pellicano et al. (2014) showed that the distribution of autism research funding in the UK did not align with community priorities for research. In a large-scale consultation (n = 1,517), members of the autism community—including autistic people, their family members, professionals, and researchers—consistently highlighted services and life skills for autistic people as the highest priorities for autism research. Other priorities included community acceptance, co-occurring conditions, treatment and interventions, lifespan issues, gender differences, and thinking and learning. Notably, research into biological factors relevant to autism—while valued by community members, because they felt that not enough was known about autism—was not considered a priority at present, despite receiving the bulk of funding (56% in the UK during 2007–2011).

More recent consultations with community members have identified similar priorities. In the UK, a consultation conducted by autism research charity, Autistica (2016), produced a list of UK community priorities that focused heavily on supports and interventions for autistic people across the lifespan, including interventions for mental health, interventions for the development of communication and language, and support for autistic adults within the top three priorities. In the US, Frazier et al. (2018) similarly found, in a large sample (n = 6,004) consisting mostly of family members, that community priorities centred around health and well-being, adult transition, lifespan issues, and co-occurring conditions. Comparatively little is known about research priorities in the Australian autism community. The exception to this are the findings from a small-scale study (n = 158), which indicated that the Australian autism community may also prioritise research into support and intervention for autistic people, with therapies and interventions, "understanding autism", and education identified as the top three research priorities (Gatfield, Mangan, Harr, Kinniburgh, & Rodger, 2016).

Thus far, the findings suggest a disconnect between the research that community members would like to see done, and the research that actually gets done. To address this discrepancy, Pellicano et al. (2013) suggested three potential courses of action. First, a top-down approach led by research funders, with greater funding allocated to research areas that are currently under-funded, to support capacity building in these fields. Second, strategic oversight of autism research funding, to monitor and coordinate research funding at a national level. And third, a bottom-up approach, involving greater engagement with the autistic and broader autism communities at all stages of the research process.

In Australia, the bulk of autism research has historically been funded by two federal government entities: the National Health and Medical Research Council (NHMRC), which primarily funds health and medical research; and the Australian Research Council (ARC), which provides funding for research across science, the social sciences and the humanities. In 2013, the Cooperative Research Centre for Living with Autism (Autism CRC) was established, under the Australian Government's Cooperative Research Centres (CRC) Program, as the world's first national cooperative research centre focused on autism. The CRC Program is an initiative designed to support collaborations between industry, researchers, and the community, to address a specified industry challenge. Each CRC is funded for a period of up to ten years, and comprises a team of industry entities working in partnership with relevant research organisations (Australian Government, 2019). Autism CRC has more than 50 participant organisations, including universities, autism service providers, autistic and other advocacy organisations, industry entities, and government departments.

Autism CRC takes a whole-of-life approach to autism research, investing in projects across three research programs, "Early Years", "School Years", and "Adulthood", and a progressive, participatory approach to autism research, placing the autistic community at the

centre of its research efforts. Autism CRC's stated mission is "to motivate, facilitate, and translate collaborative autism research across the life span, underpinned by inclusive practices" (Autism CRC, 2018). With this mission statement guiding its investment choices, Autism CRC has the potential to shift the distribution of autism research funding in Australia, in line with Pellicano et al.'s (2013) recommendations, to create a funding landscape that is more consistent with the priorities of the autistic and autism communities.

In this study, we aimed to conduct the first comprehensive analysis of Australian expenditure on autism research over a 10-year period (2008–2017). In doing so, we examined whether:

1) The pattern of autism research funding in Australia was similar to patterns of research funding identified in the US, UK, and Canada using the IACC Strategic Plan questions, and;

2) The establishment of Autism CRC was associated with a shift in Australian research funding, towards a pattern of funding that is more in line with community priorities.

To address this latter question, we directly compared the pattern of funding for the five years prior to the launch of Autism CRC (2008–2012) with the pattern of funding during Autism CRC's first five years of operation (2013–2017).

