CENTRE FOR COMMUNITY-DRIVEN RESEARCH

National Patient Organisation Network

Contribution to the Australian Health System

2024 report

Organisation Centre for Community-Driven Research
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Background

The Centre for Community-Driven Research (CCDR) started in 2012 and is a non-profit organisation bringing much needed change to the way we think about community engagement in health and research. Our vision is to create health systems that are based on equitable decision-making as they are person-centric and driven by the community: CCDR is taking the community from being the guests in the process, to the hosts.

CCDR provides services in primary care, and listens to the issues that people (patients), researchers, and healthcare and industry partners face and develop solutions - through community engagement - to solve those issues. We do this so that research, healthcare programs, policies and products being developed can reach the patients at the bedside sooner, and better address the needs patients and their families.

CCDR currently have offices in Australia, Switzerland and the United Kingdom and aim to reach our goal of a more person-centric health sector globally through our core programs; the Patient (Personal) Experience Expectations and Knowledge Program (PEEK), the National Patient Organisation Network program, and Piloting Community Engagement and Community-Based Health Delivery Approaches (Pilots).

Infrastructure for patient engagement and advocacy

When we talk about infrastructure we often think of the physical structures and systems needed to deliver health services, basic research, clinical trials and so on. What we do not often talk about is the infrastructure needed to create an environment that supports patient organisations to systematically collect patient experience data. It is this kind of infrastructure that CCDR helps to create.

At CCDR, we have four clear goals.

1. Providing a platform for patients and their families to engage in decisions about health
2. Conducting studies to understand patient experience and expectations, and inform future treatments, services, support and information. **We provide the real, 'real world evidence'.**
3. Testing approaches to community engagement and community-based health service provision; and
4. Building capacity within the non-profit sector and raising the profile of the important role of patient organisations in the health system.

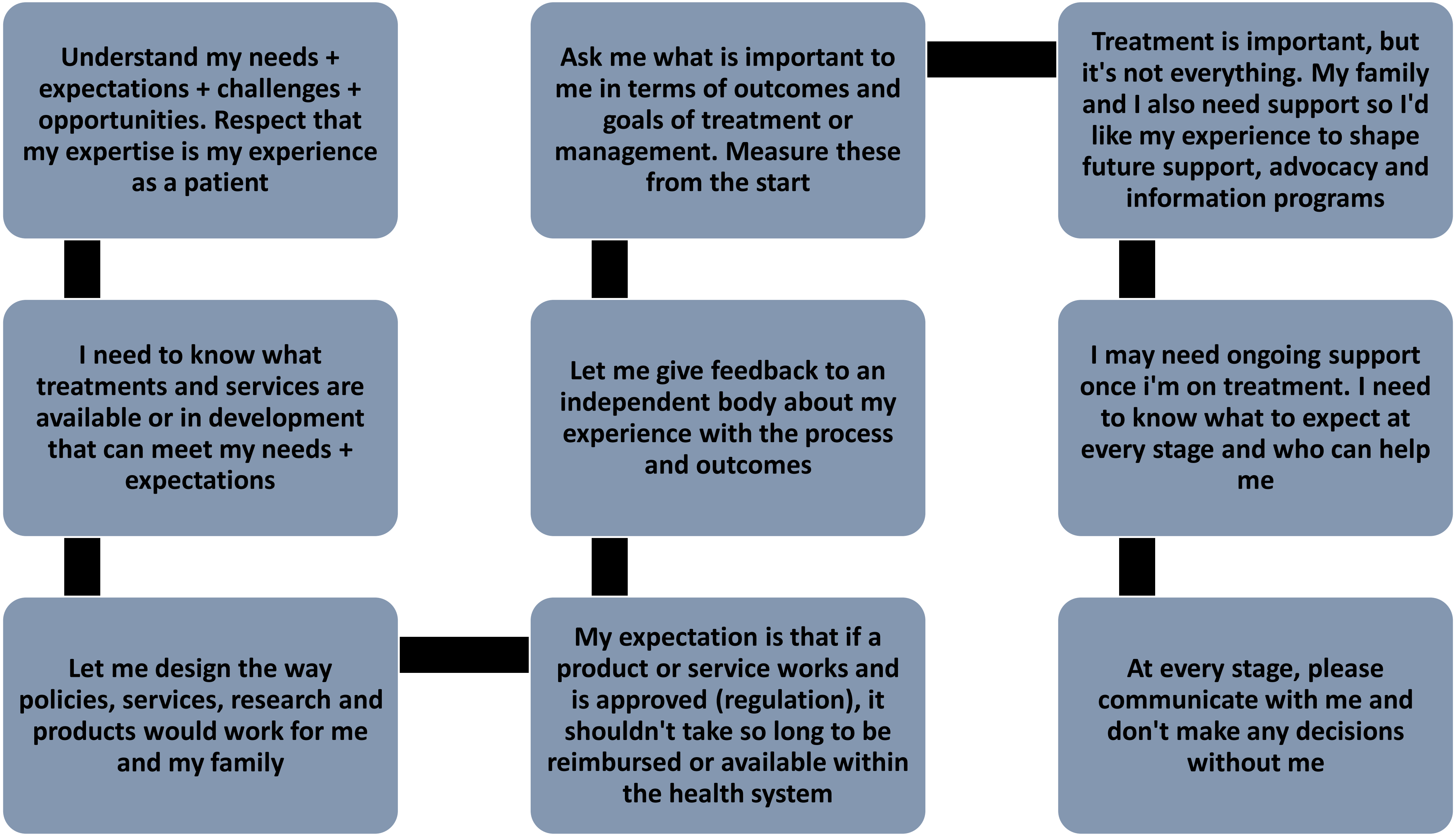
We do this through our core programs:

The Personal Experience Expectations and Knowledge or 'PEEK' program
- **Building a global repository of lived experience data and reports**

The National Patient Organisation Network program (NPON) program; and
- **Building networks of patient and community organisations as a part of the health system and health workforce**

Piloting Community Engagement and Community-Based Health Delivery Approaches (Pilots)
- Testing different approaches to how people access care and engage in decisions about health.

Health system orientation
- **Supporting professionals working in any role within companies that have an impact on how patients experience the health system or access services, treatments, diagnostics or other products.**



Understand my needs + expectations + challenges + opportunities. Respect that my expertise is my experience as a patient

I need to know what treatments and services are available or in development that can meet my needs + expectations

Let me design the way policies, services, research and products would work for me and my family

My expectation is that if a product or service works and is approved (regulation), it shouldn't take so long to be reimbursed or available within the health system

Let me give feedback to an independent body about my experience with the process and outcomes

Ask me what is important to me in terms of outcomes and goals of treatment or management. Measure these from the start

Treatment is important, but it's not everything. My family and I also need support so I'd like my experience to shape future support, advocacy and information programs

I may need ongoing support once i'm on treatment. I need to know what to expect at every stage and who can help me

At every stage, please communicate with me and don't make any decisions without me

A patient’s expectation of the product, policy and service development pipeline

Section 1: INTRODUCTION AND SUMMARY

introduction

Background

Australia has a vibrant health charity sector and the National Patient Organisation Network (NPON) was convened to support the sector and strengthen its impact through collaboration.

This report draws on data collected from the 2019 and 2022 Australian Information Statement where charities respond to questions about finances and operations over a 12 month period. It also draws on a survey conducted by CCDR that collects information about the activities of member organisations, and the importance and accessibility of care and treatment for the communities they serve, as part of the health system.

Data from the 2022 Australian Information Statement (Australian Charities and Not-for-Profit Commission)

Data were extracted for charities that are NPON members. There were 84 organisations with data in 2019 and 87 organisations with data in 2022 (https://www.acnc.gov.au/for-charities/annual-information-statement).

Data from the Australian Information Statement is presented in sections 2 to 5 and cover details about the charity, income, expenditure and employment.

Data from the 2024 CCDR NPON questionnaire

There were 83 organisations that responded to the questionnaire. Data from the questionnaire are presented in sections 6 to 14 and covers advocacy activities, support services, healthcare professionals, NDIS application support, information and education, clinical trials and research, palliative care, pain management, programs and outreach to specific communities, and the importance and accessibility of care and treatment.

Summary

What do NPON organisations do with a combined $200 million income, 700 full time equivalent employment, and 3,000 volunteers?

SUPPORT SERVICES

☐ 73% peer-to-peer support
☐ 57% support groups (face-to-face)
☐ 51% support groups (telephone)
☐ 44% helplines
☐ 19% financial aid
☐ 25% telehealth nurse structured services
☐ 4% transport
☐ 1% legal aid

ADVOCACY

☐ 63% are active in patient rights advocacy
☐ 59% are active in health system/service change advocacy
☐ 53% participate in policy and Senate Inquiries
☐ 48% deliver PBAC/MSAC submissions & access
☐ 48% aids access to clinical trials
☐ 45% deliver research funding

INFORMATION

☐ 96% online information
☐ 80% research updates
☐ 77% written information (hard copies)
☐ 73% webinars
☐ 67% patient information days or conferences
☐ 60% clinical updates
☐ 21% apps

NDIS SUPPORT

☐ 28% online information tailored to community
☐ 20% written information tailored to community
☐ 16% a helpline
☐ 7% a telephone structured service

CLINICAL TRIALS

☐ 68% direct patients to clinical trials
☐ 52% clinical trial co-design, connect patients with CT
☐ 22% fund clinical trials
☐ 15% manage a clinical registry

RESEARCH

☐ 63% research co-design, connect patients
☐ 40% fund research
☐ 30% conduct research
☐ 27% develop national research strategy

PROFESSIONAL EDUCATION

☐ 78% information for professionals
☐ 65% presentations on request
☐ 59% webinars to professionals
☐ 57% written information for professionals
☐ 52% conferences to professionals

PAIN MANAGEMENT

☐ 37% information about pain management
☐ 28% carer support for pain management
☐ 25% advocacy or policy for pain management
☐ 19% referral to pain management specialists
☐ 13% support or education for health professionals

PALLIATIVE CARE

☐ 28% carer support for palliative care
☐ 24% information about palliative care
☐ 23% advocacy or policy for palliative care
☐ 16% support or education for health professionals
☐ 13% referral to palliative care services

Most NPON member organisations are small charities with an income of less than $250,000

About NPON members

Data was extracted from the 2019 and 2022 Annual Information Statement Data from the Australian Charities and Not-for-profits commission (ACNC) (available from https://data.gov.au).

In 2019 and in 2022, most NPON members were small charities.

In 2019 the most common main activities were civic health service delivery, health service deliveries and education. The most common secondary activities were research, social services education and health service delivery.

In 2019 the most common main beneficiaries were people with chronic illness, the general community in Australia and people with disabilities. The most common secondary beneficiaries were families, people with disabilities, the general community in Australia, people with chronic illness and children and youth aged 6 to 25.

In 2019 most charities were located in New South Wales, Victoria or Queensland and these are the states that charities most commonly operated in.

In 2019, fundraising most commonly occurred in New South Wales, followed by Victoria, South Australia and online. In 20022 fundraising was most commonly online followed by New South Wales, Victoria, and South Australia.

Total revenue

Data was extracted from the 2019 and 2022 Annual Information Statement Data from the Australian Charities and Not-for-profits commission (ACNC) (available from https://data.gov.au).

NPON members received revenue from the government, donations and bequests, goods and services, and interest. In 2019 the total revenue for NPON members ranged from $0 to $40,123,178 (median=$203,060; IQR = 1,309,706), and in total 84 member charities had a combined revenue of $174,225,904.

In 2022 the total revenue for NPON members ranged from 0 to 52,577,000 (median=$238,609; IQR=$1,094,001), and in total 87 member charities had a combined revenue of $213,762,418.

In 2019 84 NPON members had a combined income of $174,225,904.	In 2022 87 NPON members had a combined income of $213,762,418.

Total expenses

Data was extracted from the 2019 and 2022 Annual Information Statement Data from the Australian Charities and Not-for-profits commission (ACNC) (available from https://data.gov.au).

NPON members had expenses from employees, interest, and grants and donations both within and outside Australia.

In 2019 82 NPON organisations had total expenses ranging from $1988 to $39677000 (median = $210,918.50; IQR = $1,207,956.25), and in total 84 member charities had combined expenses of $16,5701,905.

In 2022 86 NPON organisations had total expenses ranging from $762 to $52,233,000 (median = $211,233.50; IQR = $1,249,855), and in total 87 member charities had combined expenses of $211,183,329.

In 2019, 84 NPON member charities had combined expenses of $16,5701,905.	In 2022, 87 NPON member charities had combined expenses of $211,183,329.

Employees

Staff overview

Data was extracted from the 2019 and 2022 Annual Information Statement Data from the Australian Charities and Not-for-profits commission (ACNC) (available from https://data.gov.au).

In 2019, NPON member organisations employed a total of 454 full time staff 377 part time staff, 55 casual staff, a total full time equivalent of 681.97 staff. In addition, they had a total of 3996 volunteers.

In 2022, NPON member organisations employed a total of 505 full time staff 529 part time staff, 83 casual staff, a total full time equivalent of 767.47 staff. In addition, they had a total of 2892 volunteers.

2019 Staff in NPON member organisations

- Full time: 454
- Part time: 377
- Casual: 55
- Full time equivalent: 681.97
- Volunteers: 3996

2022 Staff in NPON member organisations

- Full time: 505
- Part time: 529
- Casual: 83
- Full time equivalent: 767.47
- Volunteers:2892

NPON advocacy activities

Data was collected from NPON members in 2024 about advocacy activities/services that organisation is involved with or would like to initiate in the future.

Over 60% of NPON organisations advocate for patient rights, and nearly 60% are involved in health symptom or service change. Approximately half of the organisations deliver PBAC or MSAC submissions & access, aids access to clinical trials, and offer research funding.

NPON organisations described the amount of interaction with the PBAC or other government feedback opportunities. In general, following submission there was very little feedback. Approximately 59% of organisations never or rarely received detailed information on how patient representation was used. About 60% sometimes or rarely received detailed information on the impact of patient representation. Approximately half of the organisations were never invited to provide additional clarifications after the submission period is closed, and 62% of organisations never or rarely were informed of any new policies, guidelines or reports that patient representation contributed to.

NPON organisations comments about advocacy activities

As a very small organisation with limited funding (funds raised by our own efforts - no government support) there is a clear limit to what we can achieve in any of these areas. What matters most is the extent to which we can partner with alliances/groups/organisations (incl APON) who can ensure that our shared concerns are raised. To the extent that there is something very specific to Fragile X, such as carrier screening, testing then we ensure we prepare something targetted that is within the capacity of one of our Board members to write.

It would be great to do this, or deliver this but... this would require resources and funds

NPON advocacy activities

- 62.65% are active in patient rights advocacy
- 59.04% are active in health system/service change advocacy
- 53.01% participate in policy and Senate Inquiries
- 48.19% deliver PBAC/MSAC submissions & access
- 48.19% aids access to clinical trials
- 45.78% deliver research funding

Submissions or representing patients in government feedback

- 59% never or rarely received information on how patient representation was used
- 60% sometimes or rarely received information on the impact of patient representation
- 48% were never invited to provide additional clarifications after the submission period is closed
- 62% never or rarely were informed of any new policies, guidelines or reports that patient representation contributed to

NPON support services

Data was collected from NPON members in 2024 about support services that the organisation is involved with or would like to initiate in the future.

The most common services offered, and that were offered by more than half of the organisations are peer-to-peer support, support groups (face-to-face), and support groups (telephone). Other services offered include, helplines, financial aid, telehealth nurse structured services, transport and legal aid

Self-care interventions are tools which support self-care. Self-care interventions include evidence-based, quality drugs, vitamins & minerals, lotions and creams, devices, diagnostics and/or digital products (including apps) which can be provided fully or partially outside of formal health services and can be used with or without health worker. The majority of organisations engaged in self care interventions either by informing patients of self care opportunities, reviewing the evidence/literature related to self-care opportunities, and referring patients to self-care opportunities.

The top five self care interventions listed by NPON organisations were evidence-based quality drugs, digital products (including apps), diagnostics, devices, and lotions and creams.

NPON support services

- 73% offer peer-to-peer support
- 57% offer support groups (face-to-face)
- 51% offer support groups (telephone)
- 44% offer helplines
- 19% offer financial aid
- 25% offer telehealth nurse structured services
- 4% offer transport
- 1% offer legal aid

Self care interventions

- 61% offer inform patients of self-care opportunities
- 36% offer review the evidence/literature related to self-care opportunities
- 28% offer refer patients to self-care opportunities

Self care interventions important to community

- 62% Evidence-based quality drugs
- 42% Digital products (including apps)
- 41% Diagnostics
- 39% Devices
- 25% Lotions and creams

Employment of healthcare professionals

Data was collected from NPON members in 2024 about employment of healthcare professionals in the organisation. .

The majority of organisations (n=49, 71.01%) do not employ healthcare professionals, for those that do, approximately half work in non-clinical services, and approximately a third of nurses deliver clinical services.

Healthcare professional employment

- 71% do not employ any healthcare professionals
- 16% employ registered nurses
- 9% employ counsellors
- 6% employ an occupational therapist
- 3% employ a medical doctor
- 3% employ a physiotherapist
- 1% employ a genetic counsellor
- 1% employ a psychologist
- 53% of healthcare professionals work in non-clinical services
- 36% of nurses deliver clinical services

NPON NDIS support services

Data was collected from NPON members in 2024 about any NDIS support or information that they offer.

There were 5 organisations (7.25%) that offered a structured telephone service, 11 organisations (15.94%) that offered a helpline for NDIS, 19 organisations (27.54%) that offered online information and 14 organisations (20.29%) that offered written information.

NPON organisations comments about NDIS support services

Dysphonia not currently recognised for NDIS purposes

I would love this for our community - but this would be really difficult for me to put together. I don't have the knowhow or expertise in the area.

Our NDIS service is used to guide the NF Community through this often-complex process. We write support letters explaining NF, as it can cause invisible but significant disabilities. Our NDIS workload has increased recently. We are dealing with families who are distraught and struggling to access services. They're only able to access these essential services, like speech and phsyiotherapy, due to NDIS funding, an increasing number of families are having their access denied.

We provide the above by paying a 3rd party provider. We pay for families to have time with an external provider to discuss their applications,

NDIS support services

- 7% offer a telephone structured service
- 16% offer a helpline
- 28% offer online information tailored to their community
- 20% offer written information tailored to their community

NPON information and education services

Data was collected from NPON members in 2024 about information provided for patients and education provided for healthcare professionals.

Almost all the organisations offered online information for patients, and most organisations offered research update, written information (hard copies), webinars, patient information days or conferences, and clinical updates. A few organisations offered apps.

NPON organisations offered various forms of education for healthcare professionals. The majority of organisations offered online information, gave presentations on request, offered webinars, provided written (hard copy) information and offered conferences.

NPON organisations comments about information and education

Whilst we do conferences and patient days, we find this to be the most challenging activity for our volunteer organisation. Funding from NDIS, or Dept of Health (that does not require lengthy grant application process) for volunteer NFP patient organisations to deliver conferences that provide unmatched support, information and resources to rare disease organisations would be a game changer for us and our community. This has to become a reality.

I would love a funded family conference, it would allow families to see each other and work on that connection, and also gives them the opportunity to hear from our current research advisory committee on the research projects we have underway and what is to come in a face-to-face setting.

The ATF is proactive in educating patients and HCP's about the importance of good thyroid health, identifying, testing, treatments and monitoring.

It would be good if NFP's did not have to self fund to attend and educate HCPs

Little to no information about Immune Thrombocytopenia for those working in the emergency departments of hospitals - resulting in unwell patients having to educate HCPs

NPON patient Information services

- 96% offered online information
- 80% offered research updates
- 77% offered written information (hard copies)
- 73% offered webinars
- 67% offered patient information days or conferences
- 60% offered clinical updates
- 21% offered apps

NPON healthcare professional education

- 78% offered information for professionals
- 65% gave presentations on request
- 59% offered webinars to professionals
- 57% offered written information for professionals
- 52% offered conferences to professionals

Clinical trials and research

Data was collected from NPON members in 2024 about participation in clinical trials and research.

Approximately 68% of organisations direct patients to clinical trial, and about half of the organisations participate in clinical trial co-design or connecting patients with researchers. There were 18 organisations (21.69%) that fund clinical trials and 12 organisations (14.63%) manage clinical registries.

The majority of NPON organisations were involved with research co-design and/or connecting patients with researchers (n=52, 62.65%). NPON organisations also funded research (n=33, 39.76%), conduct research (n=25, 30.12%), and develop national research strategy (n=22, 26.51%).

NPON organisations comments about clinical trials and research

Same as previous comments. We have no income and few volunteers. We receive no funding and charge no membership fees. So our resources are extremely limited.

Our funds are reliant on donations by our community $10K doesn't get far in terms of running an org funding research, and so on.

We do not have sufficient funds to lead research - but have advocated for research to be undertaken and assisted in design.

Clinical trials

- 68% direct patients to clinical trials
- 52% clinical trial co-design and/or connecting patients with researchers
- 22% fund clinical trials
- 15% manage a clinical registry

Research

- 63% research co-design and/or connecting patients with researchers
- 40% fund research
- 30% conduct research
- 27% develop national research strategy

NPON palliative care and pain management

Data was collected from NPON members in 2024 about palliative care services and pain management services that the organisation is involved with or would like to initiate in the future.

The most common services offered for palliative care , were carer support, information, and advocacy and policy. Other services were support or education for health professionals, and referral to palliative care.

The most common services or activities for pain management were to provide information, provide care support, and provide advocacy or policy. Other services were referrals to pain management specialists and to provide support or education for health professionals.

NPON palliative care

- 28% provide carer support for palliative care
- 24% provide information about palliative care
- 23% provides advocacy or policy for palliative care
- 16% provide support or education for health professionals for palliative care
- 13% offer referral to palliative care services

NPON pain management

- 37% provide information about pain management
- 28% provide carer support for pain management
- 25% provides advocacy or policy for pain management
- 19% offer referral to pain management specialists
- 13% provide support or education for health professionals for pain management

NPON support services

Data was collected from NPON members in 2024 about programs and outreach to regional and rural populations, Aboriginal and Torres Strait Islander, people from a non-English speaking population, low income and/or homeless people, and LGBTQ+ populations,

Outreach programs were most commonly delivered to regional and rural populations (n=22, 26.51%). There were 7 organisations (8.43%) that offered outreach to non-English speaking background populations, 5 organisations (6.02%) that offered outreach to low income and/or homeless populations, and two organisations that each provided outreach to Aboriginal and Torres Strait Islander populations (2.41%), and LGBTQ+ populations (2.41%).

Specific programs were most commonly delivered to regional and rural populations (n=15, 18.07%). There were 8 organisations (9.64%) that offered specific programs for non-English speaking background populations, 3 organisations (3.61%) that offered specific programs for Aboriginal and Torres Strait Islander populations, two organisations that each provided specific programs for low income and/or homeless populations (2.41%), and LGBTQ+ populations (2.41%).

NPON organisations reported that all programs have a component that addresses the following: regional and rural populations (n=36, 43.37%), Aboriginal and Torres Strait Islander populations (n=17, 20.48%), non-English speaking background (n=16, 19.28%), LGBTQ+ populations (n=15, 18.07%), and low income and/or homeless populations (n=14, 16.87%).

NPON organisations comments about support services

In rural and remote areas of Australia, some services may not be available at all. As most cancer treatment centres and experts are based in metro areas, many people living outside of major cities need to travel, often at significant expense, spending extended time away from their jobs, support systems and families. Regional and Rural

populations can access our online support groups and services. We promote the health of our regional and rural populations but assisting with transport and travel cost to ensure they can access services.
We are in the process of developing a program plan which includes hiring a Health Promotion Officer.
We provide each patient with access to their own Specialist Cancer Navigator for personalised clinical, emotional, financial and practical support throughout their diagnosis, treatment and beyond.

The ATSI population are greatly impacted by T2 diabetes and inturn amputation resulting from this disease. We have been looking into ways that we can assist with greater education and access to information to support those members of our community.

We utilise interpreter services when necessary to ensure that we are able to deliver adequate support and intervention to those who come from a non english speaking background. We are in the process of translating our reading materials and support guides so they are more accessible to those who don't speak English as their first language.

Our services are truly personalised. We have provided letters to government agencies for housing, healthcare cards, etc. If a person has an issue related to their NF then we are willing to support them in whatever is needed. It can be hard for people to explain the impacts of NF so we always aim to provide assistant to low income populations where required.

Regional and rural populations • 27% offer outreach programs • 18% delivers specific programs • 43% all programs have a component that addresses this population	**Low-income and/or homeless populations** • 6% offer outreach programs • 2% delivers specific programs • 17% all programs have a component that addresses this population
Aboriginal and Torres Strait Islander populations • 2% offer outreach programs • 4% delivers specific programs • 20% all programs have a component that addresses this population	**LGBTQ+ populations** • 2% offer outreach programs • 2% delivers specific programs • 18% all programs have a component that addresses this population
Non-English speaking background populations • 8% offer outreach programs • 10% delivers specific programs • 19% all programs have a component that addresses this population	

Importance and accessibility of aspects of care and treatment

Data was collected from NPON members in 2024 about The importance of aspects of care and treatment and how accessible they were.

The top five aspects of treatment and care that were described as extremely important or very important were: access to appropriate treatments/devices in a timely manner (n=72, 94.74%), affordable treatments (n=70, 92.11%), access to specialists (n=72, 94.74%), up to date information and research findings (n=67, 88.16%), and access to allied health professionals (n=66, 86.84%).

For these aspects of care of treatments, NPON organisations described these as extremely accessible or very accessible: access to appropriate treatments/devices in a timely manner (n=7, 9.21%), access to affordable treatments (n=7, 9.21%), access to specialists (n=10, 13.16%), access to allied health professionals (n=12, 15.79%), and access to up to date information and research findings (n=21, 27.63%).

Aspects of care and treatment	Extremely or very Important	Extremely or very accessible
Access to appropriate treatments/devices in a timely manner	95%	9%
Access to specialists	95%	13%
Access to affordable treatments	92%	9%
Access to up to date information and research findings	88%	28%
Access to allied health professionals	87%	16%
Access to earlier diagnostic tests	86%	12%
Access to clinical trials	76%	14%
Support for carers	74%	17%
Reducing stigma related to their condition/illness	72%	14%
Support in navigating the health system/ coordination of care	64%	12%
Access to genetic testing	62%	13%
Access to home care	62%	12%
Support in navigating the NDIS	59%	8%
Access to equipment	58%	11%
Access to pain management	50%	16%
Access to palliative care	33%	11%

NPON Australia Members

22q Foundation Australia & NZ
Addisons Australia
Allergy & Anaphylaxis Australia
Angelman Syndrome Association Australia
Ankylosing Spondylitis Victoria Inc
Arthritis Australia
Arthritis NSW
Arthritis Queensland
ausEE Inc.
Australia Alopecia Areata Foundation
Australian Dysphonia Network
Australian Sickle Cell Advocacy Inc
Australian Thyroid Foundation
Australiasian Mastocytosis Society
Batten Disease Australia
BEAT Bladder Cancer
Better Access Australia
Brain Foundation
Brain Tumour Alliance Australia
Brainwave
Cancer Council Australia
Cancer Voices NSW
Cataract Kids Australia
Centre for Community-Driven Research
Charcot-Marie-Tooth Association Australia
CHARGE Syndrome Australasia
Childhood Dementia Initiative
Cystic Fibrosis Australia
Cystic Fibrosis Community Care
Cystic Fibrosis Queensland
Dystonia Network of Australia Inc.
Eczema Association Australiasia
Eczema Support Australia
Ehlers-Danlos Syndrome Australia
FARA
FOP Australia
Foundation for Angelman Syndrome Therapeutics Australia
Fragile X Association of Australia
Genetic Alliance Australia
Genetic Support Network of Victoria
Global Healthy Living Foundation Australia
HAE Australasia
Haemochromatosis Australia
HCU Network Australia
Head and Neck Cancer Australia
HeartKids
Her Heart
Hidradentitis Supurrativa
HSP Research Foundation Inc
Hyperemesis Gravidarum Australia
Hypersomnolence Australia
Immune Deficiencies Foundation Australia (IDFA)
ITP Australia Ltd
Kidney Health Australia
Leukaemia Foundation
Limbs4Life
Lipoedema Australia
Liver Kids Australia
LiverWELL
Lyme Disease Association of Australia
Lymphoma Australia
Migraine Australia
Miracle Babies
Mito Foundation
MND Australia
Multiple Sclerosis Australia
Muscular Dystrophy Australia
Muscular Dystrophy New South Wales
Musculoskeletal Australia
Myeloproliferative Neoplasms Alliance Australia
Neuroendocrine Australia
Neuromuscular WA
Pain Australia
Pancare
Parenteral Nutrition Down Under Inc. (PNDU)
Pink Hope
PKD Australia
Prader-Willi Research Foundation Australia
Primary Ciliary Dyskinesia Australia
Racing for MNDi Foundation
Rare Cancers Australia
Rett Syndrome Association of Australia
Sanfilippo Children's Foundation
SATB2 Australia
Save Our Sons Duchenne Foundation
Scleroderma Victoria
SCNA2
Sleep Disorders Australia
So Brave Ltd.
Sotos Syndrome Association of Australasia
Spark of Gold
Stroke Foundation
Syndromes Without A Name (SWAN) Australia
Thalassaemia and Sickle Cell Australia
The Children’s Tumour Foundation
The Obesity Collective
Tourette Syndrome Association of Australia inc
Tuberous Sclerosis Australia
UsherKids Australia Ltd
Without A Ribbon

Section 2: About NPON members

About NPON members

NPON members overview

Data was extracted from the 2019 and 2022 Annual Information Statement Data from the Australian Charities and Not-for-profits commission (ACNC) (available from https://data.gov.au).

In 2019 and in 2022, most NPON members were small charities.

In 2019 the most common main activities were civic health service delivery, health service deliveries and education. The most common secondary activities were research, social services education and health service delivery.

In 2019 the most common main beneficiaries were people with chronic illness, the general community in Australia and people with disabilities. The most common secondary beneficiaries were families, people with disabilities, the general community in Australia, people with chronic illness and children and youth aged 6 to 25.

In 2019 most charities were located in New South Wales, Victoria or Queensland and these are the states that charities most commonly operated in.

In 2019, fundraising most commonly occurred in New South Wales, followed by Victoria, South Australia and online. In 20022 fundraising was most commonly online followed by New South Wales, Victoria, and South Australia.

Size of charity

Charity size is defined by revenue, small charities have a revenue of les than $250,000, medium have a revenue of between $250,000 to $999,999 and large have a revenue of $1,000,000 or more.

In 2019 there were 24 large charities (28.57%), 17 medium charities (20.24%), and 43 small charities (51.19%).

In 2022 there were 11 large charities (12.64%), 22 medium charities (25.29%), and 54 small charities (62.07%).

Table 2.1: Size of charity

Size of charity	2019		2022	
	n=84	Percent	n=87	Percent
Large	24	28.57	11	12.64
Medium	17	20.24	22	25.29
Small	43	51.19	54	62.07

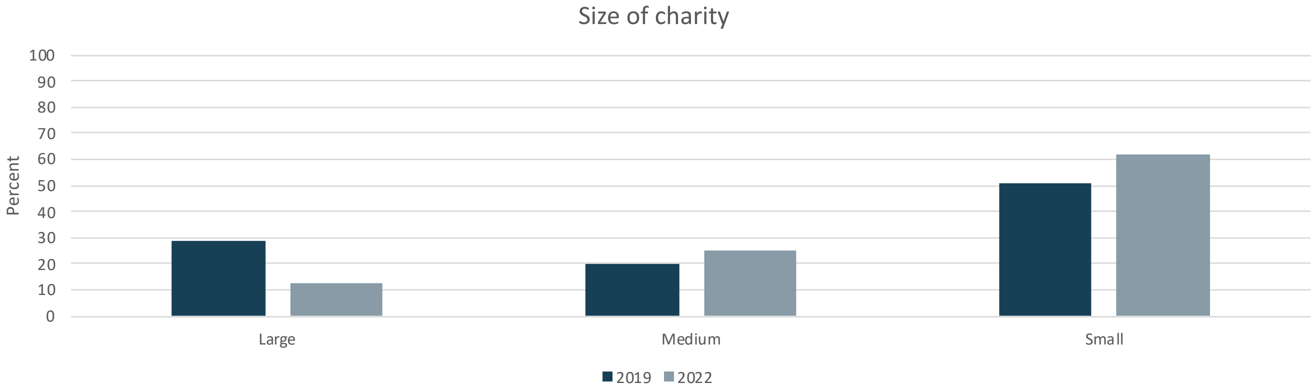


Figure 2.1: Size of charity

Main activities

The main activities were collected in 2019 only. The most common activities were civic and advocacy activities (n=29, 34.52%), other health service delivery (n=25, 29.76%), and other education (n=7, 8.33%). Other main activities included research (n=7, 8.33%), social services (n=7, 8.33%), grant-making activities (n=4, 4.76%), economic, social and community development (n=2, 2.38%), hospital services and rehabilitation activities (n=1, 1.19%), housing activities (n=1, 1.19%), mental health and crisis intervention (n=1, 1.19).

2019 Most common main activities

- Civic health service delivery
- Health service delivery
- Education

Table 2.2: Main activities

Main activity	2019	
	n=84	Percent
Civic and advocacy activities	29	34.52
Other health service delivery	25	29.76
Other education	7	8.33
Research	7	8.33
Social services	7	8.33
Grant-making activities	4	4.76
Economic, social and community development	2	2.38
Hospital services and rehabilitation activities	1	1.19
Housing activities	1	1.19
Mental health and crisis intervention	1	1.19

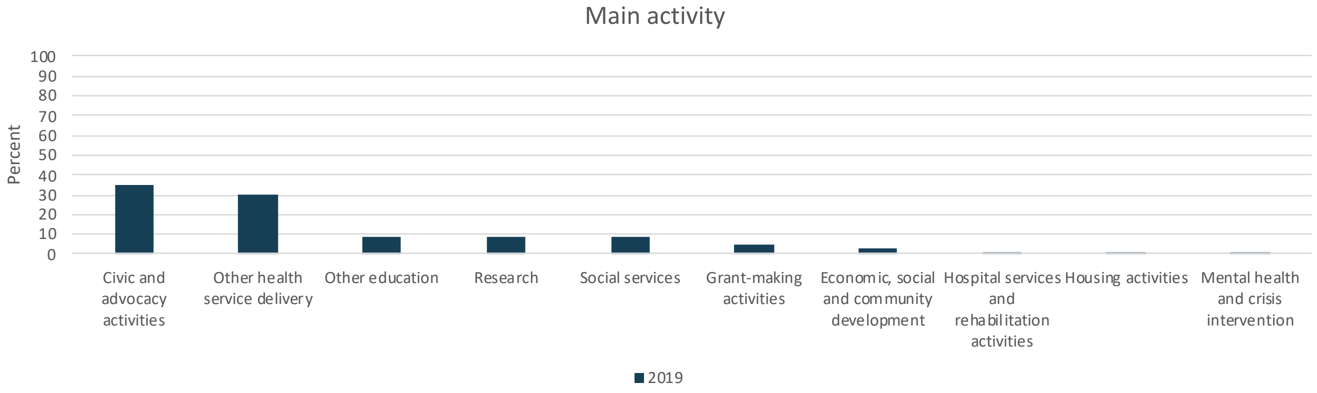


Figure 2.2: Main activities

Other activities

Other activities were collected in 2019 only. The most common activities were research (n=17, 20.24%), social services (n=16, 19.05%), other education (n=16, 19.05%), and other health service delivery (n=16, 19.05%). Other activities included grant-making activities (n=9, 10.71%), civic and advocacy activities (n=8, 9.52%), hospital services and rehabilitation activities (n=6, 7.14%), income support and maintenance (n=2, 2.38%), mental health and crisis intervention (n=2, 2.38%), other recreation (n=2, 2.38), other philanthropic intermediaries and voluntarism promotion (n=2, 2.38%), emergency relief (n=1, 1.19%), higher education (n=1, 1.19%), and primary and secondary education (n=1, 1.19%).

2019 Most common other activities

- Research
- Social services
- Education
- Health service delivery

Table 2.3: Other activities

All activities	2019	
	n=84	Percent
Research	17	20.24
Social services	16	19.05
Other education	16	19.05
Other health service delivery	16	19.05
Grant-making activities	9	10.71
Civic and advocacy activities	8	9.52
Hospital services and rehabilitation activities	6	7.14
Income support and maintenance	2	2.38
Mental health and crisis intervention	2	2.38
Other recreation	2	2.38
Other philanthropic intermediaries and voluntarism promotion	2	2.38
Emergency relief	1	1.19
Higher education	1	1.19
Primary and secondary education	1	1.19

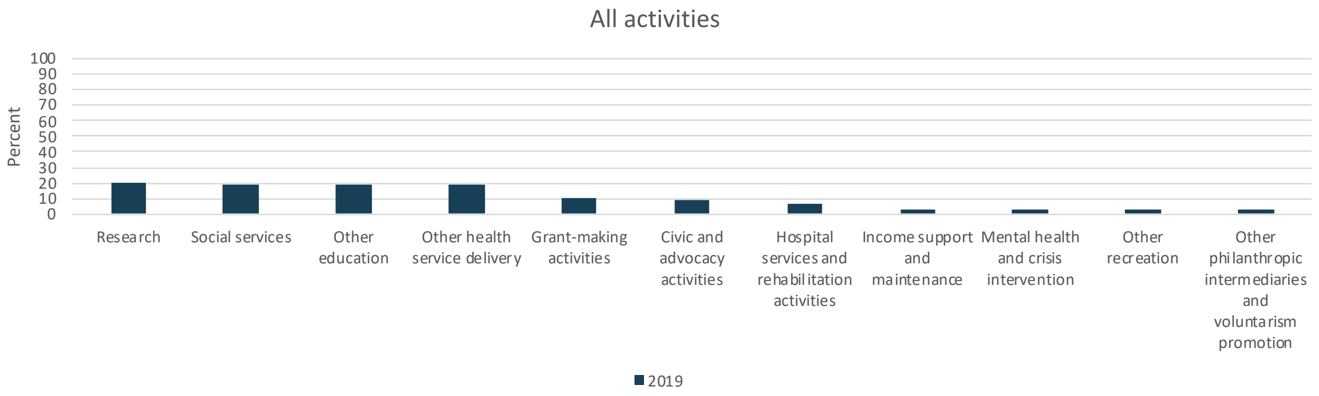


Figure 2.3: Other activities

International activities

Very few of the NPON member organisations engaged in international activities. In 2019 one organisation engaged in other international activities, and in 2022 there were 2 organisations that operated overseas programs and 1 in other international activities.

2019 International activities	**2022 full International activities**
- Other international activities	- Operating overseas including programs - Other international activities

Table 2.4: International activities

International actvities	2019		2022	
	n=84	Percent	n=87	Percent
Transferring goods or services overseas	0	0.00	0	0.00
Operating overseas including programs	0	0.00	2	2.30
Other international activities	1	1.19	1	1.15

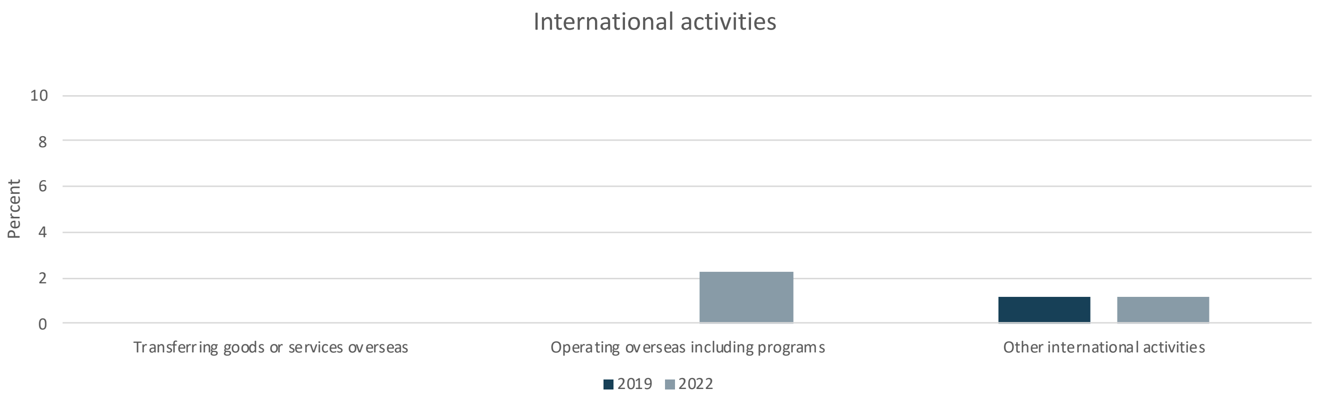


Figure 2.4: International activities

Main beneficiaries

The main beneficiaries were collected in 2019 only. The most common beneficiaries were people with chronic illness (including terminal illness) (n=36, 42.86%), general community in Australia (n=18, 21.43%), and people with disabilities (n=16, 19.05%). Other main beneficiaries included families (n=7, 8.33%), females (n=3, 3.57%), children - aged 6 to under 15 (n=2, 2.38%), adults - aged 25 to under 65 (n=1, 1.19%), and early childhood - aged under 6 (n=1, 1.19%).

2019 Most common main beneficiaries

- People with chronic illness
- General community in Australia
- People with disabilities

Table 2.5: Main beneficiaries

Main beneficiaries	2019	
	n=84	Percent
People with chronic illness (including terminal illness)	36	42.86
General community in Australia	18	21.43
People with disabilities	16	19.05
Families	7	8.33
Females	3	3.57
Children - aged 6 to under 15	2	2.38
Adults - aged 25 to under 65	1	1.19
Early childhood - aged under 6	1	1.19

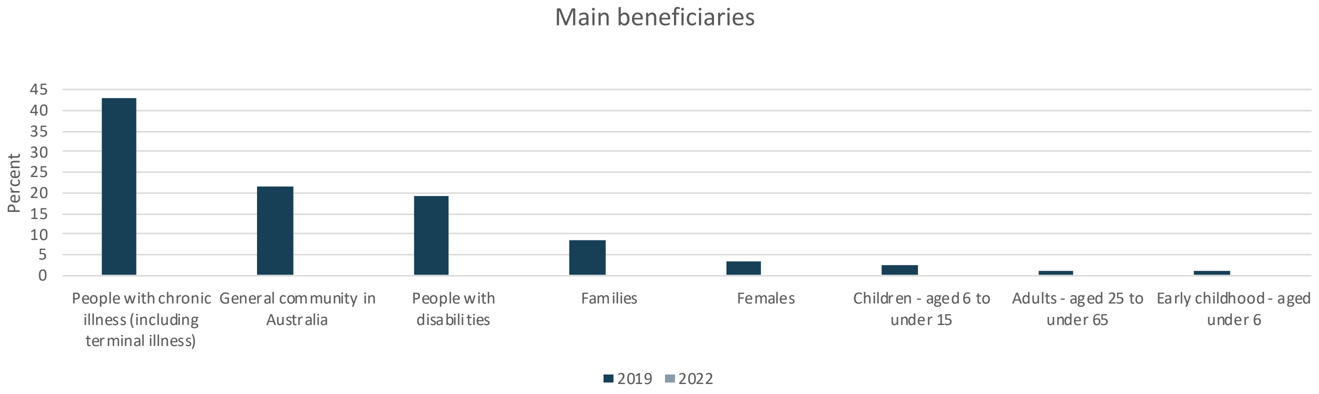


Figure 2.5: Main beneficiaries

Other beneficiaries

Other beneficiaries were collected in 2019 only. The most common beneficiaries were research (n=17, 20.24%), social services (n=16, 19.05%), other education (n=16, 19.05%), and other health service delivery (n=16, 19.05%). Other beneficiaries included, grant-making activities (n=9, 10.71%), civic and advocacy activities (n=8, 9.52%), hospital services and rehabilitation activities (n=6, 7.14%), income support and maintenance (n=2, 2.38%), mental health and crisis intervention (n=2, 2.38%), other recreation (n=2, 2.38).

Other beneficiaries were collected in 2019 only. The most common beneficiaries were families (n=22, 26.19%), people with disabilities (n=21, 25.00%), general community in australia (n=17, 20.24%), people with chronic illness (n=17, 20.24%), children - aged 6 to under 15 (n=14, 16.67%), and youth 15 to under 25 (n=13, 15.48%),

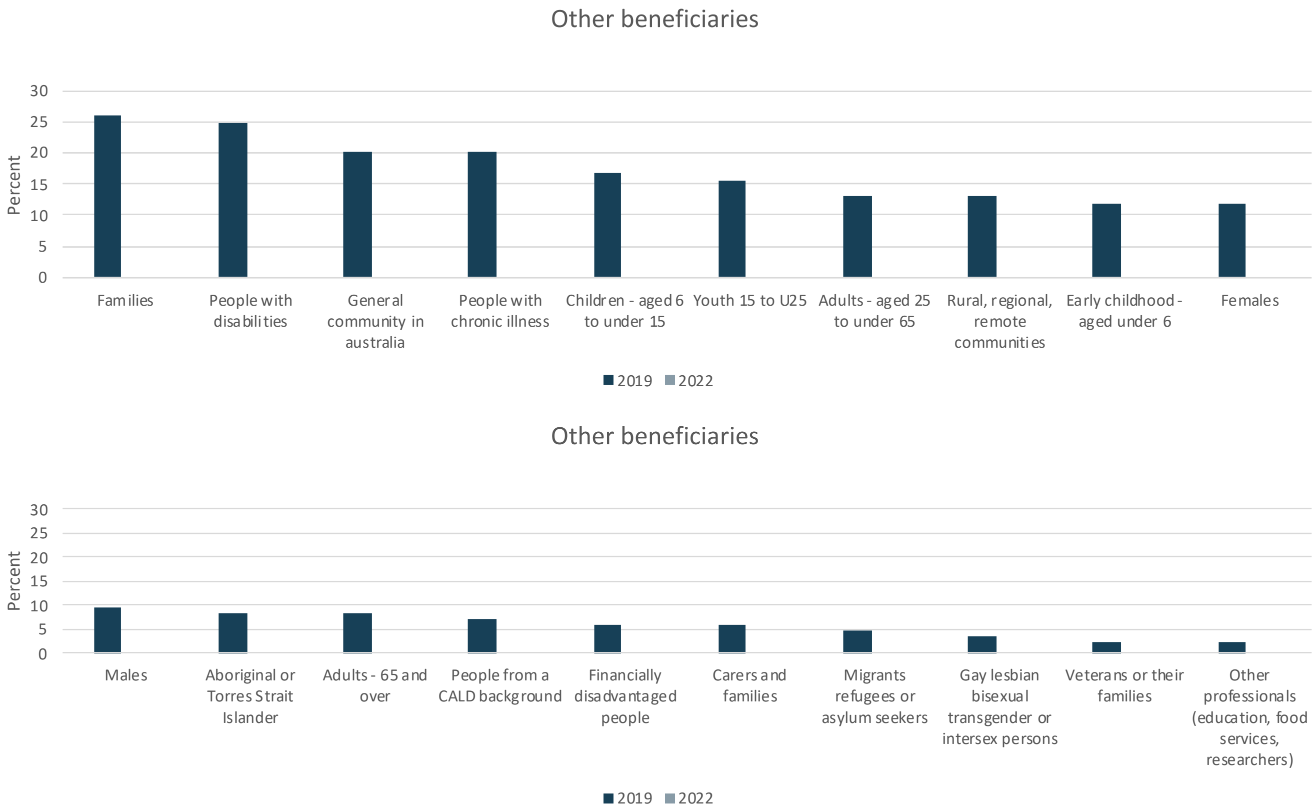
Other beneficiaries included adults - aged 25 to under 65 (n=11, 13.10%), rural, regional, remote communities (n=11, 13.10%), early childhood - aged under 6 (n=10, 11.90%), females (n=10, 11.90), males (n=8, 9.52%), Aboriginal or Torres Strait Islander (n=7, 8.33%), and adults - 65 and over (n=7, 8.33%). people from a CALD background (n=6, 7.14%), financially disadvantaged people (n=5, 5.95%), carers and families (n=5, 5.95%), migrants refugees or asylum seekers (n=4, 4.76%), gay lesbian bisexual transgender or intersex persons (n=3, 3.57%), veterans or their families (n=2, 2.38%), other professionals (education, food services, researchers) (n=2, 2.38), unemployed persons (n=1, 1.19%), and other charities (n=1, 1.19).

