

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 improving the health outcomes of musculoskeletal 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

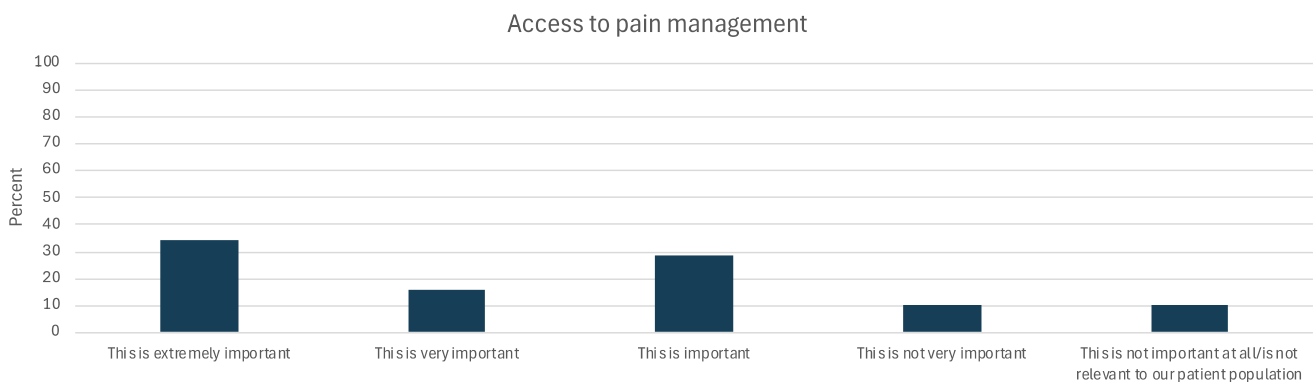


Figure 14.1: Importance of access to pain management

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

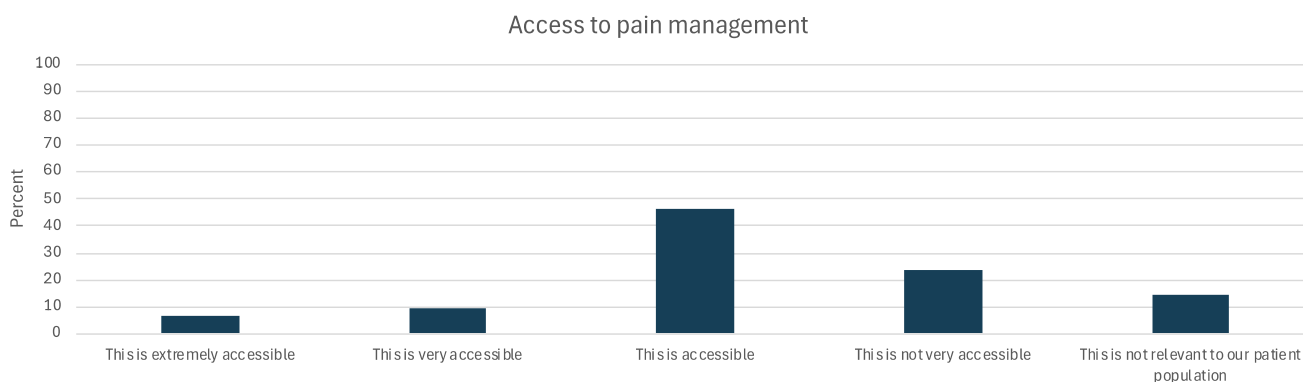


Figure 14.2: Accessibility of pain management