Method

Funding search

An initial search for autism-relevant research grants was undertaken using the Dimensions Plus database (https://app.dimensions.ai/), with search terms "autism" OR "ASD" OR "Autism Spectrum Disorder" OR "Asperger Syndrome" OR "Autistic" OR "Autistic Behaviour" OR "AUTS1" OR "AUTS2". This database and string of search terms were

selected to replicate the methods employed by Daniels and Warner (2018) in a similar portfolio analysis of autism research funding in the UK. The Dimensions Plus database is a data platform with listings comprising 140 million research grants, publications, clinical trials, patents, and policy documents. The search was limited to research grants active between 2008 and 2017, with a listed location of Australia. Searching the Dimensions Plus database returned a total of 133 research grants, the majority of which were funded by either the NHMRC or ARC. As data regarding Autism CRC investment in autism research were not available in the Dimensions Plus database, this information was gained from publicly available annual reports published on the Autism CRC website (Autism CRC, 2014, 2015, 2016, 2017, 2018) and a direct request to the organisation for further details of their investment portfolio. This yielded a total of 61 research investments from Autism CRC. Additional searches of publicly available databases listing research grants awarded by NHMRC and ARC identified an additional seven grants not listed in the Dimensions Plus database. Finally, the websites of other relevant Australian government entities and major Australian philanthropic organisations were also reviewed, yielding a further 11 research grants that met the search criteria. Where necessary, these organisations were contacted directly to request additional information regarding identified grants. Together, these searches identified a total of 212 unique research grants.

Inclusion/exclusion of grants

Grants were initially excluded from analyses if (1) funding was awarded by a source external to Australia (n = 22), or (2) insufficient information was available regarding the grant or associated research project to determine eligibility for inclusion (n = 9). Next, the authors reviewed the remaining 181 grants to determine whether the primary focus of the funded research was autism specifically. The process for determining relevance was as follows: The first author reviewed the title and abstract of all 181 remaining grants. When a grant was not

obviously relevant to the current analysis, the grant was flagged for further review (n = 52). These grants were then blind-coded for relevance by both authors, with 83% agreement. Where authors disagreed on relevance, consensus was reached through discussion. As a result of this process, 45 additional grants were deemed to not have autism as a primary research focus, and were excluded from analyses. This resulted in a final sample of 136 autism-relevant research grants active in Australia between 2008 and 2017 (see Figure 1).

[insert Figure 1 about here]

Coding and analyses

To enable comparisons with existing funding portfolio analyses, grants in this analysis were coded for research topic using the IACC Strategic Plan questions and corresponding research areas (Office of Autism Research Coordination, 2019; see Table 1). The Strategic Plan was originally developed by the IACC, in consultation with members of the public, academic and advocacy communities, and government and non-government organisations, in 2009. The plan was intended to identify the current state of autism research, highlight gaps in knowledge, and facilitate future research (IACC, 2009).

Each grant included in this analysis was coded for research topic initially by the first author, and then blind-coded by the second author. The two authors reached 92% agreement on coding of Strategic Plan questions, and 83% agreement on coding of specific IACC research areas. Where the authors disagreed on coding, consensus was reached through discussion and these consensus codes are reported below. One grant awarded in the 2013–2017 period was coded as not aligning with any of the IACC Strategic Plan questions or research areas.

[insert Table 1 about here]

Descriptive analyses were conducted to identify the relative proportions of autism research funding allocated to each IACC Strategic Plan question in Australia. Analyses were performed separately on grants active between 2008 and 2012, and those active between 2013 and 2017. Consistent with the methods employed in previous portfolio analyses (e.g., Office of Autism Research Coordination, 2019), we included those grants that were active during or before 2012 and remained active during or after 2013 (n = 17) in both the 2008–2012 and the 2013–2017 analyses. The current analyses were based on cash investments only; in-kind contributions to autism research were not included.

Results

Between 2008 and 2012, a total of 40 autism-specific research grants were active in Australia, equating to a total investment of just under AUD$14 million. Of these 40 grants, 38 were funded by either the ARC (with a total investment of $5,160,463) or the NHMRC (with a total investment of $8,538,562). As shown in Figure 2, 47% of the total research funding in this period was allocated to biological research. Research into treatments and interventions for autism received just under a quarter (22%) of total funding. From 2008 to 2012, no research funding was allocated to lifespan issues or infrastructure and surveillance.

[Insert Figure 2 about here]

Between 2013 and 2017, a total of 113 autism-specific research grants were active in Australia. Research investment during this period equated to a total of almost AUD$44 million, representing a 215% increase in autism research funding from the previous five years. The bulk of research funding during this period was invested by Autism CRC ($19,751,166), NHMRC ($19,319,780), and ARC ($4,247,252). As can be seen in Figure 2, research funding was distributed somewhat more evenly during this time period. As in the previous period, biological research received the largest proportion of investment, with 27%

of total research funding. Treatments and interventions, and infrastructure and surveillance each received 20% of total funding, while screening and diagnosis was the least funded area, receiving 5% of total research funding.