2019 Most common other beneficiaries

- Families
- People with disabilities
- General community in Australia
- People with chronic illness
- Children aged 6 to under 15
- Youth aged 15 to under 25

Table 2.6: Other beneficiaries

Other beneificiaries	2019	
	n=84	Percent
Families	22	26.19
People with disabilities	21	25.00
General community in Australia	17	20.24
People with chronic illness	17	20.24
Children - aged 6 to under 15	14	16.67
Youth 15 to U25	13	15.48
Adults - aged 25 to under 65	11	13.10
Rural, regional, remote communities	11	13.10
Early childhood - aged under 6	10	11.90
Females	10	11.90
Males	8	9.52
Aboriginal or Torres Strait Islander	7	8.33
Adults - 65 and over	7	8.33
People from a CALD background	6	7.14
Financially disadvantaged people	5	5.95
Carers and families	5	5.95
Migrants refugees or asylum seekers	4	4.76
Gay lesbian bisexual transgender or intersex persons	3	3.57
Veterans or their families	2	2.38
Other professionals (education, food services, researchers)	2	2.38
Unemployed persons	1	1.19
Other charities	1	1.19
Healthcare professionals	1	1.19


Other beneficiaries

Other beneficiaries

Figure 2.6: Other beneficiaries

Location of charity

Data was collected for location of charity in 2019 only. Charities were most commonly located in New South Wales (n=42, 54.55%), Victoria (n=17, 22.08%), and Queensland (n=12, 15.58%). There were four charities (5.19%) located in the Australian Capital Territory, one in South Australia (1.30%), and one in Western Australia (1.30%).

2019 Most common location of charities

- New South Wales
- Victoria
- Queensland

Table 2.7: Operates in states and territories

Location of charity: state or territiry	2019	
	n=84	Percent
New South Wales	42	54.55
Victoria	17	22.08
Queensland	12	15.58
Australian Capital Territory	4	5.19
South Australia	1	1.30
Western Australia	1	1.30

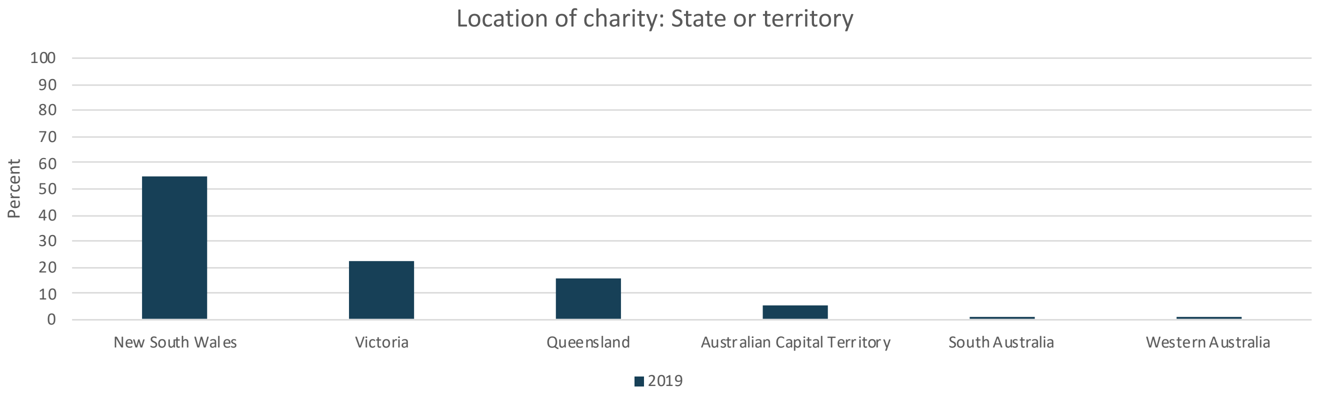


Figure 2.7: Operates in states and territories

Operates in states and territories

Data was collected for operations in states in territories in 2019 only. Charities most commonly operated in in New South Wales (n=75, 89.29%), Victoria (n=70, 83.33%), Queensland (n=65,77.38%), and Western Australia (n= 62,73.81%). There were 58% that operated in South Australia (69.05%), 57 in Tastmania (67.86%), 56 in the Australian Capital Territory (66.67%), and 48 charities in the Northern Territory (57.14%).

2019 Most common states and territories that charities operate in

- New South Wales
- Victoria
- Queensland
- Western Australia

Table 2.8: Operates in states and territories

Operates in states and territories	2019	
	n=84	Percent
NSW	75	89.29
Victoria	70	83.33
Queesnland	65	77.38
WA	62	73.81
SA	58	69.05
Tasmania	57	67.86
ACT	56	66.67
NT	48	57.14

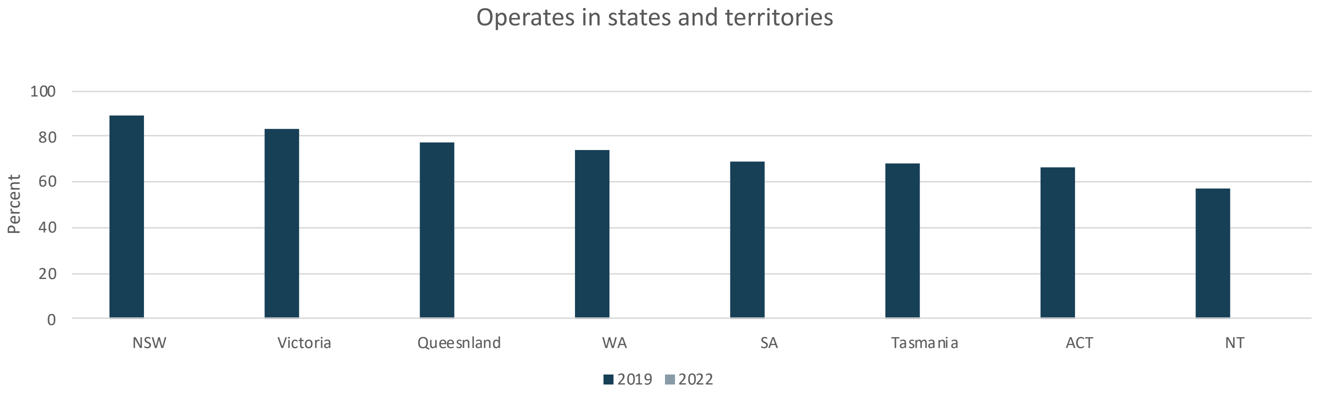


Figure 2.8: Operates in states and territories

Operates overseas

In 2019, some NPON charities operated overseas, there were 7 charities that operated in New Zealand, and one each that operated in Italy, United States, India, Malaysia and, Singapore.

2019 Operates overseas

- New Zealand
- Italy
- United State
- India
- Malaysia
- Singapore

Table 2.9: Operates overseas

Operates overseas	2019	
	n=84	Percent
New Zealand	6	7.14
Italy	1	1.19
United States	1	1.19
India	1	1.19
Malaysia	1	1.19
Singapore	1	1.19

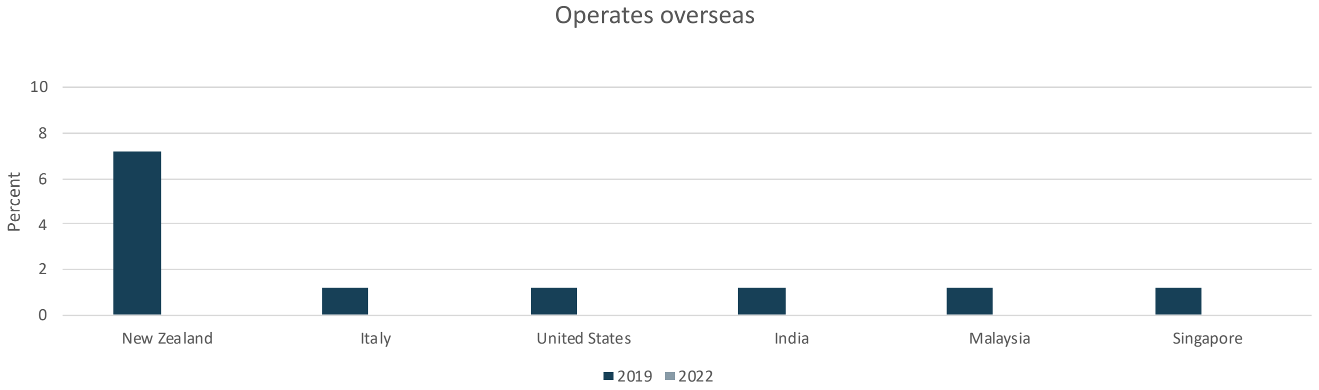


Figure 2.9: Operates overseas

Fundraising states, territories and online

In 2019, NPON charities most commonly conducted fundraising activies in New South Wales (n=57, 67.86%), Victoria (n=47, 55.95%), South Australia (n=43, 51.19%), and online (n=42, 50.00%). Fundraising was also conducted in Tasmania (n=34, 40.48%), the Australian Capital Territory (n=28, 33.33%), the Northern Territory (n=26, 30.95, and Western Australia (n=26, 30.95%).

In 2019, NPON charities most commonly conducted fundraising activies in online (n=62, 71.26%), New South Wales (n=61, 70.11%), Victoria (n=49, 56.32%), and South Australia (n=45, 51.72%),. Fundraising was also conducted in Tasmania (n=39, 44.83%), the Australian Capital Territory (n=32, 36.78%), Western Australia (n=29, 33.33%), the Northern Territory (n=28, 32.18%).

2019 Most common fundraising states, territories and online

- New South Wales
- Victoria
- South Australia
- Online

2022 Most common fundraising states, territories and online

- Online
- New South Wales
- Victoria
- South Australia

Table 2.10: Fundraising states, territories and online

Fundraising states, territories and online	2019		2022	
	n=84	Percent	n=87	Percent
ACT	28	33.33	32	36.78
NSW	57	67.86	61	70.11
NT	26	30.95	28	32.18
SA	43	51.19	45	51.72
Tasmania	34	40.48	39	44.83
Victoria	47	55.95	49	56.32
WA	26	30.95	29	33.33
Online	42	50.00	62	71.26

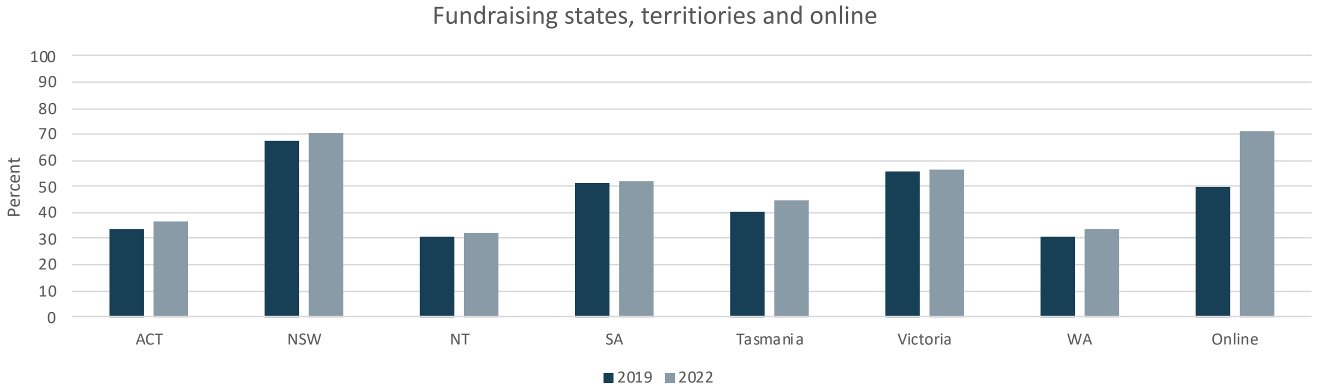


Figure 2.10: Fundraising states, territories and online

Section 3: Funding

Revenue

Total revenue

Data were extracted from the 2019 and 2022 Annual Information Statement Data from the Australian Charities and Not-for-profits commission (ACNC) (available from https://data.gov.au).

NPON members received revenue from the government, donations and bequests, goods and services, and interest. In 2019 the total revenue for NPON members ranged from $0 to $40,123,178 (median=$203,060; IQR = 1,309,706), and in total 84 member charities had a combined revenue of $174,225,904.

In 2022 the total revenue for NPON members ranged from 0 to 52,577,000 (median=$238,609; IQR=$1,094,001), and in total 87 member charities had a combined revenue of $213,762,418.

In 2019 84 NPON members had a combined income of $174,225,904.	In 2022 87 NPON members had a combined income of $213,762,418.

Table 3.1: Total revenue

Total revenue	2019		2022	
	n=84	Percent	n=87	Percent
0	3	3.57	1	1.15
5,000 or less	5	5.95	4	4.60
5,001 to 10,000	4	4.76	3	3.45
10,001 to 20,000	3	3.57	5	5.75
20,001 to 50,000	8	9.52	7	8.05
50,001 to 100,000	7	8.33	12	13.79
100,001 to 500,000	21	25.00	22	25.29
500,001 to 1,000,000	9	10.71	8	9.20
1,000,001 to 10,000,000	20	23.81	20	22.99
10,000,001 or more	4	4.76	5	5.75

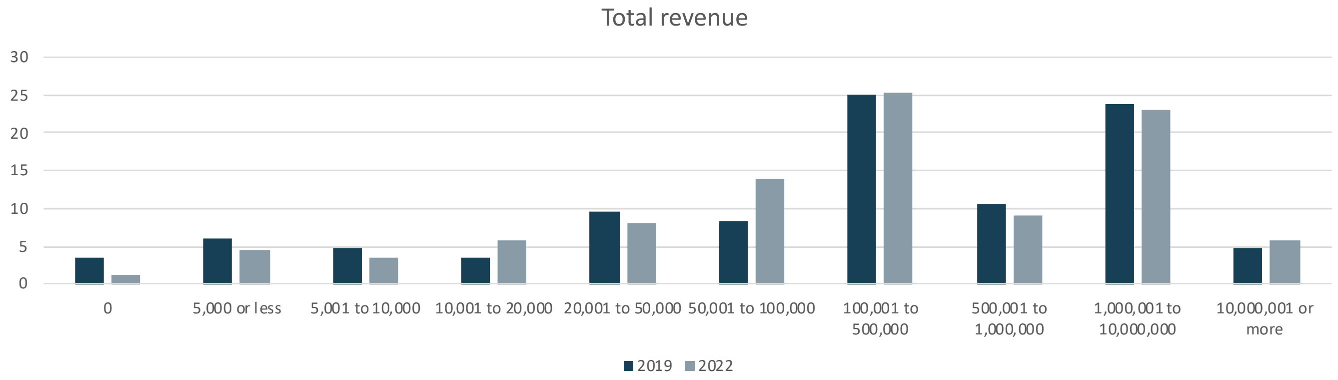


Figure 3.1: Total revenue

Revenue sources

Revenue sources overview

NPON members received most revenue from donations and bequests, followed by revenue from goods and services, the government and from investments.

In 2019 NPON members had a combined revenue of $84,172,049 from donations and bequests,

$49,531,630 from goods and services, $25,033,645 from the government, $4,157,929 from investments and $11,330,651 from other sources.

In 2022 NPON members had a combined revenue of $82,602,071 from donations and bequests, $64,201,383 from goods and services, $43,970,562 from the government, $2,959,915 from investments, and $20,029,473 from other sources.

Of the organisations that received government funding, two received over $10M, three received between one and $4M, four received between $500,000 and $1M, nineteen received between $100,000 and $300,000, fourteen received between $10,000 and $99,000, and six received between $900 and $6,000.

2019 NPON members combined revenue:	**2022 NPON members combined revenue:**
$84,172,049 from donations and bequests $49,531,630 from goods and services $25,033,645 from the government $4,157,929 from investments $11,330,651 from other sources	$82,602,071 from donations and bequests $64,201,383 from goods and services $43,970,562 from the government $2,959,915 from investments $20,029,473 from other sources

Revenue from donations and bequests

In 2019 76 NPON organisations had revenue from donations and bequests ranging from $20 to $35,511,285 (median = $87,554.50; IQR = $60,1139.25).

There were 8 organisations (9.52%) that had no revenue from donations and bequests, 9 organisations (10.71%) that had a revenue of $5,000 or less, 6 organisations (7.14%) that had revenue of between $5,001 and $10,000, 7 organisations (8.33%) had between $10,001 and $20,000 and 8 organisations (9.52%) had between $20,001 and $50,000.

At the higher end of revenue, there were 10 organisations (11.90%) that recieved between $50,001 and $100,000, 12 organisations (14.29%) that had a revenue of $100,001 and $500,000, 12 organisations (14.29%) that had revenue of between $500,001 and $1,000,000, 10 organisations (11.90%) had between $1,000,001 and $10,000,000 and 2 organisations (2.38%) had between $10,000,001 or more .

In 2022 81 NPON organisations had revenue from donations and bequests ranging from $45 to $25,277,983 (median = $126,679; IQR = $511,699).

There were 6 organisations (6.90%) that had no revenue from donations and bequests, 10 organisations (11.49%) that had a revenue of $5,000 or less, 6 organisations (6.90%) that had revenue of between $5,001 and $10,000, 6 organisations (6.90%) had between $10,001 and $20,000 and 12 organisations (13.79%) had between $20,001 and $50,000.

At the higher end of revenue, there were 5 organisations (5.75%) that recieved between $50,001 and $100,000, 20 organisations (22.99%) that had a revenue of $100,001 and $500,000, 9 organisations (10.34%) that had revenue of between $500,001 and $1,000,000, 11 organisations (12.64%) had between $1,000,001 and $10,000,000 and 2 organisations (2.30%) had between $10,000,001 or more .

2019 revenue from donations and bequests	**2022 revenue from donations and bequests**
• 76 organisations received donations and bequests • Average (median) $87,554.50; IQR = $60,1139.25 • Range from $20 to $35,511,285 • 2019 NPON members combined revenue of $84,172,049	• 81 organisations received donations and bequests • Average (median) $126,679; IQR = $511,699 • Range from $45 to $25,277,983 • 2022 NPON members combined revenue of $82,602,071

Table 3.2: Revenue from donations and bequests

Donations and bequests	2019		2022	
	n=84	Percent	n=87	Percent
0	8	9.52	6	6.90
5,000 or less	9	10.71	10	11.49
5,001 to 10,000	6	7.14	6	6.90
10,001 to 20,000	7	8.33	6	6.90
20,001 to 50,000	8	9.52	12	13.79
50,001 to 100,000	10	11.90	5	5.75
100,001 to 500,000	12	14.29	20	22.99
500,001 to 1,000,000	12	14.29	9	10.34
1,000,001 to 10,000,000	10	11.90	11	12.64
10,000,001 or more	2	2.38	2	2.30

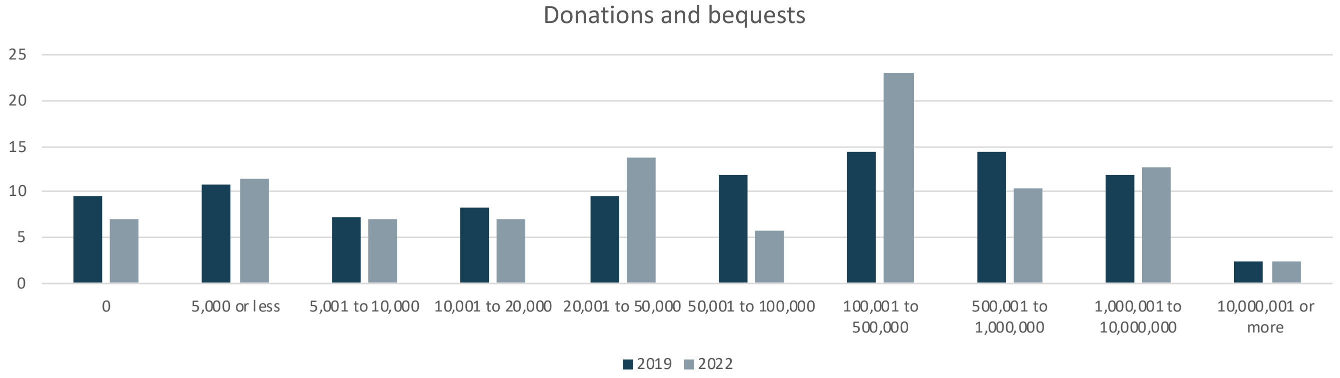


Figure 3.2: Revenue from donations and bequests

Revenue from goods and services

In 2019 53 NPON organisations had revenue from goods and services ranging from $82 to $31,505,000 (median = $26,171; IQR = $239,027).

There were 31 organisations (36.90%) that had no revenue from goods ans services, 16 organisations (19.05%) that had a revenue of $5,000 or less, 2 organisations (2.38%) that had revenue of between $5,001 and $10,000, 5 organisations (5.95%) had between $10,001 and $20,000 and 9 organisations (10.71%) had between $20,001 and $50,000.

At the higher end of revenue, there were 4 organisations (4.76%) that recieved between $50,001 and $100,000, 10 organisations (11.90%) that had a revenue of $100,001 and $500,000, 1 organisations (1.19%) that had revenue of between $500,001 and $1,000,000, 5 organisations (5.95%) had between $1,000,001 and $10,000,000 and 1 organisations (1.19%) had between $10,000,001 or more .

In 2022 52 NPON organisations had revenue from goods and services ranging from $27 to $41,224,000 (median = $53,780; IQR = $189,312.25).

There were 35 organisations (40.23%) that had no revenue from goods ans services, 19 organisations (21.84%) that had a revenue of $5,000 or less, 1 organisations (1.15%) that had revenue of between $5,001 and $10,000, 3 organisations (3.45%) had between $10,001 and $20,000 and 2 organisations (2.30%) had between $20,001 and $50,000.

At the higher end of revenue, there were 9 organisations (10.34%) that recieved between $50,001 and $100,000, 11 organisations (12.64%) that had a revenue of $100,001 and $500,000, 1 organisations (1.15%) that had revenue of between $500,001 and $1,000,000, 5 organisations (5.75%) had between $1,000,001 and $10,000,000 and 1 organisations (1.15%) had between $10,000,001 or more .

2019 revenue from goods and services

- 53 organisations received revenue from goods and services
- Median = $26,171; IQR = $239,027
- Range from $82 to $31,505,000
- 2019 NPON members combined revenue of $49,531,630

2022 revenue from goods and services

- 52 organisations received revenue from goods and services
- Median = $53,780; IQR = $189,312.25
- Range from $27 to $41,224,000
- 2022 NPON members combined revenue of $64,201,383

Table 3.3: Revenue from goods and services

Revenue from goods and services	2019		2022	
	n=84	Percent	n=87	Percent
0	31	36.90	35	40.23
5,000 or less	16	19.05	19	21.84
5,001 to 10,000	2	2.38	1	1.15
10,001 to 20,000	5	5.95	3	3.45
20,001 to 50,000	9	10.71	2	2.30
50,001 to 100,000	4	4.76	9	10.34
100,001 to 500,000	10	11.90	11	12.64
500,001 to 1,000,000	1	1.19	1	1.15
1,000,001 to 10,000,000	5	5.95	5	5.75
10,000,001 or more	1	1.19	1	1.15

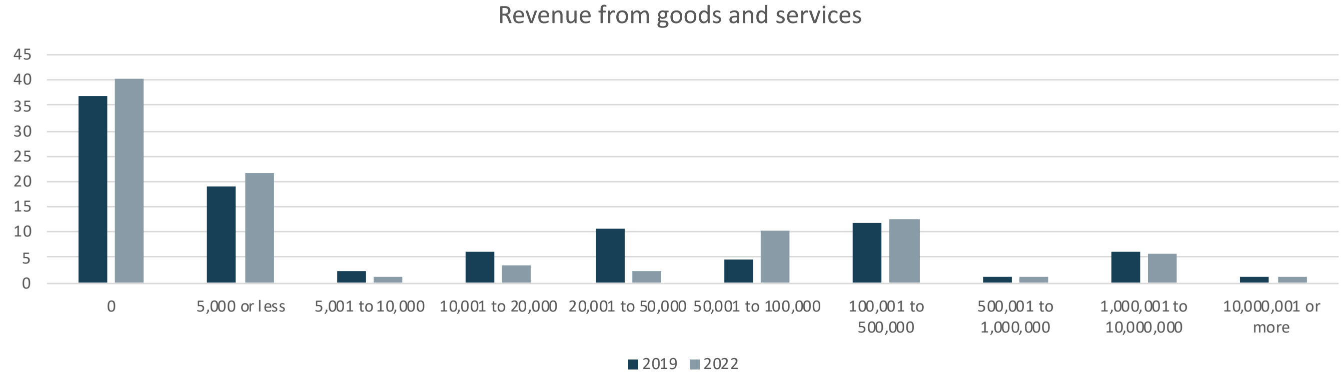


Figure 3. 3: Revenue from goods and services

Revenue from the government

In 2019 40 NPON organisations had revenue from government ranging from $2,760 to $7,879,000 (median = $87,650; IQR = $378,299).

There were 44 organisations (52.38%) that had no revenue from government, 3 organisations (3.57%) that had a revenue of $5,000 or less, 5 organisations (5.95%) that had revenue of between $5,001 and $10,000, 3 organisations (3.57%) had between $10,001 and $20,000 and 5 organisations (5.95%) had between $20,001 and $50,000.

At the higher end of revenue, there were 5 organisations (5.95%) that recieved between $50,001 and $100,000, 11 organisations (13.10%) that had a revenue of $100,001 and $500,000, 3 organisations (3.57%) that had revenue of between $500,001 and $1,000,000, 5 organisations (5.95%) had between $1,000,001 and $10,000,000 and 0 organisations (0.00%) had between $10,000,001 or more .

In 2022 48 NPON organisations had revenue from government ranging from $940 to $1,7302,295 (median = $157,954; IQR = $290,319.50).

There were 39 organisations (44.83%) that had no revenue from government, 5 organisations (5.75%) that had a revenue of $5,000 or less, 2 organisations (2.30%) that had revenue of between $5,001 and $10,000, 6 organisations (6.90%) had between $10,001 and $20,000 and 5 organisations (5.75%) had between $20,001 and $50,000.

At the higher end of revenue, there were 2 organisations (2.30%) that recieved between $50,001 and $100,000, 19 organisations (21.84%) that had a revenue of $100,001 and $500,000, 4 organisations (4.60%) that had revenue of between $500,001 and $1,000,000, 3 organisations (3.45%) had between $1,000,001 and $10,000,000 and 2 organisations (2.30%) had between $10,000,001 or more .

2019 revenue from the government

- 40 organisations received from the government
- Median = $87,650; IQR = $378,299
- Range from $2,760 to $7,879,000
- 2019 NPON members combined revenue of $25,033,645

2022 revenue from the government

- 48 organisations received from the government
- Median = $157,954; IQR = $290,319.50
- Range from $940 to $17,302,295
- 2022 NPON members combined revenue of $43,970,562

Table 3.4: Revenue from the government

Revenue from government	2019		2022	
	n=84	Percent	n=87	Percent
0	44	52.38	39	44.83
5,000 or less	3	3.57	5	5.75
5,001 to 10,000	5	5.95	2	2.30
10,001 to 20,000	3	3.57	6	6.90
20,001 to 50,000	5	5.95	5	5.75
50,001 to 100,000	5	5.95	2	2.30
100,001 to 500,000	11	13.10	19	21.84
500,001 to 1,000,000	3	3.57	4	4.60
1,000,001 to 10,000,000	5	5.95	3	3.45
10,000,001 or more	0	0.00	2	2.30

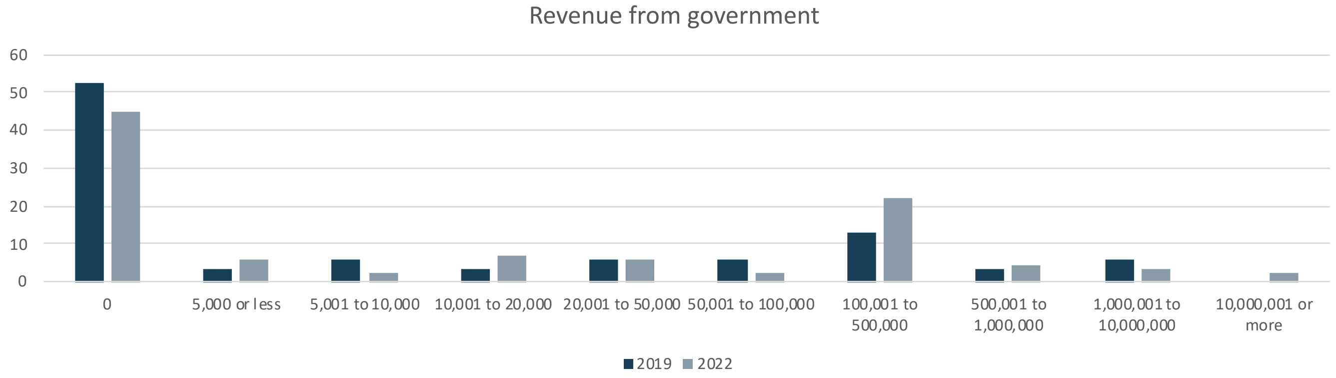


Figure 3. 4: Revenue from the government

Revenue from investments

In 2019 58 NPON organisations had revenue from investments ranging from $7 to $669,878 (median = $5313.50; IQR = $25557.50).

There were 26 organisations (30.95%) that had no revenue from investments, 29 organisations (34.52%) that had a revenue of $5,000 or less, 6 organisations (7.14%) that had revenue of between $5,001 and $10,000, 3 organisations (3.57%) had between $10,001 and $20,000 and 8 organisations (9.52%) had between $20,001 and $50,000.

At the higher end of revenue, there were 10 organisations (11.90%) that recieved between $50,001 and $100,000, and 2 organisations (2.38%) that had a revenue of $100,001 and $500,000.

In 2022 51 NPON organisations had revenue from investments ranging from $1 to $647,292 (median = $1,158; IQR = $21,539).

There were 36 organisations (41.38%) that had no revenue from investments, 32 organisations (36.78%) that had a revenue of $5,000 or less, 4 organisations (4.60%) that had revenue of between $5,001 and $10,000, 2 organisations (2.30%) had between $10,001 and $20,000 and 3 organisations (3.45%) had between $20,001 and $50,000.

At the higher end of revenue, there was 1 organisation (1.15%) that recieved between $50,001 and $100,000, 8 organisations (9.20%) that had a revenue of $100,001 and $500,000, and 1 organisation (1.15%) that had revenue of between $500,001 and $1,000,000.

2019 revenue from investments

- 58 organisations received investments
- Median = $5313.50; IQR = $25557.50
- Range from $7 to $669,878
- 2019 NPON members combined revenue of $4,157,929

2022 revenue from investments

- 51 organisations received investments
- Median = $1,158; IQR = $21,539
- Range from $1 to $647,292
- 2022 NPON members combined revenue of $2,959,915

Table 3.5: Revenue from investments

Income from investments	2019		2022	
	n=84	Percent	n=87	Percent
0	26	30.95	36	41.38
5,000 or less	29	34.52	32	36.78
5,001 to 10,000	6	7.14	4	4.60
10,001 to 20,000	3	3.57	2	2.30
20,001 to 50,000	8	9.52	3	3.45
50,001 to 100,000	10	11.90	1	1.15
100,001 to 500,000	2	2.38	8	9.20
500,001 to 1,000,000	0	0.00	1	1.15
1,000,001 or more	0	0.00	0	0.00

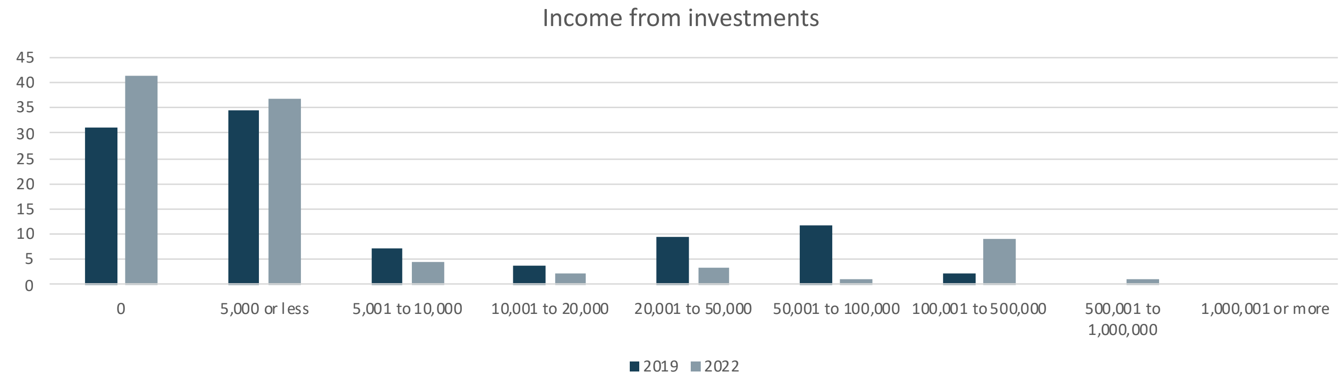


Figure 3. 5: Revenue from investments

Revenue from other sources

In 2019 57 NPON organisations had all other revenue ranging from $16 to $4,162,050 (median = $34,996; IQR = $120,249).

There were 27 organisations (32.14%) that had no revenue from other sources, 21 organisations (25.00%) that had a revenue of $5,000 or less, 2 organisations (2.38%) that had revenue of between $5,001 and $10,000, 3 organisations (3.57%) had between $10,001 and $20,000 and 5 organisations (5.95%) had between $20,001 and $50,000.

At the higher end of revenue, there were 8 organisations (9.52%) that recieved between $50,001 and $100,000, 13 organisations (15.48%) that had a revenue of $100,001 and $500,000, 2 organisations (2.38%) that had revenue of between $500,001 and $1,000,000, 2 organisations (2.38%) had between $1,000,001 and $10,000,000 and 1 organisation (1.19%) had between $10,000,001 or more .

In 2022 54 NPON organisations had all other revenue ranging from $10 to $11,239,601 (median = $18,591; IQR = $105,068.75).

There were 33 organisations (37.93%) that had no revenue from other sources, 18 organisations (20.69%) that had a revenue of $5,000 or less, 2 organisations (2.30%) that had revenue of between $5,001 and $10,000, 8 organisations (9.20%) had between $10,001 and $20,000 and 6 organisations (6.90%) had between $20,001 and $50,000.

At the higher end of revenue, there were 5 organisations (5.75%) that recieved between $50,001 and $100,000, 11 organisations (12.64%) that had a revenue of $100,001 and $500,000, 3 organisations (3.45%) had between $1,000,001 and $10,000,000 and 1 organisation (1.15%) had between $10,000,001 or more .

2019 revenue from other sources

- 57 organisations received
- Median = $34,996; IQR = $120,249
- Range from $16 to $4,162,050
- 2019 NPON members combined revenue of $11,330,651

2022 revenue from other sources

- 54 organisations received other sources
- Median = $18,591; IQR = $105,068.75
- Range from $10 to $11,239,601
- 2022 NPON members combined revenue of $20,029,473

Table 3.6: Revenue from other sources

Income from other sources	2019		2022	
	n=84	Percent	n=87	Percent
0	27	32.14	33	37.93
5,000 or less	21	25.00	18	20.69
5,001 to 10,000	2	2.38	2	2.30
10,001 to 20,000	3	3.57	8	9.20
20,001 to 50,000	5	5.95	6	6.90
50,001 to 100,000	8	9.52	5	5.75
100,001 to 500,000	13	15.48	11	12.64
500,001 to 1,000,000	2	2.38	0	0.00
1,000,001 to 10,000,000	2	2.38	3	3.45
10,000,001 or more	1	1.19	1	1.15

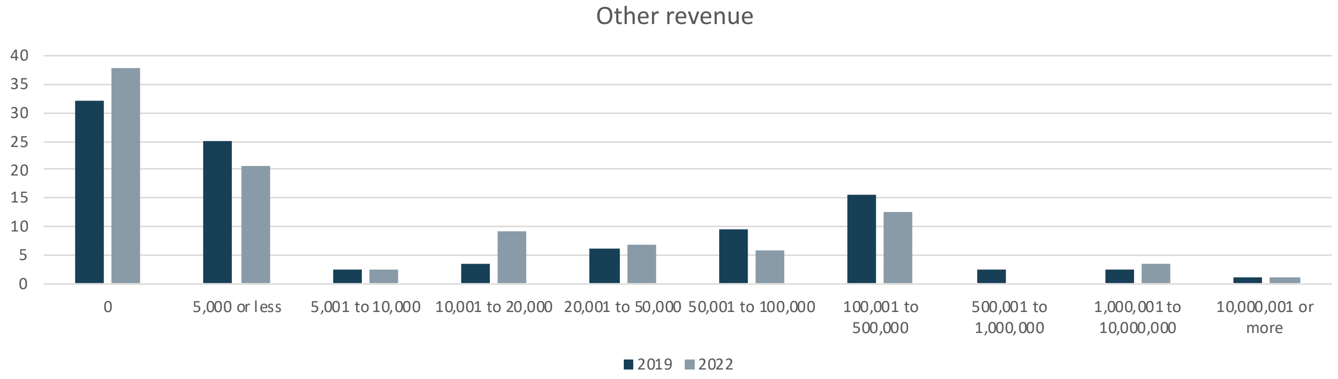


Figure 3. 6: Revenue from other sources

Net surplus/deficit

Net surplus/deficit

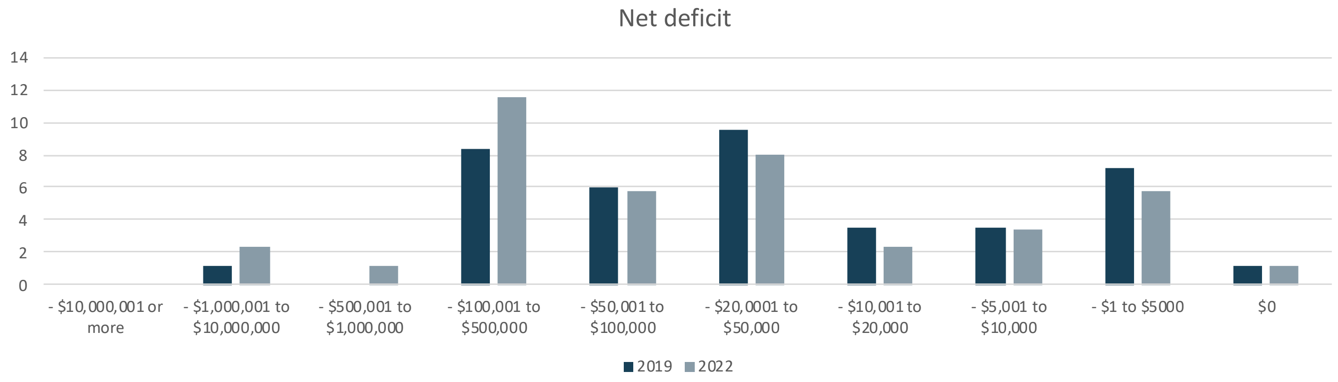
In 2019 33 NPON organisations were in deficit ranging from -$332 to -$1342248 (median = -$26542.50; IQR = $85986.25). 51 organisations were even or had a surplus ranging from $0 to $4,670,694 (median = $65,153; IQR = $199,142.50).

In 2022 35 NPON organisations were in deficit ranging from -$822 to -$3,453,489 (median = -$55,856; IQR = $172,057). 52 organisations were even or had a surplus ranging from $0 to $5,022,824 (median = $65,153; IQR = $199,142.50).

2019 Net surplus/deficit	2022 Net surplus/deficit
• 33 NPON organisations were in deficit ranging from -$332 to -$1342248 • 51 organisations were even or had a surplus ranging from $0 to $4,670,694	• 35 NPON organisations were in deficit ranging from -$822 to -$3,453,489 (median = -$55,856; IQR = $172,057). • 52 organisations were even or had a surplus ranging from $0 to $5,022,824

Table 3.7: Net surplus/deficit

Net surplus/deficit	2019		2022	
	n=84	Percent	n=87	Percent
- $10,000,001 or more	0	0.00	0	0.00
- $1,000,001 to $10,000,000	1	1.19	2	2.30
- $500,001 to $1,000,000	0	0.00	1	1.15
- $100,001 to $500,000	7	8.33	10	11.49
- $50,001 to $100,000	5	5.95	5	5.75
- $20,0001 to $50,000	8	9.52	7	8.05
- $10,001 to $20,000	3	3.57	2	2.30
- $5,001 to $10,000	3	3.57	3	3.45
- $1 to $5000	6	7.14	5	5.75
$0	1	1.19	1	1.15
$5,000 or less	10	11.90	7	8.05
$5,001 and $10,000	3	3.57	2	2.30
$10,001 and $20,000	7	8.33	6	6.90
$20,001 and $50,000	2	2.38	9	10.34
$50,001 and $100,000	5	5.95	3	3.45
$100,001 and $500,000	18	21.43	17	19.54
$500,001 and $1,000,000	1	1.19	6	6.90
$1,000,001 and $10,000,000	4	4.76	1	1.15
$10,000,001 or more	0	0.00	0	0.00



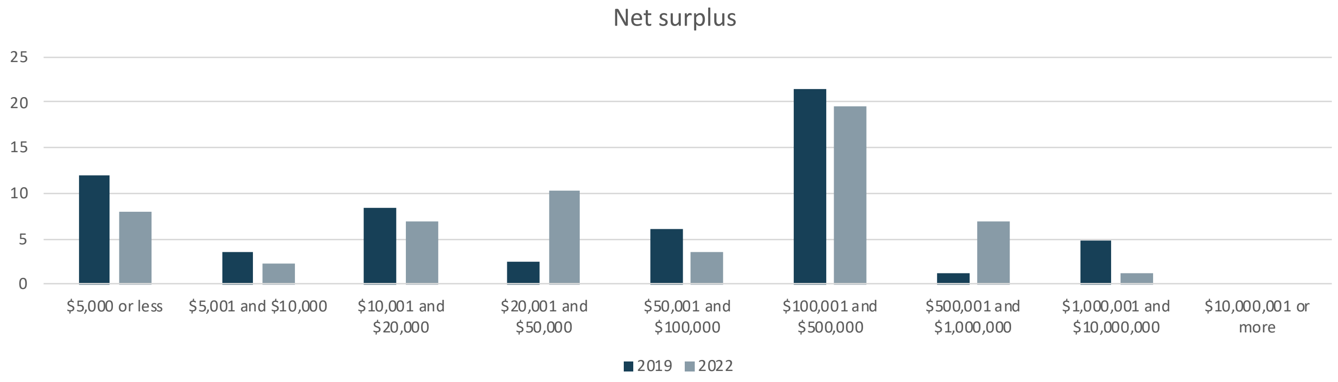


Figure 3.7: Revenue from donations and bequests

Section 4: Expenditure

Total expenses

Total expenses

Data were extracted from the 2019 and 2022 Annual Information Statement Data from the Australian Charities and Not-for-profits commission (ACNC) (available from https://data.gov.au).

NPON members had expenses from employees, interest, and grants and donations both within and outside Australia.

In 2019 82 NPON organisations had total expenses ranging from $1988 to $39677000 (median = $210,918.50; IQR = $1,207,956.25), and in total 84 member charities had combined expenses of $16,5701,905.

In 2022 86 NPON organisations had total expenses ranging from $762 to $52,233,000 (median = $211,233.50; IQR = $1,249,855), and in total 87 member charities had combined expenses of $211,183,329.

In 2019, 84 NPON member charities had combined expenses of $16,5701,905.

In 2022, 87 NPON member charities had combined expenses of $211,183,329.

Table 4.1: Total expenses

Total expenses	2019		2022	
	n=84	Percent	n=87	Percent
0	2	2.38	1	1.15
5,000 or less	5	5.95	5	5.75
5,001 to 10,000	0	0.00	8	9.20
10,001 to 20,000	4	4.76	3	3.45
20,001 to 50,000	13	15.48	8	9.20
50,001 to 100,000	8	9.52	8	9.20
100,001 to 500,000	19	22.62	20	22.99
500,001 to 1,000,000	9	10.71	8	9.20
1,000,001 to 10,000,000	20	23.81	21	24.14
10,000,001 or more	4	4.76	5	5.75

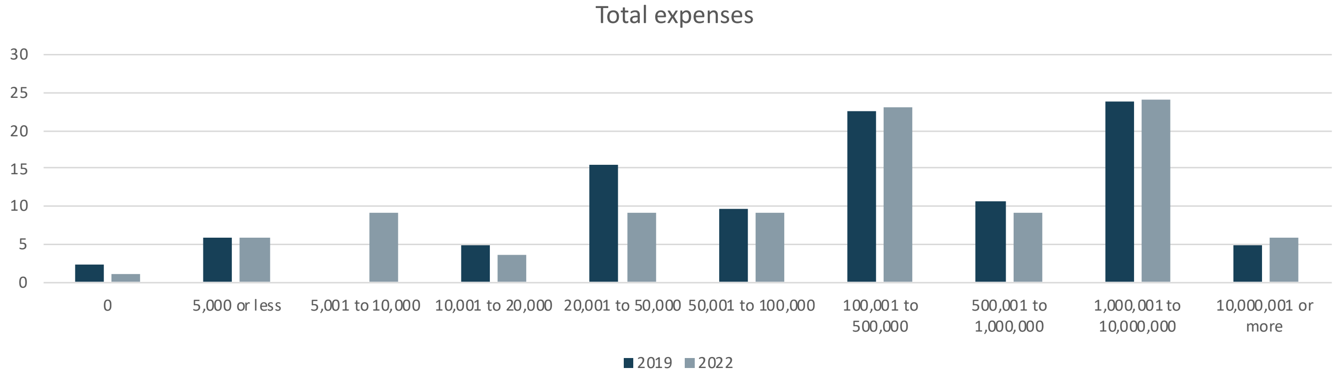


Figure 4.1: Total expenses

Total expenses overview

Total expenses overview

NPON members had most expenses from employees, grants and donations, and from interest.

In 2019 NPON members had a combined revenue of $84,172,049 from donations and bequests, $49,531,630 from goods and services, $25,033,645 from the government, $4,157,929 from investments and $11,330,651 from other sources.

In 2022 NPON members had a combined revenue of $82,602,071 from donations and bequests, $64,201,383 from goods and services, $43,970,562 from the government, $2,959,915 from investments, and $20,029,473 from other sources.

n 2019 48 NPON organisations had employee expenses ranging from $3500 to $21,837,000 (median = $400,102.50; IQR = $694,150), and in total 84 member charities had combined expenses of $72,897,705.

84 member charities had combined expenses of:

- Employee expenses: $72,897,705.
- Grants and donations made for use in Australia: $12,567,468
- Grants and donations made for use outside Australia: $985,087
- Interest expenses: $122,047

87 member charities had combined expenses of:

- Employee expenses: $84,559,608.
- Grants and donations made for use in Australia: $13,094,383.
- Grants and donations made for use outside Australia: $1,191,294.
- Interest expenses: $84,245.

Expenses sources

Employee expenses

In 2019 48 NPON organisations had employee expenses ranging from $3500 to $21,837,000 (median = $400,102.50; IQR = $694,150), and in total 84 member charities had combined expenses of $72,897,705.

There were 36 organisations (42.86%) that had no expenses from employee expenses, 1 organisation (1.19%) that had a expenses of $5,000 or less, and 4 organisations (4.76%) had expenses between $20,001 and $50,000.