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

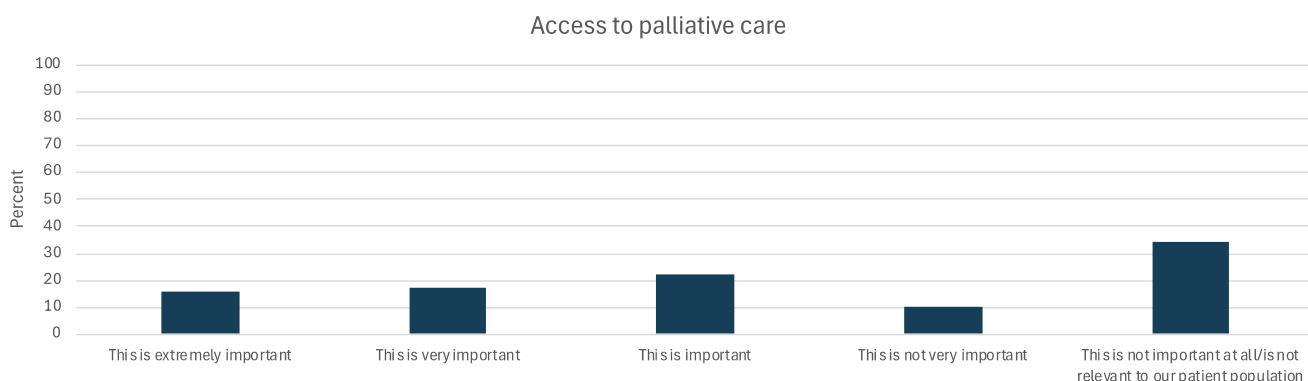


Figure 14.3: Importance of access to palliative care

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

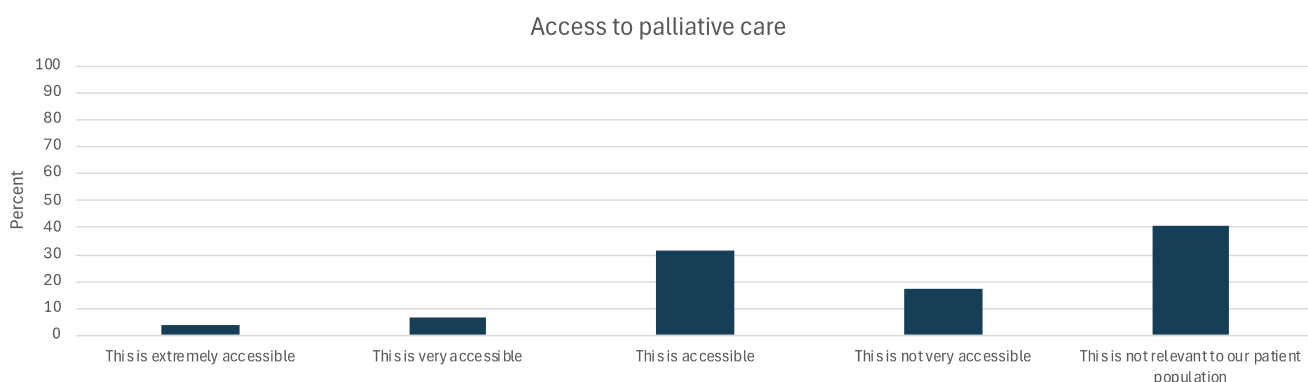


Figure 14.4: Accessibility of palliative care

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 common 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