To examine more closely the potential impact of the establishment of the Autism CRC on the pattern of autism research funding in Australia, analyses on 2013–2017 data were repeated with all Autism CRC investments excluded; Autism CRC investment data were also analysed in isolation. When Autism CRC investments were excluded from analyses, the pattern of autism research funding in the period 2013–2017 was similar to the period 2008–2012 (see Figure 3). Biological research again received the bulk of research funding (38%), and research into treatments and interventions for autism again received just under a quarter (23%) of total funding. Investment in research investigating the causes of autism increased somewhat, from 7% of total research funding in the period 2008–2012, to 24% of funding in the period 2013–2017. Services, lifespan issues, screening and diagnosis, and infrastructure and surveillance each received minimal or no research investment, accounting for a total of 16% of research funding collectively.

[Insert Figure 3 about here]

In contrast, analysis of Autism CRC investment data indicates a heavy focus on autism research infrastructure, with almost half (45%) of Autism CRC funds invested in infrastructure and surveillance (Figure 3). Biological research, treatments and interventions, and lifespan issues received roughly equal investment from Autism CRC (14%, 15%, and 14% of total investment, respectively), with the remaining IACC Strategic Plan questions collectively accounting for 12% of Autism CRC investment.

Importantly, closer examination of funding patterns reveals that different funding bodies tended to invest in different research areas even within the same IACC Strategic Plan

questions. For example, of the $3,018,010 invested by Autism CRC in treatment and interventions in the period 2013–2017, the majority of funds (84%) went to projects investigating educational supports for autistic students, with the remainder invested in studies regarding technology-based supports (10%) and behavioural interventions (6%). In contrast, of the $5,571,312 invested in treatment and interventions by other funding bodies during the same period, 48% was invested in human pharmacological trials aimed at reducing core autistic characteristics; 26% was invested in studies using animal models of autism; and 20% went to projects investigating behavioural interventions, with only 7% invested in educational supports.

It is possible that different fields of autism research may require differing levels of investment to produce meaningful outputs. Given this possibility, it is important also to consider the number of individual research projects active within each Strategic Plan question, in addition to examining actual research investment. As shown in Tables S1 and S2, the distribution of individual research projects across IACC Strategic Plan questions is similar to the distribution of research funding.

Of the 40 research projects active in the 2008-2012 period, 19 (48%) projects focused on biological research, with 11 projects (28%) investigating treatments and interventions for autism, and 6 projects (15%) exploring autism screening and diagnosis. Of the 113 projects active in the 2013-2017 period, biological research accounted for 28 (25%) projects, while 27 (24%) projects were focused on treatment and interventions. Notably, infrastructure and surveillance accounted for only seven (6%) projects in this period, despite receiving 20% of research funding.

In the 2013-2017 period, Autism CRC's research investment supported 16 (26%) treatment and intervention projects, 13 (21%) lifespan issues projects, and 12 (20%) services

projects. In contrast, investment from other organisations primarily funded biological research (21 projects, 40%), and research into autism treatment and interventions (11 projects, 21%).

To further investigate the notion that different autism research topics may require differing levels of investment, average investments per research project were calculated for each IACC Strategic Plan question. As shown in Table 2, average investment per project was lowest for services projects (median $86,738; mean $199,454), and highest for infrastructure and surveillance projects (median $955,527; mean $1,271,757). Average investment per project was also relatively high for research into the causes of autism (median $589,977; mean $655,973), while the mean investment per project for each of the four remaining IACC Strategic Plan questions was between $200,000 and $400,000.

[Insert Table 2 about here]

To identify whether different organisations offer equivalent funding opportunities, levels of investment across the three major funding organisations were also examined. Average investment per grant was largest for the NHMRC (median $411,536; mean $487,134), and smallest for Autism CRC (median $128,224; mean $323,790). Grants were then classified as small (<$100,000), small-moderate ($100,000 - $499,999), moderate-large ($500,000 - $999,999) and large ($1,000,000+), with each funding body's pattern of investment shown in Figure 4. As shown, Autism CRC invested in a larger proportion of small research grants, while NHMRC invested in more moderate-large grants, and the ARC invested only in small-moderate and moderate-large grants.