At the higher end of expenses, there were 7 organisations (8.33%) that spent between $50,001 and $100,000, 18 organisations (21.43%) that had expenses of $100,001 and $500,000, 9 organisations (10.71%) that had costs of between $500,001 and $1,000,000, 7 organisations (8.33%) had expenses between $1,000,001 and $10,000,000 and 2 organisations (2.38%) had expenses between $10,000,001 or more .

In 2022 52 NPON organisations had employee expenses ranging from $4,760 to $29,292,000 (median = $385,325; IQR = $760,894), and in total 87 member charities had combined expenses of $84,559,608.

There were 35 organisations (40.23%) that had no expenses from employee expenses, 1 organisations (1.15%) that had a expenses of $5,000 or less, 0 organisations (0.00%) that had expenses of between $5,001 and $10,000, 3 organisations (3.45%) had between $10,001 and $20,000 and 4 organisations (4.60%) had expenses between $20,001 and $50,000.

At the higher end of expenses, there were 5 organisations (5.75%) that spent between $50,001 and $100,000, 17 organisations (19.54%) that had expenses of $100,001 and $500,000, 10 organisations (11.49%) that had costs of between $500,001 and $1,000,000, 10 organisations (11.49%) had expenses between $1,000,001 and $10,000,000 and 2 organisations (2.30%) had expenses between $10,000,001 or more .

2019 employee expenses

- 48 NPON organisations had employee expenses
- Range: $3500 to $21837000
- Median = $400102.5; IQR = $694150
- 84 member charities had combined expenses of $72,897,705.

2022 employee expenses

- 52 NPON organisations had employee expenses
- Range: $4,760 to $29,292,000
- Median = $385,325; IQR = $760,894
- 87 member charities had combined expenses of $84559608.

Table 4.2: Employee expenses

Employee expenses	2019		2022	
	n=84	Percent	n=87	Percent
0	36	42.86	35	40.23
5,000 or less	1	1.19	1	1.15
5,001 to 10,000	0	0.00	0	0.00
10,001 to 20,000	0	0.00	3	3.45
20,001 to 50,000	4	4.76	4	4.60
50,001 to 100,000	7	8.33	5	5.75
100,001 to 500,000	18	21.43	17	19.54
500,001 to 1,000,000	9	10.71	10	11.49
1,000,001 to 10,000,000	7	8.33	10	11.49
10,000,001 or more	2	2.38	2	2.30

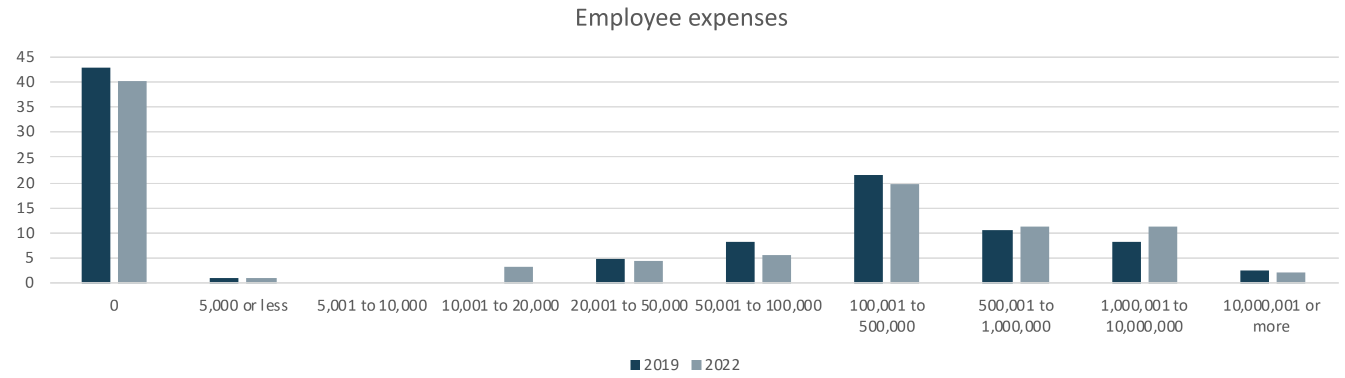


Figure 4.2: Employee expenses

Grants and donations made for use in Australia

In 2019 36 NPON organisations had grants and donations made for use in Australia ranging from $1,955 to $2,450,747 (median = $149,025; IQR = $503,955.25), and in total 84 member charities had combined expenses of $12,567,468.

There were 48 organisations (57.14%) that had no expenses from grants and donations made for use in Australia, 3 organisations (3.57%) that had a expenses of $5,000 or less, 2 organisations (2.38%) had between $10,001 and $20,000 and 6 organisations (7.14%) had expenses between $20,001 and $50,000.

At the higher end of expenses, there were 3 organisations (3.57%) that spent between $50,001 and $100,000, 12 organisations (14.29%) that had expenses of $100,001 and $500,000, 7 organisations (8.33%) that had costs of between $500,001 and $1,000,000, and 3 organisations (3.57%) had expenses between $1,000,001 and $10,000,000.

In 2022 32 NPON organisations had grants and donations made for use in Australia ranging from $2 to $6,092,203 (median = $97,374; IQR =

$420,230.25), and in total 87 member charities had combined expenses of $13,094,383.

There were 55 organisations (63.22%) that had no expenses from grants and donations made for use in Australia, 5 organisations (5.75%) that had a expenses of $5,000 or less, 2 organisations (2.30%) that had expenses of between $5,001 and $10,000, 1 organisation (1.15%) had between $10,001 and $20,000 and 3 organisations (3.45%) had expenses between $20,001 and $50,000.

At the higher end of expenses, there were 5 organisations (5.75%) that spent between $50,001 and $100,000, 10 organisations (11.49%) that had expenses of $100,001 and $500,000, 4 organisations (4.60%) that had costs of between $500,001 and $1,000,000, and 2 organisations (2.30%) had expenses between $1,000,001 and $10,000,000.

2019 Grants and donations made for use in Australia

- 36 NPON organisations had grants and donations made for use in Australia
- Range: $1,955 to $2,450,747
- Median = $149,025; IQR = $503,955.25
- 84 member charities had combined expenses of $12,567,468

2022 Grants and donations made for use in Australia

- 32 NPON organisations had grants and donations made for use in Australia
- Range: $2 to $6,092,203
- Median = $97,374; IQR = $420,230.25
- 87 member charities had combined expenses of $13,094,383.

Table 4.3: Grants and donations made for use in Australia

Grants and donations made for use in Australia	2019		2022	
	n=84	Percent	n=87	Percent
0	48	57.14	55	63.22
5,000 or less	3	3.57	5	5.75
5,001 to 10,000	0	0.00	2	2.30
10,001 to 20,000	2	2.38	1	1.15
20,001 to 50,000	6	7.14	3	3.45
50,001 to 100,000	3	3.57	5	5.75
100,001 to 500,000	12	14.29	10	11.49
500,001 to 1,000,000	7	8.33	4	4.60
1,000,001 to 10,000,000	3	3.57	2	2.30
10,000,001 or more	0	0.00	0	0.00

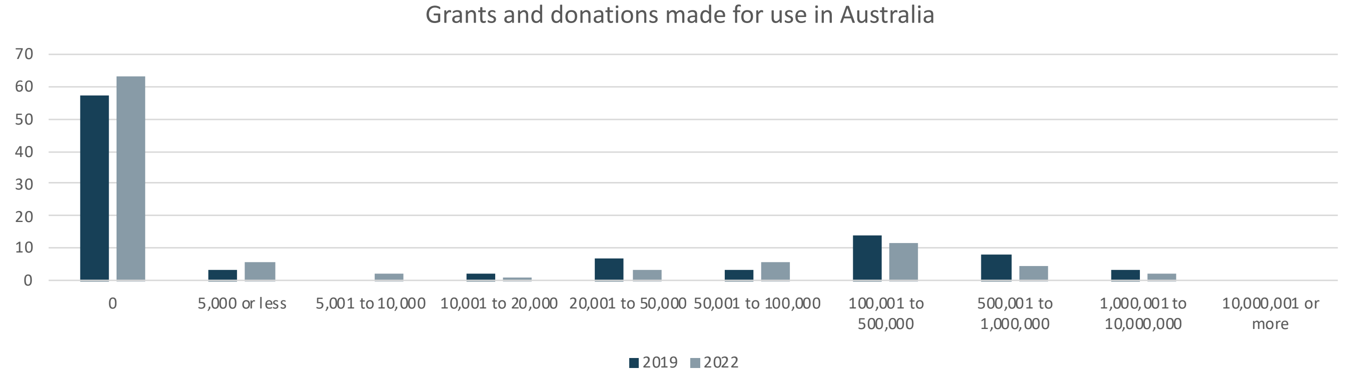


Figure 4.3: Grants and donations made for use in Australia

Grants and donations made for use outside Australia

In 2019 8 NPON organisations had grants and donations made for use outside Australia ranging from $28,173 to $301,999 (median = $94,789.5; IQR = $123,904), and in total 84 member charities had combined expenses of $985,087.

There were 76 organisations (90.48%) that had no expenses from grants and donations made for use outside Australia, 3 organisations (3.57%) that had a expenses of $20,001 and $50,000, 1 organisations (1.19%) that had expenses of between $50,001 and $100,000, and 4 organisations (4.76%) had between $100,001 and $500,000.

In 2022 4 NPON organisations had grants and donations made for use outside Australia ranging from $34,461 to $895,596 (median = $130,618.50; IQR = $268,711.50), and in total 87 member charities had combined expenses of $1,191,294.

There were 83 organisations (95.40%) that had no expenses from grants and donations made for use outside Australia, 1 organisation (1.15%) had a expenses of $50,001 and $100,000, 1 organisation (1.15%) that had expenses of between $100,001 and $500,000, and 1 organisation (1.15%) had between $500,001 and $1,000,000 .

2019 Grants and donations made for use outside Australia	**2022 Grants and donations made for use outside Australia**
• 8 NPON organisations had grants and donations made for use outside Australia • Range: $28,173 to $301,999 • Median = $94,789.5; IQR = $123,904 • 84 member charities had combined expenses of $985,087	• 4 NPON organisations had grants and donations made for use outside Australia • Range: $34,461 to $895,596 • Median = $130,618.50; IQR = $268,711.50 • 87 member charities had combined expenses of $1,191,294.

Table 4.4: Grants and donations made for use outside Australia

Grants and donations made for use outside Australia	2019		2022	
	n=84	Percent	n=87	Percent
0	76	90.48	83	95.40
5,000 or less	0	0.00	0	0.00
5,001 to 10,000	0	0.00	0	0.00
10,001 to 20,000	0	0.00	0	0.00
20,001 to 50,000	3	3.57	1	1.15
50,001 to 100,000	1	1.19	1	1.15
100,001 to 500,000	4	4.76	1	1.15
500,001 to 1,000,000	0	0.00	1	1.15
1,000,001 to 10,000,000	0	0.00	0	0.00
10,000,001 or more	0	0.00	0	0.00

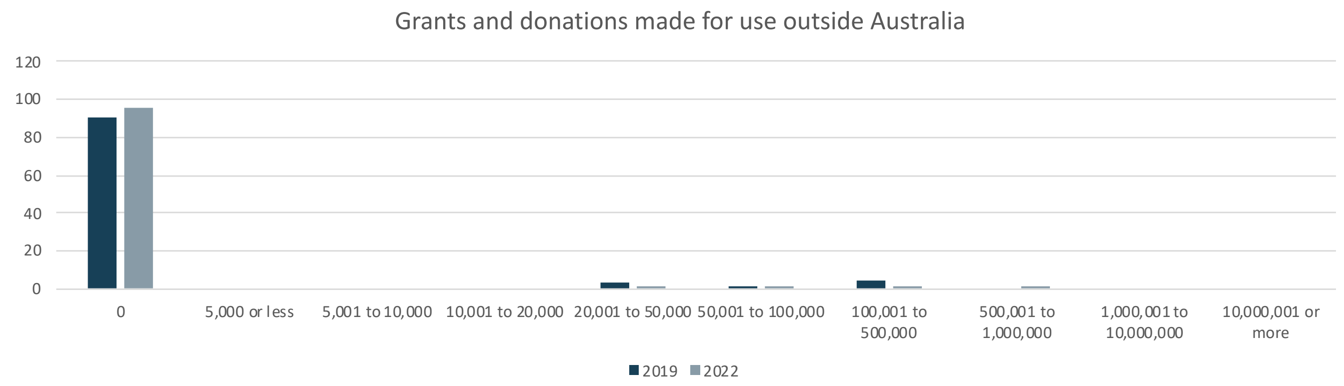


Figure 4.4: Grants and donations made for use outside Australia

Interest expenses

In 2019 6 NPON organisations had interest expenses ranging from $1447 to $55453 (median = $13182.5; IQR = $31942.25), and in total 84 member charities had combined expenses of $122047.

There were 78 organisations (92.86%) that had no expenses from Interest expenses, 3 organisations (3.57%) that had a expenses of $5,000 or less, 2 organisations (2.38%) had between $20,001 and $50,000 and 1 organisation (1.19%) had expenses between $50,001 and $100,000.

In 2022 3 NPON organisations had interest expenses ranging from $13,198 to $56,470 (median = $14,577; IQR = $21,636), and in total 87 member charities had combined expenses of $84,245.

There were 84 organisations (96.55%) that had no expenses from Interest expenses, 2 organisations (2.30%) had between $10,001 and $20,000 and 1 organisation (1.15%) had expenses between $50,001 and $100,000.

2019 interest expenses

- 6 NPON organisations had interest expenses
- Range: $1447 to $55453 (
- Median = $13182.5; IQR = $31942.25
- 84 member charities had combined expenses of $122047

2022 interest expenses

- 3 NPON organisations had interest expenses
- Range: $13,198 to $56,470 (
- Median = $14,577; IQR = $21,636
- 87 member charities had combined expenses of $84,245.

Table 4.5: Interest expenses

Interest expenses	2019		2022	
	n=84	Percent	n=87	Percent
0	78	92.86	84	96.55
5,000 or less	3	3.57	0	0.00
5,001 to 10,000	0	0.00	0	0.00
10,001 to 20,000	0	0.00	2	2.30
20,001 to 50,000	2	2.38	0	0.00
50,001 to 100,000	1	1.19	1	1.15

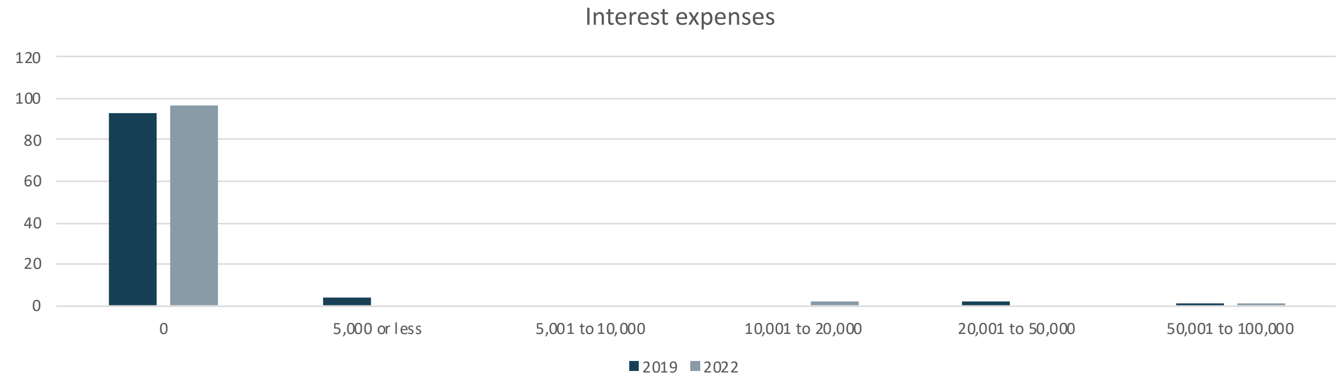


Figure 4.5: Interest expenses

All other expenses

In 2019 80 NPON organisations had other expenses ranging from $1,101 to $17,840,000 (median = $115,372.50; IQR = $424,512.25), and in total 84 member charities had combined expenses of $79,129,598.

There were 4 organisations (4.76%) that had no expenses from other expenses, 7 organisations (8.33%) that had a expenses of $5,000 or less, , 9 organisations (10.71%) had between $10,001 and $20,000 and 11 organisations (13.10%) had expenses between $20,001 and $50,000.

At the higher end of expenses, there were 12 organisations (14.29%) that spent between $50,001 and $100,000, 22 organisations (26.19%) that had expenses of $100,001 and $500,000, 7 organisations (8.33%) that had costs of between $500,001 and $1,000,000, 10 organisations (11.90%) had expenses between $1,000,001 and $10,000,000 and 2 organisations (2.38%) had expenses between $10,000,001 or more .

In 2022 85 NPON organisations had other expenses ranging from $584 to $28,643,578 (median = $111,479; IQR = $484,138), and in total 87 member charities had combined expenses of $112,253,799.

There were 2 organisations (2.30%) that had no expenses from other expenses, 6 organisations (6.90%) that had a expenses of $5,000 or less, 7 organisations (8.05%) that had expenses of between $5,001 and $10,000, 7 organisations (8.05%) had between $10,001 and $20,000 and 12 organisations (13.79%) had expenses between $20,001 and $50,000.

At the higher end of expenses, there were 9 organisations (10.34%) that spent between $50,001 and $100,000, 22 organisations (25.29%) that had expenses of $100,001 and $500,000, 8 organisations (9.20%) that had costs of between $500,001 and $1,000,000, 10 organisations (11.49%) had expenses between $1,000,001 and $10,000,000 and 4 organisations (4.60%) had expenses between $10,000,001 or more .

2019 other expenses	**2022 other expenses**
• 80 NPON organisations had other expenses • Range: $1,101 to $17,840,000 • Median = $115,372.50; IQR = $424,512.25 • 84 member charities had combined expenses of $79,129,598.	• 85 NPON organisations had other expenses • Range: $584 to $28,643,578 • Median = $111,479; IQR = $484,138 • 87 member charities had combined expenses of $112,253,799

Table 4.6: All other expenses

All other expenses	2019		2022	
	n=84	Percent	n=87	Percent
0	4	4.76	2	2.30
5,000 or less	7	8.33	6	6.90
5,001 to 10,000	0	0.00	7	8.05
10,001 to 20,000	9	10.71	7	8.05
20,001 to 50,000	11	13.10	12	13.79
50,001 to 100,000	12	14.29	9	10.34
100,001 to 500,000	22	26.19	22	25.29
500,001 to 1,000,000	7	8.33	8	9.20
1,000,001 to 10,000,000	10	11.90	10	11.49
10,000,001 or more	2	2.38	4	4.60

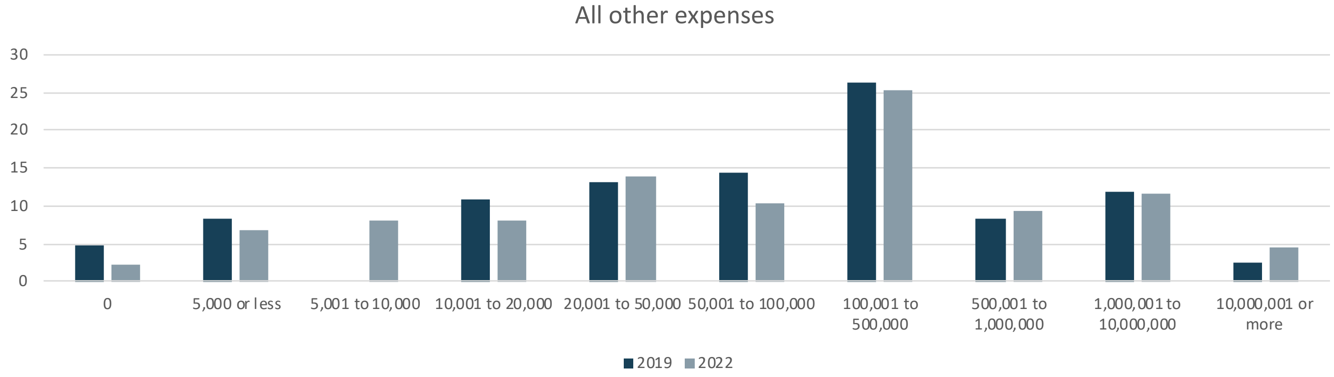


Figure 4.6: All other expenses

Section 5: Employees

Employees

Staff overview

Data were extracted from the 2019 and 2022 Annual Information Statement Data from the Australian Charities and Not-for-profits commission (ACNC) (available from https://data.gov.au).

In 2019, NPON member organisations employed a total of 454 full time staff 377 part time staff, 55 casual staff, a total full time equivalent of 681.97 staff. In addition, they had a total of 3996 volunteers.

In 2022, NPON member organisations employed a total of 505 full time staff 529 part time staff, 83 casual staff, a total full time equivalent of 767.47 staff. In addition, they had a total of 2892 volunteers.

2019 Staff in NPON member organisations

- Full time: 454
- Part time: 377
- Casual: 55
- Full time equivalent: 681.97
- Volunteers: 3996

2022 Staff in NPON member organisations

- Full time: 505
- Part time: 529
- Casual: 83
- Full time equivalent: 767.47
- Volunteers:2892

Full time staff

In 2019, 37 NPON organisations had between 1 and 132 (median = 3; IQR = 5) full time staff.

There were 47 organisations (55.95%) that had no full time staff, 26 organisations (30.95%) had 1 to 5 full time staff, 4 organisations (4.76%) that had 6 to 10, 3 organisations (3.57%) that had 11 to 20 part time staff, 2 organisations (2.38%) had 21 to 50 and 2 organisations (2.38%) 51 or more full time staff.

In 2022, 38 NPON organisations had between 1 and 193 (median = 4; IQR = 4) full time staff.

There were 49 organisations (56.32%) that had no full time staff, 27 organisations (31.03%) had 1 to 5 full time staff, 5 organisations (5.75%) that had 6 to 10, 1 organisations (1.15%) that had 11 to 20 3 organisations (3.45%) had 21 to 50 and 2 organisations (2.30%) 51 or more full time staff.

2019 full time staff

- 37 NPON organisations had full time staff
- Range: 1 to 132 full time staff
- Median = 3; IQR = 5
- 2019 NPON members combined 454 full time staff

2022 full time staff

- 38 NPON organisations had full time staff
- Range: 1 to 193 full time staff.
- Median = 4; IQR = 4
- 2022 NPON members combined 505 full time staff

Table 5.1: Full time staff

Full time staff	2019		2022	
	n=84	Percent	n=87	Percent
0	47	55.95	49	56.32
1 to 5	26	30.95	27	31.03
6 to 10	4	4.76	5	5.75
11 to 20	3	3.57	1	1.15
21 to 50	2	2.38	3	3.45
51 or more	2	2.38	2	2.30

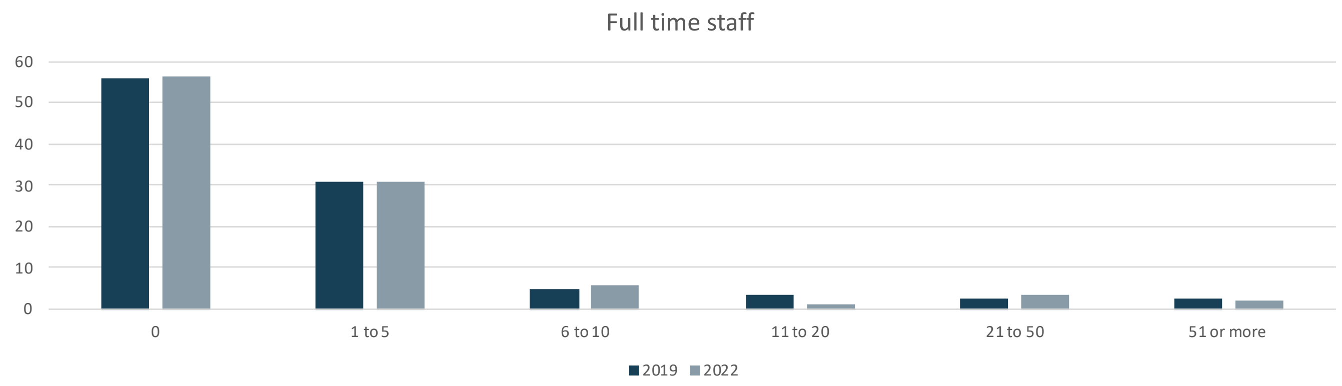


Figure 5.1: Full time staff

Part time staff

In 2019, 43 NPON organisations had between 1 and 79 (median = 4; IQR = 5.5), part time staff.

There were 41 organisations (48.81%) that had no part time staff, 30 organisations (35.71%) had 1 to 5 part time staff, 7 organisations (8.33%) that had 6 to 10, 2 organisations (2.38%) that had 11 to 20 part time staff, 2 organisations (2.38%) had 21 to 50, and 2 organisations (2.38%) 51 or more part time staff.

In 2022, 51 NPON organisations had between 1 and 109 (median = 4; IQR = 5.5), part time staff.

There were 36 organisations (41.38%) that had no part time staff, 32 organisations (36.78%) had 1 to 5 part time staff, 9 organisations (10.34%) that had 6 to 10 part time staff, 5 organisations (5.75%) that had 11 to 20, 1 organisation (1.15%) had 21 to 50 and 4 organisations (4.60%) 51 or more part time staff.

2019 part time staff

- 43 NPON organisations had part time staff
- Range: 1 to 79 part time staff
- Median = 4; IQR = 5.5
- 2019 NPON members combined 377 part time staff

2022 part time staff

- 51 NPON organisations had part time staff
- Range: 1 to 109 part time staff.
- Median = 4; IQR = 5.5
- 2022 NPON members combined 529 part time staff

Table 5.2: Part time staff

Part time staff	2019		2022	
	n=84	Percent	n=87	Percent
0	41	48.81	36	41.38
1 to 5	30	35.71	32	36.78
6 to 10	7	8.33	9	10.34
11 to 20	2	2.38	5	5.75
21 to 50	2	2.38	1	1.15
51 or more	2	2.38	4	4.60

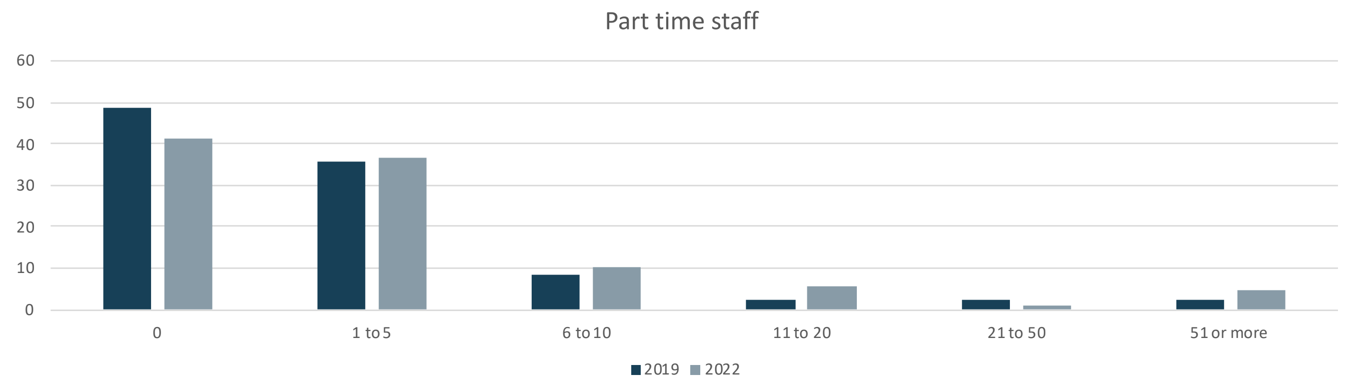


Figure 5.2: Part time staff

Casual staff

In 2019, 22 NPON organisations had between 1 and 10 (median = 2; IQR = 1.75), casual staff.

There were 62 organisations (73.81%) that had no casual staff, 19 organisations (22.62%) had 1 to 5 casual staff, and 3 organisations (3.57%) that had 6 to 10 casual staff.

In 2022, 17 NPON organisations had between 1 and 22 (median = 2; IQR = 5), casual staff.

There were 70 organisations (80.46%) that had no casual staff, 12 organisations (13.79%) had 1 to 5 casual staff, 2 organisations (2.30%) that had 6 to 10, and 3 organisations (3.45%) that had 11 to 20 casual staff.

2019 casual staff

- 22 NPON organisations had casual staff
- Range: 1 to 10 casual staff
- Median = 2; IQR = 1.75
- 2019 NPON members combined 55 casual staff

2022 casual staff

- 17 NPON organisations had casual staff
- Range: 1 to 22 casual staff.
- Median = 2; IQR = 5
- 2022 NPON members combined 83 casual staff

Table 5.3: Casual staff

Casual staff	2019		2022	
	n=84	Percent	n=87	Percent
0	62	73.81	70	80.46
1 to 5	19	22.62	12	13.79
6 to 10	3	3.57	2	2.30
11 to 20	0	0.00	3	3.45
21 to 50	0	0.00	0	0.00
51 or more	0	0.00	0	0.00

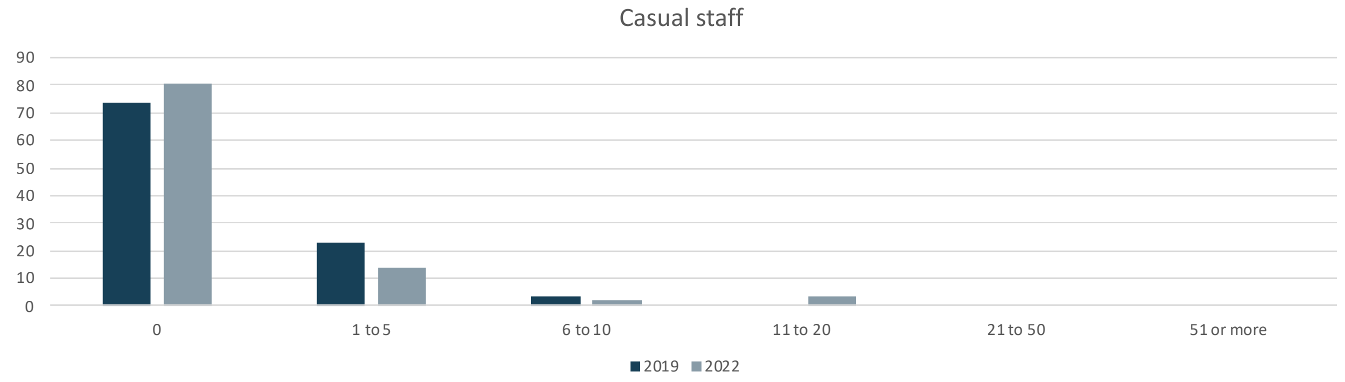


Figure 5.3: Casual staff

Full time equivalent staff

In 2019, 47 NPON organisations had between 0.4 and 183.23 (median = 4.2; IQR = 7.33), total full time equivalent staff.

There were 37 organisations (44.05%) that had no staff, 27 organisations (32.14%) had 0.1 to 5 total full time equivalent staff, 10 organisations (11.90%) that had 5.1 to 10 total full time equivalent staff, 5 organisations (5.95%) that had 10.1 to 20 total full time equivalent staff, 2 organisations (2.38%) had 20.1 to 50 and 3 organisations (3.57%) 50.1 or more total full time equivalent staff.

In 2022, 50 NPON organisations had between 0.2 and 235 (median = 4.575; IQR = 9.0275), total full time equivalent staff.

There were 37 organisations (42.53%) that had no staff, 25 organisations (28.74%) had 0.1 to 5 total full time equivalent staff, 10 organisations (11.49%) that had 5.1 to 10 total full time equivalent staff, 9 organisations (10.34%) that had 10.1 to 20 total full time equivalent staff, 3 organisations (3.45%) had 20.1 to 50 and 3 organisations (3.45%) 50.1 or more total full time equivalent staff.

2019 full time equivalent staff
- 47 NPON organisations had staff
- Range: 0.4 and 183.23 full time equivalent staff
- Median = 4.2; IQR = 7.33
- 2019 NPON members combined 681.97 full time equivalent staff

2022 full time equivalent staff
- 50 NPON organisations had staff
- Range: 0.2 and 235 full time equivalent staff.
- Median = 4.575; IQR = 9.0275
- 2022 NPON members combined 767.47 full time equivalent staff

Table 5.4: full time equivalent staff

Full time equivalent	2019		2022	
	n=84	Percent	n=87	Percent
0	37	44.05	37	42.53
0.1 to 5	27	32.14	25	28.74
5.1 to 10	10	11.90	10	11.49
10.1 to 20	5	5.95	9	10.34
20.1 to 50	2	2.38	3	3.45
50.1 or more	3	3.57	3	3.45

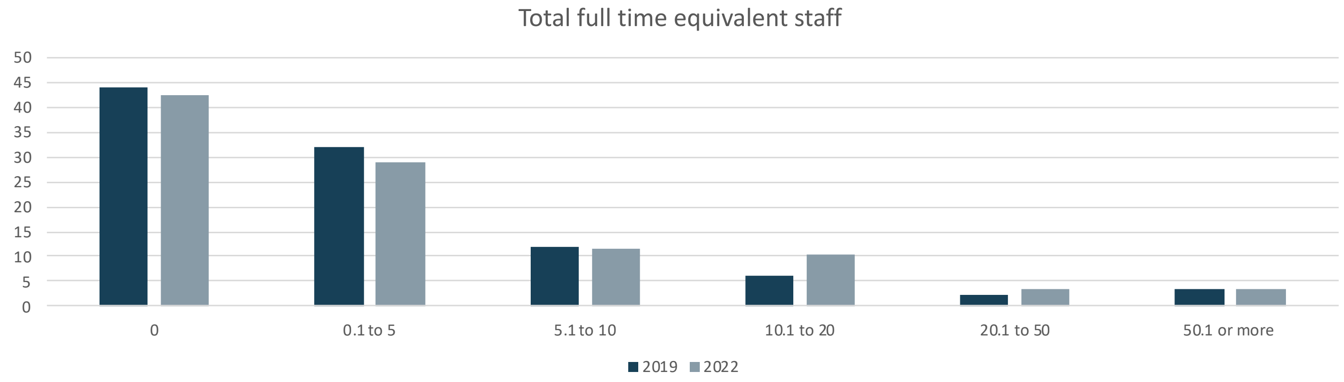


Figure 5.4: full time equivalent staff

Volunteers

In 2019, 79 NPON organisations had between 1 and 1042 (median = 15; IQR = 20), volunteers.

There were 5 organisations (5.95%) that had no volunteers, 9 organisations (10.71%) had 1 to 5 volunteers, 22 organisations (26.19%) that had 6 to 10 volunteers, 22 organisations (26.19%) that had 11 to 20 volunteers, 12 organisations (14.29%) had 21 to 50 volunteers, 6 organisations (7.14%) 51 to 100 volunteers, and 8 organisations (9.52%) had 101 or more volunteers.

In 2022, 80 NPON organisations had between 1 and 400 (median = 13.5; IQR = 21.25), volunteers.

There were 7 organisations (8.05%) that had no volunteers, 10 organisations (11.49%) had 1 to 5 volunteers, 25 organisations (28.74%) that had 6 to 10 volunteers, 19 organisations (21.84%) that had 11 to 20 volunteers, 15 organisations (17.24%) had 21 to 50 volunteers, 6 organisations (6.90%) 51 to 100 volunteers, and 5 organisations (5.75%) that had 101 or more volunteers).

2019 volunteers

- 79 NPON organisations had volunteers
- Range: 1 and 1042 volunteers
- Median = 15; IQR = 20
- 2019 NPON members combined 3996 volunteers

2022 volunteers

- 80 NPON organisations had volunteers
- Range: 1 and 400 volunteers.
- Median = 13.5; IQR = 21.25
- 2022 NPON members combined 2892 volunteers

Table 5.5: Volunteers

Volunteers	2019		2022	
	n=84	Percent	n=87	Percent
0	5	5.95	7	8.05
1 to 5	9	10.71	10	11.49
6 to 10	22	26.19	25	28.74
11 to 20	22	26.19	19	21.84
21 to 50	12	14.29	15	17.24
51 to 100	6	7.14	6	6.90
101 or more	8	9.52	5	5.75

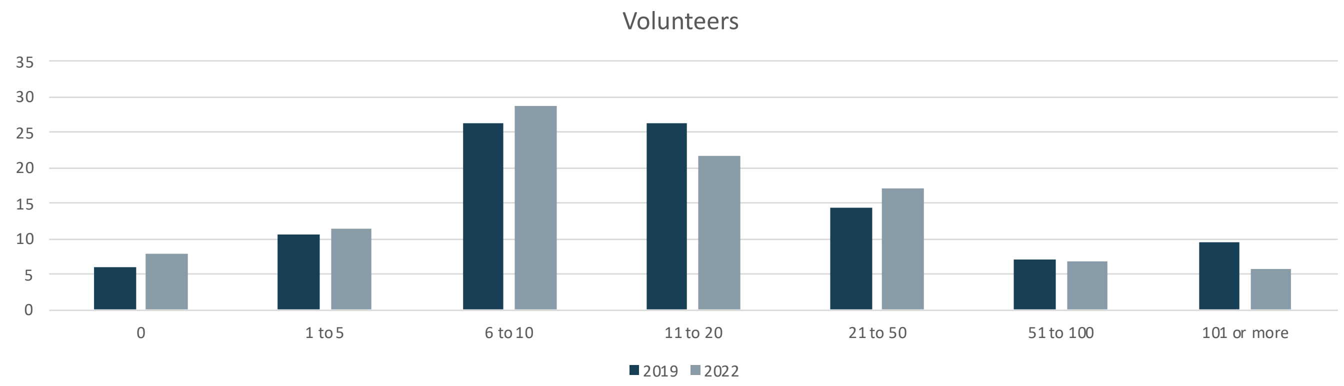


Figure 5.5: Volunteers

Section 6: Advocacy activities

Summary of NPON advocacy activities

Summary of NPON advocacy activities

Data was collected from NPON members in 2024 about advocacy activities/services that organisation is involved with or would like to initiate in the future.

Over 60% of NPON organisations advocate for patient rights, and nearly 60% are involved in health symptom or service change. Approximately half of the organisations deliver PBAC or MSAC submissions & access, aids access to clinical trials, and offer research funding.

NPON organisations described the amount of interaction with the PBAC or other government feedback opportunities. In general, following submission there was very little feedback. Approximately 59% of organisations never or rarely received detailed information on how patient representation was used. About 60% sometimes or rarely received detailed information on the impact of patient representation. Approximately half of the organisations were never invited to provide additional clarifications after the submission period is closed, and 62% of organisations never or rarely were informed of any new policies, guidelines or reports that patient representation contributed to.

NPON organisations comments about advocacy activities

As a very small organisation with limited funding (funds raised by our own efforts - no government support) there is a clear limit to what we can achieve in any of these areas. What matters most is the extent to which we can partner with alliances/groups/organisations (incl APON) who can ensure that our shared concerns are raised. To the extent that there is something very specific to Fragile X, such as carrier screening, testing then we ensure we prepare something targetted that is within the capacity of one of our Board members to write.

It would be great to do this, or deliver this but... this would require resources and funds

NPON advocacy activities

- 62.65% are active in patient rights advocacy
- 59.04% are active in health system/service change advocacy
- 53.01% participate in policy and Senate Inquiries
- 48.19% deliver PBAC/MSAC submissions & access
- 48.19% aids access to clinical trials
- 45.78% deliver research funding

Submissions or representing patients in government feedback

- 59% never or rarely received information on how patient representation was used
- 60% sometimes or rarely received information on the impact of patient representation
- 48% were never invited to provide additional clarifications after the submission period is closed
- 62% never or rarely were informed of any new policies, guidelines or reports that patient representation contributed to

NPON advocacy activities

Policy and Senate Inquiries

More than half of the organisations (n=44, 53.01%) took part in Policy and Senate Inquiries, and a quarter of organisations (n=26, 31.33%) do not currenly offer this but would like to in the future. Approximately 15% (n=13, 15.66%) do not offer this and thought they were unlikely to do so in the future.

NPON organisations comments about policy and Senate Inquiries

We are always keen to be involved in submissions and policy updates, but usually have to search for things ourselves, or we chance upon them. It would be great if we were automatically notified or invited to submit. As a small organisation that services the whole country it can be difficult to keep up to date with all the different health systems and processes and policies, but we do our best.

With current capacity we do want to provide intensive support and focus on policy and advocacy

Table 6.1: Policy and Senate Inquiries

Policy and Senate Inquiries	n=83	Percent
Our organisation currently delivers this activity/service	44	53.01
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	26	31.33
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	13	15.66

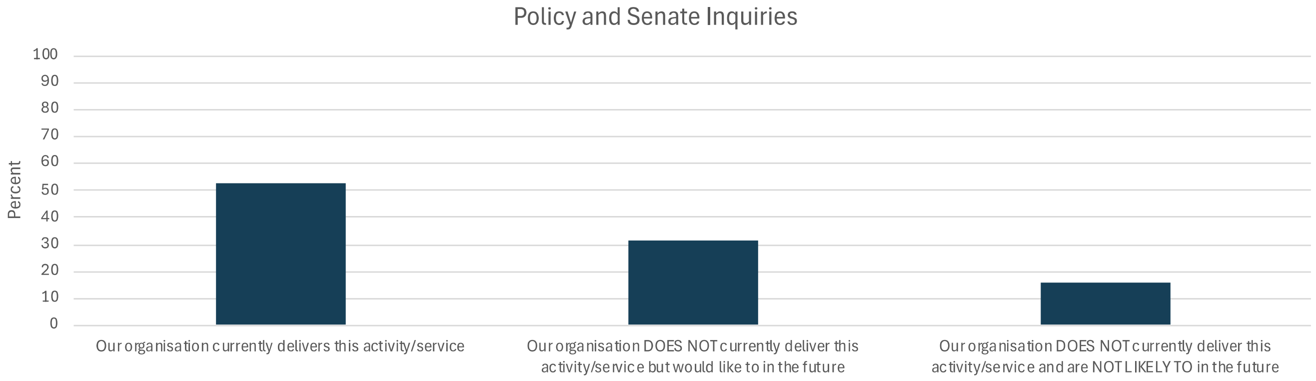


Figure 6.1: Policy and Senate Inquiries

PBAC/MSAC submissions & access

Almost half of the organisations (n=40, 48.19%) took part in PBAC/MSAC submissions & access, and almost a third (n=26, 31.33%) do not currenly offer this but would like to in the future. There were approximately 20% (n=17, 20.48%) that do not offer this service and are unlikely to in the future.

NPON organisations comments about PBAC/MSAC submissions & access

PNDU has had the opportunity to provide a detailed PBAC submission which included patient representation for adults' children and a follow up implementation report, we were informed and supported by the PBAC during the three submissions.

The Leukaemia foundation actively advocates for access to life-saving treatments for patients, without which, many would face a dire prognosis.

Leukaemia Foundation supports patient access to emerging therapies and have been active in this space by reaching out to patients for their experiences trialing new medications and therapies. Their experiences are collated as submissions and are provided to regulatory bodies such as the Pharmaceutical Benefits Advisory Committee (PBAC) and Medical Services Advisory Committee (MSAC) to support the recommendation of the new therapy to be listed on the Pharmaceutical Benefits Scheme (PBS) or Medicare Benefits Schedule (MBS).

Listing on the PBS or MBS, or through other government funding agreements and schemes, allows patients easier and cheaper access to vital medications and therapies.

Table 6.2: PBAC/MSAC submissions & access

PBAC/MSAC submissions & access	n=83	Percent
Our organisation currently delivers this activity/service	40	48.19
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	26	31.33
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	17	20.48

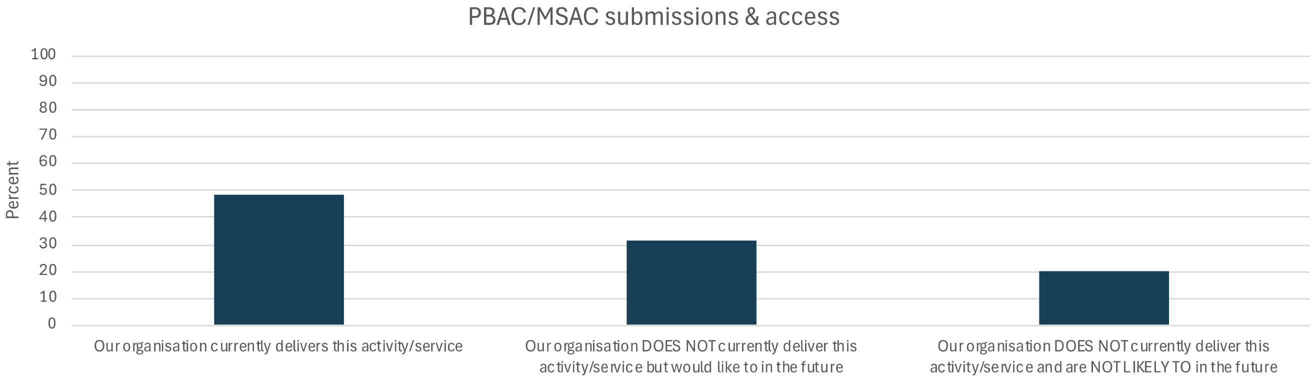


Figure 6.2: PBAC/MSAC submissions & access

Health system/service change

Nearly 60% of organisations (n=49, 59.04%) took part in health system/service change, and almost a third (n=27, 32.53%) do not currenly offer this but would like to in the future. There were approximatley 8% (n=7, 8.43%) that do not offer this service and are unlikely to in the future.

NPON organisations comments about health system/service change

We advocate for improved care and change for parents with a premature or sick baby. There is so much more to do and we need to get better at it. We are improving a little each year but any support/education around government lobbying and advocacy would be greatly appreciated.

Funding for patient support services like mental health and wound care support

Table 6.3: Health system/service change

Health system/service change	n=83	Percent
Our organisation currently delivers this activity/service	49	59.04
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	27	32.53
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	7	8.43

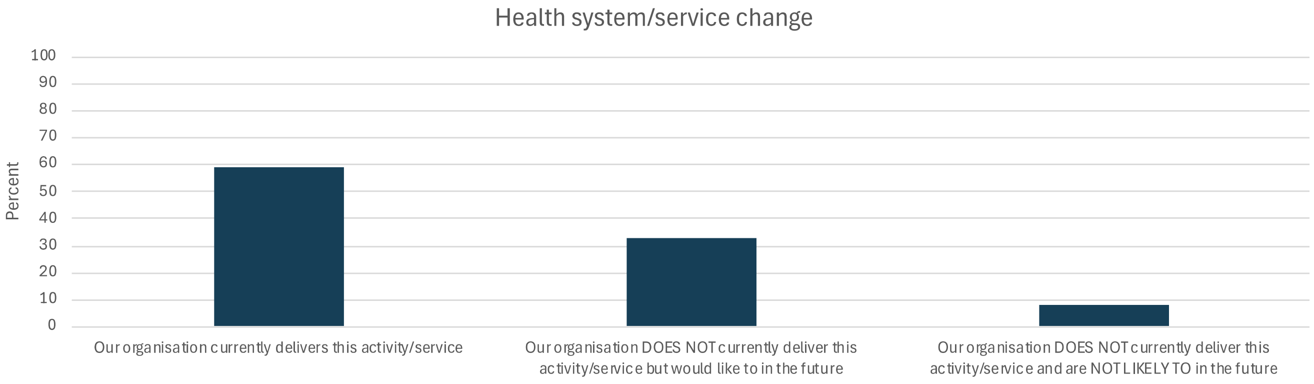


Figure 6.3: Health system/service change

Research funding

Approximately 46% of organisations (n=38, 45.78%) took part in research funding, and almost 29% (n=24, 28.92%) do not currenly offer this but would like to in the future. There were approximatley a quarter (n=21, 25.30%) that do not offer this service and are unlikely to in the future.