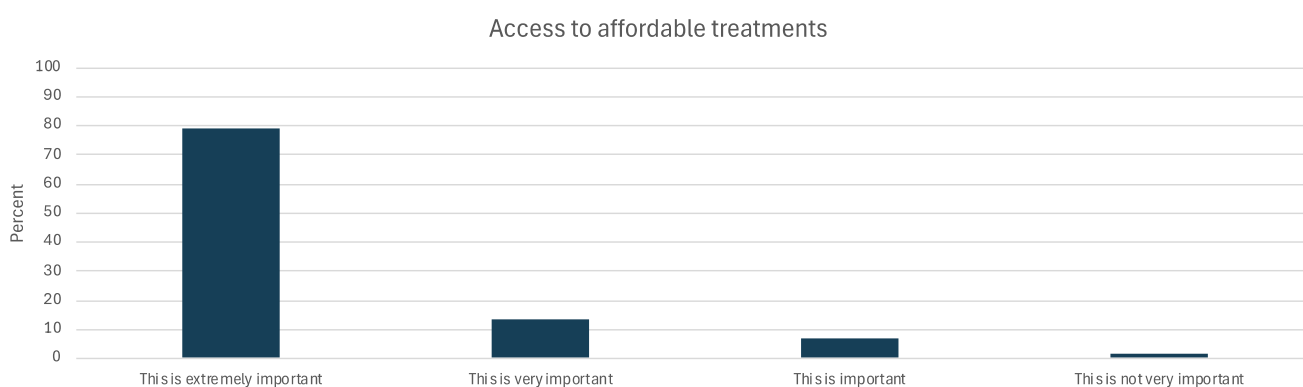


Figure 14.5: Importance of access to affordable treatments

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

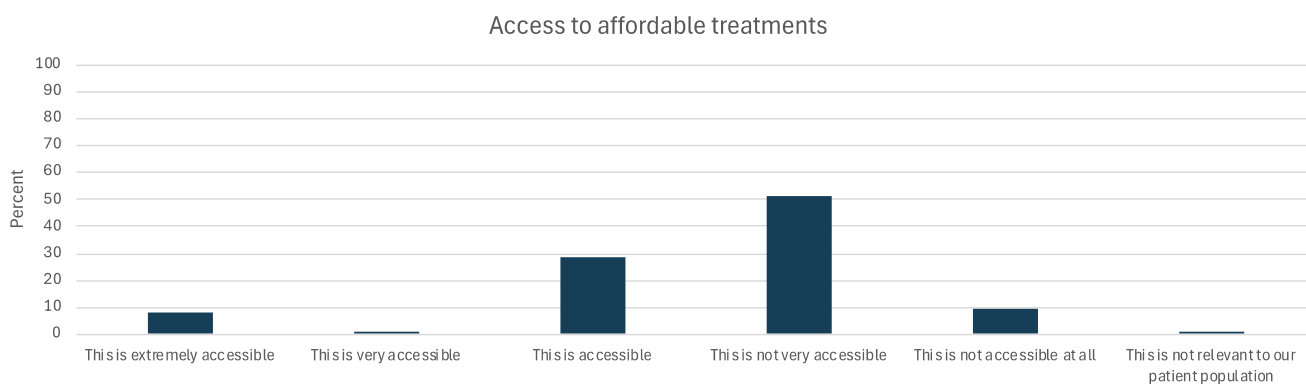


Figure 14.6: Accessibility of affordable treatments

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 but 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 reasonable 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

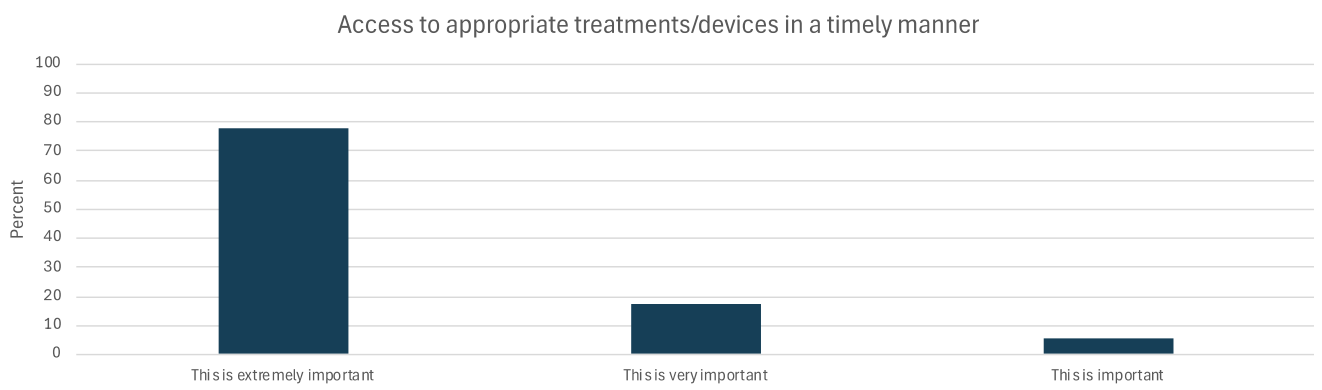


Figure 14.7: Importance of access to appropriate treatments/devices in a timely manner