[Insert Figure 4 about here]

Discussion

Previous portfolio analyses have revealed that a disproportionately large amount of autism research funding is allocated to biological research across the US, UK, and Canada (Daniels & Warner, 2018; Office of Autism Research Coordination, 2019; Pellicano et al., 2013). The current study is the first to examine the distribution of autism research funding in Australia. We showed that, in the 2008–2012 period, the distribution of autism research funding in Australia was similar to Canada, the UK, and the US. The bulk of funding was allocated to biological research, and minimal or no funding was allocated to topics prioritised by the autism community, such as services and lifespan issues. The pattern of autism research funding in the 2013–2017 period showed a considerably more even distribution of funding across the IACC Strategic Plan questions. In this period, research grants representing all seven of the IACC Strategic Plan questions were identified, although biological research remained the most-funded research area. Of note, clear differences are evident in the distribution of research funding invested by different funding bodies during the 2013–2017 period. Having excluded Autism CRC research investments from the analysis, the 2013–2017 pattern of research funding (as shown in Figure 3) is quite similar to the previous period. This suggests that the shift in the pattern of autism research funding between the 2008–2012 period and the 2013–2017 period may be explained by the establishment of Autism CRC, rather than a broader shift in the allocation of autism research investment across Australian funding bodies. Separate examination of the pattern of Autism CRC research investment (shown in Figure 3) supports this possibility.

It is important to acknowledge also that the total cash investment in autism research in Australia substantially increased between the 2008–2012 period and the 2013–2017 period. Although this increase can largely be attributed to the establishment of Autism CRC and the associated investment of almost AUD$20 million, it is notable that NHMRC's contribution to

autism research more than doubled between the two time periods. This boost to autism research funding is encouraging, and suggests that autism research in general may be gaining recognition as a priority in Australia.

Given Autism CRC's mission statement, which highlights the organisation's focus on inclusive and collaborative research across the lifespan, it is perhaps not surprising that Autism CRC's investment portfolio differs from other funding bodies supporting autism research in Australia. This is particularly true given that the second largest funder of autism research in the period 2013–2017 was NHMRC, an entity which specifically funds health and medical research and therefore can reasonably be expected to conceptualise autism using a medical paradigm. What is perhaps more surprising is the very large proportion of Autism CRC funding invested in research infrastructure and surveillance, and the relatively small proportion invested in services and lifespan issues. Autism CRC annual reports indicate, however, that the bulk of investment in infrastructure and surveillance is expended on the development of Early Career Researchers and Research Assistants, with 40% of Autism CRC's total infrastructure and surveillance investment funding the development of Early Career Researchers who work within the organisation's "Adulthood" research program (Autism CRC, 2018). Therefore, this investment is arguably consistent with the organisation's mission of conducting research across the lifespan.

Consistent with findings in previous portfolio analyses, it appears that autism research funding in Australia has historically failed to target the priorities of the autism community. Although there has not been, to date, a large-scale investigation of community research priorities in Australia, a small study (Gatfield et al., 2016) suggests that Australian community priorities are consistent with those identified in other countries. Going forward, it will be important, first, to gain a clearer understanding of research priorities within the Australian autism community and, second, to ensure that these priorities are reflected in the

allocation of research funding. Previous research in the UK and US (Autistica, 2016; Frazier et al., 2018; Pellicano et al., 2014) has consistently found that the autism community tends to prioritize research topics that are likely to have an immediate, real-world impact on the lives of autistic people. Empirical evidence indicates that the community's priorities are justified: among other inequities, autistic people experience poor mental and physical health (Croen et al., 2015), poor outcomes in adulthood (Howlin & Magiati, 2017), and face difficulty accessing appropriate support and services, particularly in adulthood (Turcotte, Mathew, Shea, Brusilovskiy, & Nonnemacher, 2016).

To address these inequities, autism research must be responsive to the needs and priorities of the autism community. The findings of this portfolio analysis suggest that a top-down approach led by funding organisations can bring about considerable change in funding patterns, even over a relatively brief time frame. To capitalise on this shift in Australian autism research funding, the existing top-down approach should be paired with bottom-up engagement by researchers themselves (Pellicano et al., 2013). By partnering with autistic people and other community stakeholders at all stages of the research process, researchers can ensure that their work is guided by community priorities. This will result in research that is more relevant to the autistic community, tailored to the specific needs of autistic people, and consistent with community values (Lloyd & White, 2011; Partridge & Scadding, 2004).