NPON organisations comments about research funding

Our main role has been to facilitate research and would like to support clinical trials. Our focus is changing more to the living with the condition to assist our members with their daily activities.

We predominantly fund research. Our main challenges are:
** grant applications - not being given feedback to unsuccessful grants*
** funding in general - State and Fed government to look favourably at the 'underdogs' in research instead of continually funding the large organisations*
** providing patients with information about clinical trials that are being run in Australia are few and far between. We need more availability in Australia.*

Table 6.4: Research funding

Research funding	n=83	Percent
Our organisation currently delivers this activity/service	38	45.78
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	24	28.92
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	21	25.30

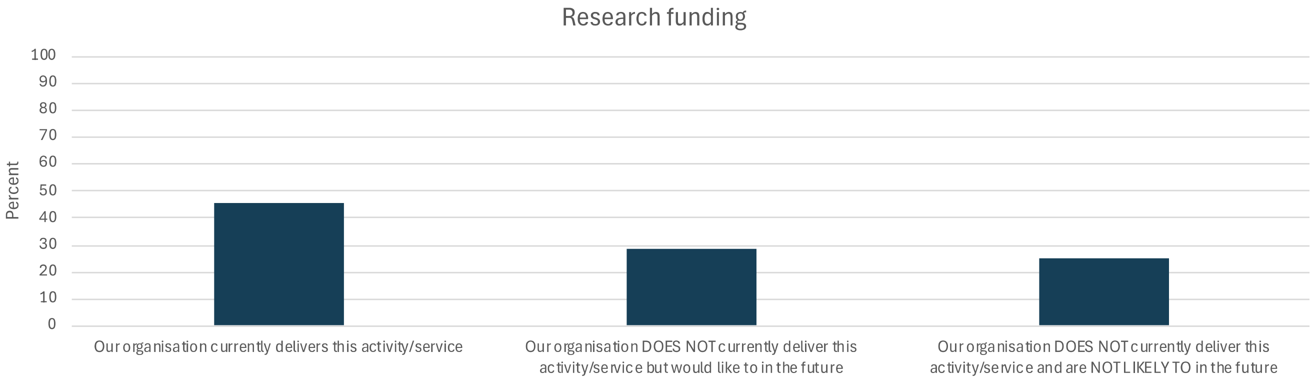


Figure 6.4: Research funding

Access to clinical trials

Nearly a half of organisations (n=40, 48.19%) took part in helping with access to clinical trials, and approximately 30% (n=25, 30.12%) do not currenly offer this but would like to in the future. There were approximatley 22% (n=18, 21.69%) that do not offer this service and are unlikely to in the future.

NPON organisations comments about access to clinical trials

Limbs 4 Life offers early intervention peer support for people pre or immediately post amputation.

This support is included in some but not all states and territories. We regularly respond to matters and government inquiries whereby members are impacted. We have also partnered Universities in research funding and clinical trials for therapies and products which immediately impact stakeholders.

Save Our Sons has funded clinical trial teams in children's hospitals across Australia to be clinical trial ready and this has meant that clinical trials are now coming to Australia.

Table 6.5: Access to clinical trials

Access to clinical trials	n=83	Percent
Our organisation currently delivers this activity/service	40	48.19
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	25	30.12
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	18	21.69

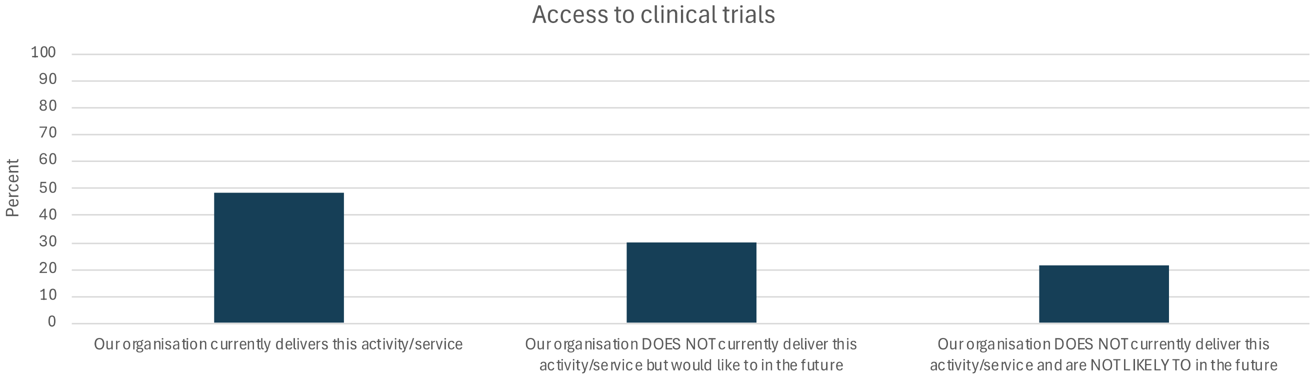


Figure 6.5: Access to clinical trials

Patient rights

Almost 63% organisations (n=52, 62.65%) took part in patient right advocacy, and approximately a quarter (n=22, 26.51%) do not currenly offer this but would like to in the future. About 10% of organisations (n=9, 10.84%) do not offer this service and are unlikely to in the future.

Table 6.6: Patient rights

Patient rights	n=83	Percent
Our organisation currently delivers this activity/service	52	62.65
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	22	26.51
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	9	10.84

Figure 6.6: Patient rights

PBAC or submitting feedback to the government

Received detailed information on how the submission or patient feedback was used

Detailed information about how submission or patient feedback was given to 11 organisations always or most of the time (18.03%), given sometimes to 14 organisations (22.95%), and given rarely or never to 36 organisation (59.02%).

NPON organisations comments about receiving detailed information on how the submission or patient feedback was used

We have not been involved in many formal submission processes; instead we have advocated on particular issues.

We monitor other bodies in terms of submissions. We are a small volunteer based body and do not have the capacity to be active in this area other than perhaps supporting other submissions where considered appropriate.

Table 6.7: Received detailed information on how the submission or patient feedback was used

We receive detailed information on how the submission or patient feedback was used	n=61	Percent
Always	5	8.20
Most of the time	6	9.84
Sometimes	14	22.95
Rarely	21	34.43
Never	15	24.59

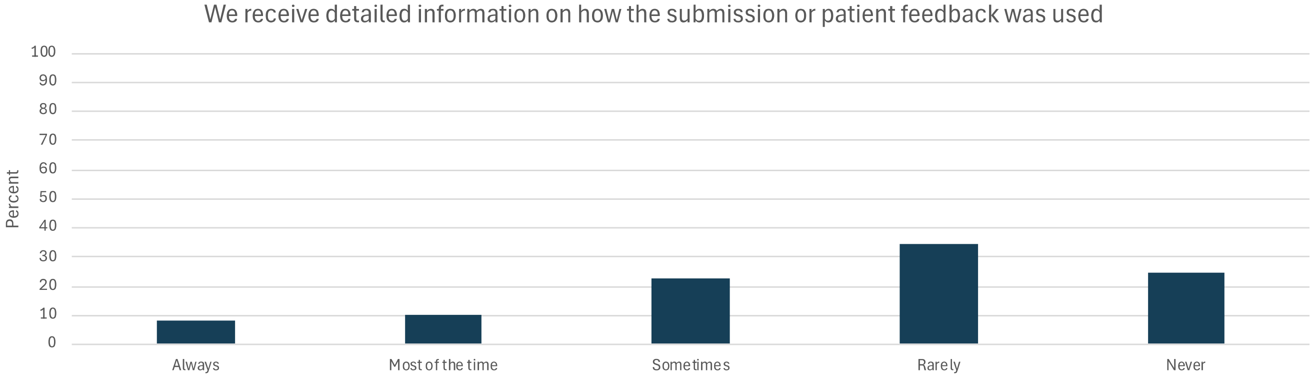


Figure 6.7: Received detailed information on how the submission or patient feedback was used

Received detailed information on the impact or outcome of the submission or patient feedback

Detailed information about impact or outcomes of the submission or patient feedback was given to 8 organisations always or most of the time (13.11%), given sometimes to 19 organisations (31.15%), and given rarely or never to 34 organisations (55.74%).

NPON organisations comments about receiving detailed information on the impact or outcome of the submission or patient feedback

This varies - for PBAC submissions for medications we rarely get feedback unless it is from the sponsor company. For things like submissions on Frameworks with health department we are usually provided with the report that summarises feedback / findings.

Table 6.8: Received detailed information on the impact or outcome of the submission or patient feedback

We receive detailed information on the impact or outcome of the submission or patient feedback	n=61	Percent
Always	4	6.56
Most of the time	4	6.56
Sometimes	19	31.15
Rarely	18	29.51
Never	16	26.23

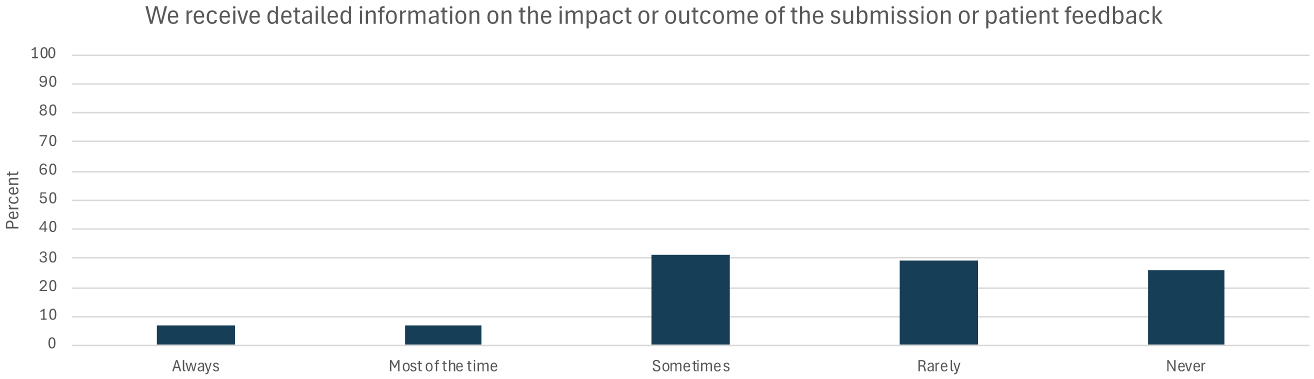


Figure 6.8: Received detailed information on the impact or outcome of the submission or patient feedback

Invited to provide additional clarifications after the submission period is closed

There were 6 organisations (9.84%) that were always or most of the time invited to provide additional clarifications after the submission period is closed, while 17 organisations (27.87%) were sometimes invited, and 38 organisations (62.30%) were rarely or never invited.

NPON organisations comments about being invited to provide additional clarifications after the submission period is closed

Following the submission of feedback or evidence related to a consultation or inquiry we often receive notification of progress of the consultation. We will be contacted for further opportunities to contribute where relevant.

Table 6.9: Invited to provide additional clarifications after the submission period is closed

We are invited to provide additional clarifications after the submission period is closed	n=61	Percent
Always	4	6.56
Most of the time	2	3.28
Sometimes	17	27.87
Rarely	9	14.75
Never	29	47.54

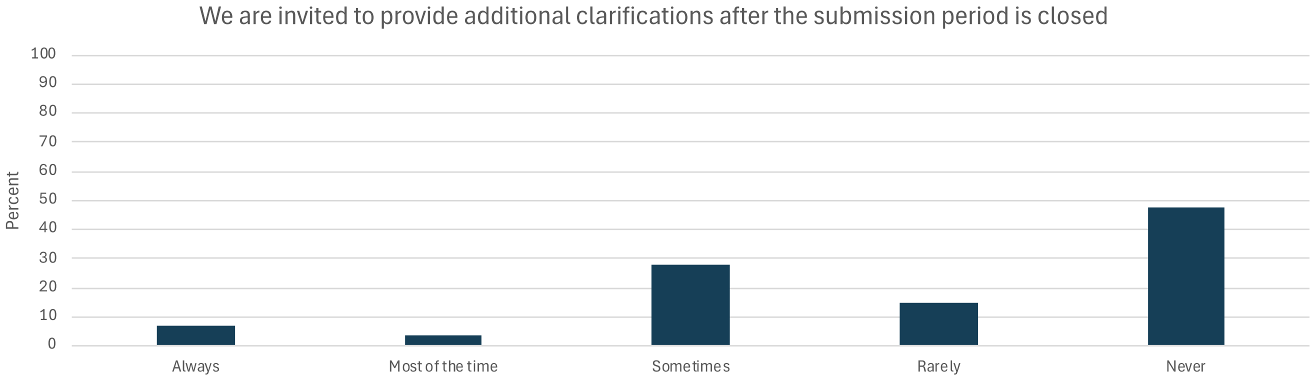


Figure 6.9: Invited to provide additional clarifications after the submission period is closed

Informed of any new policies, guidelines or reports that our submission or feedback contributed to

There were 9 organisations (14.75%) that were always or most of the time informed of any new policies, guidelines or reports that our submission or feedback contributed to, while 14 organisations (22.95%) were sometimes informed, and 38 organisations (62.30%) were rarely or never informed.

NPON organisations comments about being informed of any new policies, guidelines or reports that our submission or feedback contributed to

PNDU participated in a Healthpact report into intestinal failure, we received a copy of the final report but have never received any feedback or implementation of the recommendations.

Table 6.10: Informed of any new policies, guidelines or reports that our submission or feedback contributed to

We are informed of any new policies , guidelines or reports that our submission or feedback contributed to	n=61	Percent
Always	5	8.20
Most of the time	4	6.56
Sometimes	14	22.95
Rarely	16	26.23
Never	22	36.07

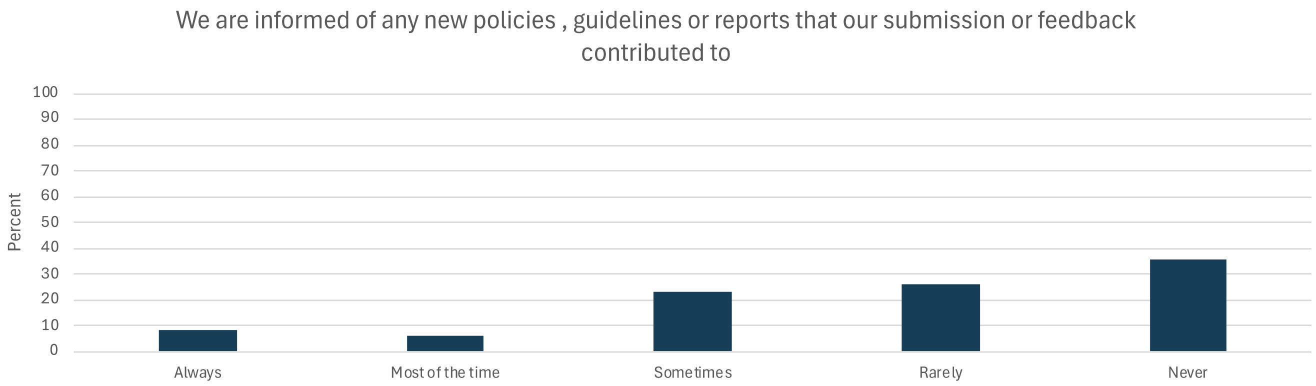


Figure 6.10: Informed of any new policies, guidelines or reports that our submission or feedback contributed to

Section 7: Support services

Summary of NPON support services

Summary of NPON support services

Data was collected from NPON members in 2024 about support services that the organisation is involved with or would like to initiate in the future.

The most common services offered, and that were offered by more than half of the organisations are peer-to-peer support, support groups (face-to-face), and support groups (telephone). Other services offered include, helplines, financial aid, telehealth nurse structured services, transport and legal aid

Self-care interventions are tools which support self-care. Self-care interventions include evidence-based, quality drugs, vitamins & minerals, lotions and creams, devices, diagnostics and/or digital products (including apps) which can be provided fully or partially outside of formal health services and can be used with or without health worker. The majority of organisations engaged in self-care interventions either by informing patients of self-care opportunities, reviewing the evidence/literature related to self-care opportunities, and referring patients to self-care opportunities.

The top five self-care interventions listed by NPON organisations were evidence-based quality drugs, digital products (including apps), diagnostics, devices, and lotions and creams.

NPON support services

- 73% offer peer-to-peer support
- 57% offer support groups (face-to-face)
- 51% offer support groups (telephone)
- 44% offer helplines
- 19% offer financial aid
- 25% offer telehealth structured services
- 4% offer transport
- 1% offer legal aid

Self care interventions

- 61% offer inform patients of self-care opportunities
- 36% offer review the evidence/literature related to self-care opportunities
- 28% offer refer patients to self-care opportunities

Self care interventions important to community

- 62% Evidence-based quality drugs
- 42% Digital products (including apps)
- 41% Diagnostics
- 39% Devices
- 25% Lotions and creams

NPON support services

Telehealth nurse structured service

Telehealth nurse structured service is a virtual clinic or case management service where patients need to make an appointment to talk with a nurse.

There were 20 organisations (25.00%) that offered a telehealth nurse structured service, 32 organisations (40.00%), do not offer this at the moment but would like to in the future, and 28 organisations (35.00%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about Telehealth nurse structured service

Since Save Our Sons has funded nurses to coordinate the appointments and care of young people when newly diagnosed with DMD/BMD, the families have experienced the benefits of all appointments organised on one day and specialists who understand the treatment and stages of the condition.

Difficult to get engagement from these populations but slowly increasing awareness & trust by having culturally safe care provided by telehealth nurse

Table 7.1: Telehealth nurse structured service

Telehealth nurse structured service (This means a virtual clinic or case management service where patients need to make an appointment to talk with a nurse)	n=80	Percent
Our organisation currently delivers this activity/service	20	25.00
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	32	40.00
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	28	35.00

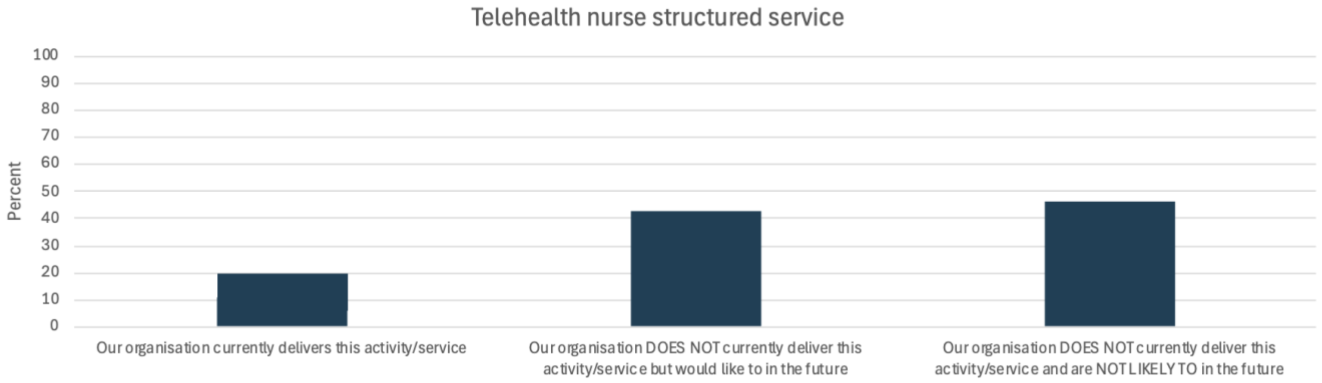


Figure 7.1: Telehealth nurse structured service

Helpline

A helpline is a general helpline that anyone can call at any time for information or support.

There were 36 organisations (44.44%) that offered a helpline, 21 organisations (25.93%), do not offer this at the moment but would like to in the future, and 24 organisations (29.63%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about helplines

Support is via email and group chat and peer connection (rather than telephone) - given difficulty with telephone experienced by people living with Dysphonia

Our members have established a support network separate the foundation and we are available to assist if approached or consdiered appropriate.

We do not have a Helpline but people can submit via email and we will respond to queries.

Table 7.2: Helpline

Helpline (This is a general helpline that anyone can call at any time for information or support)	n=81	Percent
Our organisation currently delivers this activity/service	36	44.44
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	21	25.93
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	24	29.63

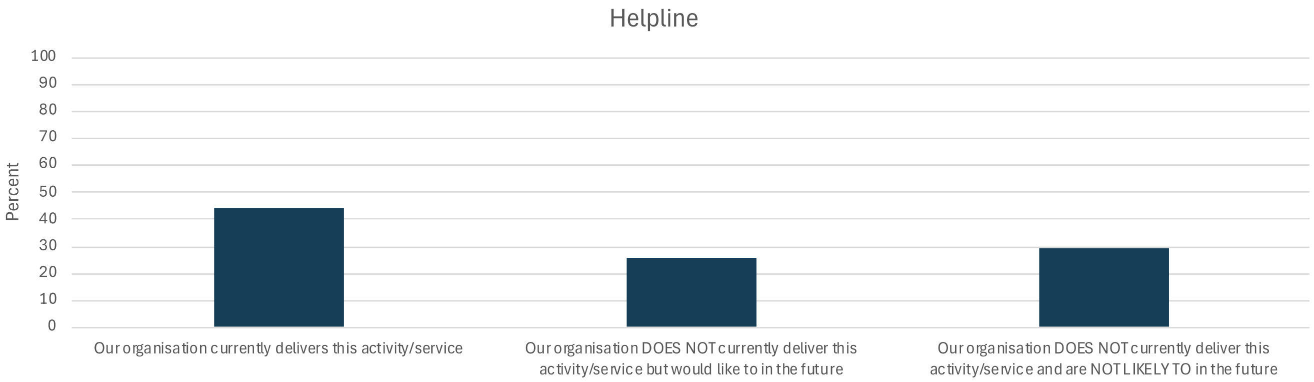


Figure 7.2: Helpline

Face-to-face support groups

There were 47 organisations (56.63%) that offered face to face support groups, 17 organisations (20.48%), do not offer this at the moment but would like to in the future, and 19 organisations (22.89%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about Face-to-face support groups

It is great to have these, but resources and funds are a huge missing part in this happening. Even the current face-to-face support groups are on a minimal level (both in attendance and activity) and usually fall on me to facilitate and manage.

Due to infection control we would never hold in person activities for consumers and currently deliver online

Peer to peers support tends to be online and we provide insurance and guidence for f2f groups

Table 7.3: Face-to-face support groups

Support groups (Face-to-face)	n=83	Percent
Our organisation currently delivers this activity/service	47	56.63
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	17	20.48
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	19	22.89

Figure 7.3: Face-to-face support groups

Telephone support groups

There were 42 organisations (50.60%) that offered telephone support groups, 20 organisations (24.10%), do not offer this at the moment but would like to in the future, and 21 organisations (25.30%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about telephone support groups

Due to infection control we would never hold in person activities for consumers and currently deliver online

'Telephone support' = Zoom groups for us.

Table 7.4: Telephone support groups

Support groups (Telephone)	n=83	Percent
Our organisation currently delivers this activity/service	42	50.60
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	20	24.10
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	21	25.30

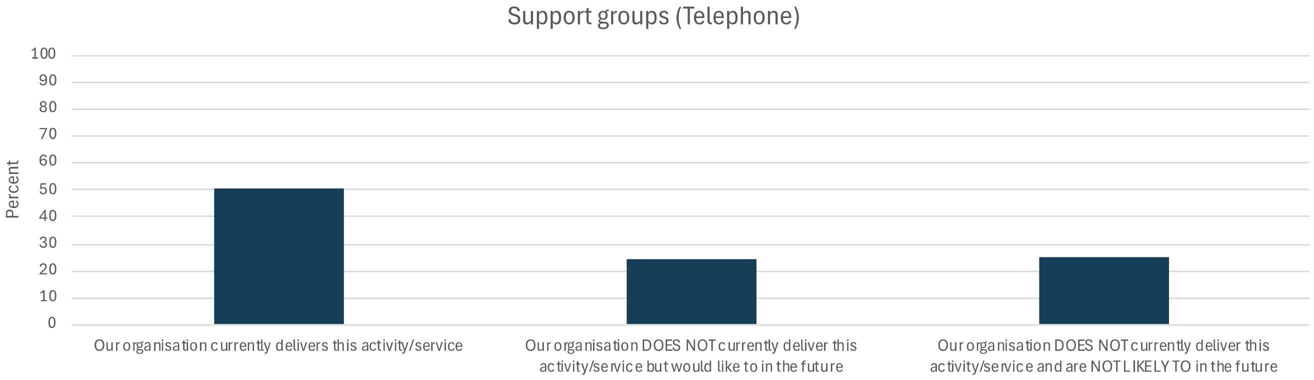


Figure 7.4: Telephone support groups

Peer-to-peer support

There were 60 organisations (73.17%) that offered peer-to-peer support, 12 organisations (14.63%), do not offer this at the moment but would like to in the future, and 10 organisations (12.20%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about peer-to-peer support

Peer to peers support tends to be online and we provide insurance and guidence for f2f groups

Our members have established a support network separate the foundation and we are available to assist if approached or consdiered appropriate. We do not have a Helpline but people can submit via email and we will respond to queries.

PNDU offers support to our members through to closed forums an email forum and closed facebook page. PNDU can be contacted via a link on their website

Table 7.5: Peer-to-peer support

Peer-to-peer support	n=82	Percent
Our organisation currently delivers this activity/service	60	73.17
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	12	14.63
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	10	12.20

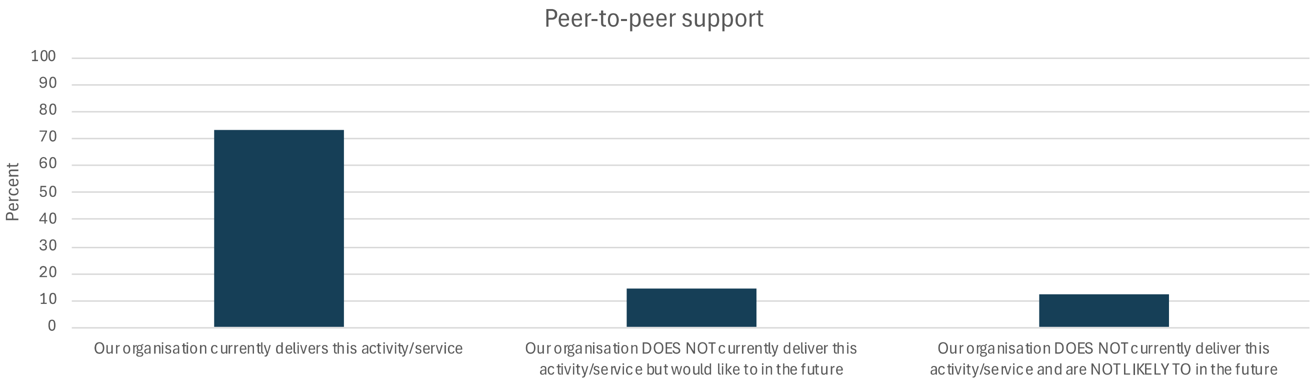


Figure 7.5: Peer-to-peer support

Financial aid

There were 16 organisations (19.28%) that offered financial aid, 16 organisations (19.28%), do not offer this at the moment but would like to in the future, and 51 organisations (61.45%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about financial aid

We don't provide direct financial assistance, but fund equipment and therapy.

Although we don't offer financial aid or legal aid or transport, we offer referral services to other organisations. So we often act as a focal point for people to connect to other services that we are unable to offer.

Table 7.6: Financial aid

Financial aid	n=83	Percent
Our organisation currently delivers this activity/service	16	19.28
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	16	19.28
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	51	61.45

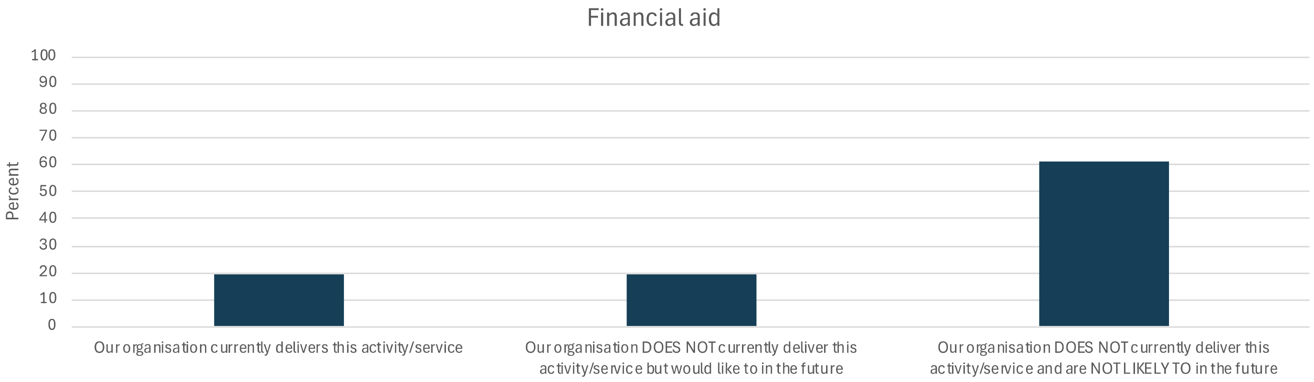


Figure 7.6: Financial aid

Legal aid

There were 1 organisations (1.22%) that offered legal aid, 14 organisations (17.07%), do not offer this at the moment but would like to in the future, and 67 organisations (81.71%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about legal aid

Although we don't offer financial aid or legal aid or transport, we offer referral services to other organisations. So we often act as a focal point for people to connect to other services that we are unable to offer.

Financial, legal aid is not offered, but we do direct people where/how they can access assistance.

Table 7.7: Legal aid

Legal aid	n=82	Percent
Our organisation currently delivers this activity/service	1	1.22
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	14	17.07
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	67	81.71

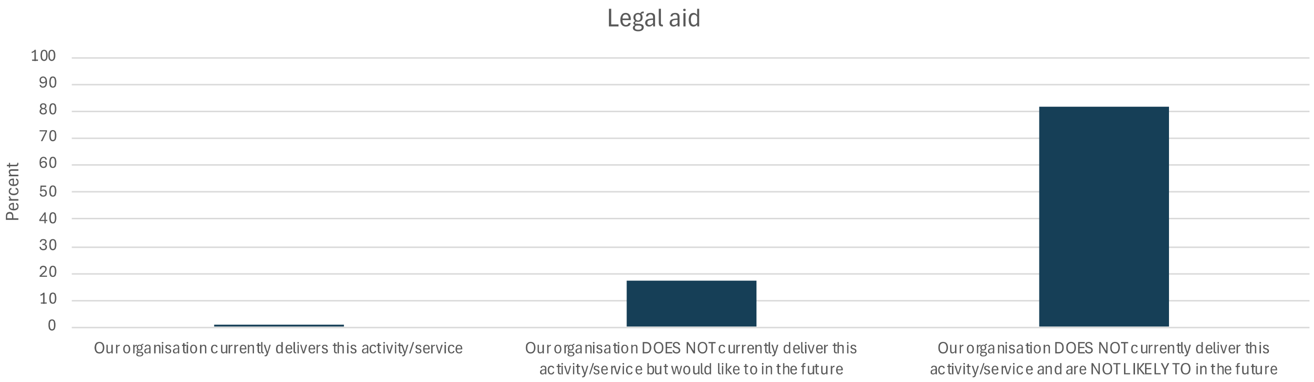


Figure 7.7: Legal aid

Transport

There were 3 organisations (3.80%) that offered transport, 8 organisations (10.13%), do not offer this at the moment but would like to in the future, and 68 organisations (86.08%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about transport

CF is not demographically based and as the population all rely on capital city based services, we fund out of pocket transport expenses as well as a range of specific equipment, support and service program for people in regional, remote and rural locations to assist in the management of health at home. We also support remote services delivered by clinicians.

In rural and remote areas of Australia, some services may not be available at all. As most cancer treatment centres and experts are based in metro areas, many people living outside of major cities need to travel, often at significant expense, spending extended time away from their jobs, support systems and families. Regional and Rural populations can access our online support groups and services. We promote the health of our regional and rural populations but assisting with transport and travel cost to ensure they can access services.

Table 7.8: Transport

Transport	n=79	Percent
Our organisation currently delivers this activity/service	3	3.80
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	8	10.13
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	68	86.08

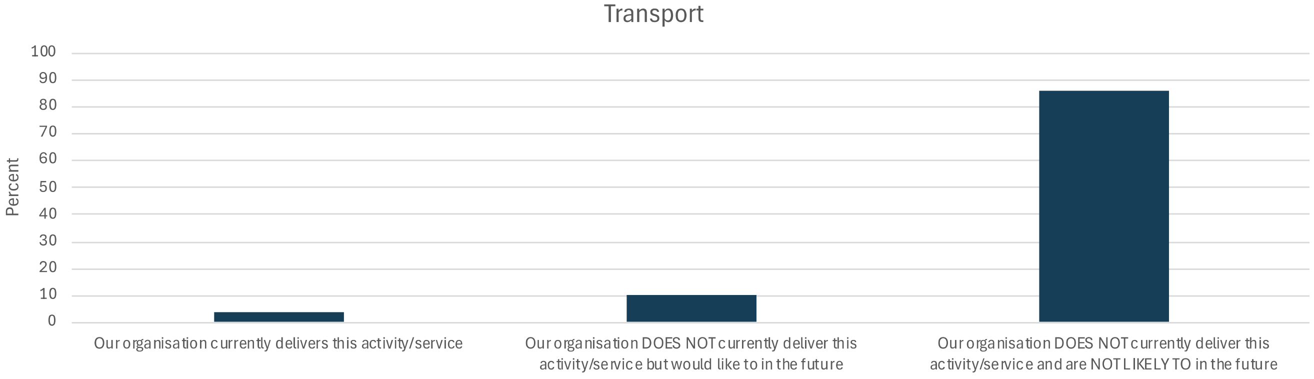


Figure 7.8: Transport

Self care interventions

Self-care interventions

Self-care interventions are tools which support self-care. Self-care interventions include evidence-based, quality drugs, vitamins & minerals, lotions and creams, devices, diagnostics and/or digital products (including apps) which can be provided fully or partially outside of formal health services and can be used with or without health worker.

There were 42 organisations (60.87%) that informed patients of self-care opportunities, 25 organisations (36.23%), reviewed the evidence/literature related to self-care opportunities, and 19 organisations (27.54%) referred patients to self-care opportunities. There were 20 organisations (28.99%) that did not engage in any self care initiatives.

Table 7.9: Self-care interventions

Does your organisation engage in any self care initiatives	n=69	Percent
Yes, we inform patients of self-care opportunities	42	60.87
Yes, we review the evidence/literature related to self-care opportunities	25	36.23
No, we do not engage in any self care initiatives	20	28.99
Yes, we refer patients to self-care opportunities	19	27.54

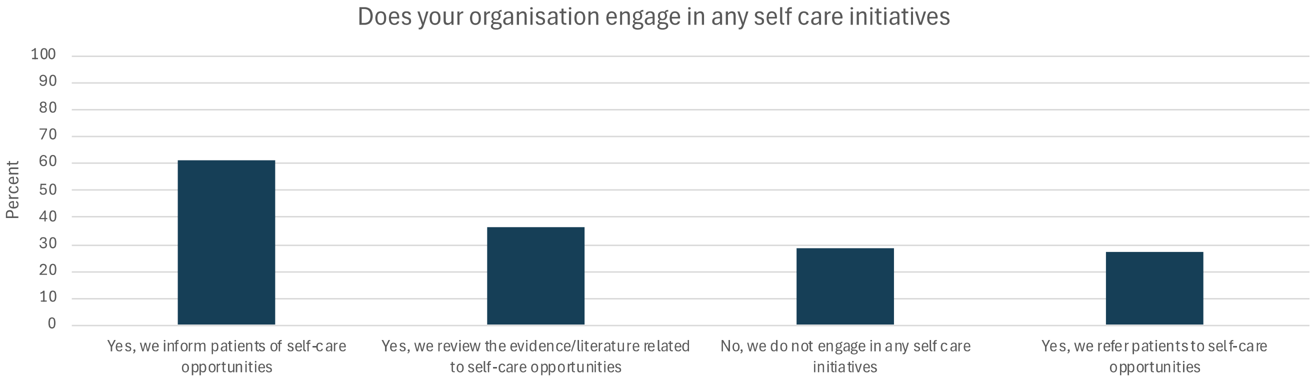


Figure 7.9: Self-care interventions

Self-care products that are most important to community

Organisations noted the self care products that were most important for their community. The most common products were evidence-based quality drugs, (n=43, 62.32%), digital products (including apps), (n=29, 42.03%), diagnostics, (n=28, 40.58%), and devices, (n=27, 39.13%). Other important self-care products were lotions and creams, (n=17, 24.64%), vitamins and minerals, (n=12, 17.39%), and information and courses, (n=2, 2.90%).

NPON organisations comments about self care

The collective support from other rare disease support groups. We learn from each other and help each other. The progression in genomics has helped early diagnosis for our families which means they can access the right seizures medication which can make things worse if they are prescribed the wrong one.

Wound care support and mental health support are two of our priorities

Drugs are not accessible or restrictive as are disease area specific - should be available if patients have demonstrated receptors or markers which indicate the medication will be effective.

Table 7.10: Self-care products that are most important to community

What self-care products are most important to your community	n=69	Percent
Evidence-based quality drugs	43	62.32
Digital products (including apps)	29	42.03
Diagnostics	28	40.58
Devices	27	39.13
Lotions and creams	17	24.64
None of the above	14	20.29
Vitamins and minerals	12	17.39
Information and courses	2	2.90
Other	3	4.35

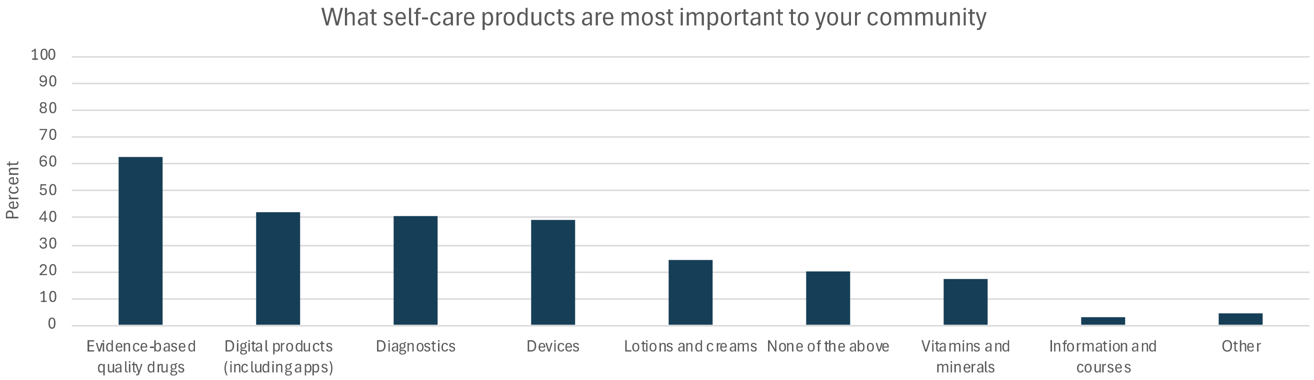


Figure 7.10: Self-care products that are most important to community

Section 8: NDIS Support

Summary of NPON NDIS support services

Summary of NPON NDIS support services

Data was collected from NPON members in 2024 about any NDIS support or information that they offer.

There were 5 organisations (7.25%) that offered a structured telephone service, 11 organisations (15.94%) that offered a helpline for NDIS, 19 organisations (27.54%) that offered online information and 14 organisations (20.29%) that offered written information.

NPON organisations comments about NDIS support services

Dysphonia not currently recognised for NDIS purposes

I would love this for our community - but this would be really difficult for me to put together. I don't have the knowhow or expertise in the area.

Our NDIS service is used to guide the NF Community through this often-complex process. We write support letters explaining NF, as it can cause invisible but significant disabilities. Our NDIS workload has increased recently. We are dealing with families who are distraught and struggling to access services. They're only able to access these essential services, like speech and phsyiotherapy, due to NDIS funding, an increasing number of families are having their access denied.

We provide the above by paying a 3rd party provider. We pay for families to have time with an external provider to discuss their applications,

NDIS support services

- 7% offer a telephone structured service
- 16% offer a helpline
- 28% offer online information tailored to their community
- 20% offer written information tailored to their community

NPON support services

Telephone structured service

NPON organisations were asked if they offered a telephone structured service for NDIS, this means a virtual clinic or case management service where patients need to make an appointment to talk with an NDIS support worker.

There were 5 organisations (7.25%) that offered a telephone structured service, 10 organisations (14.49%), do not offer this at the moment but would like to in the future, and 54 organisations (78.26%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about telephone structured service

re: option 1 (telephone service): We have an NDIS support coordination service which is available over the phone as well as home visits.

Table 9.1: Telephone structured service

Telephone structured service (This means a virtual clinic or case management service where patients need to make an appointment to talk with an NDIS support worker)	n=69	Percent
Our organisation currently delivers this activity/service	5	7.25
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	10	14.49
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	54	78.26

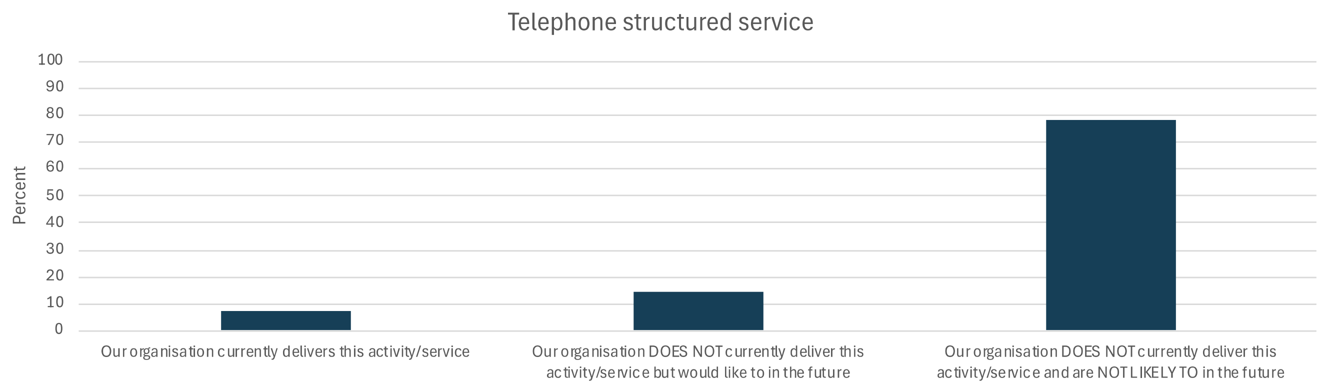


Figure 9.1: Telephone structured service

Helpline

NPON organisations were asked if they offered a helpline for NDIS, this is a general helpline that anyone can call at any time for information or support with a focus on NDIS.

There were 11 organisations (15.94%) that offered an NDIS helpline, 10 organisations (14.49%), do not offer this at the moment but would like to in the future, and 48 organisations (69.57%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about helplines

We are too small an organisation to provide this support formally. We do take phone calls from people enquiring about NDIS access for kids affected by cataract.

Table 9.2: Helpline

Helpline (This is a general helpline that anyone can call at any time for information or support with a focus on NDIS)	n=69	Percent
Our organisation currently delivers this activity/service	11	15.94
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	10	14.49
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	48	69.57

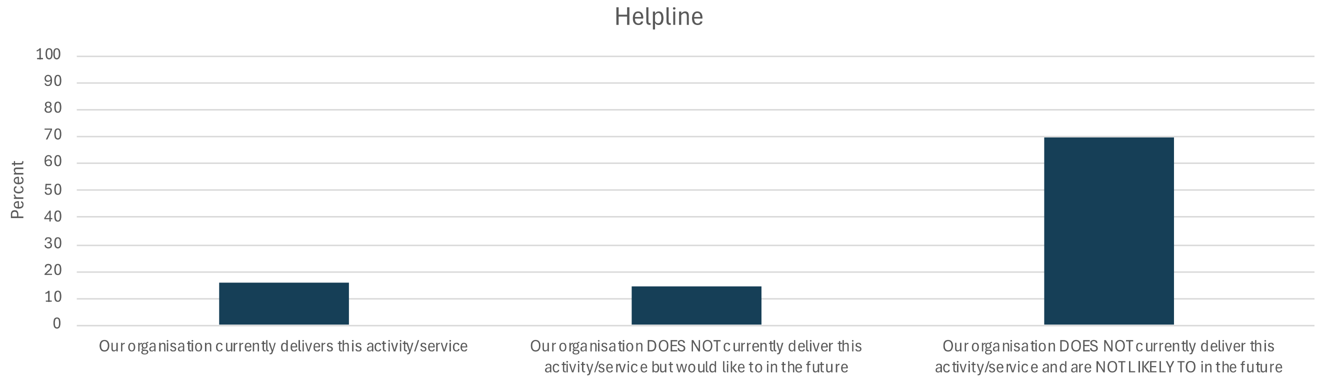


Figure 9.2: Helpline

Online information about NDIS specifically tailored to community

NPON organisations were asked if they offered online information about NDIS that is specific to their community.

There were 19 organisations (27.54%) that offered Online information about NDIS specifically tailored to their community, 21 organisations (30.43%), do not offer this at the moment but would like to in the future, and 29 organisations (42.03%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about information about NDIS specifically tailored to community

We're not that interested in offering NDIS services - we are too small for that, and many of our population do not access the NDIS.
But we would like to be able to formalise information for those families who do access the NDIS - either family members with Fragile X syndrome, or those with the Fragile X associated Tremor Ataxia Condition.

Table 9.3: Online information about NDIS specifically tailored to community

Online information about NDIS specifically tailored to your community	n=69	Percent
Our organisation currently delivers this activity/service	19	27.54
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	21	30.43
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	29	42.03

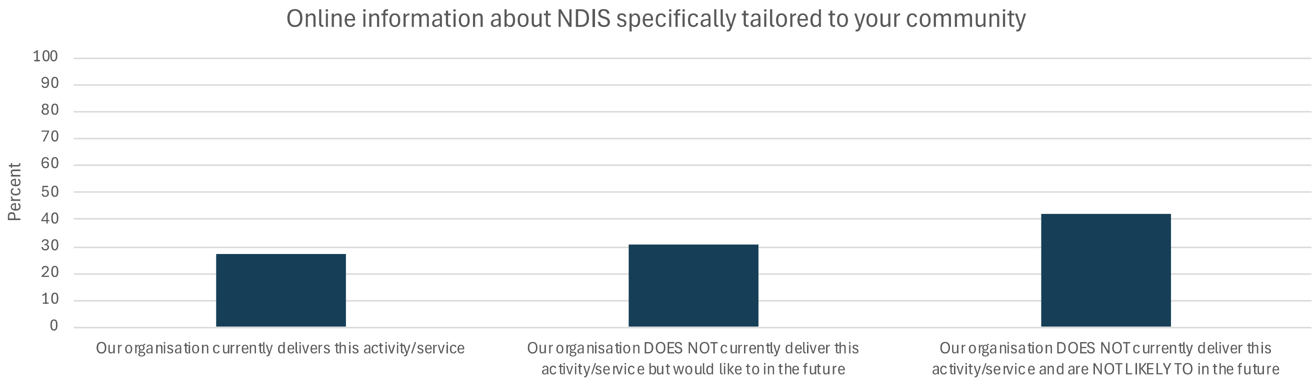


Figure 9.3: Online information about NDIS specifically tailored to community

Written (hard copy) information about NDIS specifically tailored to community

NPON organisations were asked if they offered written, hard copy information about NDIS that is specific to their community.

There were 14 organisations (20.29%) that offered written information about NDIS, 19 organisations (27.54%), do not offer this at the moment but would like to in the future, and 36 organisations (52.17%) do not offer this and are unlikely to offer it in the future.

Table 9.4: Written (hard copy) information about NDIS specifically tailored to community

Written (hard copy) information about NDIS specifically tailored to your community	n=69	Percent
Our organisation currently delivers this activity/service	14	20.29
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	19	27.54
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	36	52.17

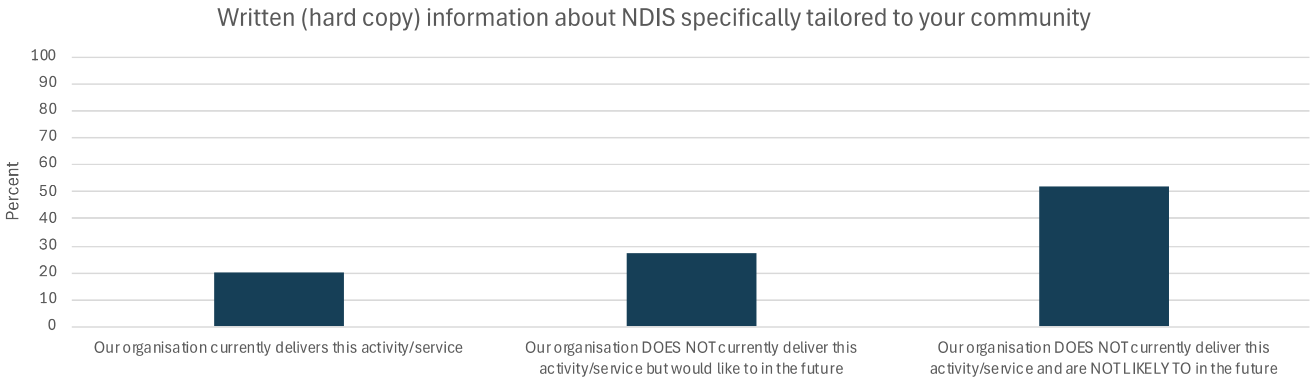


Figure 9.4: Written (hard copy) information about NDIS specifically tailored to community

Section 9: Information and education

Summary of NPON information and education services

Summary of NPON information and education services

Data was collected from NPON members in 2024 about information provided for patients and education provided for healthcare professionals.

Almost all the organisations offered online information for patients, and most organisations offered research update, written information (hard copies), webinars, patient information days or conferences, and clinical updates. A few organisations offered apps.

NPON organisations offered various forms of education for healthcare professionals. The majority of organisations offered online information, gave presentations on request, offered webinars, provided written (hard copy) information and offered conferences.

NPON organisations comments about information and education

Whilst we do conferences and patient days, we find this to be the most challenging activity for our volunteer organisation. Funding from NDIS, or Dept of Health (that does not require lengthy grant application process) for volunteer NFP patient organisations to deliver conferences that provide unmatched support, information and resources to rare disease organisations would be a game changer for us and our community. This has to become a reality.

I would love a funded family conference, it would allow families to see each other and work on that connection, and also gives them the opportunity to hear from our current research advisory committee on the research projects we have underway and what is to come in a face-to-face setting.

The ATF is proactive in educating patients and HCP's about the importance of good thyroid health, identifying, testing, treatments and monitoring.

It would be good if NFP's did not have to self fund to attend and educate HCPs

Little to no information about Immune Thrombocytopenia for those working in the emergency departments of hospitals - resulting in unwell patients having to educate HCPs

NPON patient Information services

- 96% offered online information
- 80% offered research updates
- 77% offered written information (hard copies)
- 73% offered webinars
- 67% offered patient information days or conferences
- 60% offered clinical updates
- 21% offered apps

NPON healthcare professional education

- 78% offered information for professionals
- 65% gave presentations on request
- 59% offered webinars to professionals
- 57% offered written information for professionals
- 52% offered conferences to professionals

Patient information

Online information

There were 80 organisations (96.39%) that offered online information, 1 organisation (1.20%), that does not offer this at the moment but would like to in the future, and 2 organisations (2.41%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about online information

We provide services to regional & rural patients via virtual media - telehealth, support groups. Also send resources via mail or links to online information.

We offer online peer support groups, online information day and occasionally meetups and retreats in regional areas where we have a client base.

Table 10.1: Online information

Online information	n=83	Percent
Our organisation currently delivers this activity/service	80	96.39
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	1	1.20
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	2	2.41

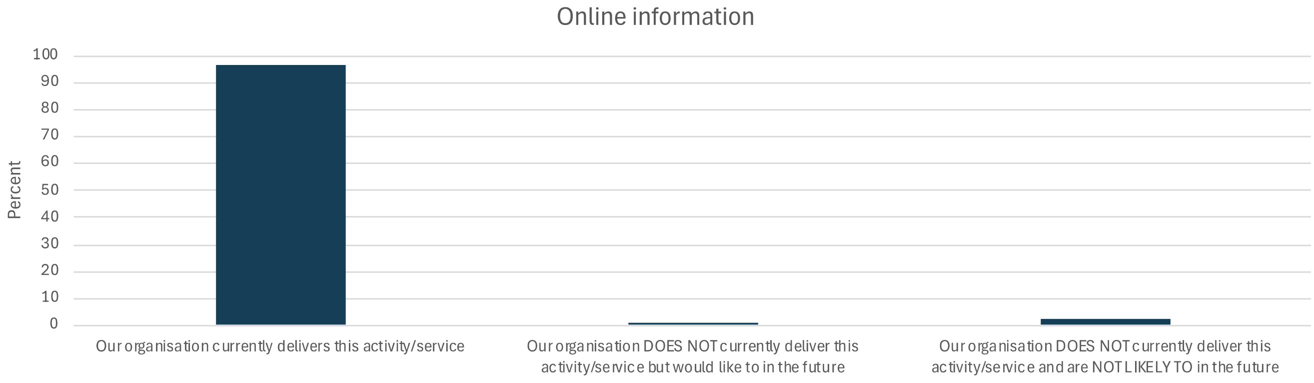


Figure 10.1: Online information

Written information (hard copy)

There were 64 organisations (77.11%) that offered written information (hard copy), 9 organisations (10.84%) that do not offer this at the moment but would like to in the future, and 10 organisations (12.05%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about written information

Funded and supported a project that printed brain tumour information in several different languages.

Need to provide information to these populations in print as they rarely have access to internet & printing. Important to tell them that the service is free & non-judgmental as well as suggest getting assistance via our Financial Assistance Program

Table 10.2: Written information (hard copy)

Written information (hard copy)	n=83	Percent
Our organisation currently delivers this activity/service	64	77.11
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	9	10.84
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	10	12.05

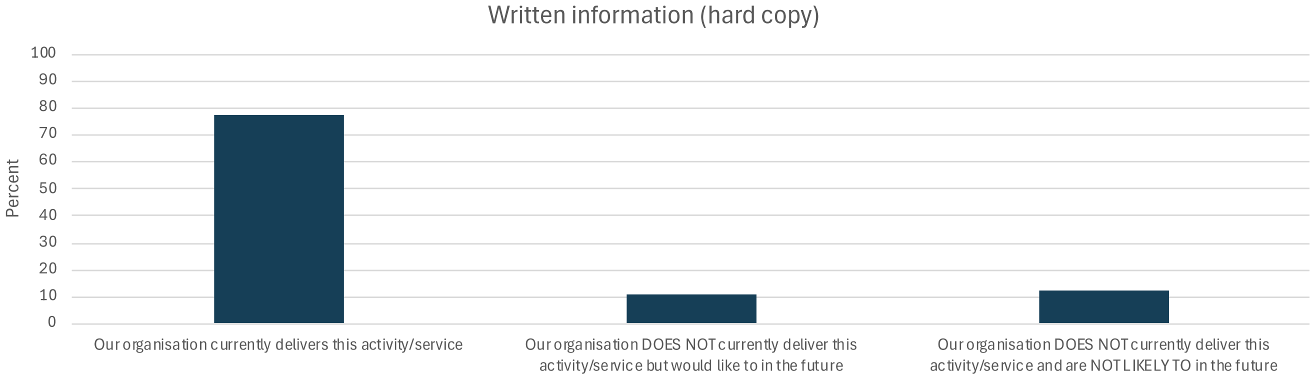


Figure 10.2: Written information (hard copy)

Apps

There were 17 organisations (20.99%) that offered apps, 41 organisations (50.62%)that do not offer this at the moment but would like to in the future, and 23 organisations (28.40%) do not offer this and are unlikely to offer it in the future.

Table 10.3: Apps

Apps	n=81	Percent
Our organisation currently delivers this activity/service	17	20.99
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	41	50.62
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	23	28.40

Figure 10.3: Apps

Research updates

There were 66 organisations (79.52%) that offered research updates, 13 organisations (15.66%) that do not offer this at the moment but would like to in the future, and 4 organisations (4.82%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about research updates

We would provide research and clinical updates for projects that we are involved in or where information is provided that is relevant to our community.

A family conference to bring all patients, researchers and clinicians together to give them updates on current status of research projects and disseminate information would be wonderful.

Table 10.4: Research updates

Research updates	n=83	Percent
Our organisation currently delivers this activity/service	66	79.52
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	13	15.66
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	4	4.82

Figure 10.4: Research updates

Clinical updates

There were 49 organisations (59.76%) that offered clinical updates, 21 organisations (25.61%) that do not offer this at the moment but would like to in the future, and 12 organisations (14.63%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about clinical updates

PNDU doesn't provide medical information or recommendations, PNDU refers members back to their treating medical teams.

Earlier patient access to new treatment
Visibility & awareness of new treatments

Table 10.5: Clinical updates

Clinical updates	n=82	Percent
Our organisation currently delivers this activity/service	49	59.76
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	21	25.61
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	12	14.63

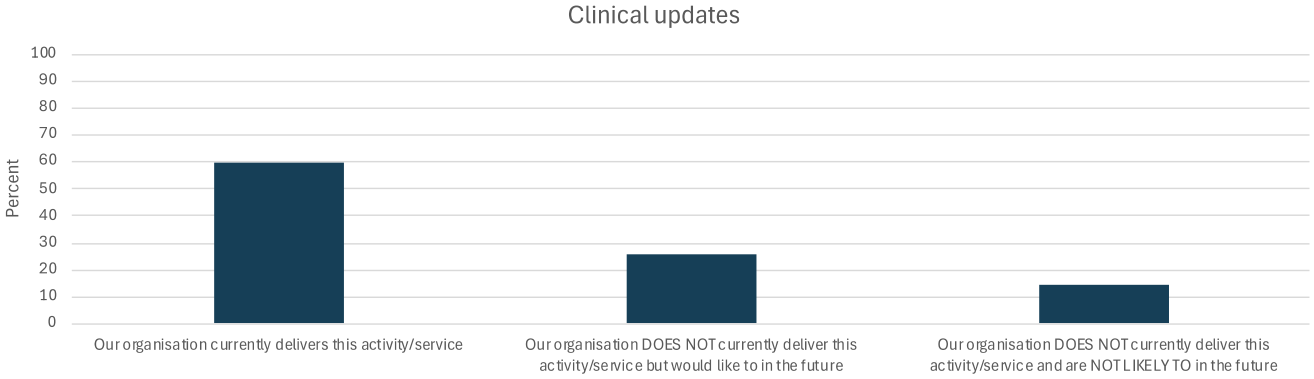


Figure 10.5: Clinical updates

Webinars

There were 61 organisations (73.49%) that offered webinars, 19 organisations (22.89%) that do not offer this at the moment but would like to in the future, and 3 organisations (3.61%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about webinars

We do provide webinars and patient information days but not nearly as often as we would like because we have no income. We receive no funding and charge no membership fees.

We run multiple webinars on a range of topics associated with Fragile X in some way - about Fragile X syndrome interventions & supports, Fragile X premutation (eg - PGD, or FX-related early menopause), or about future planning for families thinking about finances/ accommodation/ care etc for their adult child into the future.

Table 10.6: Webinars

Webinars	n=83	Percent
Our organisation currently delivers this activity/service	61	73.49
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	19	22.89
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	3	3.61

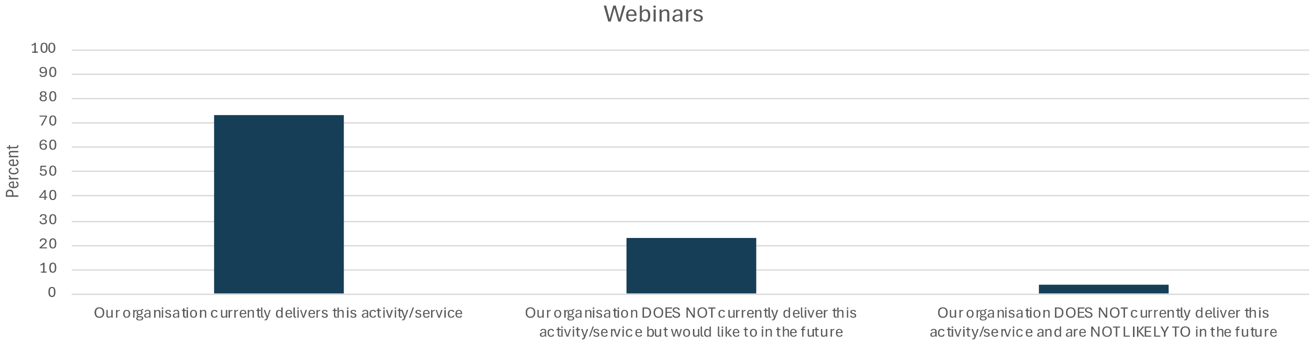


Figure 10.6: Webinars

Conferences or Patient information days

There were 56 organisations (67.47%) that offered conferences or Patient information days, 21 organisations (25.30%) that do not offer this at the moment but would like to in the future, and 6 organisations (7.23%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about conferences or patient information days

A family conference to bring all patients, researchers and clinicians together to give them updates on current status of research projects and disseminate information would be wonderful.

Conferences/Patient information days. We would LOVE to run these type of in-person events in different parts of the country to get the community together face to face in different locations. We don't do this because our current funding based (donations) doesn't support that.

Information days / symposiums are important to us - we have held 3 but need to secure funds to make this sustainable.

Table 10.7: Conferences or Patient information days

Conferences or Patient information days	n=83	Percent
Our organisation currently delivers this activity/service	56	67.47
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	21	25.30
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	6	7.23

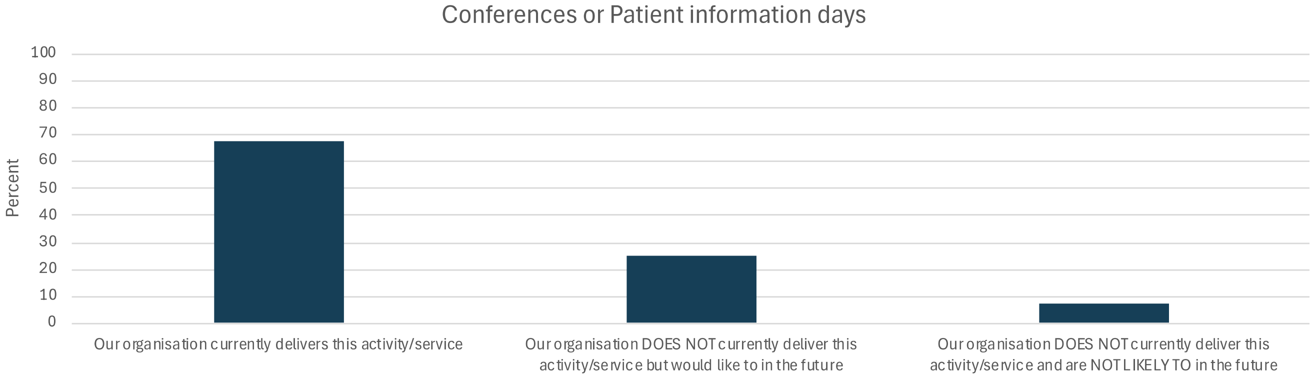


Figure 10.7: Conferences or Patient information days

Healthcare professional education

Online information

There were 54 organisations (78.26%) that offered online information, 5 organisations (7.25%) do not offer this at the moment but would like to in the future, and 10 organisations (14.49%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about online information

Also have developed online training programs for health professionals

Same as previous comment. We do provide these services but not nearly as much as we would like because we have no income. We receive no funding and charge no membership fees.

Table 10.8: Online information

Online information	n=69	Percent
Our organisation currently delivers this activity/service	54	78.26
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	5	7.25
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	10	14.49

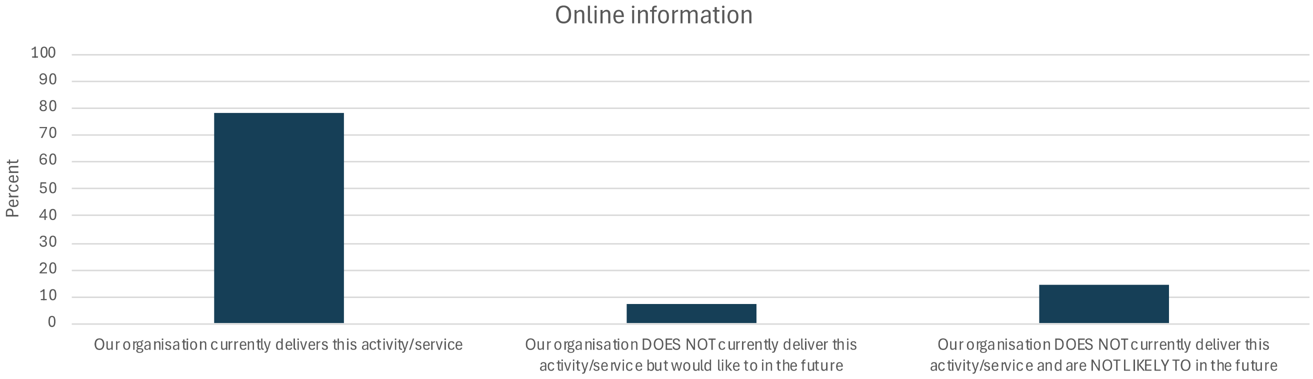


Figure 10.8: Online information

Written information

There were 39 organisations (56.52%) that offered written information, 12 organisations (17.39%) do not offer this at the moment but would like to in the future, and 18 organisations (26.09%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about written information

Limbs 4 Life provides information and resources which are available to whole of community. Often healthcare proivders will share our information and resources with their patients.

Table 10.9: Written information

Written information	n=69	Percent
Our organisation currently delivers this activity/service	39	56.52
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	12	17.39
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	18	26.09

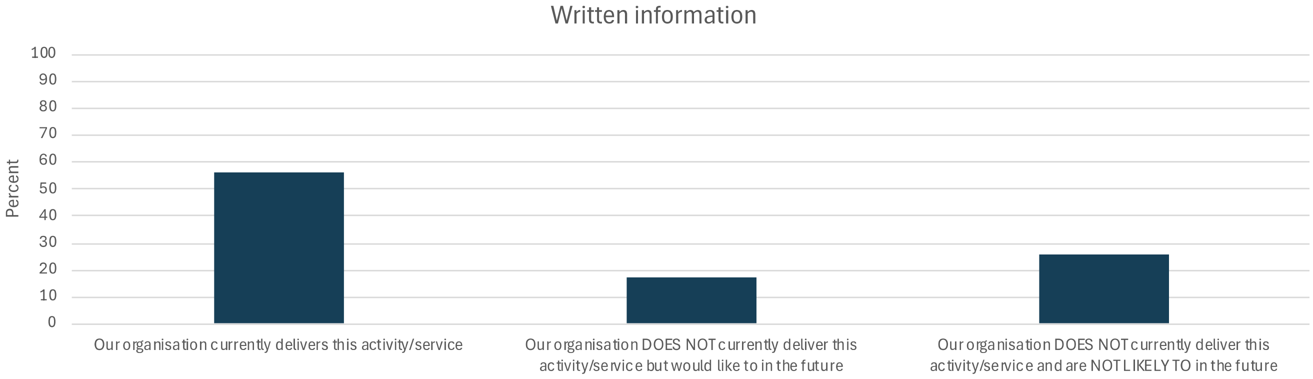


Figure 10.9: Written information

Presentations on request

There were 45 organisations (65.22%) that offered presentations on request, 14 organisations (20.29%) do not offer this at the moment but would like to in the future, and 10 organisations (14.49%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about presentations on request

PNDU work closely with the professional society AuSPEN to deliver an annual Home Parenteral Nutrition Consumer Workshop, believed to be the only consumer workshop of its kind anywhere in the world.
PNDU provide patient voice/experience presentations on request.

The ATF is proactive in educating patients and HCP's about the importance of good thyroid health, identifying, testing, treatments and monitoring.

Table 10.10: Presentations on request

Presentations on request	n=69	Percent
Our organisation currently delivers this activity/service	45	65.22
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	14	20.29
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	10	14.49

Figure 10.11: Presentations on request

Webinars

There were 41 organisations (59.42%) that offered webinars, 18 organisations (26.09%) do not offer this at the moment but would like to in the future, and 10 organisations (14.49%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about webinars

Some health professionals, specifically OTs and speech therapists, do access some of our webinars and access the recordings. We'd love to do more in this space but don't have the capacity.

We run a neuromuscular information and research day manually online which is available to people living with NMCs and health professionals.

Table 10.11: Webinars

Webinars	n=69	Percent
Our organisation currently delivers this activity/service	41	59.42
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	18	26.09
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	10	14.49

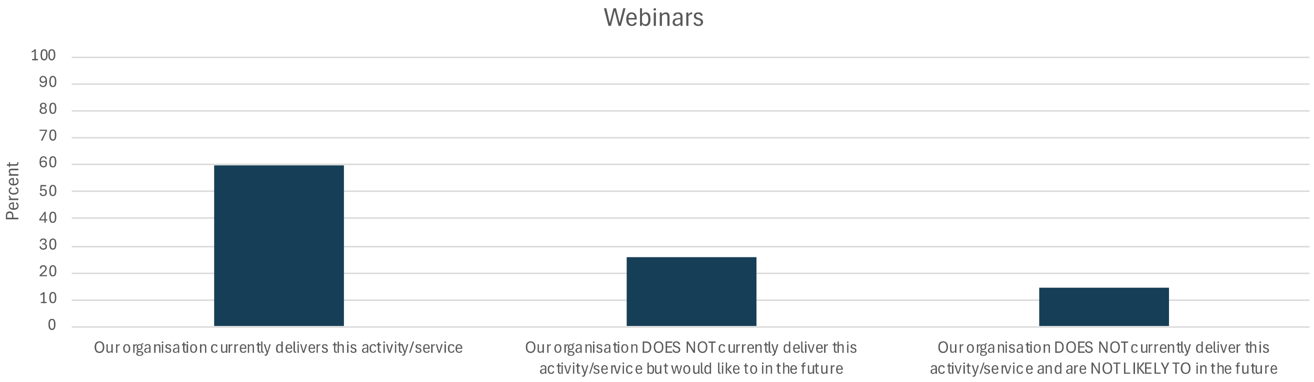


Figure 10.11: Webinars

Conferences

There were 36 organisations (52.17%) that offered conferences, 19 organisations (27.54%) do not offer this at the moment but would like to in the future, and 14 organisations (20.29%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about conferences

Have participated in professional organisation conferences to bring lived experience. Hopeful of expanding this

the conference will have international medical and research experts and there will be sessions for patients/parents/carers and additional sessions for professionals.

We are unlikely to deliver a conference in our own right but may partner with others to do so. We also actively engage with a range of health professionals in research projects, on working groups etc.

We currently attend the relevant medical conferences but do not run our own.

We provide information to patients to help keep their doctors informed about recommended NF Health Guidelines. Lack of knowledge about NF by clinicians can add an extra burden to an already vulnerable population. We run an NF Clinicial Symposium and Health Professional workshops with the aim of encouraging Clinicians to better understand NF. We also feel it's important to educate the NF Community to ensure they're empowered and able to advocate for themselves.

Table 10.12: Conferences

Conferences	n=69	Percent
Our organisation currently delivers this activity/service	36	52.17
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	19	27.54
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	14	20.29

Figure 10.12: Conferences

Section 11: Clinical trials and research

Summary of clinical trials and research

Summary of clinical trials and research

Data was collected from NPON members in 2024 about participation in clinical trials and research.

Approximately 68% of organisations direct patients to clinical trial, and about half of the organisations participate in clinical trial co-design or connecting patients with researchers. There were 18 organisations (21.69%) that fund clinical trials and 12 organisations (14.63%) manage clinical registries.

The majority of NPON organisations were involved with research co-design and/or connecting patients with researchers (n=52, 62.65%). NPON organisations also funded research (n=33, 39.76%), conduct research (n=25, 30.12%), and develop national research strategy (n=22, 26.51%).

NPON organisations comments about clinical trials and research

Same as previous comments. We have no income and few volunteers. We receive no funding and charge no membership fees. So our resources are extremely limited.

Our funds are reliant on donations by our community $10K doesn't get far in terms of running an org funding research, and so on.

We do not have sufficient funds to lead research - but have advocated for research to be undertaken and assisted in design.

Clinical trials	**Research**
- 68% direct patients to clinical trials - 52% clinical trial co-design and/or connecting patients with researchers - 22% fund clinical trials - 15% manage a clinical registry	- 63% research co-design and/or connecting patients with researchers - 40% fund research - 30% conduct research - 27% develop national research strategy

Clinical trials

Fund clinical trials

There were 18 organisations (21.69%) that funded clinical trials, 18 organisations (21.69%), do not offer this at the moment but would like to in the future, and 47 organisations (56.63%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about funding clinical trials

Save Our Sons has funded clinical trial teams in children's hospitals across Australia to be clinical trial ready and this has meant that clinical trials are now coming to Australia.

Limbs 4 Life offers early intervention peer support for people pre or immediately post amputation. This support is included in some but not all states and territories.

Table 11.1: Fund clinical trials

Fund clinical trials	n=83	Percent
Our organisation currently delivers this activity/service	18	21.69
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	18	21.69
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	47	56.63

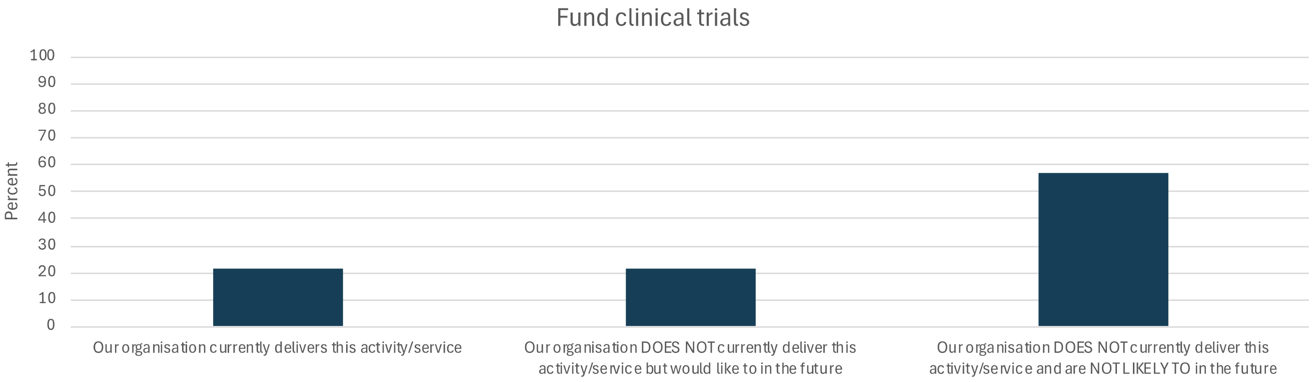


Figure 11.1: Fund clinical trials

Direct patients to clinical trials

There were 56 organisations (68.29%) that directed patients to clinical trials, 18 organisations (21.95%), do not offer this at the moment but would like to in the future, and 8 organisations (9.76%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about directing patients to clinical trials

Direction to clinical trials is through the clinicaltrials.gov website

There are no Australian clinical trials relevant to patients with congenital cataract.

We have a contact registry that is used for clinical trial recruitment, but not a clinical registry.

Table 11.2: Direct patients to clinical trials

Direct patients to clinical trials	n=82	Percent
Our organisation currently delivers this activity/service	56	68.29
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	18	21.95
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	8	9.76

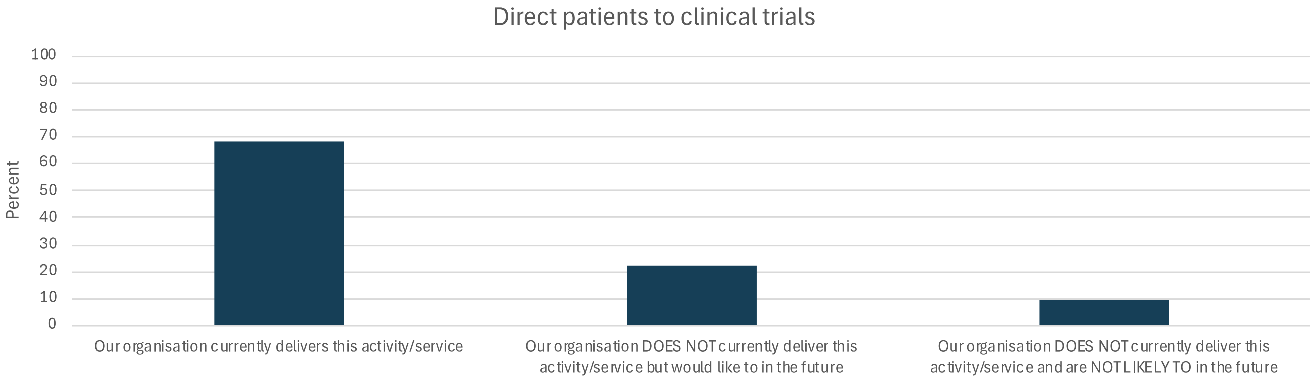


Figure 11.2: Direct patients to clinical trials

Clinical trial co-design and/or connecting patients with researchers

There were 43 organisations (52.44%) that that participated in clinical trial co-design and/or connecting patients with researchers, 26 organisations (31.71%), do not offer this at the moment but would like to in the future, and 13 organisations (15.85%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about clinical trial co-design and/or connecting patients with researchers

Ours is a small field but we are well connected with research bodies and are happy to promote participation.

We advocate internationally for Australian participation in clinical trials from the co-design stage through to delivery.

We work with researcher to run our registry.

Table 11.3: Clinical trial co-design and/or connecting patients with researchers

Clinical trial co-design and/or connecting patients with researchers	n=82	Percent
Our organisation currently delivers this activity/service	43	52.44
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	26	31.71
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	13	15.85

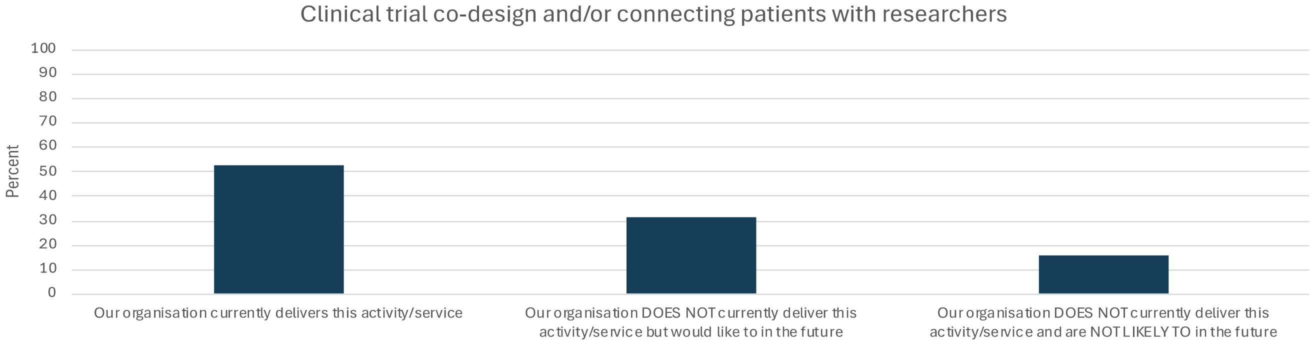


Figure 11.3: Clinical trial co-design and/or connecting patients with researchers

Manage a clinical registry

There were 12 organisations (14.63%) that managed a clinical registry, 29 organisations (35.37%), do not offer this at the moment but would like to in the future, and 41 organisations (50.00%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about managing a clinical registry

Again, same as previous comments. We do provide these services (or would like to) but not nearly as well as we would like because we have no income. We receive no funding and charge no membership fees. We have a patient registry but it requires updating however we don't have the funds to do it.

No funding has been made available federally or state level for the registry

We are launching a National patients register in August 2024

We don't manage the clinical registry however we have funded the startup and implementation of the national registry. It sits with Murdoch Research Institute.

We would like to have a registry established, but most likely would require outsourcing to manage and oversight.

We would not create a clinical registry but would support the establishment of a rare disease registry with patient owned and entered data or would consider other options. We make the community aware of trials and research projects and leave connecting to the patient/community if they wish.

Within the Childhood onset Heart Disease community there is the CHAANZ Registry and Fontan Registry which HeartKids support, but dont directly manage.

Table 11.4: Manage a clinical registry

Manage a clinical registry	n=82	Percent
Our organisation currently delivers this activity/service	12	14.63
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	29	35.37
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	41	50.00

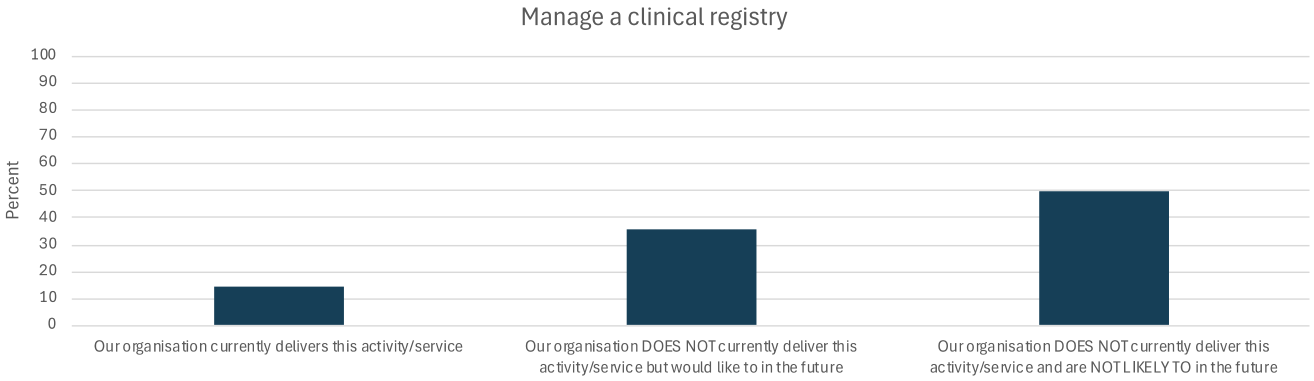


Figure 11.4: Manage a clinical registry

Research

Develop national research strategy

There were 22 organisations (26.51%) that developed national research strategy, 18 organisations (21.69%), do not offer this at the moment but would like to in the future, and 43 organisations (51.81%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about developing national research strategy

For the National research strategy, as a member and secretariat of the Blood Cancer Taskforce, leading the development of a 10-year Research Roadmap for blood cancer. This project has commenced, with the Roadmap to be publicly available in second half of 2024.

We are currently working through a national research strategy but are also finding it difficult to move forward given our capacity and understanding of what needs to be embedded for a strategy plan to be viable.

While we support the importance of appropriate and effective direction of research funding, we would be unlikely to initiate the development of a strategy however, if a consultation occurred we would be open to contributing from a cancer perspective.

Table 11.5: Develop national research strategy

Develop national research strategy	n=83	Percent
Our organisation currently delivers this activity/service	22	26.51
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	18	21.69
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	43	51.81

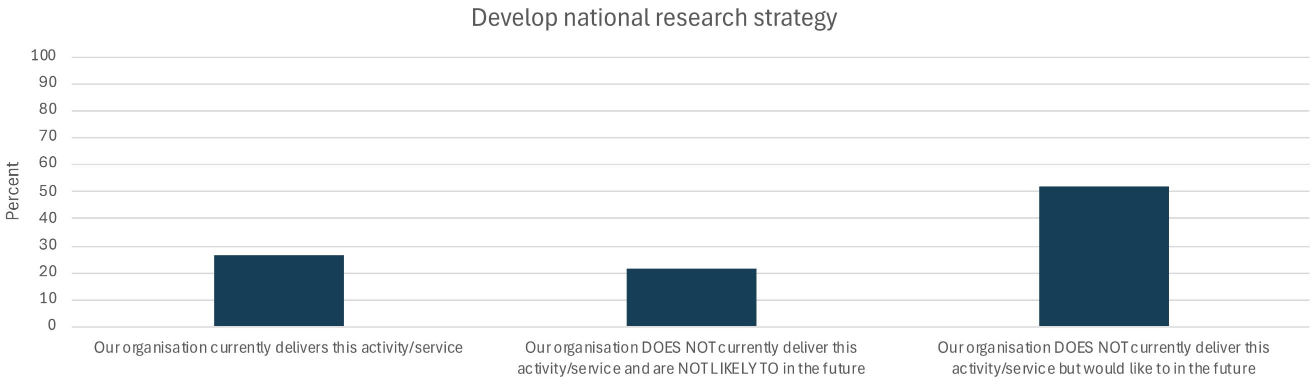


Figure 11.5: Develop national research strategy

Fund research

There were 33 organisations (39.76%) that funded research, 28 organisations (33.73%), do not offer this at the moment but would like to in the future, and 22 organisations (26.51%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about funding research

There is very little research in our area in Australia. We have funded very small elements of research activites (eg. $500 bursary).

We predominantly fund research. Our main challenges are:
* grant applications - not being given feedback to unsuccessful grants
* funding in general - State and Fed government to look favourably at the 'underdogs' in research instead of continually funding the large organisations
* providing patients with information about clinical trials that are being run in Australia are few and far between. We need more availability in Australia.

Table 11.6: Fund research

Fund research	n=83	Percent
Our organisation currently delivers this activity/service	33	39.76
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	28	33.73
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	22	26.51

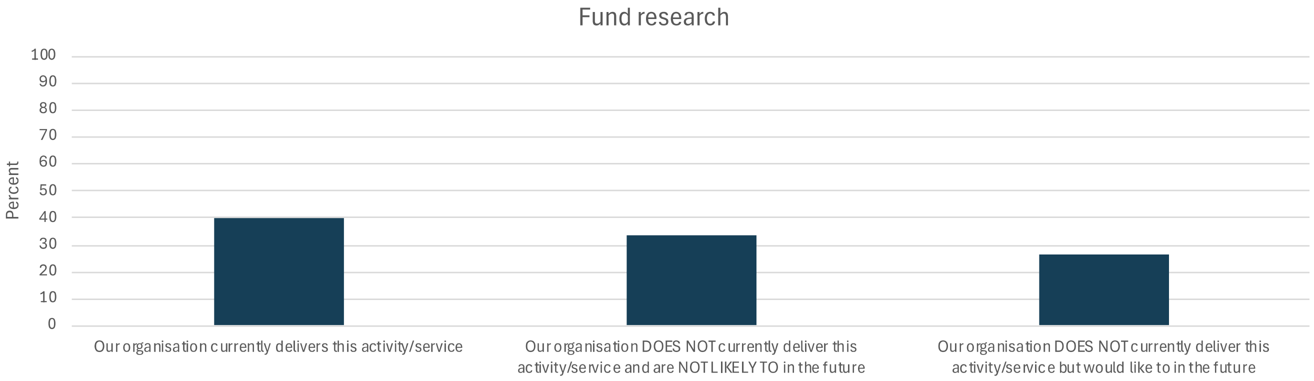


Figure 11.6: Fund research

Conduct research

There were 22 organisations (26.51%) that developed national research strategy, 18 organisations (21.69%), do not offer this at the moment but would like to in the future, and 43 organisations (51.81%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about conducting research

For the first time - we are engaged in a small research project which we designed and sought/received grant funding for. This is a study in partnership with Centre for Disability Studies, looking at adults/ageing with Fragile X syndrome - support needs gaps. Our charitable objects don't include RESEARCH as a core object, rather supporting research is an object. As our core role is providing support, counselling, clinics, information, education to people with the syndrome or carriers of Fragile X - we're comfortable that this current piece will be the only research we engage in in the immediate future.

We have performed and will continue to do behavioural type research to better understand community/patient behaviours

Table 11.7: Conduct research

Conduct research	n=83	Percent
Our organisation currently delivers this activity/service	25	30.12
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	28	33.73
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	30	36.14

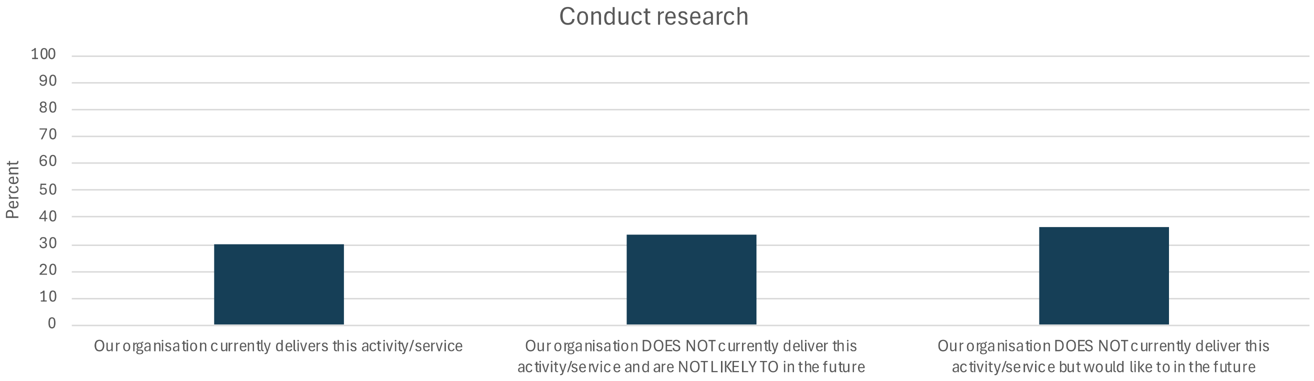


Figure 11.7: Conduct research

Research co-design and/or connecting patients with researchers

There were 22 organisations (26.51%) that developed national research strategy, 18 organisations (21.69%), do not offer this at the moment but would like to in the future, and 43 organisations (51.81%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about research co-design and/or connecting patients with researchers

Currently growing our engagement with research institutes to provide lived experience and patient perspectives to liver and hepatitis research programs.

We are CI on numerous research grants

Table 11.8: Research co-design and/or connecting patients with researchers

Research co-design and/or connecting patients with researchers	n=83	Percent
Our organisation currently delivers this activity/service	52	62.65
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	4	4.82
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	27	32.53

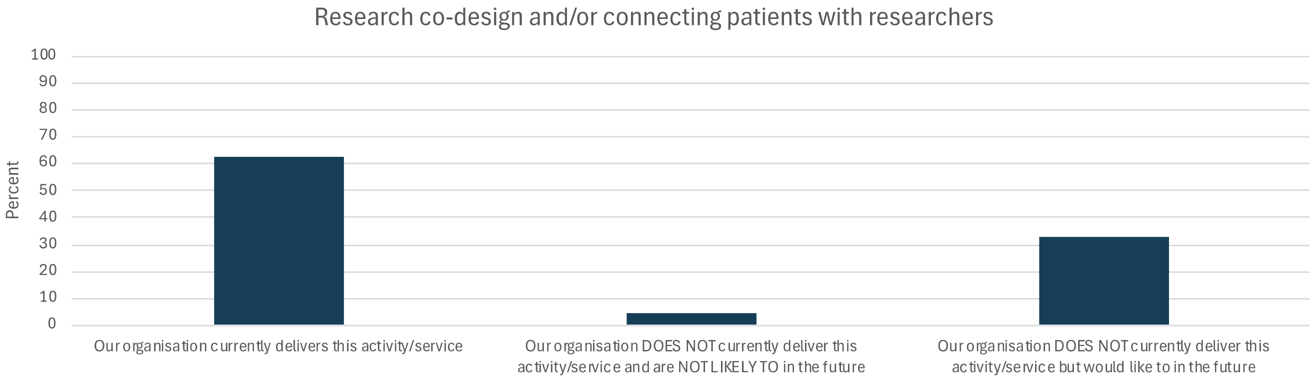


Figure 11.8: Research co-design and/or connecting patients with researchers

Section 12: Palliative care and pain management

Summary of NPON palliative care and pain management

Summary of NPON palliative care and pain management

Data was collected from NPON members in 2024 about palliative care services and pain management services that the organisation is involved with or would like to initiate in the future.

The most common services offered for palliative care , were carer support, information, and advocacy and policy. Other services were support or education for health professionals, and referral to palliative care.

The most common services or activities for pain management were to provide information, provide care support, and provide advocacy or policy. Other services were referrals to pain management specialists and to provide support or education for health professionals.

NPON palliative care

- 28% provide carer support for palliative care
- 24% provide information about palliative care
- 23% provides advocacy or policy for palliative care
- 16% provide support or education for health professionals for palliative care
- 13% offer referral to palliative care services

NPON pain management

- 37% provide information about pain management
- 28% provide carer support for pain management
- 25% provides advocacy or policy for pain management
- 19% offer referral to pain management specialists
- 13% provide support or education for health professionals for pain management

Palliative Care

Referral to palliative care services

There were 11 organisations (13.25%) that offered referral to palliative care services, 19 organisations (22.89%), do not offer this at the moment but would like to in the future, and 53 organisations (63.86%) do not offer this and are unlikely to offer it in the future.

Table 12.1: Referral to palliative care services

Referral to palliative care services	n=83	Percent
Our organisation currently delivers this activity/service	11	13.25
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	19	22.89
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	53	63.86

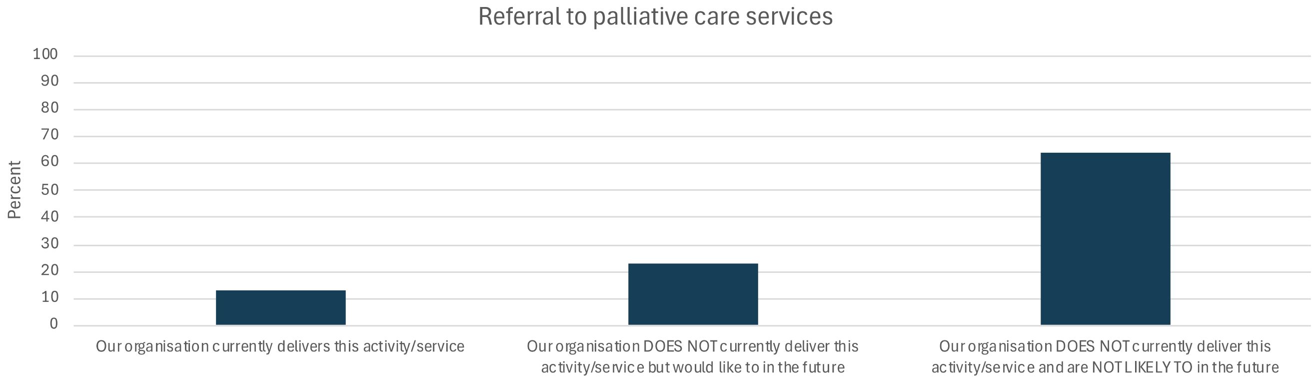


Figure 12.1: Referral to palliative care services

Palliative care information provision

There were 20 organisations (24.10%) that offered information provision about palliative care, 19 organisations (22.89%), do not offer this at the moment but would like to in the future, and 44 organisations (53.01%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about palliative care

Our education for health professionals includes our fact sheets for patients to take to their health professionals. Resources on our website and our workshops and clinical Symposium.