This study is not without its limitations. First, although the Dimensions Plus database contains comprehensive data regarding Australian (and international) research grants, it is not an exhaustive resource. To mitigate the possibility of excluding funded projects from the analyses, we conducted manual searches to identify any additional research grants, but it is possible that relevant research grants may still have been missed. Second, the coding of research grants for eligibility and on the IACC Strategic Plan questions was sometimes done with very limited information, which again might have led to inaccuracies. Yet, our

reasonably high inter-rater agreement during coding and ability to reach consensus on all grants warrants confidence in our results. Finally, we used the IACC Strategic Plan questions to code specific areas of autism research to enable cross-country comparisons. It is worth noting, however, that there are limitations inherent to the IACC Strategic Plan questions themselves. For example, (1) these questions were identified through consultation with US stakeholders and may well be different were the consultation process to be repeated in Australia; (2) many of the research areas within the IACC Strategic Plan questions lack face validity, failing to clearly relate to the associated Strategic Plan question, and; (3) the IACC did not distinguish specific research areas within the lifespan issues question. Future research efforts should be focused on a large-scale consultation on research priorities with the Australian autistic and autism communities, delineating the specific lifespan issues that matter most to these communities.

Conclusion

Results of this analysis indicate that the recent pattern of autism research funding in Australia has been similar to funding patterns seen in the US, UK, and Canada. Although the distribution of funding in Australia appears to have shifted since the establishment of Autism CRC in 2013, research investment remains disproportionately skewed toward biological research. As autism research begins to shift from the dominant medical paradigm towards a more inclusive, neurodiversity-informed paradigm (e.g., Fletcher-Watson & Happé, 2019), it is important that the distribution of autism research funding reflects this progression. In Australia, research investment in areas of community priority (such as services and lifespan issues) increased from the 2008–2012 period to the 2013–2017 period; even so, these topics received scant funding. To ensure that progress is maintained going forward, it is key that autism research funding be apportioned according not solely to the priorities of funding

bodies and researchers, but to the needs and priorities of the autistic and broader autism communities.

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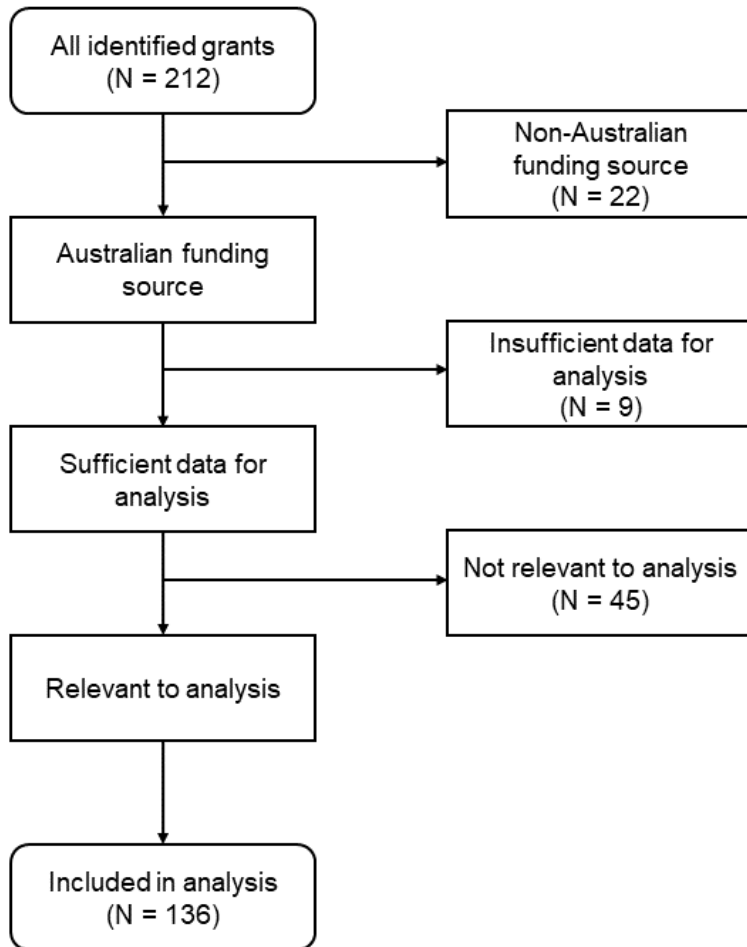Table 1. *IACC Strategic Plan questions and corresponding research areas*

IACC Strategic Plan Questions	Corresponding Research Areas
Diagnosis: When should I be concerned?	• Early signs and biomarkers • Diagnostic and screening tools • Intermediate phenotype/subgroups • Symptomatology
Biology: How can I understand what is happening?	• Cognitive studies • Computational science • Co-occurring conditions • Developmental trajectory • Immune/metabolic pathways • Molecular pathways • Neural systems • Neuropathology • Sensory and motor function • Subgroups/biosignatures
Causes: What caused this to happen and can it be prevented?	• Environmental risk factors • Epigenetics • Gene-environment interaction • Genetic risk factors
Treatments and interventions: Which treatments and interventions will help?	• Behavioural • Complementary, dietary and alternative • Educational • Medical/pharmacologic • Model systems/therapeutic targets • Occupational, physical, and sensory-based • Technology-based intervention and supports
Services: Where can I turn for services?	• Community inclusion programs • Efficacious and cost-effective service delivery • Family well-being and safety • Practitioner training • Service utilisation and access
Lifespan issues: What does the future hold, particularly for adults?*	
Infrastructure and surveillance: What other infrastructure and surveillance needs must be met?	• Biobanks • Data tools • Research infrastructure • Surveillance and prevalence studies • Research workforce development • Research recruitment and clinical care

Office of Autism Research Coordination (2019)
*The IACC Strategic Plan does not provide corresponding research areas for this question.

Table 2. *Investment across IACC Strategic Plan Questions (AUD)*

IACC Strategic Plan Question	Median	Mean	Max	Min
Diagnosis	170,000	252,619	707,000	47,889
Biology	321,906	391,588	1,172,789	40,150
Causes	589,977	655,973	1,672,306	86,907
Treatments and interventions	202,860	301,639	1,245,664	20,000
Services	86,738	199,454	704,929	40,000
Lifespan issues	150,000	210,934	568,894	50,000
Infrastructure and surveillance	955,527	1,271,757	3,520,000	49,000

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┌─────────────────────┐
│  All identified grants │
│     (N = 212)        │
└─────────────────────┘
          │         ┌─────────────────────┐
          │────────▶│   Non-Australian    │
          │         │   funding source    │
          ▼         │     (N = 22)        │
┌─────────────────────┐
│ Australian funding  │
│      source         │
└─────────────────────┘
          │         ┌─────────────────────┐
          │────────▶│ Insufficient data for│
          │         │      analysis       │
          ▼         │     (N = 9)         │
┌─────────────────────┐
│  Sufficient data for│
│      analysis       │
└─────────────────────┘
          │         ┌─────────────────────┐
          │────────▶│ Not relevant to analysis│
          │         │     (N = 45)        │
          ▼         └─────────────────────┘
┌─────────────────────┐
│ Relevant to analysis│
└─────────────────────┘
          │
          ▼
┌─────────────────────┐
│ Included in analysis│
│     (N = 136)       │
└─────────────────────┘
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Figure 1. Process for determining inclusion of grants in Australian portfolio analysis (2008–2017).