Table 12.2: Palliative care information provision

Information provision	n=83	Percent
Our organisation currently delivers this activity/service	20	24.10
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	19	22.89
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	44	53.01

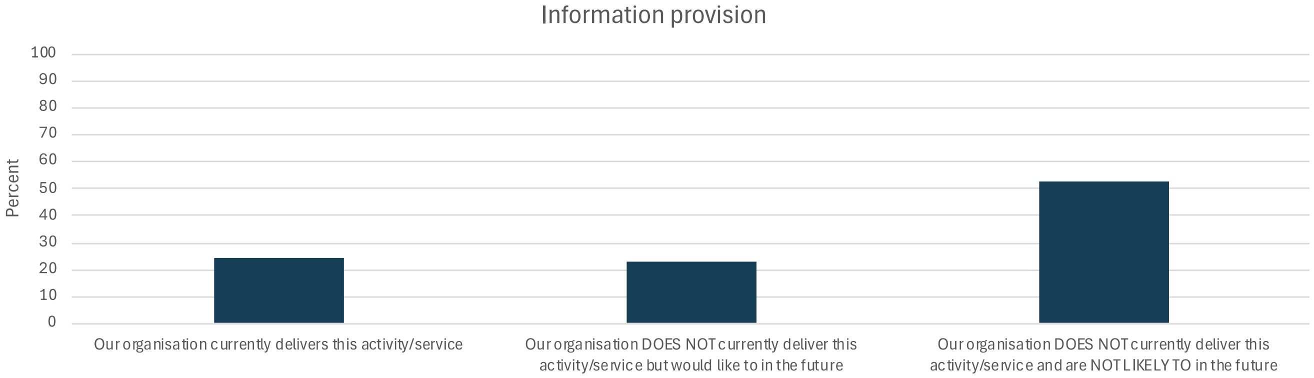


Figure 12.2: Palliative care information provision

Palliative care advocacy and policy

There were 19 organisations (22.89%) that offered palliative care advocacy and policy, 21 organisations (25.30%), do not offer this at the moment but would like to in the future, and 43 organisations (51.81%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about palliative care

We would speak on policy priorities for early access to quality, appropriate palliative care in the context of cancer at a federal policy level.

Align internal resources and partnership services to deliver a comprehensive model of support across the CoHD journey across milestones - diagnosis, surgery, preschool, primary, teen and young adult, adult and palliative care.

Table 12.3: Palliative care advocacy and policy

Advocacy and policy	n=83	Percent
Our organisation currently delivers this activity/service	19	22.89
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	21	25.30
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	43	51.81

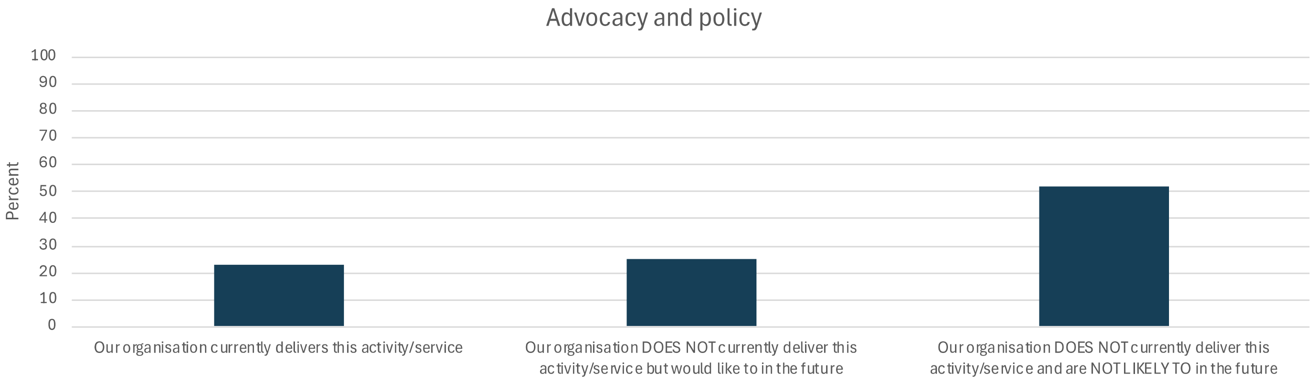


Figure 12.3: Palliative care advocacy and policy

Palliative care support for carers

There were 23 organisations (27.71%) that offered palliative care support for carers, 19 organisations (22.89%), do not offer this at the moment but would like to in the future, and 41 organisations (49.40%) do not offer this and are unlikely to offer it in the future.

Table 12.4: Palliative care support for carers

Support for carers	n=83	Percent
Our organisation currently delivers this activity/service	23	27.71
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	19	22.89
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	41	49.40

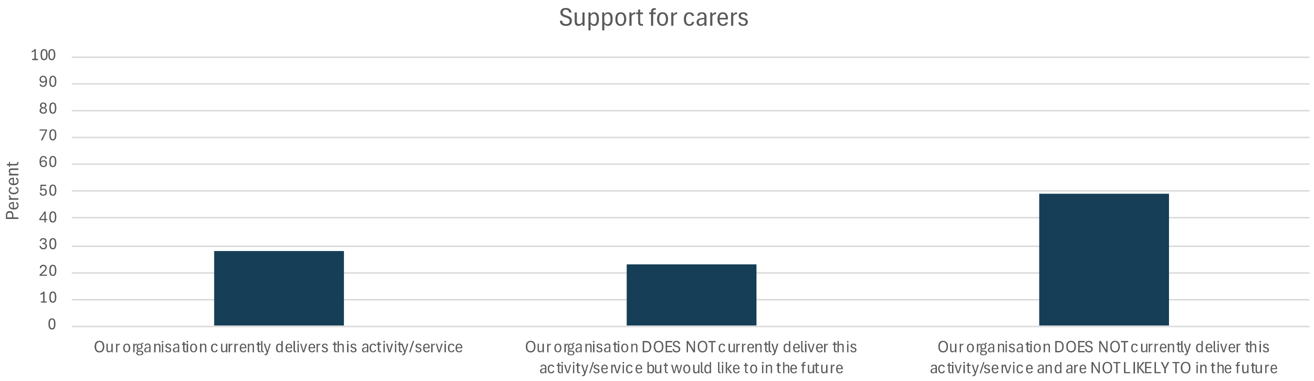


Figure 12.4: Palliative care support for carers

Palliative care support or education for health professionals

There were 13 organisations (15.66%) that offered palliative care support or education for health professionals, 24 organisations (28.92%), do not offer this at the moment but would like to in the future, and 46 organisations (55.42%) do not offer this and are unlikely to offer it in the future.

Table 12.5: Palliative care support or education for health professionals

Support or education for health professionals	n=83	Percent
Our organisation currently delivers this activity/service	13	15.66
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	24	28.92
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	46	55.42

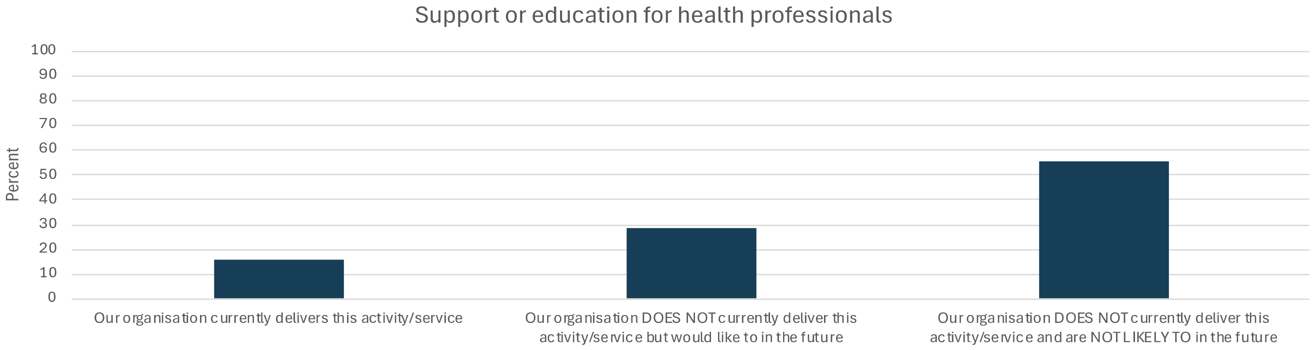


Figure 12.5: Palliative care support or education for health professionals

Pain Management

Referral to pain management specialists

There were 16 organisations (19.28%) that offered referral to pain management specialists, 19 organisations (22.89%), do not offer this at the moment but would like to in the future, and 48 organisations (57.83%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about pain

This is a huge space for our community - referring to a specialist is problematic as we do not have a list of known experts in AU to refer to.

We do not offer a clinical referral pathways, but we do offer informal referrals to specialists that are recommended by our community members.

Table 12.6: Referral to pain management specialists

Referral to pain management specialists	n=83	Percent
Our organisation currently delivers this activity/service	16	19.28
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	19	22.89
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	48	57.83

Figure 12.6: Referral to pain management specialists

Pain management information provision

There were 31 organisations (37.35%) that offered pain management information provision, 19 organisations (22.89%), do not offer this at the moment but would like to in the future, and 33 organisations (39.76%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about pain

Our Webinars are aimed at the NF Community, but we have health professionals signed up for our current Pain Webinar as well.

Table 12.7: Pain management information provision

Information provision	n=83	Percent
Our organisation currently delivers this activity/service	31	37.35
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	19	22.89
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	33	39.76

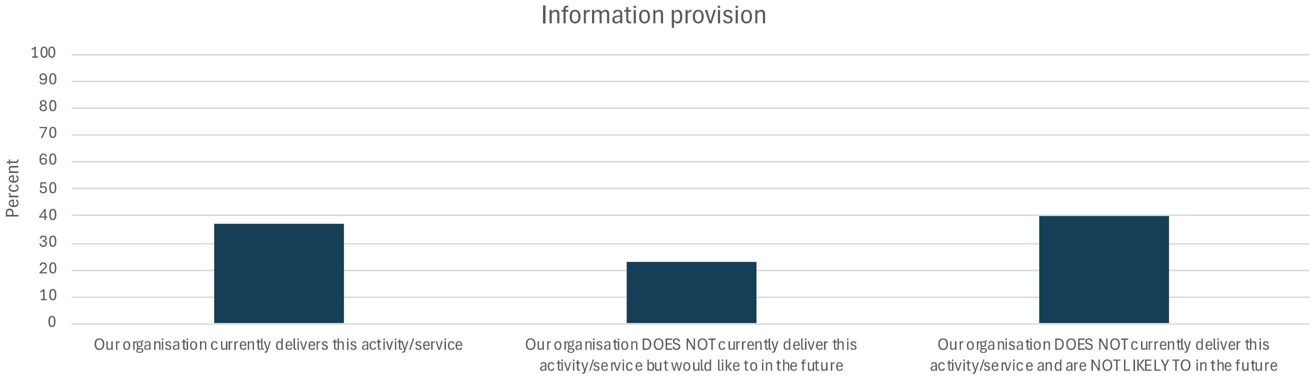


Figure 12.7: Pain management information provision

Pain management advocacy and policy

There were 21 organisations (25.30%) that offered pain management advocacy and policy, 25 organisations (30.12%), do not offer this at the moment but would like to in the future, and 37 organisations (44.58%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about pain

We would speak on policy priorities for early access to quality, appropriate pain management in the context of cancer at a federal policy level.

Table 12.8: Pain management advocacy and policy

Advocacy and policy	n=83	Percent
Our organisation currently delivers this activity/service	21	25.30
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	25	30.12
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	37	44.58

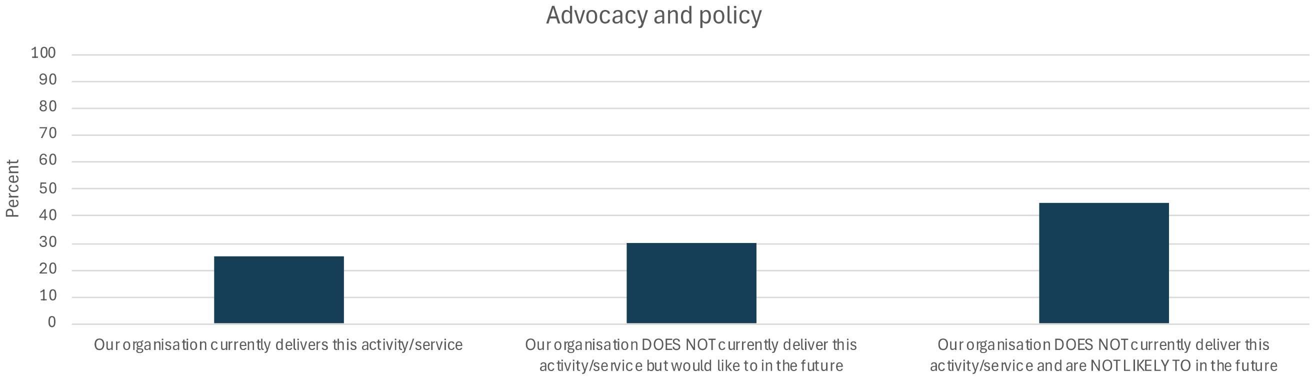


Figure 12.8: Pain management advocacy and policy

Pain management support for carers

There were 23 organisations (27.71%) that offered pain management support for carers, 24 organisations (28.92%), do not offer this at the moment but would like to in the future, and 36 organisations (43.37%) do not offer this and are unlikely to offer it in the future.

Table 12.9: Pain management support for carers

Support for carers	n=83	Percent
Our organisation currently delivers this activity/service	23	27.71
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	24	28.92
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	36	43.37

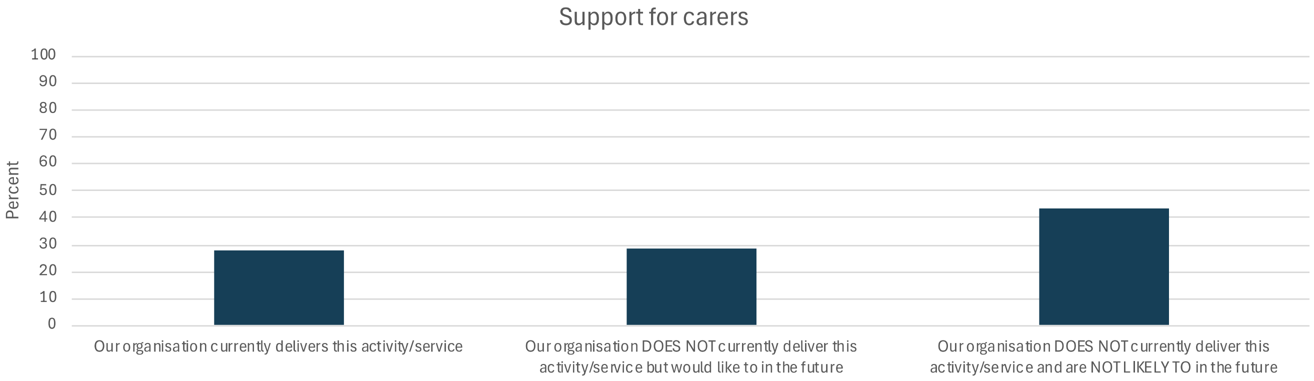


Figure 12.9: Pain management support for carers

Pain management support or education for health professionals

There were 11 organisations (13.25%) that offered pain management support or education for health professionals, 34 organisations (40.96%), do not offer this at the moment but would like to in the future, and 38 organisations (45.78%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about pain

Our Webinars are aimed at the NF Community, but we have health professionals signed up for our current Pain Webinar as well.

Table 12.10: Pain management support or education for health professionals

Support or education for health professionals	n=83	Percent
Our organisation currently delivers this activity/service	11	13.25
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	34	40.96
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	38	45.78

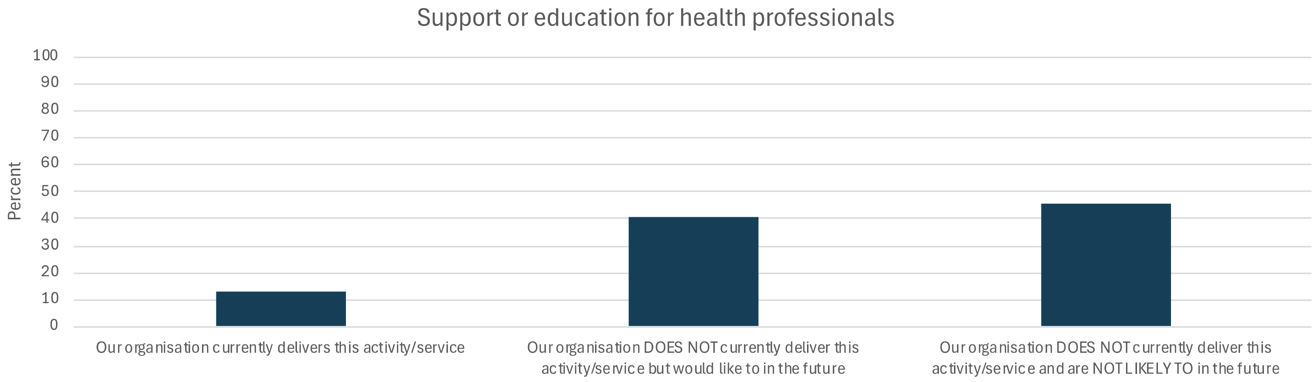


Figure 12.10: Pain management support or education for health professionals

Section 13: Programs and outreach to specific communities

Summary of NPON support services

Data was collected from NPON members in 2024 about programs and outreach to regional and rural populations, Aboriginal and Torres Strait Islander, people from a non-English speaking population, low income and/or homeless people, and LGBTQ+ populations,

Outreach programs were most commonly delivered to regional and rural populations (n=22, 26.51%). There were 7 organisations (8.43%) that offered outreach to non-English speaking background populations, 5 organisations (6.02%) that offered outreach to low income and/or homeless populations, and two organisations that each provided outreach to Aboriginal and Torres Strait Islander populations (2.41%), and LGBTQ+ populations (2.41%).

Specific programs were most commonly delivered to regional and rural populations (n=15, 18.07%). There were 8 organisations (9.64%) that offered specific programs for non-English speaking background populations, 3 organisations (3.61%) that offered specific programs for Aboriginal and Torres Strait Islander populations, two organisations that each provided specific programs for low income and/or homeless populations (2.41%), and LGBTQ+ populations (2.41%).

NPON organisations reported that all programs have a component that addresses the following: regional and rural populations (n=36, 43.37%), Aboriginal and Torres Strait Islander populations (n=17, 20.48%), non-English speaking background (n=16, 19.28%), LGBTQ+ populations (n=15, 18.07%), and low income and/or homeless populations (n=14, 16.87%).

NPON organisations comments about support services

In rural and remote areas of Australia, some services may not be available at all. As most cancer treatment centres and experts are based in metro areas, many people living outside of major cities need to travel, often at significant expense, spending extended time away from their jobs, support systems and families. Regional and Rural populations can access our online support groups and services. We promote the health of our regional and rural populations but assisting with transport and travel cost to ensure they can access services.

We are in the process of developing a program plan which includes hiring a Health Promotion Officer.

We provide each patient with access to their own Specialist Cancer Navigator for personalised clinical, emotional, financial and practical support throughout their diagnosis, treatment and beyond.

The ATSI population are greatly impacted by T2 diabetes and inturn amputation resulting from this disease. We have been looking into ways that we can assist with greater education and access to information to support those members of our community.

We utilise interpreter services when necessary to ensure that we are able to deliver adequate support and intervention to those who come from a non english speaking background. We are in the process of translating our reading materials and support guides so they are more accessible to those who don't speak English as their first language.

Our services are truly personalised. We have provided letters to government agencies for housing, healthcare cards, etc. If a person has an issue related to their NF then we are willing to support them in whatever is needed. It can be hard for people to explain the impacts of NF so we always aim to provide assistant to low income populations where required.

Regional and rural populations

- 27% offer outreach programs
- 18% delivers specific programs
- 43% all programs have a component that addresses this population

Low-income and/or homeless populations

- 6% offer outreach programs
- 2% delivers specific programs
- 17% all programs have a component that addresses this population

Aboriginal and Torres Strait Islander populations

- 2% offer outreach programs
- 4% delivers specific programs
- 20% all programs have a component that addresses this population

LGBTQ+ populations

- 2% offer outreach programs
- 2% delivers specific programs
- 18% all programs have a component that addresses this population

Non-English speaking background populations

- 8% offer outreach programs
- 10% delivers specific programs
- 19% all programs have a component that addresses this population

Regional and rural populations

Regional and rural populations: Outreach programs

There were 22 organisations (26.51%) that offered outreach programs for regional and rural populations, 28 organisations (33.73%), do not offer this at the moment but would like to in the future, and 33 organisations (39.76%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about regional and rural populations

We don't have the resources to provide enough of the services we currently provide so we couldn't even contemplate expanding them.

Our regional program is no longer funded.

Breast Health Education programs into regional Australia.
Outreach, peer connection (in person and online) to young breast cancer patients in regional Australia.

CF is not demographically based and as the population all rely on capital city based services, we fund out of pocket transport expenses as well as a range of specific equipment, support and service program for people in regional, remote and rural locations to assist in the management of health at home. We also support remote services delivered by clinicians.

Focus group recently conducted on rural and regional people in our community. There is no registry in Australia on hereditary cancer patients so its hard for us to understand where these people are but we do know they have trouble accessing genetic counselling and high risk screening.

We are currently delivering:
1. face-to-face meetings with specialist healthcare professionals in regional/rural locations.
2. all brochures/resources are downloadable from our website
3. offer a scholarship specific to this audience to our annual patient conferences

Table 13.1: Regional and rural populations: Outreach programs

Outreach programs	n=83	Percent
Our organisation currently delivers specific activities/services for this population	22	26.51
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	28	33.73
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	33	39.76

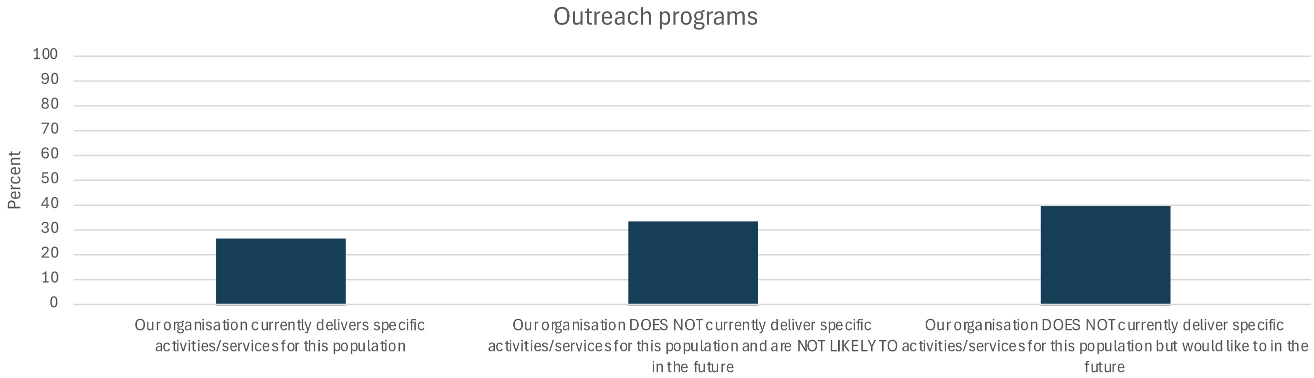


Figure.1: Regional and rural populations: Outreach programs

Regional and rural populations: Specific programs

There were 15 organisations (18.07%) that offered specific programs for regional and rural populations, 24 organisations (28.92%), do not offer this at the moment but would like to in the future, and 44 organisations (53.01%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about regional and rural populations

Some services are delivered in regional areas however more funding and resources needed to expand and meet the need.

We would like to establish a Telehealth counselling service specific to voice disorders for rural and remote people. Have submitted for funding unsuccessfully.

Approx 30% of our patients are from Regional/Rural/Remote Australia, we currently do not have specific programs that cater to them but engage with them via telehealth nursing & via our Online Patient/Carer/Grief Support groups (relies on good internet which they may not have)

Awareness and Symptoms brochures to targeted regional/rural areas via community centres and GP clinics.

Rural and regional workforce development programs and forums that bring together organisations and community to focus on identifying and addressing local challenges, issues, opportunities.

Table 13.2: Regional and rural populations: Specific programs

Specific programs for this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	15	18.07
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	24	28.92
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	44	53.01

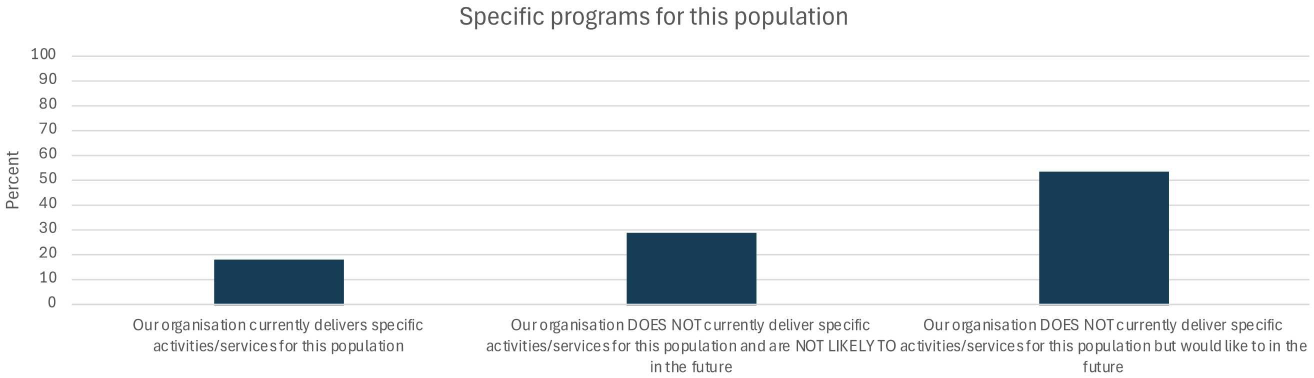


Figure.2: Regional and rural populations: Specific programs

Regional and rural populations: All programs have a component that addresses this population

There were 36 organisations (43.37%) that offered all programs have a component that addresses regional and rural populations, 17 organisations (20.48%), do not offer this at the moment but would like to in the future, and 30 organisations (36.14%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about regional and rural populations

All information we deliver is available to all. We do not deliver physical services.

We serve populations around the country, which includes remote and regional people. As our services are often delivered by phone or online or through email via resources, a significant portion of our work serves these communities, as they are often the least connected to specialist clinical services.

All our Peer to Peer support is offered online and is available to anyone Australia wide. Our annual conference is also offered to everyone Australia wide.

No specific programs directly designed for solely rural and remote but all of our healthcare professional and patient support programs are available to and promoted to people in these locations.

All our programs have digital elements and so are able to be delivered in all locations.

For health professionals we will offer CPD education, guidelines, evidence based content and in-practice programs. These would be run via virtual platforms.

Patient peer support programs and helpline are available to rural and remote individuals as these are phone services.

Kidney bus holiday dialysis service allows people from rural areas to travel and have a holiday.

Table 13.3: Regional and rural populations: All programs have a component that addresses this population

All programs have a component that addresses this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	36	43.37
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	17	20.48
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	30	36.14

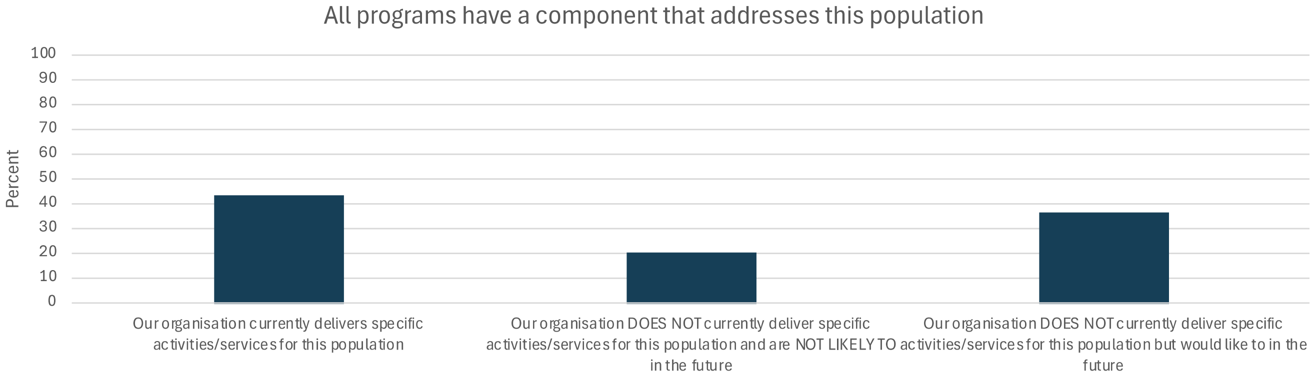


Figure.3: Regional and rural populations: All programs have a component that addresses this population

Aboriginal and Torres Strait Islander populations

Aboriginal and Torres Strait Islander populations: Outreach programs

There were 2 organisations (2.41%) that offered outreach programs for Aboriginal and Torres Strait populations, 46 organisations (55.42%), do not offer this at the moment but would like to in the future, and 35 organisations (42.17%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about Aboriginal and Torres Strait Islander populations

Support and assistance currently provided to First Nations people with existing programs.

Leukaemia Foundation does have and provides dedicated information and resources for First Nations people.

We would never consider doing this ourselves but definitely work with indigenous communities and indigenous led projects and hope to increase this in the future.

We are developing an education program - The Science Within Us in partnership with an indigenous education organisation for delivery in indigenous communities by indigenous teachers.

Table 13.4: Aboriginal and Torres Strait Islander populations: Outreach programs

Outreach programs	n=83	Percent
Our organisation currently delivers specific activities/services for this population	2	2.41
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	46	55.42
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	35	42.17

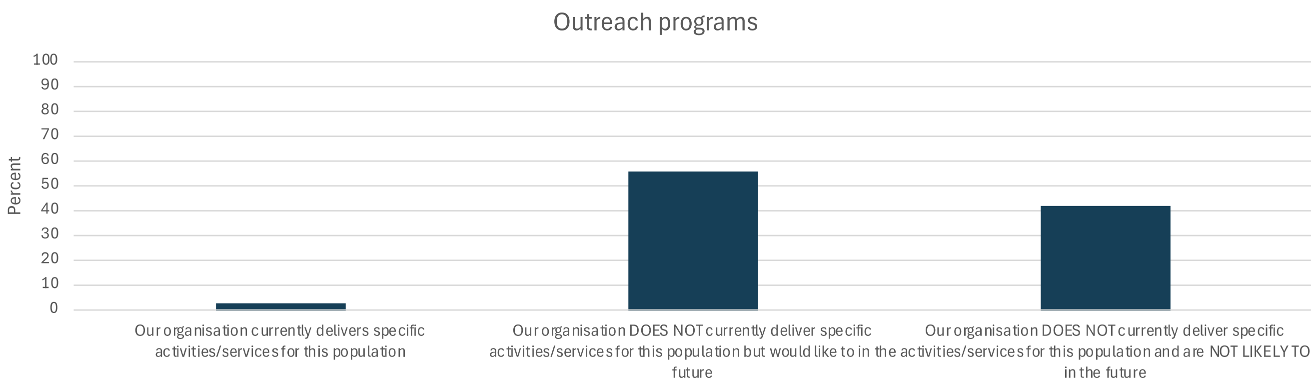


Figure.4: Aboriginal and Torres Strait Islander populations: Outreach programs

Aboriginal and Torres Strait Islander populations: Specific programs

There were 3 organisations (3.61%) that offered specific programs for Aboriginal and Torres Strait populations, 46 organisations (55.42%), do not offer this at the moment but would like to in the future, and 34 organisations (40.96%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about Aboriginal and Torres Strait Islander populations

Difficult to get engagement from these populations but slowly increasing awareness & trust by having culturally safe care provided by telehealth nurse

Pilot program developed in partnership with ACCHO's to deliver community led health promotion activities in viral hepatitis. Development of resources and materials specifically designed for Community.
LiverLine helpline and app

Table 13.5: Aboriginal and Torres Strait Islander populations: Specific programs

Specific programs for this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	3	3.61
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	46	55.42
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	34	40.96

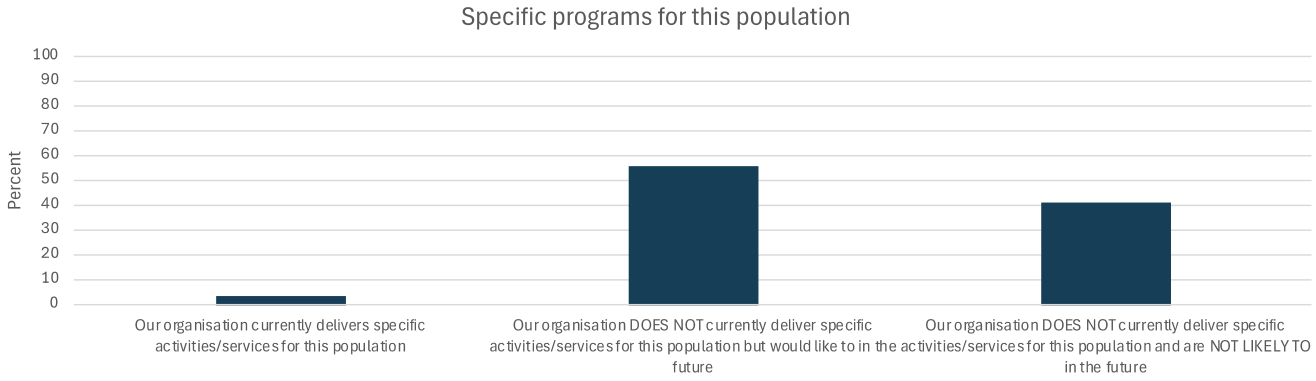


Figure.5: Aboriginal and Torres Strait Islander populations: Specific programs

Aboriginal and Torres Strait Islander populations: All programs have a component that addresses this population

There were 17 organisations (20.48%) that offered all programs have a component that addresses Aboriginal and Torres Strait populations, 41 organisations (49.40%), do not offer this at the moment but would like to in the future, and 25 organisations (30.12%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about Aboriginal and Torres Strait Islander populations

We are actively looking to develop programs specifically for First Nations populations. Currently, we have guidelines, patient and health professional resources available for First nations peoples and all our general programs include components that address first nations kidney health

Table 13.6: Aboriginal and Torres Strait Islander populations: All programs have a component that addresses this population

All programs have a component that addresses this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	17	20.48
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	41	49.40
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	25	30.12

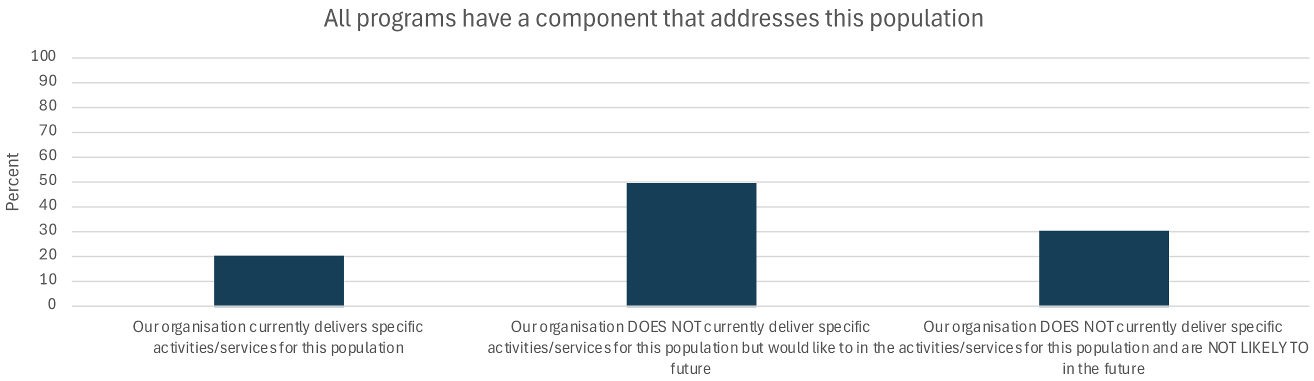


Figure.6: Aboriginal and Torres Strait Islander populations: All programs have a component that addresses this population

Non-English speaking background populations

Non-English speaking background populations: Outreach programs

There were 7 organisations (8.43%) that offered outreach programs for non-English speaking background populations, 35 organisations (42.17%), do not offer this at the moment but would like to in the future, and 41 organisations (49.40%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about non-English background populations

Resources, information and events to engage NESB communities and support access to viral hepatitis information, testing and care is developed and distributed. We work in partnership with community leaders and/or community organisations as well as local health units. Many resources provided in language. LiverLine helpline and app.

Table 13.7: Non-English speaking background populations: Outreach programs

Outreach programs	n=83	Percent
Our organisation currently delivers specific activities/services for this population	7	8.43
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	35	42.17
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	41	49.40

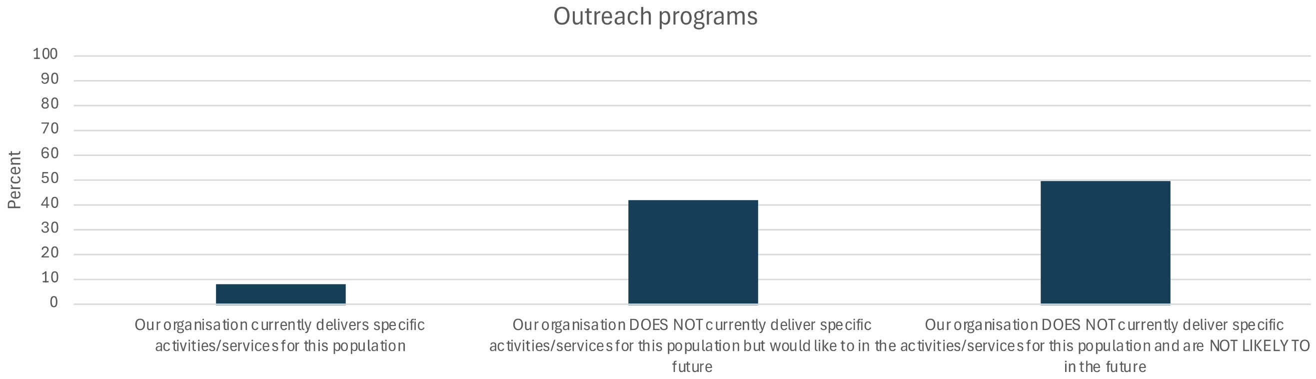


Figure.7: Non-English speaking background populations: Outreach programs

Non-English speaking background populations: Specific programs

There were 8 organisations (9.64%) that offered specific programs for non-English speaking background populations, 42 organisations (50.60%), do not offer this at the moment but would like to in the future, and 33 organisations (39.76%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about non-English background populations

Funded and supported a project that printed brain tumour information in several different languages.

Our website and online information hub is about to be linked with an inclusion/accessibility tool that will allow readers to access our website and select different languages, text to voice, vision support and many other tools.

Table 13.8: Non-English speaking background populations: Specific programs

Specific programs for this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	8	9.64
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	42	50.60
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	33	39.76

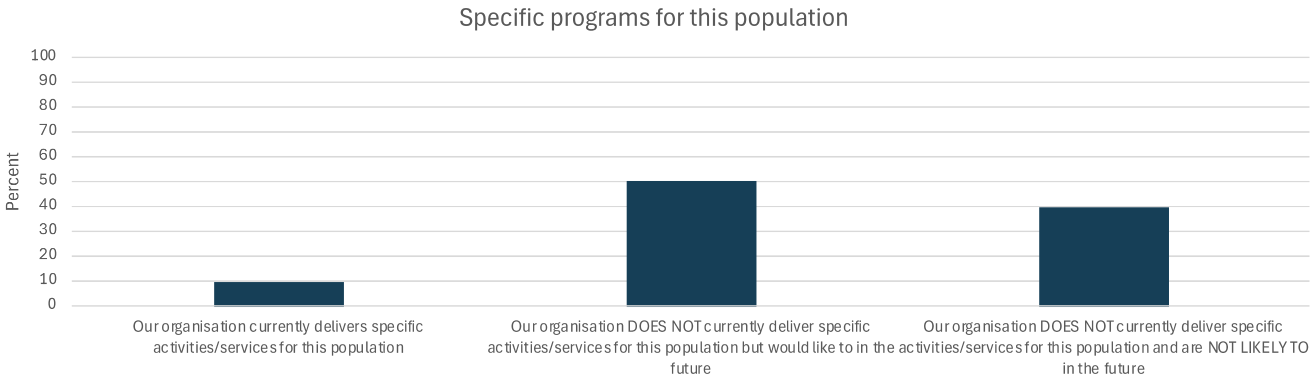


Figure.8: Non-English speaking background populations: Specific programs

Non-English speaking background populations: All programs have a component that addresses this population

There were 16 organisations (19.28%) that offered all programs have a component that addresses non-English speaking background populations, 42 organisations (50.60%), do not offer this at the moment but would like to in the future, and 25 organisations (30.12%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about non-English background populations

Support and assistance currently provided to NESB populations with existing programs and services. Leukaemia Foundation does have numerous resources translated in non-English languages.

The only thing we can offer is for a family from a non-English speaking background who needs information about Fragile X is to offer to engage the TIS service interpreter to assist our Counsellor with the meeting or query.

Table 13.9: Non-English speaking background populations: All programs have a component that addresses this population

All programs have a component that addresses this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	16	19.28
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	42	50.60
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	25	30.12

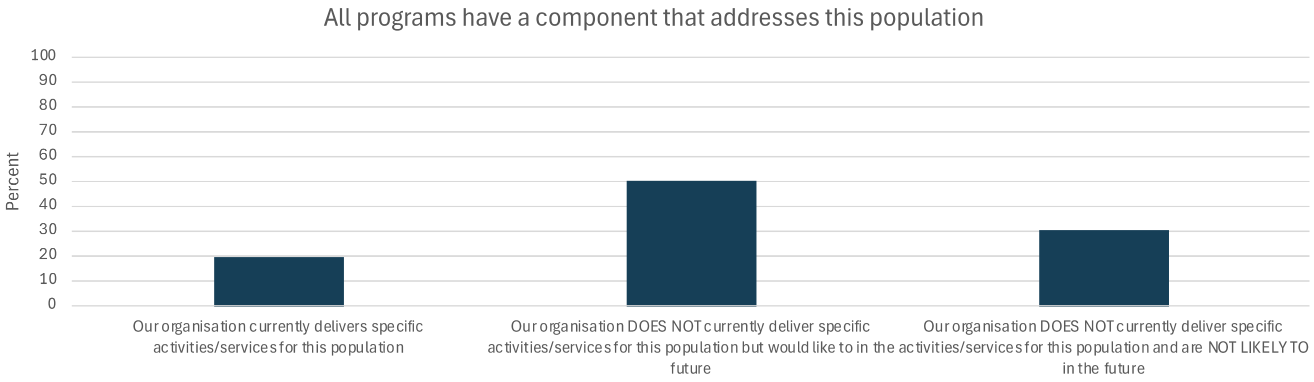


Figure.9: Non-English speaking background populations: All programs have a component that addresses this population

Low income and/or homeless populations

Low income and/or homeless populations: Outreach programs

There were 5 organisations (6.02%) that offered outreach programs for low income and/or homeless populations, 29 organisations (34.94%), do not offer this at the moment but would like to in the future, and 49 organisations (59.04%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about low income and/or homeless populations

Need to provide information to these populations in print as they rarely have access to internet & printing. Important to tell them that the service is free & non-judgmental as well as suggest getting assistance via our Financial Assistance Program

Resources, information and events to engage these communities and support access to viral hepatitis information, testing and care is developed and distributed. We work in partnership with community leaders and/or community organisations as well as local health units. LiverLine helpline and app.

Table 13.10: Low income and/or homeless populations: Outreach programs

Outreach programs	n=83	Percent
Our organisation currently delivers specific activities/services for this population	5	6.02
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	29	34.94
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	49	59.04

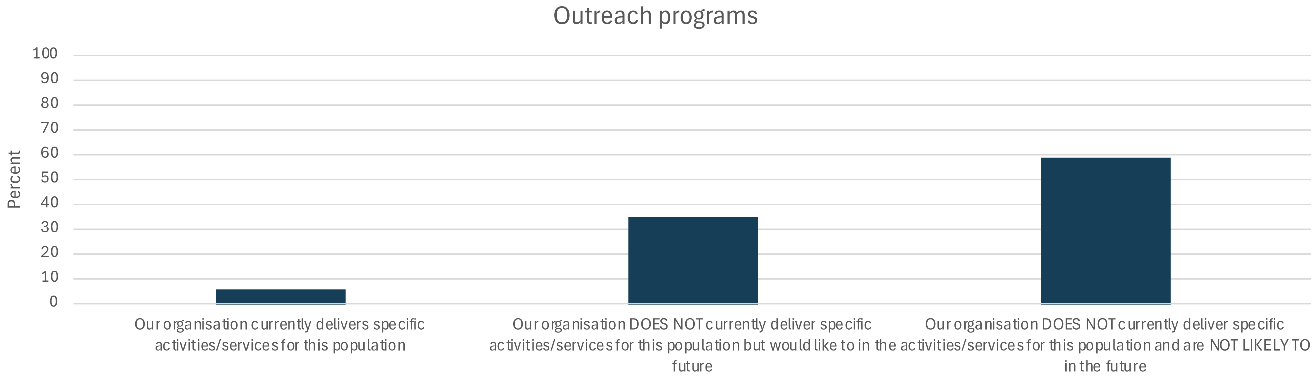


Figure.10: Low income and/or homeless populations: Outreach programs

Low income and/or homeless populations: Specific programs

There were 2 organisations (2.41%) that offered specific programs for low income and/or homeless populations, 33 organisations (39.76%), do not offer this at the moment but would like to in the future, and 48 organisations (57.83%) do not offer this and are unlikely to offer it in the future.

Rare Cancers Australia provide financial assistance and support to patients including those who come from a low-income population. Rare Cancers Australia understands the impact a cancer diagnosis can have on an individual's financial situation and the associated toxicity of trying to find money to cover your expenses. Our financial support packages are tailored to individuals and can assist with fuel, groceries and utilities, transport and medication costs.

Table 13.11: Low income and/or homeless populations: Specific programs

Specific programs for this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	2	2.41
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	33	39.76
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	48	57.83

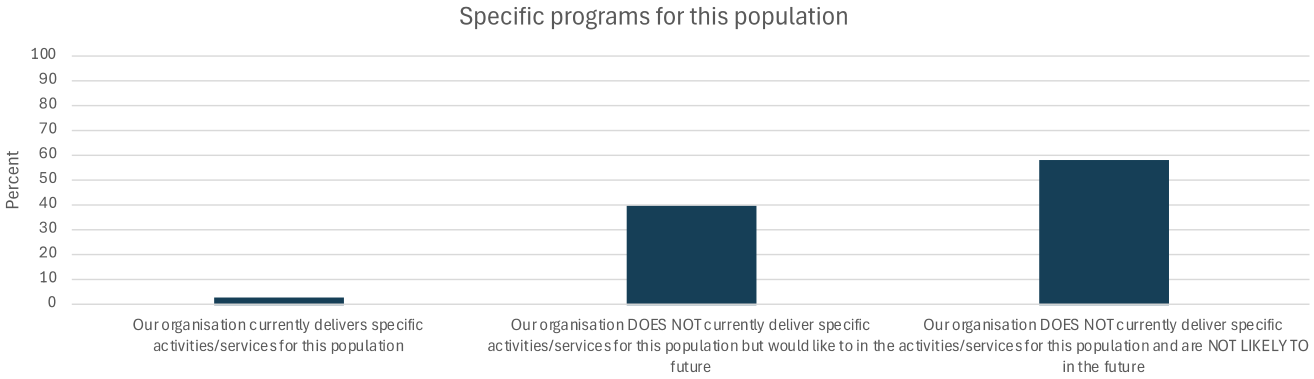


Figure.11: Low income and/or homeless populations: Specific programs

Low income and/or homeless populations: All programs have a component that addresses this population

There were 14 organisations (16.87%) that offered all programs have a component that addresses low income and/or homeless populations, 30 organisations (36.14%), do not offer this at the moment but would like to in the future, and 39 organisations (46.99%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about low income and/or homeless populations

Our services support everyone regardless of socio-economic backgrounds

Support and assistance currently provided with existing programs and services.