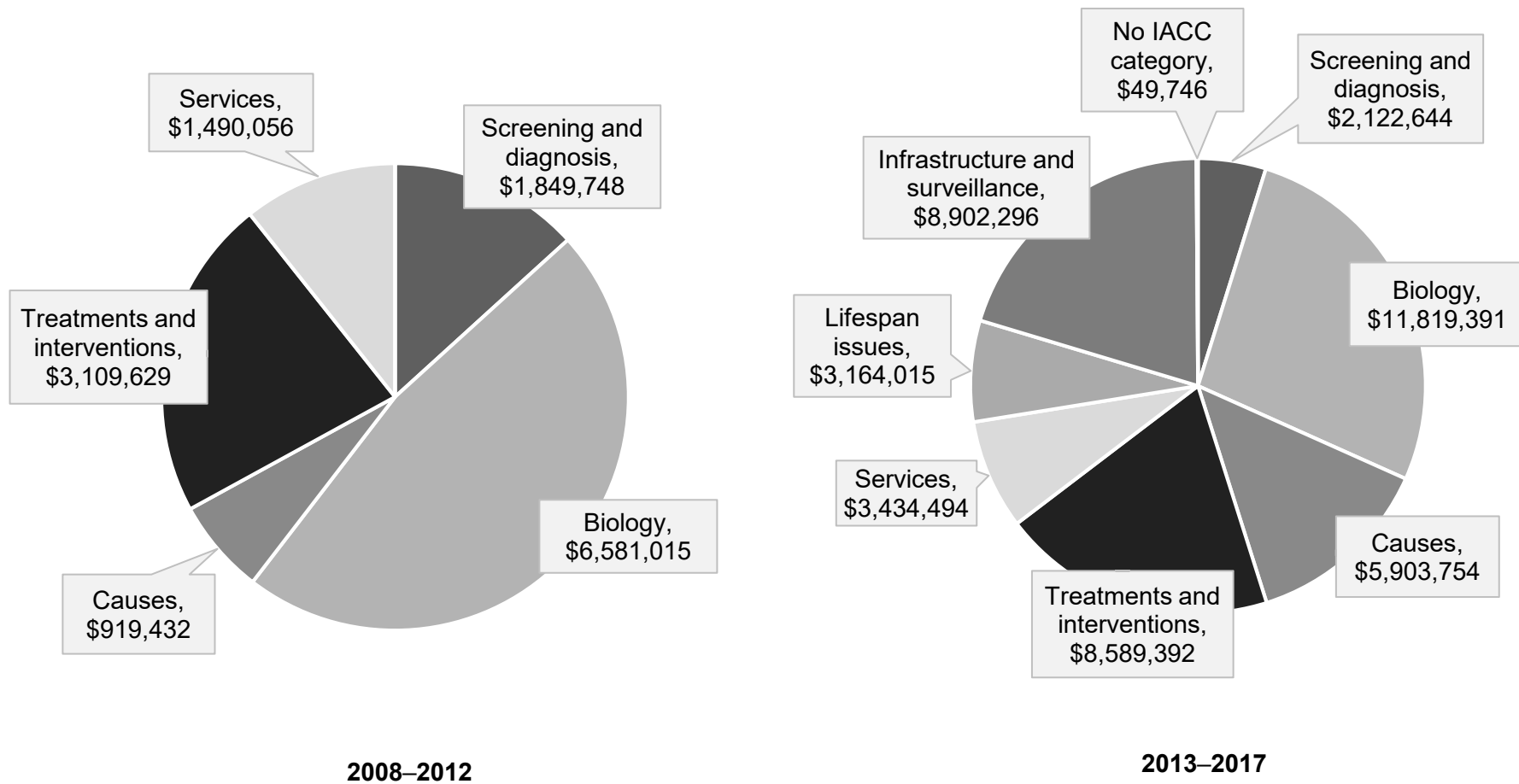**2008–2012**

2013–2017

Figure 2. Distribution of Australian autism research funding in 2008–2012 (left) and 2013–2017 (right).
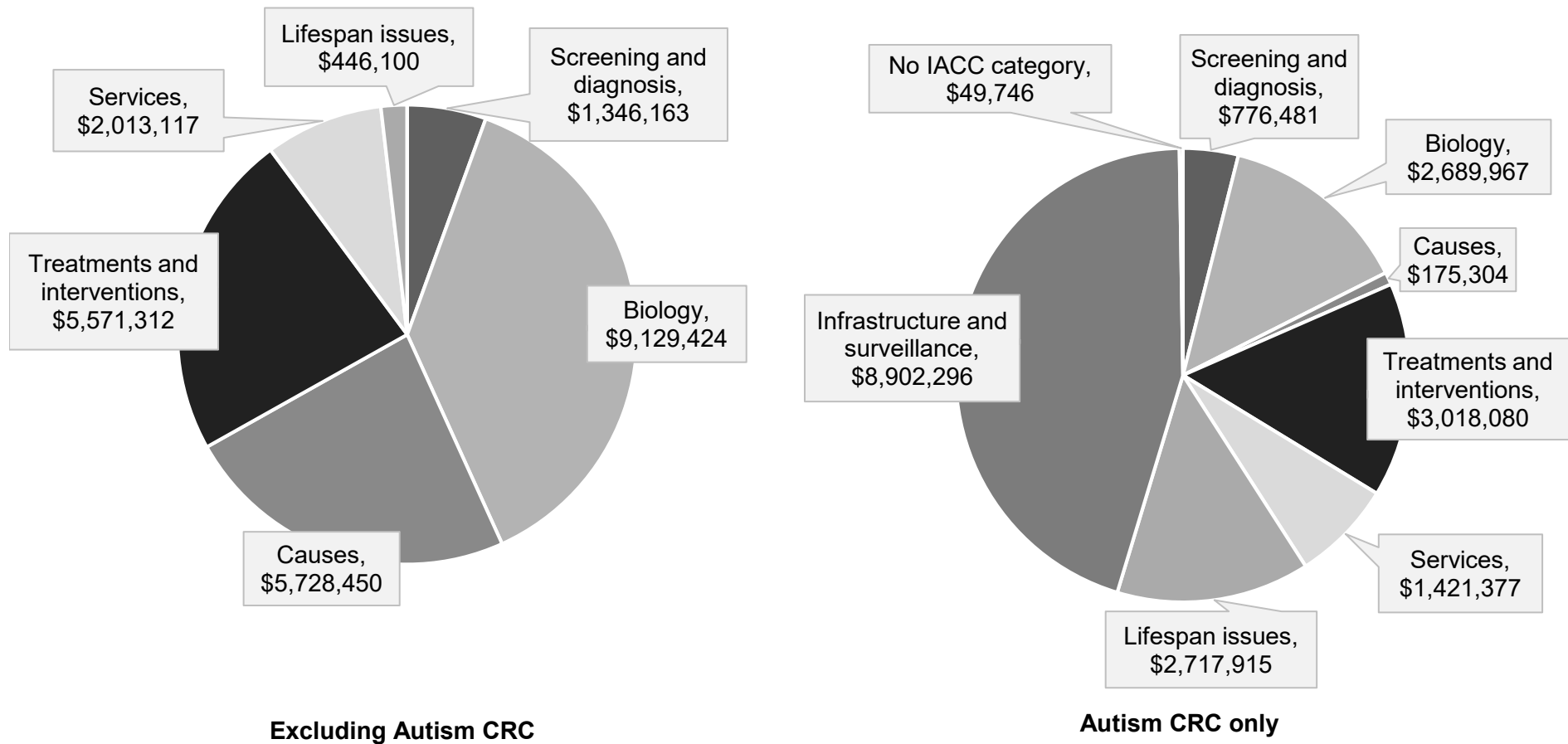
Figure 3. Distribution of Australian autism research funding excluding Autism CRC investments (left), and Autism CRC research investments (right), over the 2013–2017 period.
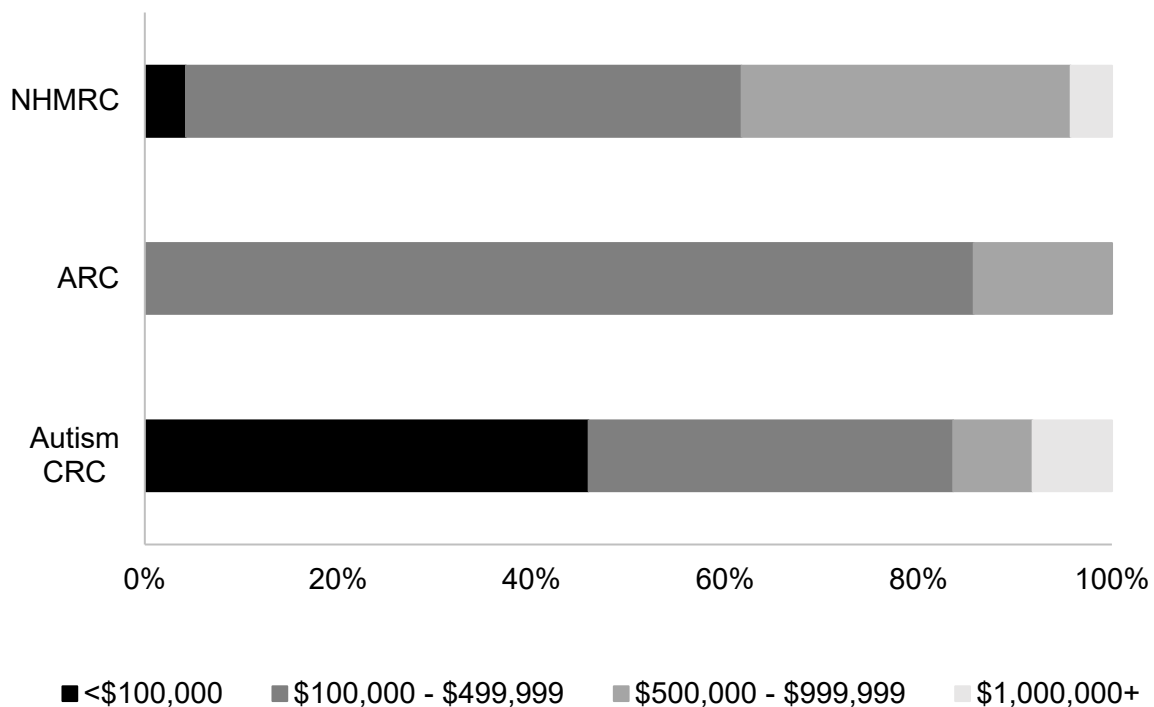
Figure 4. Number of small, small-moderate, moderate-large, and large research grants by funding organisation, 2013-2017.