Table 13.12: Low income and/or homeless populations: All programs have a component that addresses this population

All programs have a component that addresses this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	14	16.87
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	30	36.14
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	39	46.99

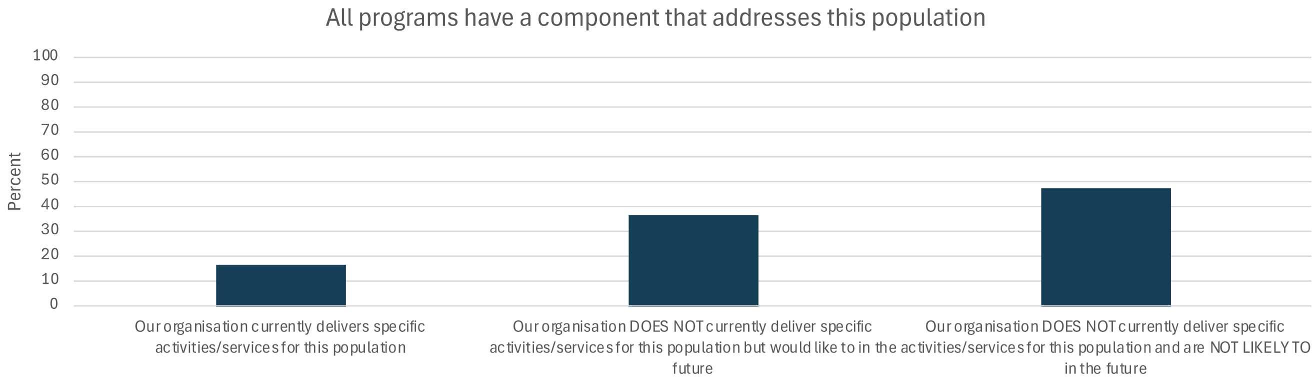


Figure.12: Low income and/or homeless populations: All programs have a component that addresses this population

LGBTQ+ populations

LGBTQ+ populations: Outreach programs

There were 2 organisations (2.41%) that offered outreach programs for LGBTQ+ populations, 31 organisations (37.35%), do not offer this at the moment but would like to in the future, and 50 organisations (60.24%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about low income and/or homeless populations

Resources, information and events to engage these communities and support access to viral hepatitis information, testing and care is developed and distributed in partnership with other community and health organisations.

Table 13.13: LGBTQ+ populations: Outreach programs

Outreach programs	n=83	Percent
Our organisation currently delivers specific activities/services for this population	2	2.41
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	31	37.35
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	50	60.24

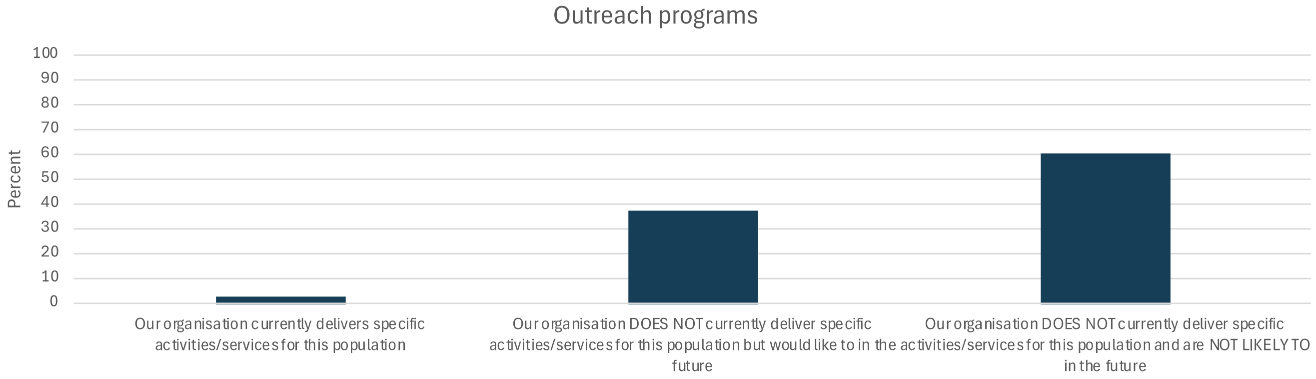


Figure.13: LGBTQ+ populations: Outreach programs

LGBTQ+ populations: Specific programs

There were 2 organisations (2.41%) that offered specific programs for LGBTQ+ populations, 33 organisations (39.76%), do not offer this at the moment but would like to in the future, and 48 organisations (57.83%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about low income and/or homeless populations

Focus group recently conducted for this group of people.

Table 13.14: LGBTQ+ populations: Specific programs

Specific programs for this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	2	2.41
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	33	39.76
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	48	57.83

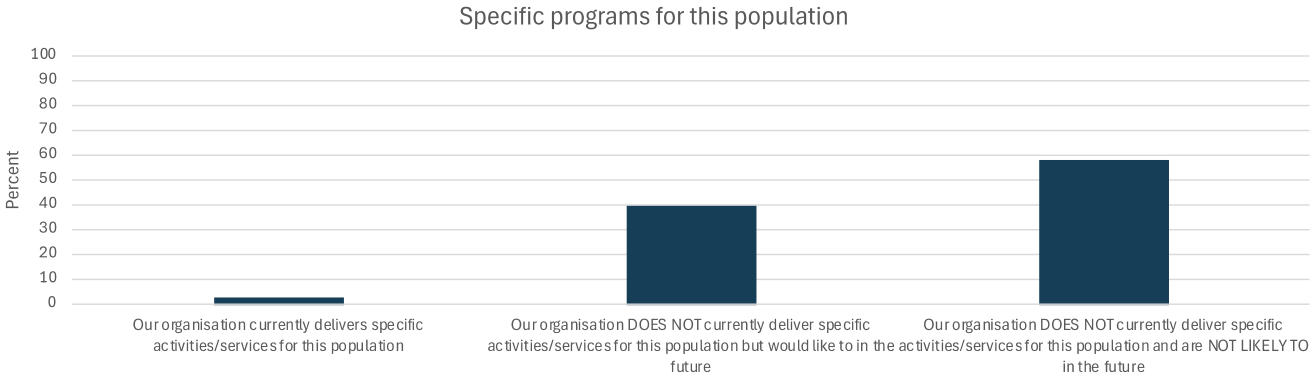


Figure.14: LGBTQ+ populations: Specific programs

LGBTQ+ populations: All programs have a component that addresses this population

There were 15 organisations (18.07%) that offered all programs have a component that addresses LGBTQ+ populations, 31 organisations (37.35%), do not offer this at the moment but would like to in the future, and 37 organisations (44.58%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about low income and/or homeless populations

Our service and support is inclusive of all populations. So we don't have targeted LGBTQ+ programs, but we ensure that ever person with NF feels welcome.

We do not have resources to address this population alone, so we integrate this into most programs or work specifically with a client to ensure we provide culturally appropriate support.

We do not currently have programs specifically for this audience but do include some general information within standard programs. We are trying to ensure that all our materials are appropriate and inclusive.

Table 13.15: LGBTQ+ populations: All programs have a component that addresses this population

All programs have a component that addresses this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	15	18.07
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	31	37.35
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	37	44.58

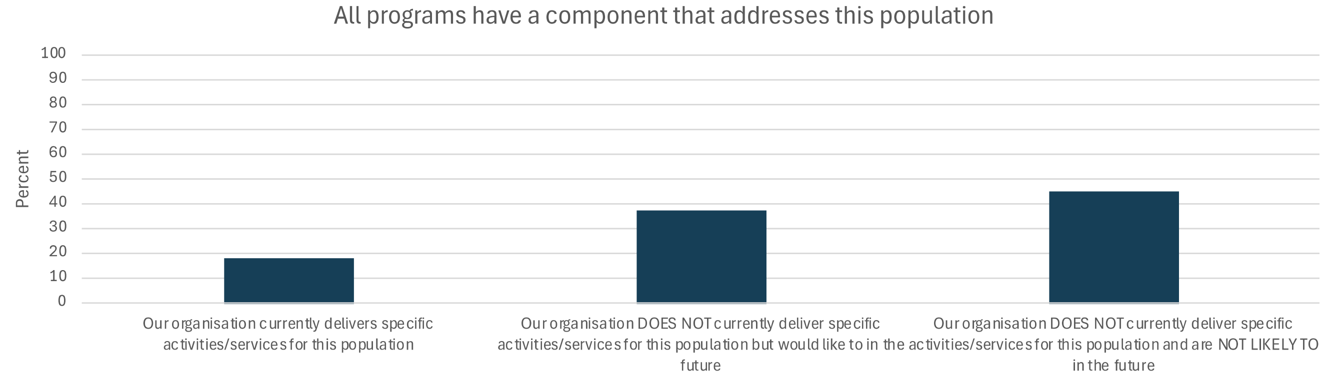


Figure.15: LGBTQ+ populations: All programs have a component that addresses this population

Section 14: Importance and accessibility of aspects of care and treatment

Summary of importance and accessibility of aspects of care and treatment

Summary of importance and accessibility of aspects of care and treatment

Data was collected from NPON members in 2024 about The importance of aspects of care and treatment and how accessible they were.

The top five aspects of treatment and care that were described as extremely important or very important were: access to appropriate treatments/devices in a timely manner (n=72, 94.74%), affordable treatments (n=70, 92.11%), access to specialists (n=72, 94.74%), up to date information and research findings (n=67, 88.16%), and access to allied health professionals (n=66, 86.84%).

For these aspects of care of treatments, NPON organisations described these as extremely accessible or very accessible: access to appropriate treatments/devices in a timely manner (n=7, 9.21%), access to affordable treatments (n=7, 9.21%), access to specialists (n=10, 13.16%), access to allied health professionals (n=12, 15.79%), and access to up to date information and research findings (n=21, 27.63%).

Aspects of care and treatment	Extremely or very Important	Extremely or very accessible
Access to appropriate treatments/devices in a timely manner	95%	9%
Access to specialists	95%	13%
Access to affordable treatments	92%	9%
Access to up to date information and research findings	88%	28%
Access to allied health professionals	87%	16%
Access to earlier diagnostic tests	86%	12%
Access to clinical trials	76%	14%
Support for carers	74%	17%
Reducing stigma related to their condition/illness	72%	14%
Support in navigating the health system/ coordination of care	64%	12%
Access to genetic testing	62%	13%
Access to home care	62%	12%
Support in navigating the NDIS	59%	8%
Access to equipment	58%	11%
Access to pain management	50%	16%
Access to palliative care	33%	11%

Pain management

Importance of access to pain management

Access to pain management was extremely or very important to 38 organisations (50.00%), important to 22 organisations (28.95%) and not very important or not important at all to 16 organisations (21.05%).

Accessibility of pain management

Access to pain management was extremely or very accessible to 12 organisations (15.79%), accessible to 35 organisations (46.05%) and not very accessible or not accessible at all to 18 organisations (23.68%).Access to pain management was not relevant to patient population for 11 organisations (14.47%).

NPON organisations comments about pain management

Provision of support for the treatment of phantom pain

Awareness and Understanding: There has been little progress made in inproving the health outcomes of musculsokeletal conditions in Australia. In addition to this, the burden of disease related to musculoskeletal conditions is increasing each and every year. The narrative around musculoskeletal conditions relate to aging, something that will happen to everyone etc. this combined with a negative narrative around specific disease and conditions (like back pain) and musculoskeletal pain more generally has further 'hidden' this global epidemic. It is essential that the narrative is shifted and that musculoskeletal health is a national priority - given it's positive implications to all other chronic health conditions and disease (including but not limited to diabetes, coronary disease, cancer etc.) -

Table 14.1: Importance of access to pain management

Access to pain management	n=76	Percent
This is extremely important	26	34.21
This is very important	12	15.79
This is important	22	28.95
This is not very important	8	10.53
This is not important at all/is not relevant to our patient population	8	10.53

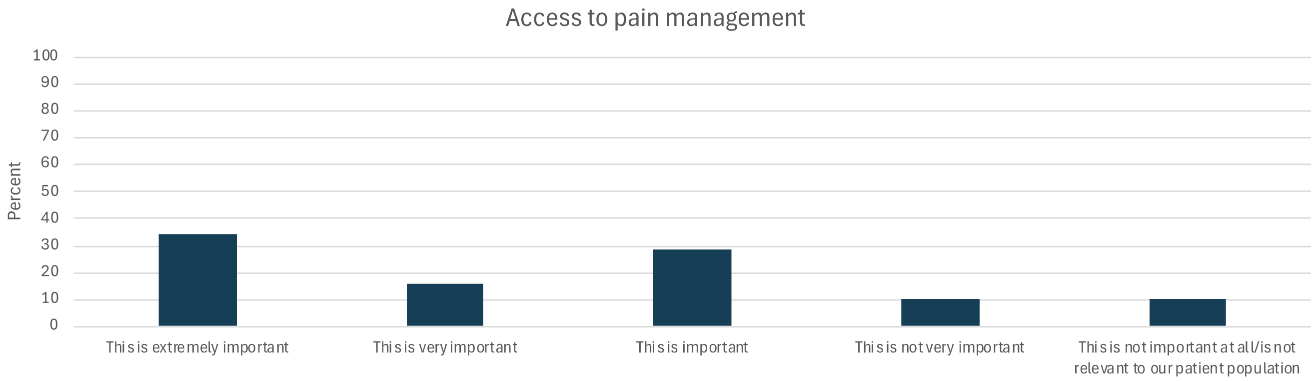


Figure 14.1: Importance of access to pain management

Table 14.2: Accessibility of pain management

Access to pain management	n=76	Percent
This is extremely accessible	5	6.58
This is very accessible	7	9.21
This is accessible	35	46.05
This is not very accessible	18	23.68
This is not relevant to our patient population	11	14.47

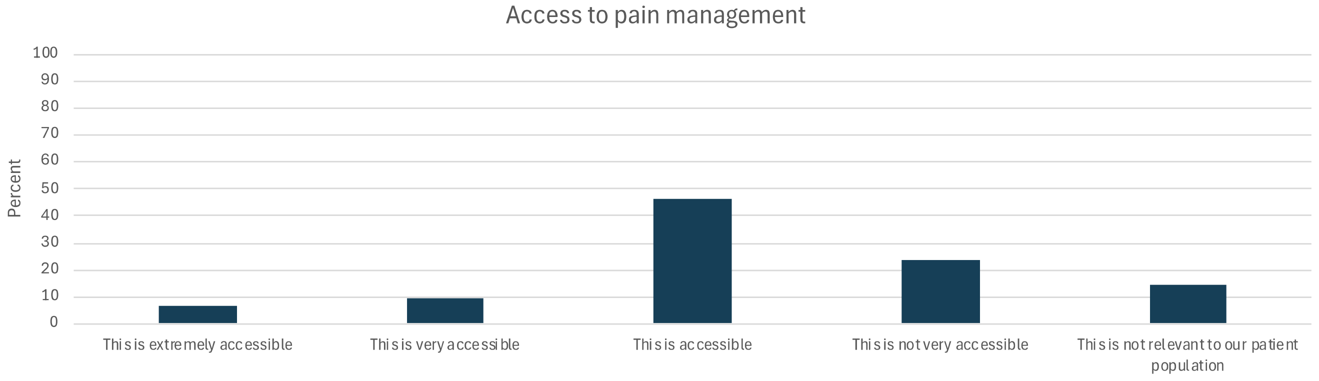


Figure 14.2: Accessibility of pain management

Palliative care

Importance of access to palliative care

Access to palliative care was extremely or very important to 25 organisations (32.89%), important to 17 organisations (22.37%) and not very important or not important at all to 34 organisations (44.74%).

Accessibility of palliative care

Access to palliative care was extremely or very accessible to 8 organisations (10.53%), accessible to 24 organisations (31.58%) and not very accessible or not accessible at all to 13 organisations (17.11%).Access to palliative care was not relevant to patient population for 31 organisations (40.79%).

NPON organisations comments about palliative care

Align internal resources and partnership services to deliver a comprehensive model of support across the CoHD journey across milestones - diagnosis, surgery, preschool, primary, teen and young adult, adult and palliative care

Table 14.3: Importance of access to palliative care

Access to palliative care	n=76	Percent
This is extremely important	12	15.79
This is very important	13	17.11
This is important	17	22.37
This is not very important	8	10.53
This is not important at all/is not relevant to our patient population	26	34.21

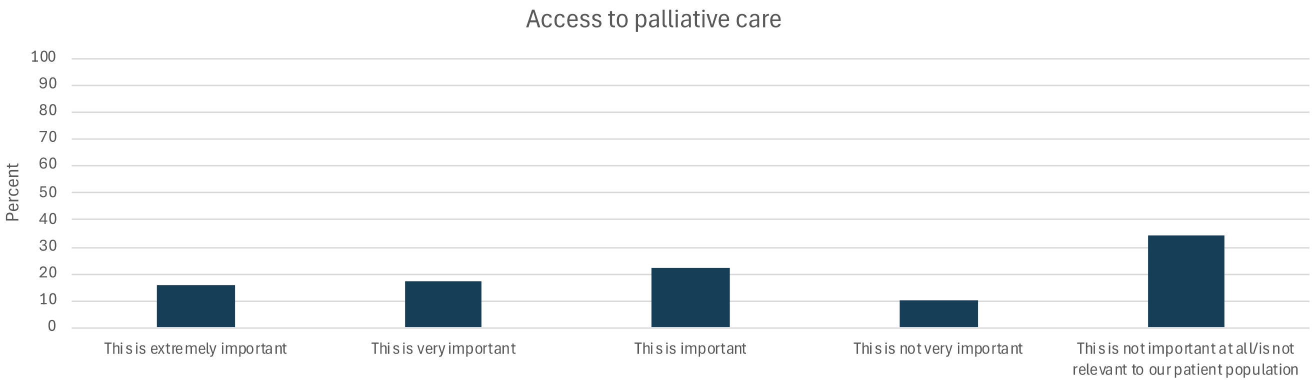


Figure 14.3: Importance of access to palliative care

Table 14.4: Accessibility of palliative care

Access to palliative care	n=76	Percent
This is extremely accessible	3	3.95
This is very accessible	5	6.58
This is accessible	24	31.58
This is not very accessible	13	17.11
This is not relevant to our patient population	31	40.79

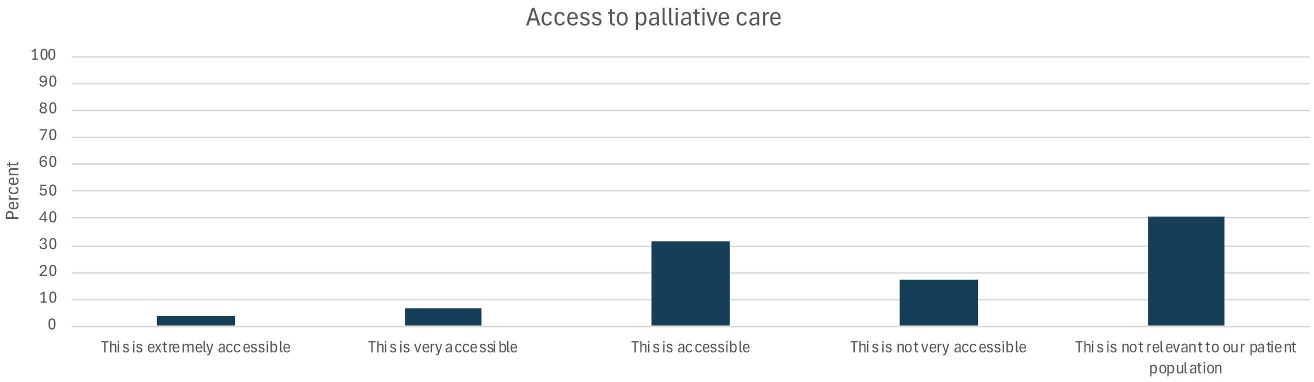


Figure 14.4: Accessibility of palliative care

Affordable treatments

Importance of access to affordable treatments

Access to affordable treatments was extremely or very important to 70 organisations (92.11%), important to 5 organisations (6.58%) and not very important or not important at all to 1 organisation (1.32%).

Accessibility of affordable treatments

Access to affordable treatments was extremely or very accessible to 7 organisations (9.21%), accessible to 22 organisations (28.95%) and not very accessible or not accessible at all to 46 organisations (60.53%).Access to affordable treatments was not relevant to patient population for 1 organisation (1.32%).

NPON organisations comments about affordable treatments

Wound care program to fund for the expensive treatments that are needed and not available at subsidised rates

A cancer diagnosis can have a devastating effect on patients and causes immense strain financially. Treatment options can often result in many out of pocket costs, with some treatments costing in excess of tens of thousands of dollars. Some people

are travelling overseas for treatments and are forced to crowdfund. Tragically, more patients are choosing to forgo treatment altogether rather than bankrupt their families for life-extending treatments.

To make it easy for sickle cell disease to be recognised as chronic condition without having to convince different departments that it is a severe condition for our members to get access to other health services like a healthcare card.

Subsidised treatments ((once they go through lengthy slow approval)

Expanded access to modulator therapies on the PBS. Currently, only people with the most commong gene mutation can access Trikafta. This medication is approved overseas for other mutation types, giving people the opportunity to access potentially life changing therapies. We need this same access here in Australia.

Table 14.5: Importance of access to affordable treatments

Access to affordable treatments	n=76	Percent
This is extremely important	60	78.95
This is very important	10	13.16
This is important	5	6.58
This is not very important	1	1.32

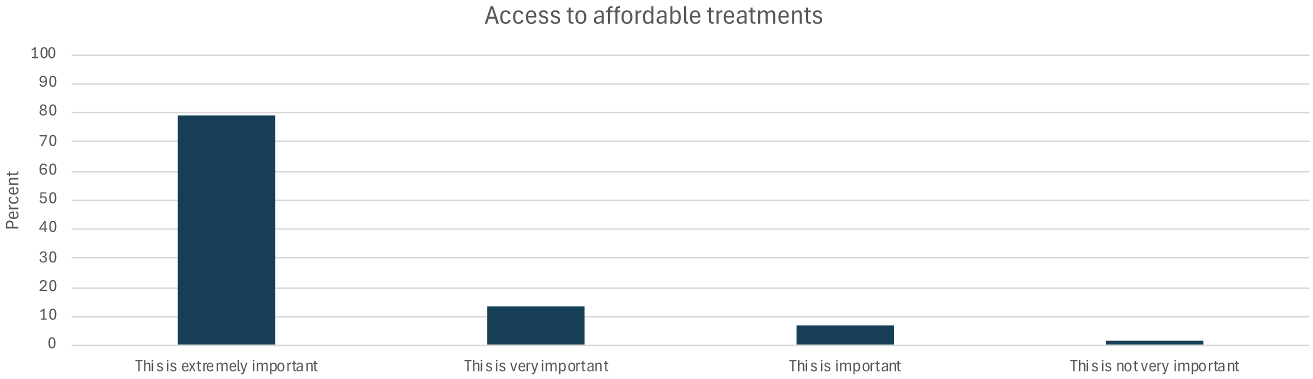


Figure 14.5: Importance of access to affordable treatments

Table 14.6: Accessibility of affordable treatments

Access to affordable treatments	n=76	Percent
This is extremely accessible	6	7.89
This is very accessible	1	1.32
This is accessible	22	28.95
This is not very accessible	39	51.32
This is not accessible at all	7	9.21
This is not relevant to our patient population	1	1.32

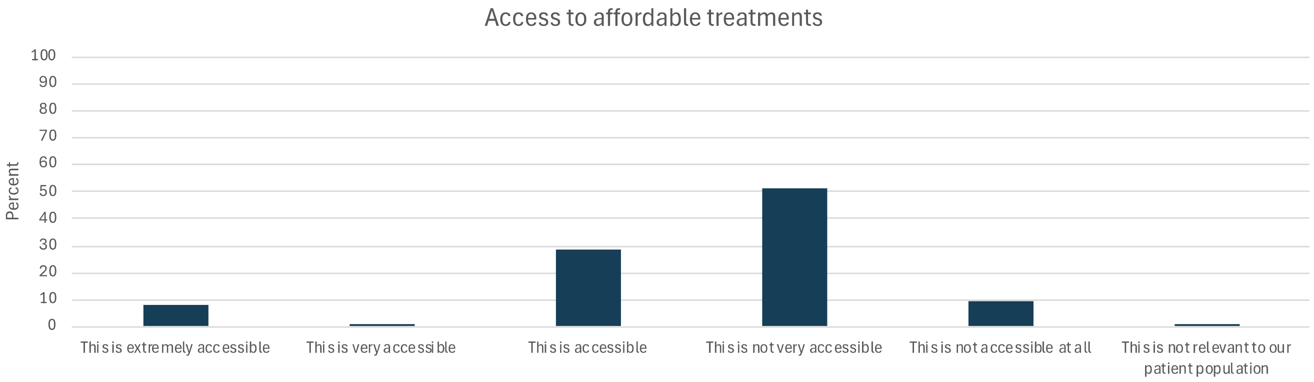


Figure 14.6: Accessibility of affordable treatments

Appropriate treatments or devices in a timely manner

Importance of access to appropriate treatments/devices in a timely manner

Access to appropriate treatments/devices in a timely manner was extremely or very important to 72 organisations (94.74%), important to 4 organisations (5.26%). There were no organisation that thought it was not very important or not important at all.

Accessibility of appropriate treatments/devices in a timely manner

Access to appropriate treatments/devices in a timely manner was extremely or very accessible to 7 organisations (9.21%), accessible to 25 organisations (32.89%) and not very accessible or not accessible at all to 43 organisations (56.58%).Access to appropriate treatments/devices in a timely manner was not relevant to patient population for 1 organisation (1.32%).

NPON organisations comments about access to appropriate treatments/devices in a timely manner

Affordable access to innovative new medicines for our condition (migraine) that are available overseas.

Drugs are not accessible or restrictive as are disease area specific - should be available if patients have demonstrated receptors or markers which indicate the medication will be effective.

Issue 1: no treatment options approved for Idiopathic Hypersomnia (IH). Patients are prescribed drugs for narcolepsy. But there are few drugs approved for narcolepsy. Treatment options are extremely limited compared to the rest of the world.

The timeframe to get treatments to patients in Australia is lengthening. At present, it takes at least 14 months for a new drug to be approved and subsidised. This is of particular concern for cancer patients with advanced disease, who may only have a short time to live.

Currently there is little to no options available to our patients through the health system beyond what is currently available to more common cancers. However, they for the vast majority of the time remain square pegs trying to fit into round holes.

In general treatment of Chronic Kidney Disease including Polycystic Kidney Disease (PKD) is covered by the public health system including dialysis and transplant bit the waiting time is often too long

1. Ongoing supply issues with lifesaving steroid medications
2. Early and accurate treatment in emergency situations
3. Access to ancillary supplies (needles & syringes) when getting prescription medication & the associated lack of knowledge/clarity in doctors and pharmacists regarding this

Access to publicly funded services to manage weight problems in a timely manner and reasonbale distance

Table 14.7: Importance of access to appropriate treatments/devices in a timely manner

Access to appropriate treatments/devices in a timely manner	n=76	Percent
This is extremely important	59	77.63
This is very important	13	17.11
This is important	4	5.26

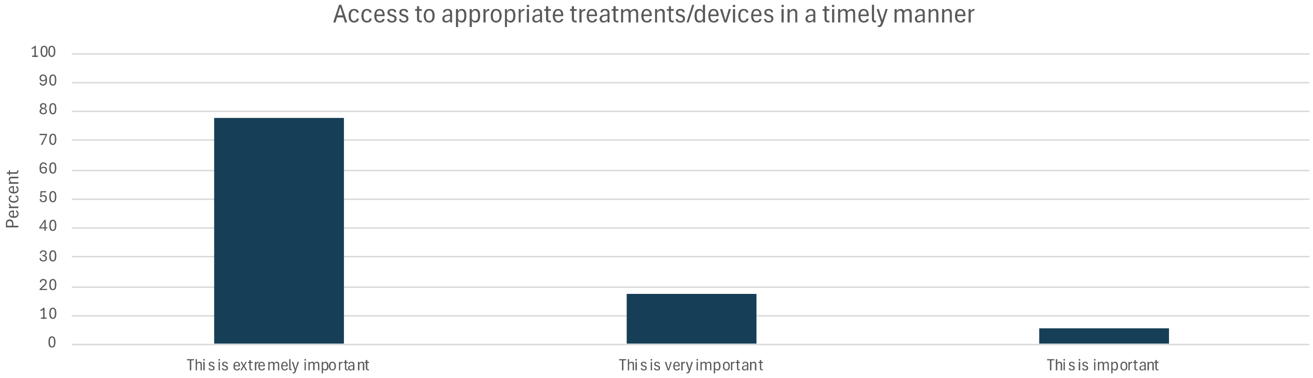


Figure 14.7: Importance of access to appropriate treatments/devices in a timely manner

Table 14.8: Accessibility of appropriate treatments/devices in a timely manner

Access to appropriate treatments/devices in a timely manner	n=76	Percent
This is extremely accessible	3	3.95
This is very accessible	4	5.26
This is accessible	25	32.89
This is not very accessible	36	47.37
This is not accessible at all	7	9.21
This is not relevant to our patient population	1	1.32

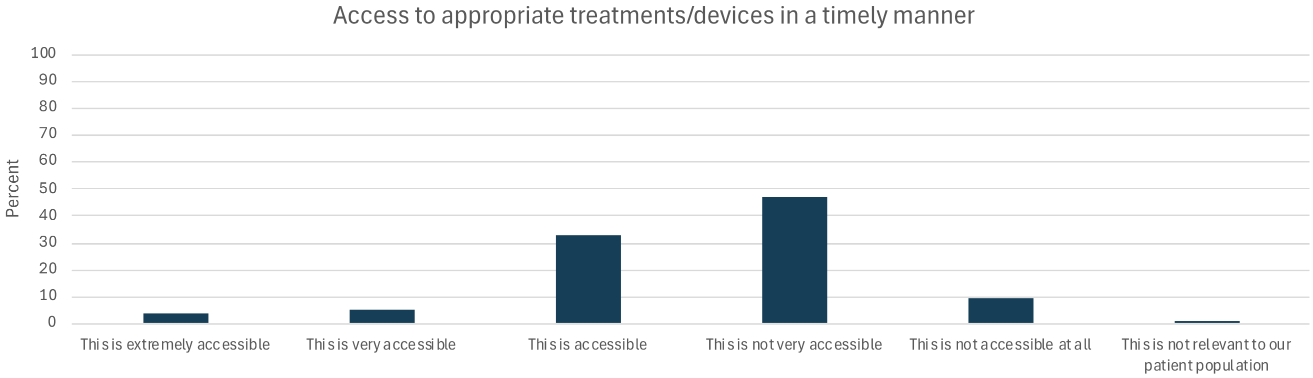


Figure 14.8: Accessibility of appropriate treatments/devices in a timely manner

Home care

Importance of access to home care

Access to home care was extremely or very important to 47 organisations (61.84%), important to 14 organisations (18.42%) and not very important or not important at all to 15 organisations (19.74%).

Accessibility of home care

Access to home care was extremely or very accessible to 9 organisations (11.84%), accessible to 23 organisations (30.26%) and not very accessible or not accessible at all to 32 organisations (42.11%).Access to home care was not relevant to patient population for 12 organisations (15.79%).

NPON organisations comments about home care

CF is not demographically based and as the population all rely on capital city based services, we fund out of pocket transport expenses as well as a range of specific equipment, support and service program for people in regional, remote and rural locations to assist in the management of health at home. We also support remote services delivered by clinicians.

Development of a national registry that records PROM, PREM and QOL information for all Chronic Intestinal Failure patients on Home Parenteral Nutrition, not just clinical information. The development and implementation of a national model of care that ensures all Chronic Intestinal Failure requiring Home Parenteral Nutrition patients have equitable access to the same level of healthcare, the current delivery of healthcare for this patient population is fragmented and varies greatly between states and local area health districts.

Issue 2: no services available to people with IH. No one in our patient community has been successful in obtaining assistance from NDIS. And there are no other services available eg; home care help or access to allied healthcare professionals. One of the reasons this is such a significant issue is because so many people in our patient community are unable to function sufficiently because they don't have access to affordable treatments. So until issue 1 is resolved issue 2 will always be a major issue.

Table 14.9: Importance of access to home care

Access to home care	n=76	Percent
This is extremely important	26	34.21
This is very important	21	27.63
This is important	14	18.42
This is not very important	8	10.53
This is not important at all/is not relevant to our patient population	7	9.21

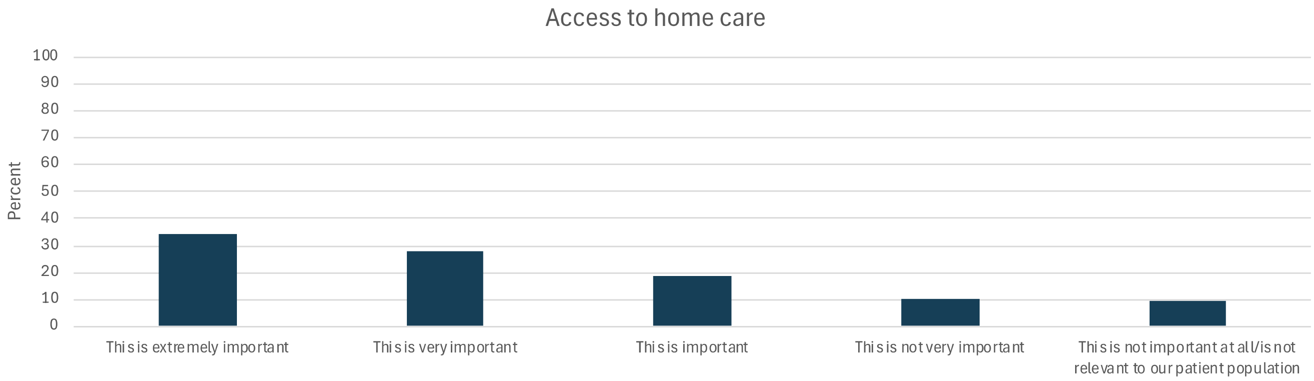


Figure 14.9: Importance of access to home care

Table 14.10: Accessibility of home care

Access to home care	n=76	Percent
This is extremely accessible	3	3.95
This is very accessible	6	7.89
This is accessible	23	30.26
This is not very accessible	27	35.53
This is not accessible at all	5	6.58
This is not relevant to our patient population	12	15.79

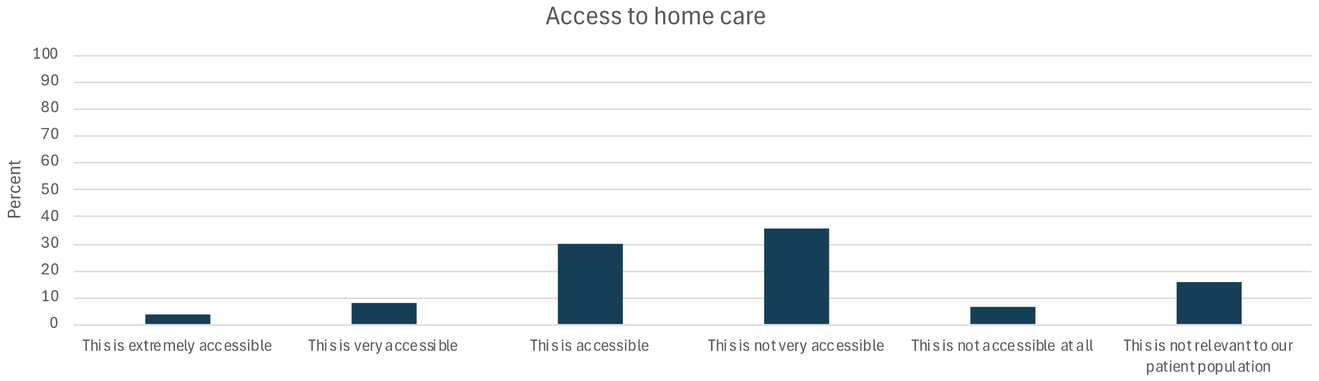


Figure 14.10: Accessibility of home care

Support for carers

Importance of access to support for carers

Support for carers was extremely or very important to 56 organisations (73.68%), important to 15 organisations (19.74%) and not very important or not important at all to 5 organisations (6.58%).

Accessibility of support for carers

Support for carers was extremely or very accessible to 13 organisations (17.11%), accessible to 23 organisations (30.26%) and not very accessible or not accessible at all to 37 organisations (48.68%).Support for carers was not relevant to patient population for 3 organisations (3.95%).

NPON organisations comments about support for carers

Additional Paid Parental Leave - Miracle Babies Foundation call on the Australian Government to provide additional paid parental leave for parents when a baby is in neonatal hospital care for more than 2 weeks. Too many parents use their PPL whilst the baby is in hospital, with no access to financial support during the critical care period. Many babies born premature or sick will be discharged from hospital vulnerable, with low immunity and many extra clinics and medical appointments. Parents of extreme preterm babies are 2.5 times more likely to suffer PND and are advised often to not take their vulnerable home in crowds, child care or social situations. A common cold to others can cause rehospitilisation to these vulnerable babies.

All babies deserve the right to be discharged from hospital with the same amount of PPL for family bonding, healing and post pregnancy recovery for the mother.

This financial support and action on preventative care will help reduce the mental health challenges, reduce the risk of rehospitalisation, reduce the cost of mental health support and help keep women in the workforce.

Holistic support for families

Recommendation 3: Support the mental health and wellbeing needs of NF patients and their caregivers as NF imposes a considerable burden on all facets of people's lives.

Table 14.11: Importance of access to support for carers

Support for carers	n=76	Percent
This is extremely important	38	50.00
This is very important	18	23.68
This is important	15	19.74
This is not very important	4	5.26
This is not important at all/is not relevant to our patient population	1	1.32

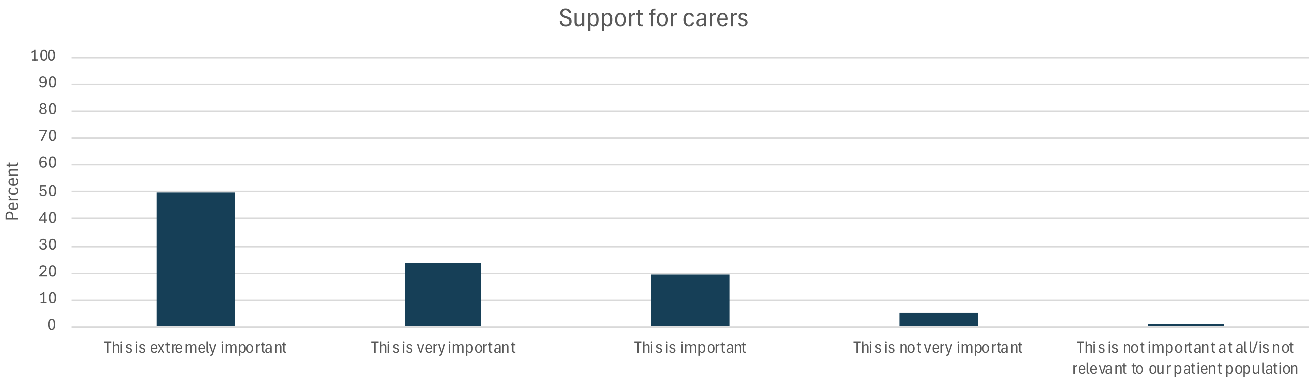


Figure 14.11: Importance of access to support for carers

Table 14.12: Accessibility of support for carers

Support for carers	n=76	Percent
This is extremely accessible	3	3.95
This is very accessible	10	13.16
This is accessible	23	30.26
This is not very accessible	32	42.11
This is not accessible at all	5	6.58
This is not relevant to our patient population	3	3.95

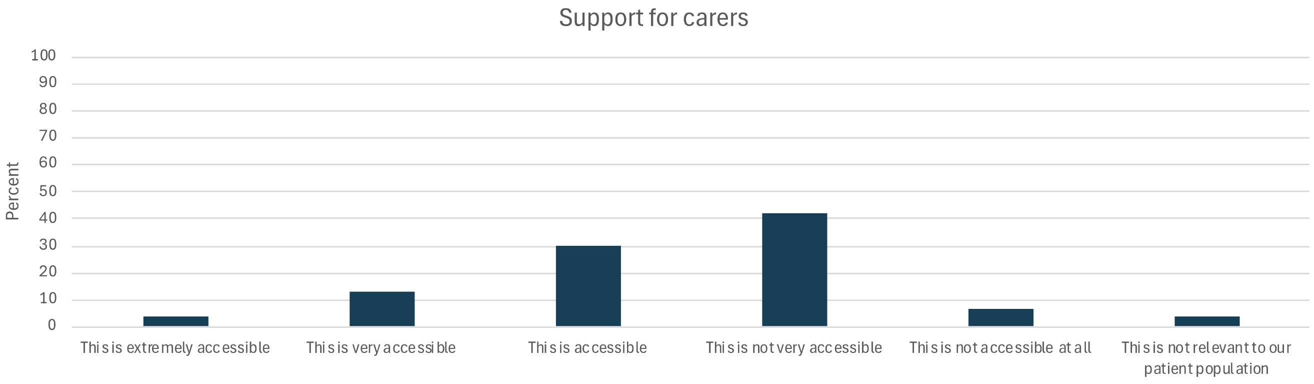


Figure 14.12: Accessibility of support for carers

Navigating the health system or coordination of care

Importance of access to support in navigating the health system/coordination of care

Support in navigating the health system/coordination of care was extremely or very important to 49 organisations (64.47%), important to 22 organisations (28.95%) and not very important or not important at all to 5 organisations (6.58%).

Accessibility of support in navigating the health system/coordination of care

Support in navigating the health system/coordination of care was extremely or very accessible to 9 organisations (11.84%), accessible to 23 organisations (30.26%) and not very accessible or not accessible at all to 42 organisations (55.26%).Support in navigating the health system/coordination of care was not relevant to patient population for 2 organisations (2.63%).

NPON organisations comments about navigating the health system/coordination of care

Access to health professionals knowledgeable about the condition. This is through diagnosis and management and includes primary care, allied health and specialist care.
We already aim to increase the number of knowledgeable professionals through education of GPs and allied health professionals, through clinical fellowships for junior specialist and through funding of a telehealth service.
However, more is needed to ensure patients are able to navigate the health system to find these professionals, GPs are supported/reimbursed for continuing education and allied health specialists are available to people with this condition (e.g. not turned away when they join the NDIS).

Care coordination particularly for our adult cohort. There is so much time wastage for people living with the conditions and their families, as well as loss of financial productivity for the individual, as well as within the health system, when different specialists/hospitals don't talk to each other.

People in our patient community are experiencing many inconsistencies in the care and medical advice they receive from hospital to hospital, and clinician to clinician, such as variances in the frequency of endoscopies, drug therapies, dietary interventions and other treatment approaches. Our members have reported having limited access to multidisciplinary chronic disease care and adequate emergency care. They report feeling that they are either not being able to actively participate in their own management or feel they have to manage their condition and make treatment decisions alone without sufficient support or guidance from medical professionals, especially those residing in regional, rural, and remote areas. Our goal has been to develop Standards of Care Guidelines to assist in addressing these issues.

The poor co-ordination in care. Our families have complex medical condition across multiple systems and there is no navigation for our families. It leaves the patient with poor health outcomes and the caregivers exhausted and frustrated in a system that doesn't cater for them

The transition from child to adult services and supports.

Changes in technology and service delivery have positively contributed to improvements in patient outcomes for people diagnosed/living with blood cancer. Two notable examples in recent years include:
Increased use of telehealth and tele trials – The pandemic response necessitated the uptake of digital technologies including telehealth. Increased uptake of telehealth marks a major change in how health care is delivered. Tele trials have also emerged as a potential tool for reducing burden faced by regional and remote patients.

A dedicated national brain cancer nurse coordinator/navigator framework. This work is in progress.

Table 14.13: Importance of access to support in navigating the health system/coordination of care

Support in navigating the health system/coordination of care	n=76	Percent
This is extremely important	49	64.47
This is very important	22	28.95
This is important	3	3.95
This is not important at all/is not relevant to our patient population	2	2.63

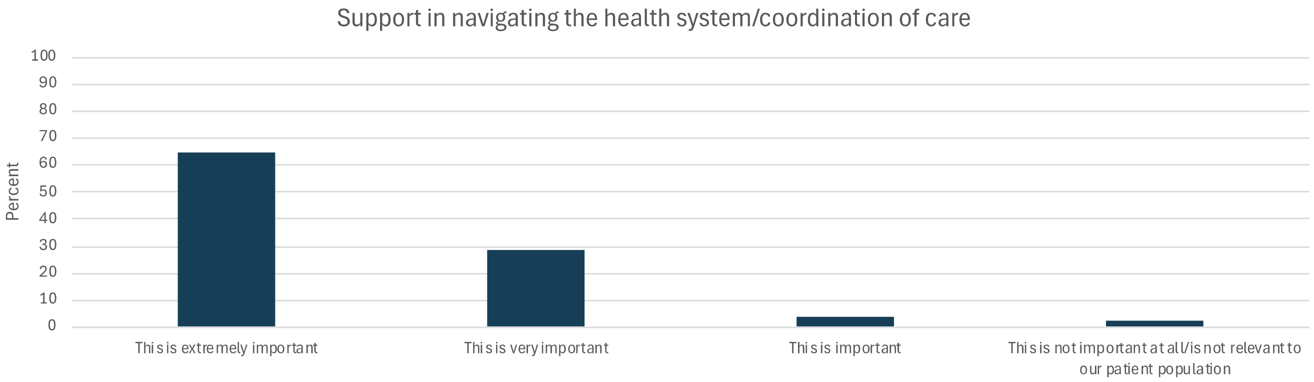


Figure 14.13: Importance of access to support in navigating the health system/coordination of care

Table 14.14: Accessibility of support in navigating the health system/coordination of care

Support in navigating the health system/coordination of care	n=76	Percent
This is extremely accessible	4	5.26
This is very accessible	5	6.58
This is accessible	23	30.26
This is not very accessible	37	48.68
This is not accessible at all	5	6.58
This is not relevant to our patient population	2	2.63

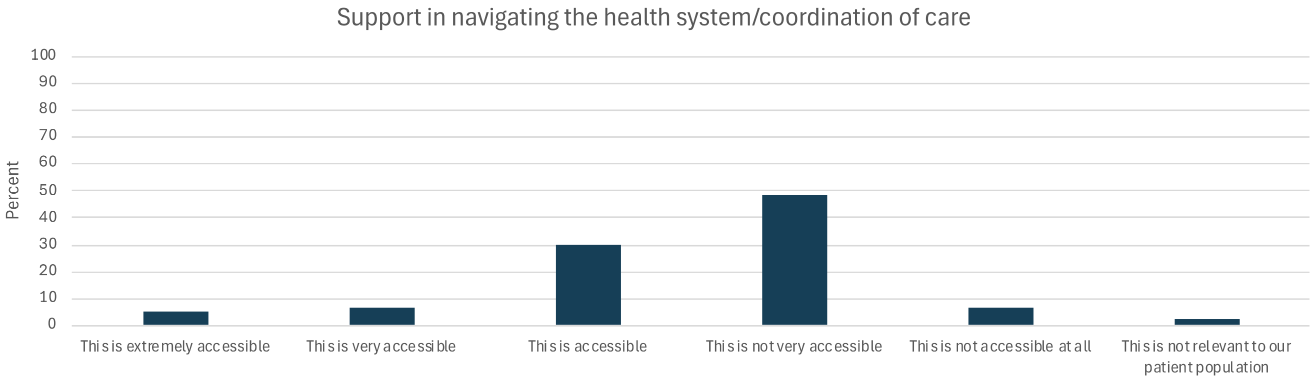


Figure 14.14: Accessibility of support in navigating the health system/coordination of care

Navigating NDIS

Importance of access to support in navigating the NDIS

Support in navigating the NDIS was extremely or very important to 45 organisations (59.21%), important to 13 organisations (17.11%) and not very important or not important at all to 18 organisations (23.68%).

Accessibility of support in navigating the NDIS

Support in navigating the NDIS was extremely or very accessible to 6 organisations (7.89%), accessible to 13 organisations (17.11%) and not very accessible or not accessible at all to 43 organisations (56.58%).Support in navigating the NDIS was not relevant to patient population for 14 organisations (18.42%).

NPON organisations comments about navigating the NDIS

Inequality in aged care and NDIS funding

Funding and access to funding (navigating funding streams) can be difficult and distressing for those who are immediately trying to recover from the impact of amputation. There are currently more than 100 different funding streams across Australia which are dependent on age, location and cause of amputation. While we work to advocate for all members of our communtiy, access to information for funding, especially those +65 ineligible for NDIS support is extremely limited and has not increased for decades. We advocate for better funding outcomes to ensure that people can participate in community, live independently and with the right technology prevent falls and in some cases hospital admissions.

Issue 2: no services available to people with IH. No one in our patient community has been successful in obtaining assistance from NDIS. And there are no other services available eg; home care help or access to allied healthcare professionals. One of the reasons this is such a significant issue is because so many people in our patient community are unable to function sufficiently because they don't have access to affordable treatments. So until issue 1 is resolved issue 2 will always be a major issue.

Access to social and disability related support through NDIS, Aged Care and other schemes. Our patient population struggles at all stages of these processes, including:
- Being found ineligible for NDIS, despite needing daily support due to their disabilities
- Insufficient supports being funded through NDIS plans
- Lack of flexibility to meet changing needs due to degeneration and episodic needs
- Lack of understanding of their rare condition through NDIA, partner organisations and the disability sector
- Insufficient supports, long wait times and out of pocket costs through aged care system

Table 14.15: Importance of access to support in navigating the NDIS

Support in navigating the NDIS	n=76	Percent
This is extremely important	34	44.74
This is very important	11	14.47
This is important	13	17.11
This is not very important	8	10.53
This is not important at all/is not relevant to our patient population	10	13.16

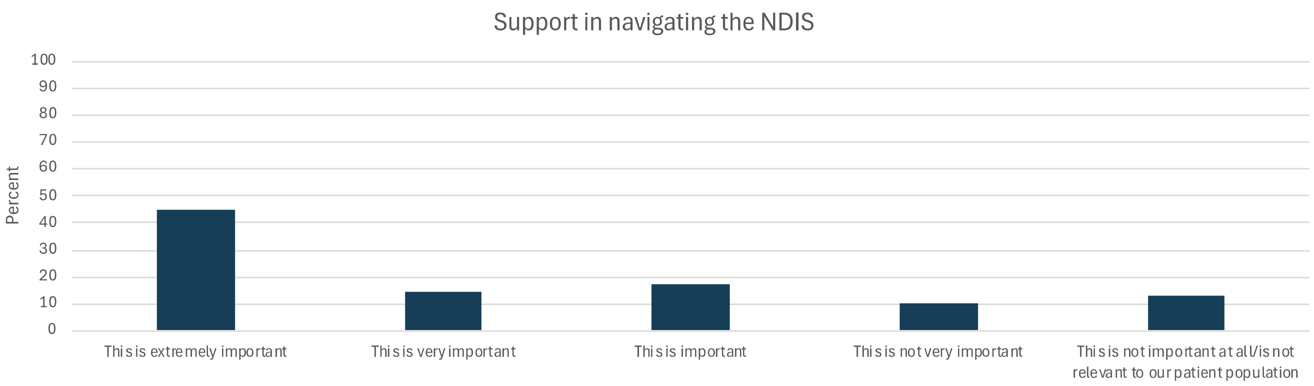


Figure 14.15: Importance of access to support in navigating the NDIS

Table 14.16: Accessibility of support in navigating the NDIS

Support in navigating the NDIS	n=76	Percent
This is extremely accessible	3	3.95
This is very accessible	3	3.95
This is accessible	13	17.11
This is not very accessible	32	42.11
This is not accessible at all	11	14.47
This is not relevant to our patient population	14	18.42

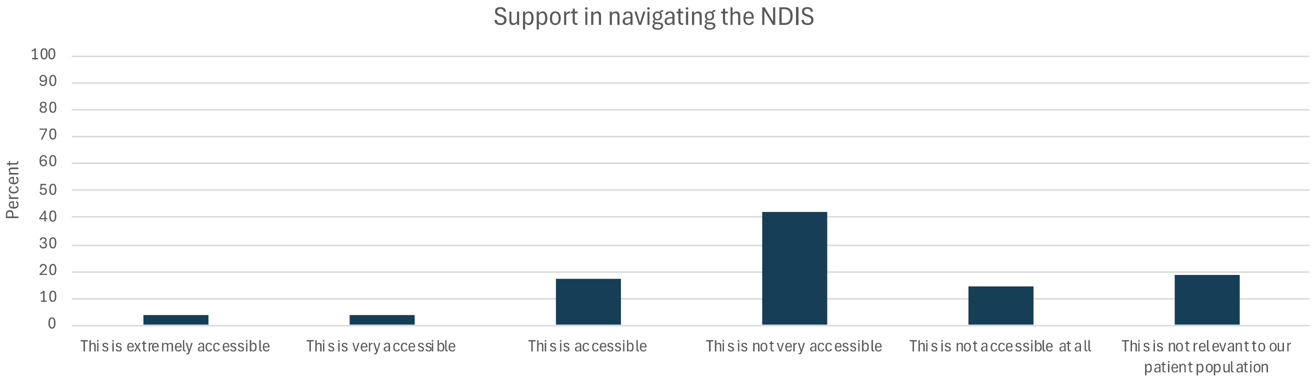


Figure 14.16: Accessibility of support in navigating the NDIS

Allied health professionals

Importance of access to allied health professionals

Access to allied health professionals was extremely or very important to 66 organisations (86.84%), important to 8 organisations (10.53%) and not very important or not important at all to 2 organisations (2.63%).

Accessibility to allied health professionals

Access to allied health professionals was extremely or very accessible to 12 organisations (15.79%), accessible to 28 organisations (36.84%) and not very accessible or not accessible at all to 34 organisations (44.74%).Access to allied health professionals was not relevant to patient population for 2 organisations (2.63%).

NPON organisations comments about allied health professionals

Allied health issues would be another area to ensure for instance physios understand the limitations of people with HSP - a neuro physio would be the best option and widening the knowledge of HSP woudll be good.

Accessing knowledgeable Professionals in CMT. Being able to create a holistic team to support and

manage the condition is very difficult. Most Medical Professionals and Allied Health Professionals are not fully aware of the condition and how to diagnose and manage it.

Access to health professionals knowledgeable about the condition. This is through diagnosis and management and includes primary care, allied health and specialist care.

Table 14.17: Importance of access to allied health professionals

Access to allied health professionals	n=76	Percent
This is extremely important	46	60.53
This is very important	20	26.32
This is important	8	10.53
This is not important at all/is not relevant to our patient population	2	2.63

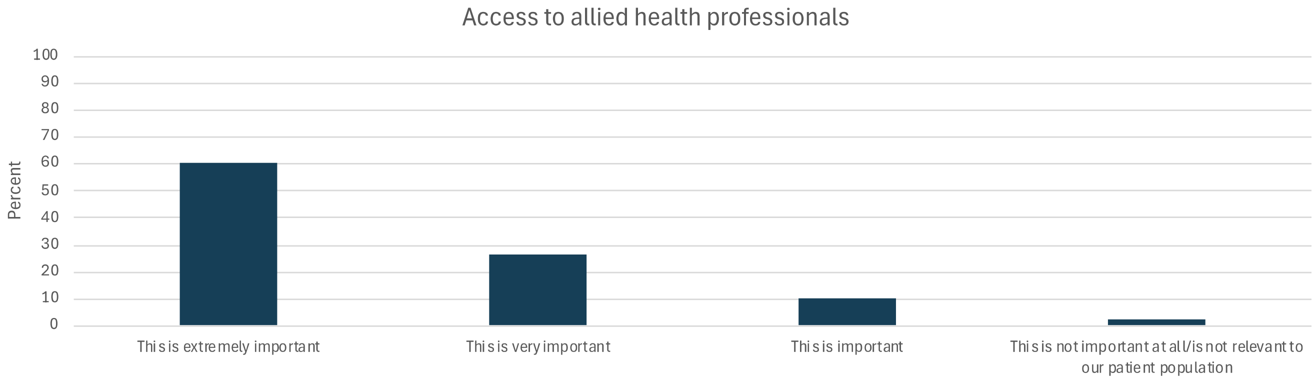


Figure 14.17: Importance of access to allied health professionals

Table 14.18: Accessibility to allied health professionals

Access to allied health professionals	n=76	Percent
This is extremely accessible	5	6.58
This is very accessible	7	9.21
This is accessible	28	36.84
This is not very accessible	32	42.11
This is not accessible at all	2	2.63
This is not relevant to our patient population	2	2.63

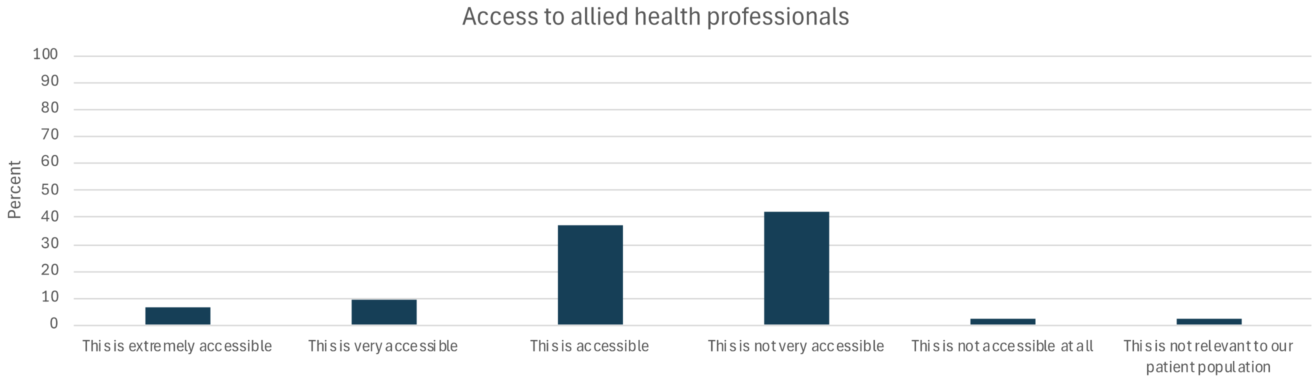


Figure 14.18: Accessibility to allied health professionals

Specialists

Importance of access to specialists

Access to specialists was extremely or very important to 72 organisations (94.74%), important to 3 organisations (3.95%) and not very important or not important at all to 1 organisation (1.32%).

Accessibility to specialists

Access to specialists was extremely or very accessible to 10 organisations (13.16%), accessible to 30 organisations (39.47%) and not very accessible or not accessible at all to 35 organisations (46.05%).Access to specialists was not relevant to patient population for 1 organisations (1.32%).

NPON organisations comments about specialists

HSP is a rare neurological condition and the knowledge among specialists and GPs is limited. Our members have difficulty finding somone who understands the condition and we invite members to recommend any that have beeen good dealing with them and we share on our website. Furthering the knowledge would be good but understand the complexity. Widening the knowledge would be a big step. The issue is that members have another issue and there may be a need to understand HSP to provide a suitable rehab programme.

What we are able to provide them with is contact with others going through a rare cancer journey. And maybe even the chance to speak to someone going through the same cancer journey.
People to bounce ideas off, discussions about individual experiences and even help with referrals to Doctors that may actually have treated people with that cancer.

Access to neurologists who see neuromuscular patients. We don't have enough neurologists, particularly adult neurologists in WA to support the community, leaving very long wait times.

Easy access to capable health professionals

Genuine committment of health professionals to help patients deal with their weight problem - if you are able to access them.

A condition that was known as a childhood condition (Duchenne muscular dystrophy) as it was rare for anyone to survive passed late teens, has seen and improvement in life expectancy to mid/late 20's. It is very confronting and said that the adult hospitals do not have the experts and coordination to support the young men in the later stages of the disease.

Table 14.19: Importance of access to specialists

Access to specialists	n=76	Percent
This is extremely important	58	76.32
This is very important	14	18.42
This is important	3	3.95
This is not very important	1	1.32

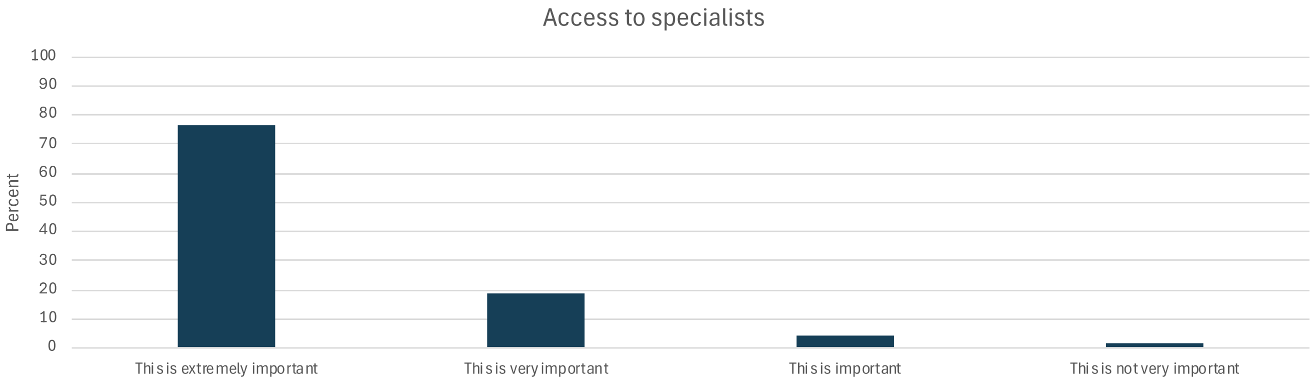


Figure 14.19: Importance of access to specialists

Table 14.20: Accessibility to specialists

Access to specialists	n=76	Percent
This is extremely accessible	4	5.26
This is very accessible	6	7.89
This is accessible	30	39.47
This is not very accessible	30	39.47
This is not accessible at all	5	6.58
This is not relevant to our patient population	1	1.32

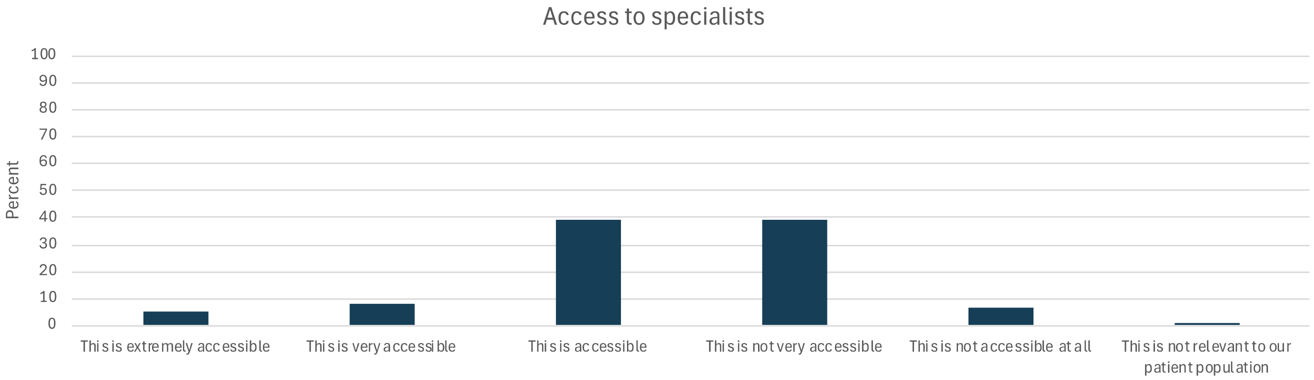


Figure 14.20: Accessibility to specialists

Earlier diagnostic tests

Importance of access to earlier diagnostic tests

Access to earlier diagnostic tests was extremely or very important to 65 organisations (85.53%), important to 6 organisations (7.89%) and not very important or not important at all to 5 organisations (6.58%).

Accessibility to earlier diagnostic tests

Access to earlier diagnostic tests was extremely or very accessible to 9 organisations (11.84%), accessible to 16 organisations (21.05%) and not very accessible or not accessible at all to 47 organisations (61.84%).Access to earlier diagnostic tests was not relevant to patient population for 4 organisations (5.26%).

NPON organisations comments about earlier diagnostic tests

Lack of GP knowledge about Dystonia due to it being a rare condition and often misdiagnosed

Earlier diagnosis by allowing members to self refer to specialists, bypassing GP's who can be a large barrier to accessing specialists, but still have medicare rebates apply

The patient barrier to management is the inability to easily and accurately diagnose and monitor their rare disease/condition, especially when compared to the test and monitoring available overseas.

When we are talking about those diagnosed with rare cancers, we are talking about cancers that affect less than 200 people per year in Australia, many go long periods of time, sometimes years being misdiagnosed. There is insufficient information available to them to decide on treatment operations available

Diagnostic testing for Immune Thrombocytopenia. Currently, patients are diagnosed through a process of elimination.

Frankly not a lot when diagnosis is delayed 7-9 years and in recent studies 10+ years. The education around the condition is lacking but I have seen a recent change where people are more open to listening and understanding our challenges.

Early detection and management of disease. Kidney disease is often undiagnosed which means that patients crash land into dialysis treatment which is costly and burdensome. We are actively advocating on the need for investment and health system change to get more people screened, diagnosed early and treatments to slow disease progression.

Table 14.21: Importance of access to earlier diagnostic tests

Access to earlier diagnostic tests	n=76	Percent
This is extremely important	49	64.47
This is very important	16	21.05
This is important	6	7.89
This is not very important	4	5.26
This is not important at all/is not relevant to our patient population	1	1.32

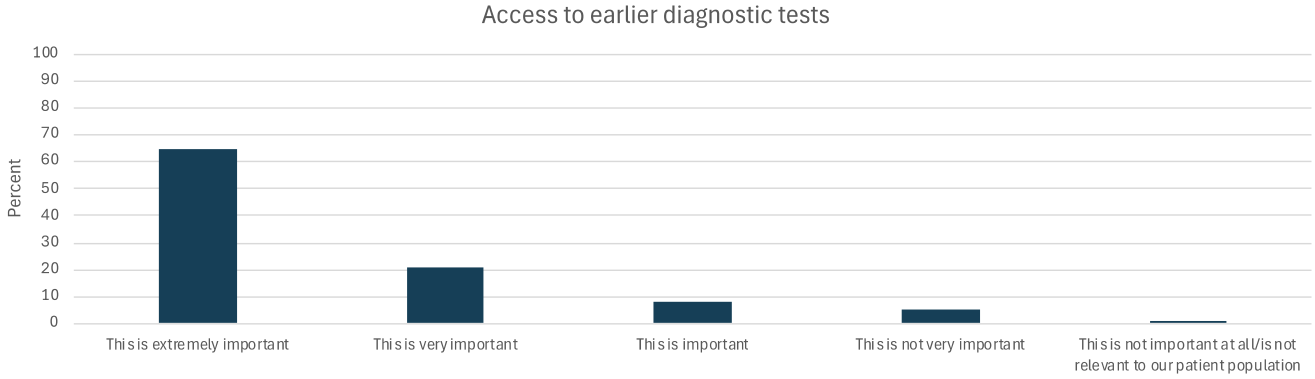


Figure 14.21: Importance of access to earlier diagnostic tests

Table 14.22: Accessibility to earlier diagnostic tests

Access to earlier diagnostic tests	n=76	Percent
This is extremely accessible	6	7.89
This is very accessible	3	3.95
This is accessible	16	21.05
This is not very accessible	39	51.32
This is not accessible at all	8	10.53
This is not relevant to our patient population	4	5.26

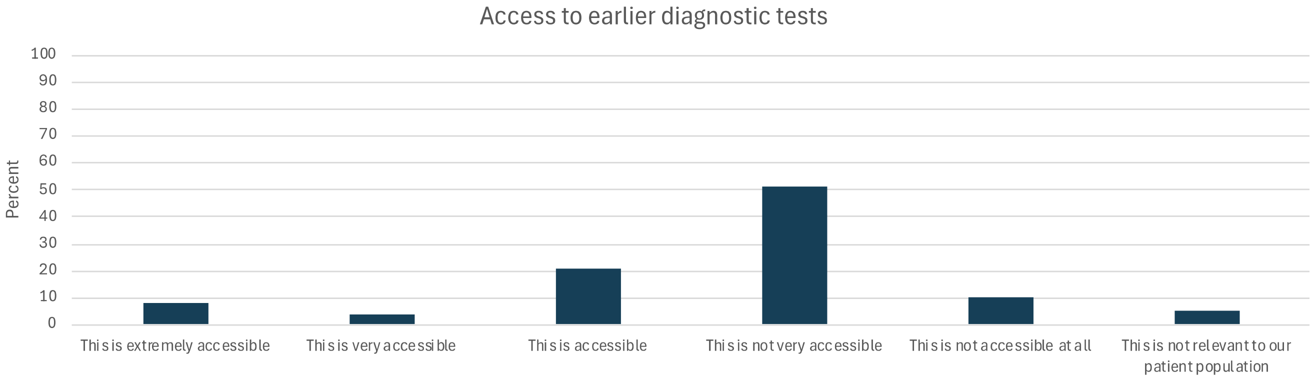


Figure 14.22: Accessibility to earlier diagnostic tests

Genetic testing

Importance of access to genetic testing

Access to genetic testing was extremely or very important to 47 organisations (61.84%), important to 11 organisations (14.47%) and not very important or not important at all to 18 organisations (23.68%).

Accessibility to genetic testing

Access to genetic testing was extremely or very accessible to 10 organisations (13.16%), accessible to 18 organisations (23.68%) and not very accessible or not accessible at all to 41 organisations (53.95%).Access to genetic testing was not relevant to patient population for 7 organisations (9.21%).

NPON organisations comments about genetic testing

More accessible genetic testing could provide better diagnostic outcomes regarding kidney decline progression

Our key issue at the moment is to have Sanfilippo syndrome included in Newborn Bloodspot Screening. The only treatments available are clinical trials and these are showing that the treatments are only effective in children if administered before 2 years of age. Children with Sanfilippo are rarely diagnosed before the age of 4 so we need it to be included in NBS.

CRITICAL ISSUE - Early access to genetic testing for ALL members of a family which is identified as carrying the Fragile X gene premutation or full mutation. Currently many families are being refused testing of children under the age of 18. The public genetic services have appalling wait times - 12 or more months in some states

More equitable access to diagnosis- Whole Exome Sequencing is not funded for children over the age of 10.

Table 14.23: Importance of access to genetic testing

Access to genetic testing	n=76	Percent
This is extremely important	38	50.00
This is very important	9	11.84
This is important	11	14.47
This is not very important	12	15.79
This is not important at all/is not relevant to our patient population	6	7.89

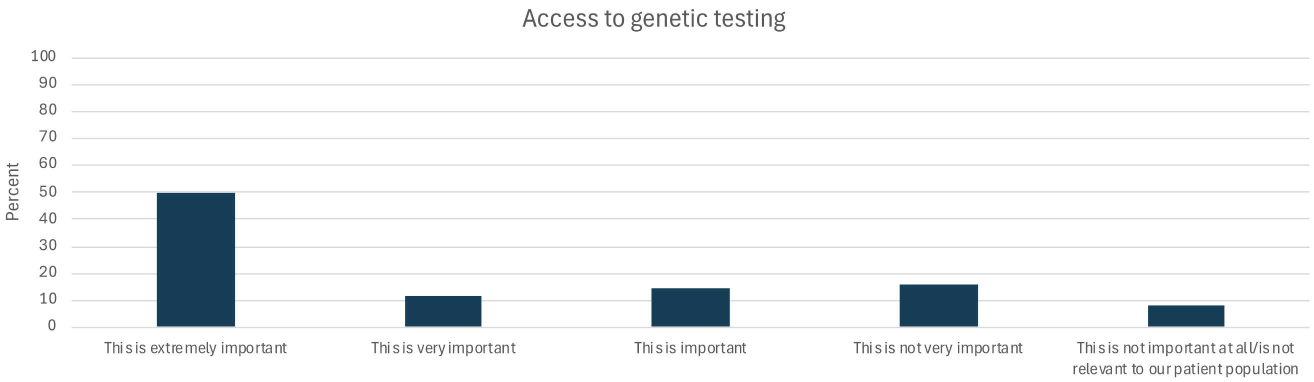


Figure 14.23: Importance of access to genetic testing

Table 14.24: Accessibility to genetic testing

Access to genetic testing	n=76	Percent
This is extremely accessible	7	9.21
This is very accessible	3	3.95
This is accessible	18	23.68
This is not very accessible	32	42.11
This is not accessible at all	9	11.84
This is not relevant to our patient population	7	9.21

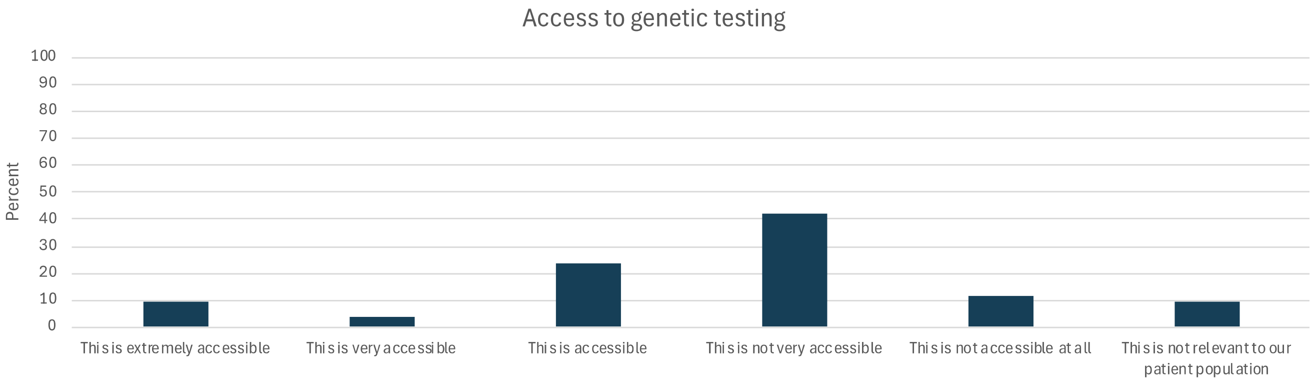


Figure 14.24: Accessibility to genetic testing

Equipment

Importance of access to equipment

Access to equipment was extremely or very important to 44 organisations (57.89%), important to 13 organisations (17.11%) and not very important or not important at all to 19 organisations (25.00%).

Accessibility of equipment

Access to equipment was extremely or very accessible to 8 organisations (10.53%), accessible to 30 organisations (39.47%) and not very accessible or not accessible at all to 25 organisations (32.89%).Access to equipment was not relevant to patient population for 13 organisations (17.11%).

NPON organisations comments about equipment

About 30% of adults living with cystic fibrosis develop cystic fibrosis-related diabetes. However, government reimbursement for continuous glucose monitors through the NDSS stops for people with cystic fibrosis once they turn 21 years old. This is a significant ongoing expense for a population that already have economic pressures.

Dialysis Capacity. Renal units around the country are full. There are waiting lists to access life-saving treatments with many patients having to travel long distances / across cities to access care. Some services are so full that patients are receiving treatment only twice per week instead of the recommended three times, and others are only able to access treatment in the middle of the night. These are not good outcomes for patients and we are actively advocating for better solutions.

Pior to NSID Save Our Sons was purchasing equipment and research. we appreciate that now with NDIS patients have access to equipment, however the difference between approvals is not equitable.

Table 14.25: Importance of access to equipment

Access to equipment	n=76	Percent
This is extremely important	30	39.47
This is very important	14	18.42
This is important	13	17.11
This is not very important	9	11.84
This is not important at all/is not relevant to our patient population	10	13.16

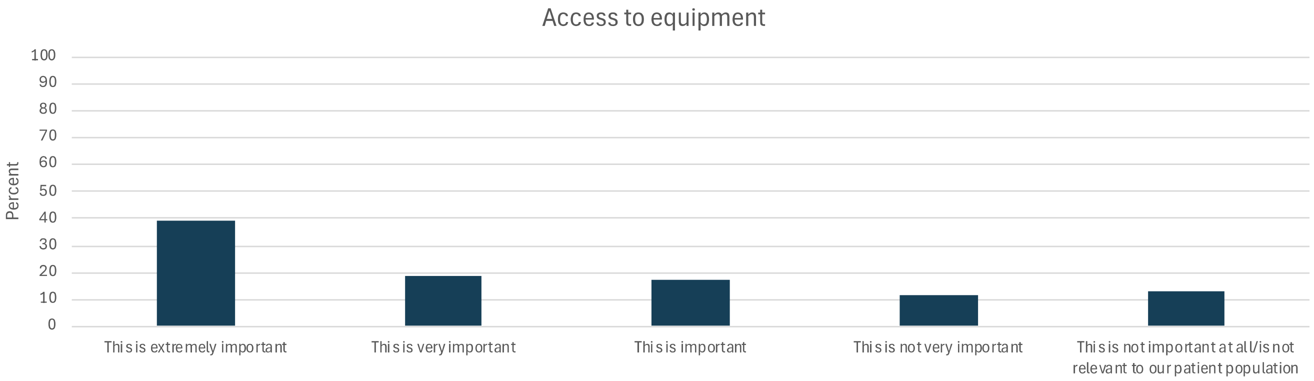


Figure 14.25: Importance of access to equipment

Table 14.26: Accessibility of equipment

Access to equipment	n=76	Percent
This is extremely accessible	5	6.58
This is very accessible	3	3.95
This is accessible	30	39.47
This is not very accessible	21	27.63
This is not accessible at all	4	5.26
This is not relevant to our patient population	13	17.11

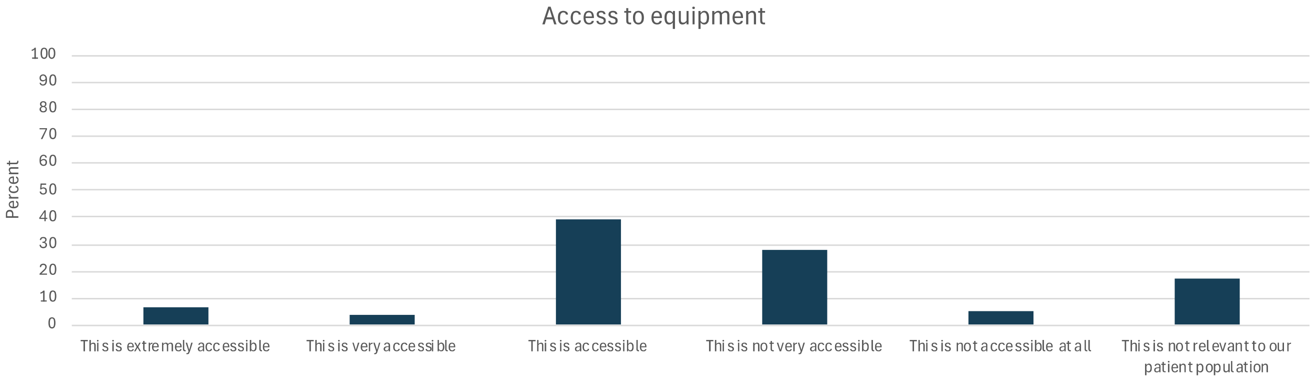


Figure 14.26: Accessibility of equipment

Reducing stigma

Accessibility of reducing stigma related to their condition/illness

Reducing stigma related to their condition/illness was extremely or very accessible to 11 organisations (14.47%), accessible to 20 organisations (26.32%) and not very accessible or not accessible at all to 43 organisations (56.58%).Reducing stigma related to their condition/illness was not relevant to patient population for 2 organisations (2.63%).

Importance of reducing stigma related to their condition/illness

Reducing stigma related to their condition/illness was extremely or very important to 55 organisations (72.37%), important to 16 organisations (21.05%) and not very important or not important at all to 5 organisations (6.58%).

NPON organisations comments about stigma related to their condition/illness

Acceptance of the medical condition.

Awareness and Understanding: There has been little progress made in inproving the health outcomes of musculsokeletal conditions in Australia. In addition to this, the burden of disease related to musculoskeletal conditions is increasing each and every year. The narrative around musculoskeletal conditions relate to aging, something that will happen to everyone etc. this combined with a negative narrative around specific disease and conditions (like back pain) and musculoskeletal pain more generally has further 'hidden' this global epidemic. It is essential that the narrative is shifted and that musculoskeletal health is a national priority - given it's positive implications to all other chronic health conditions and disease (including but not limited to diabetes, coronary disease, cancer etc.)

The assumption that all phases of the perinatal period, and all related complications and difficulties, are to be endured silently, and without complaint or request for intervention because *pregnancy is a choice and a privilege and there is no room for complaint or unhappiness within that.*

Women's health issues, particularly those relating to reproduction or pregnancy, aren't considered priority areas for research or funding from government bodies. We are left to self-diagnose, seek community support, jump from specialist to specialist looking for someone to believe or understand us. There is so much stigma associated with complaining about things that are seen as just part-and-parcel of being a woman.

Challenges in accessing viral hepatitis information, testing, treatment and ongoing support is the biggest issue facing the vulnerable and at risk populations we serve. Some of the most significant barriers to access include stigma and discrimination which can be within their own communities, the public at large and in the health system itself. For migrant and refugee populations fear of the legal ramifications of disclosing viral hepatitis is significant, they may not be eligible for treatment under the MBS, and they are faced with a complex health system that is very challenging to navigate and even more so for non english speakers.

Table 14.27: Accessibility of reducing stigma related to their condition/illness

Reducing stigma related to their condition/illness	n=76	Percent
This is extremely accessible	4	5.26
This is very accessible	7	9.21
This is accessible	20	26.32
This is not very accessible	36	47.37
This is not accessible at all	7	9.21
This is not relevant to our patient population	2	2.63

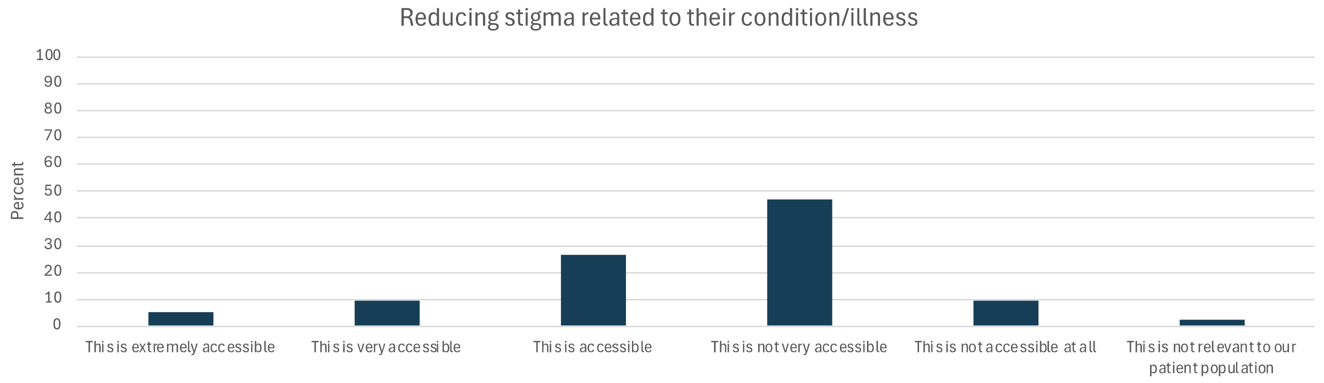


Figure 14.27: Accessibility of reducing stigma related to their condition/illness

Table 14.28: Importance of reducing stigma related to their condition/illness

Reducing stigma related to their condition/illness	n=76	Percent
This is extremely important	41	53.95
This is very important	14	18.42
This is important	16	21.05
This is not very important	5	6.58

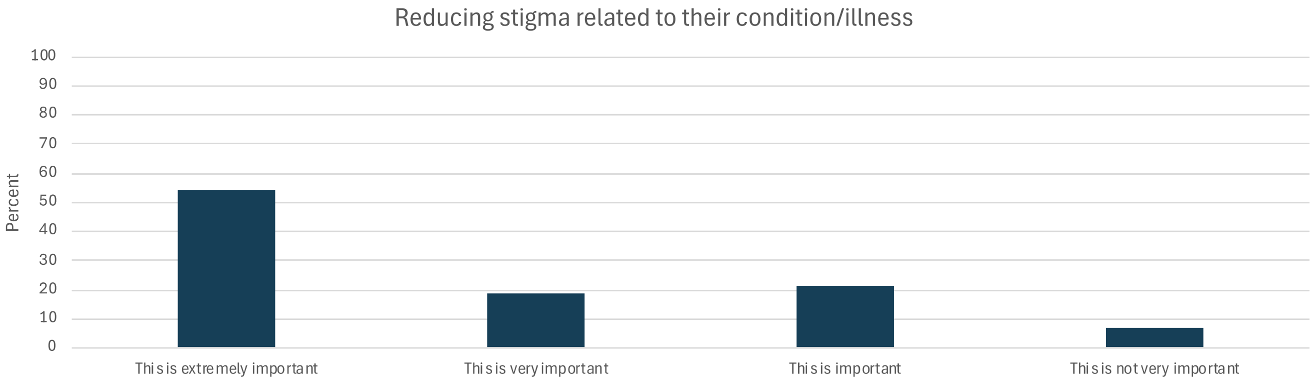


Figure 14.28: Importance of reducing stigma related to their condition/illness

Clinical trials

Importance of access to clinical trials

Access to clinical trials was extremely or very important to 58 organisations (76.32%), important to 12 organisations (15.79%) and not very important or not important at all to 6 organisations (7.89%).

Accessibility of clinical trials

Access to clinical trials was extremely or very accessible to 11 organisations (14.47%), accessible to 22 organisations (28.95%) and not very accessible or not accessible at all to 41 organisations (53.95%).Access to clinical trials was not relevant to patient population for 2 organisations (2.63%).

NPON organisations comments about clinical trials

Research an access to trial overseas - Australia is currently 10 years behind than our overseas organisation.

Access to clinical trials that are being run overseas. Despite having a contact registry and key specialists around Australia with an interest in clinical research, Australians with the health conditions we look after are missing out on many clinical trials. We are still working on understanding why, and what factors we can influence, but we believe many issues are not specific to our health condition i.e. are common across clinical trials in Australia related to high costs of running trials here.

Lack of preparedness for clinical trials in rare disease this is all levels - government, regulatory bodies, clinicians and patient groups.

There isn't as much research to rely on as evidence is still being established, and there are fewer experts who specialise in rare cancers. This can make it difficult for doctors to quickly find everything they need to care for people with rare cancers.
Treatment planning is notoriously difficult. Compared to more common cancers, fewer clinical trials and limited data to support drug registration and reimbursement means rare and less common cancer patients are left with fewer proven treatment options and fewer subsidised medicines.

-providing patients with information about clinical trials that are being run in Australia are few and far between. We need more availability in Australia.

Table 14.29: Importance of access to clinical trials

Access to clinical trials	n=76	Percent
This is extremely important	35	46.05
This is very important	23	30.26
This is important	12	15.79
This is not very important	6	7.89

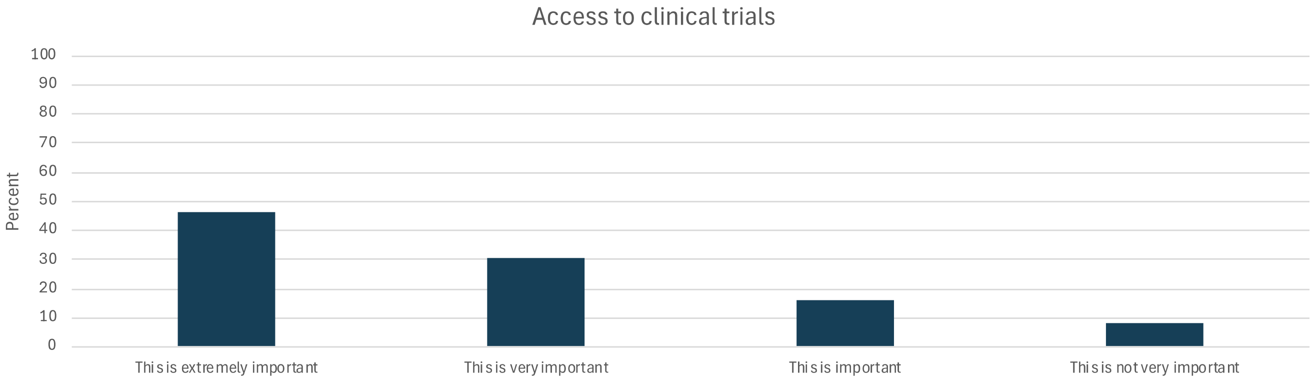


Figure 14.29: Importance of access to clinical trials

Table 14.30: Accessibility of clinical trials

Access to clinical trials	n=76	Percent
This is extremely accessible	5	6.58
This is very accessible	6	7.89
This is accessible	22	28.95
This is not very accessible	34	44.74
This is not accessible at all	7	9.21
This is not relevant to our patient population	2	2.63

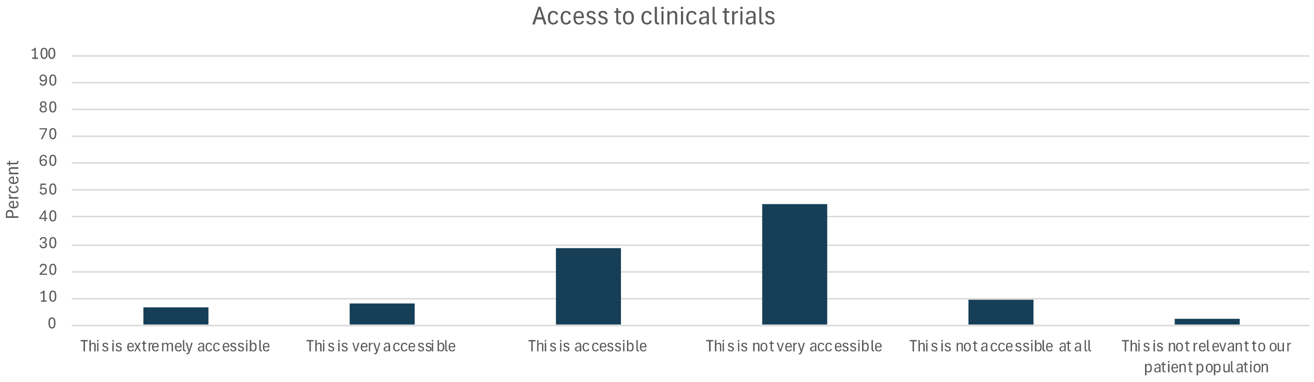


Figure 14.30: Accessibility of clinical trials

Up to date information

Importance of access to up to date information and research findings

Access to up to date information and research findings was extremely or very important to 67 organisations (88.16%), important to 8 organisations (10.53%) and not very important or not important at all to 1 organisations (1.32%).

Accessibility of up to date information and research findings

Access to up to date information and research findings was extremely or very accessible to 21 organisations (27.63%), accessible to 29 organisations (38.16%) and not very accessible or not accessible at all to 25 organisations (32.89%).Access to up to date information and research findings was not relevant to patient population for 1 organisation (1.32%).

NPON organisations comments about up to date information and research findings

Rare Cancers Australia and the National Oncology Alliance (NOA) are working to improve equitable access to the best cancer care and emerging cancer treatments and technologies. Genomic sequencing technology has enabled new frontiers of cancer research, drug discovery, and clinical care by offering the potential for precise and personalised approaches to cancer treatment. This is especially relevant for patients with rare cancers, who suffer from limited access to new targeted cancer treatments that offer hope for improved chances of survival. We believe that personalised medicine should be the standard of care in Australia.

Limited information
Typically, people living with rare cancer have gone without support resources tailored explicitly to their needs. Instead, they have had to rely on information designed for common cancers, or sometimes nothing at all. They often need to undertake extensive personal research to find the answers they need.

Effective data collection and access to information to accurately reflect the extent of the impact of a CoHD diagnosis on CoHD and broader community.

Table 14.31: Importance of access to up to date information and research findings

Access to up to date information and research findings	n=76	Percent
This is extremely important	41	53.95
This is very important	26	34.21
This is important	8	10.53
This is not very important	1	1.32

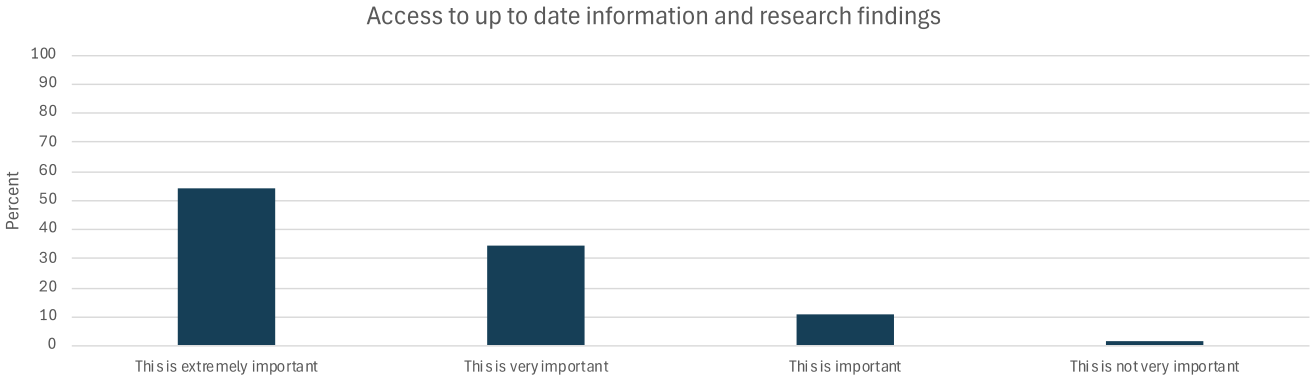


Figure 14.31: Importance of access to up to date information and research findings

Table 14.32: Accessibility of up to date information and research findings

Access to up to date information and research findings	n=76	Percent
This is extremely accessible	9	11.84
This is very accessible	12	15.79
This is accessible	29	38.16
This is not very accessible	22	28.95
This is not accessible at all	3	3.95
This is not relevant to our patient population	1	1.32

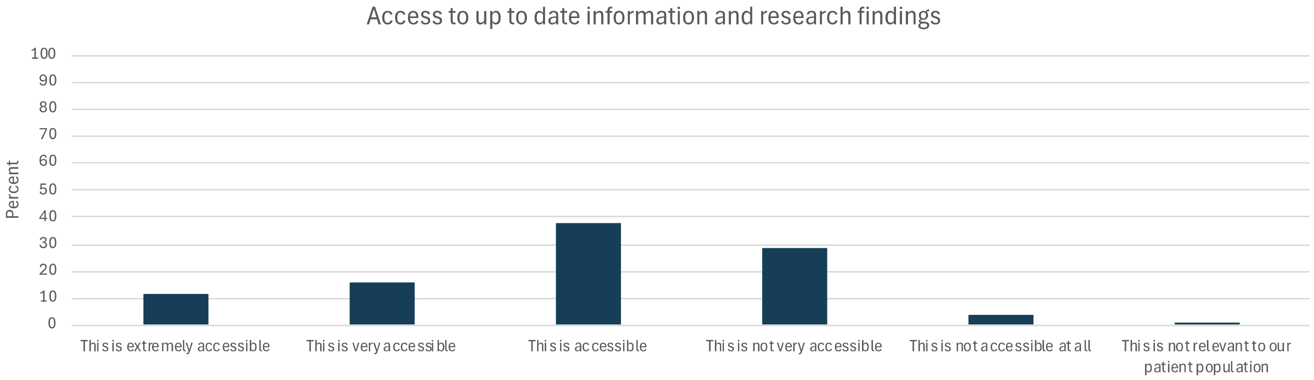


Figure 14.32: Accessibility of up to date information and research findings