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

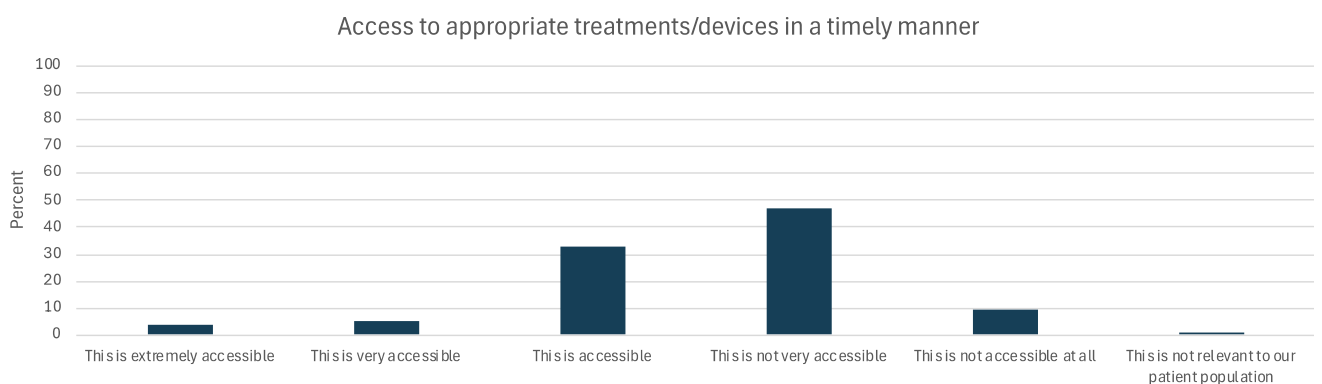


Figure 14.8: Accessibility of appropriate treatments/devices in a timely manner

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

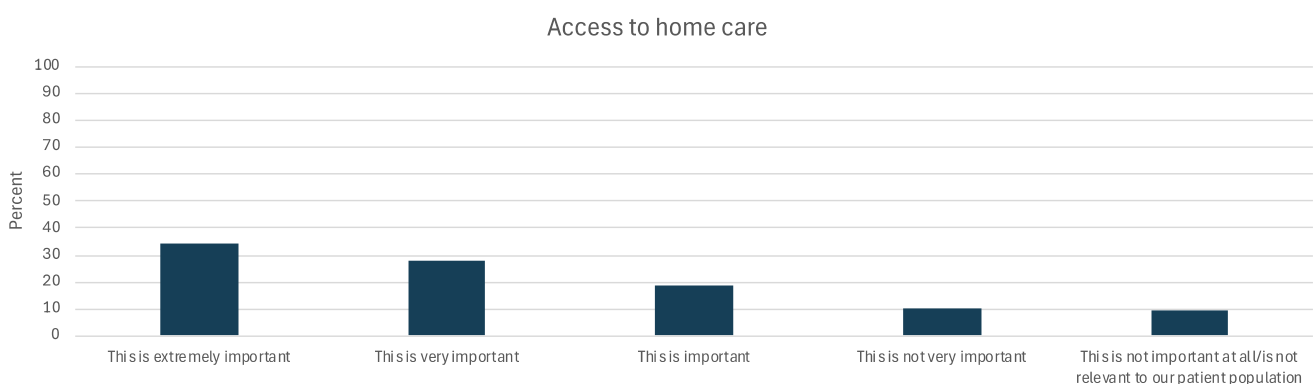


Figure 14.9: Importance of access to home care

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

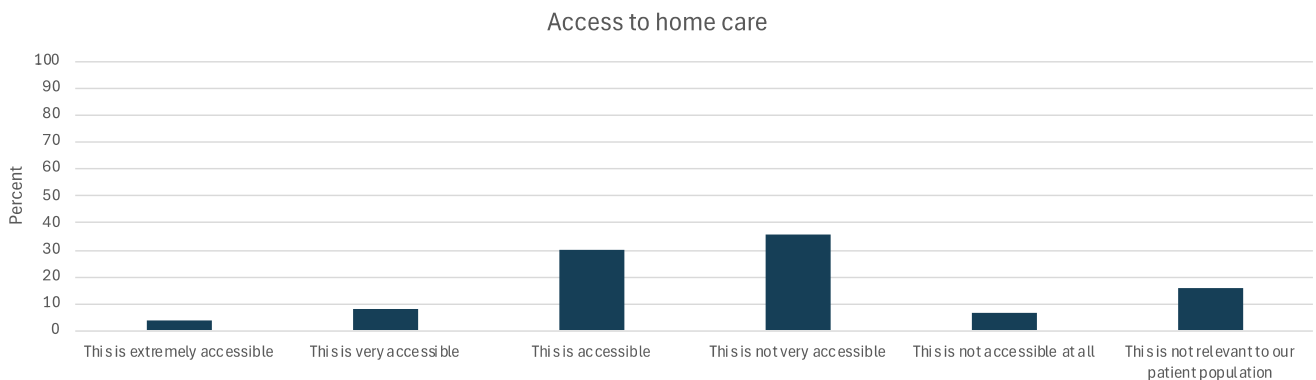


Figure 14.10: Accessibility of home care

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 rehospitalisation 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

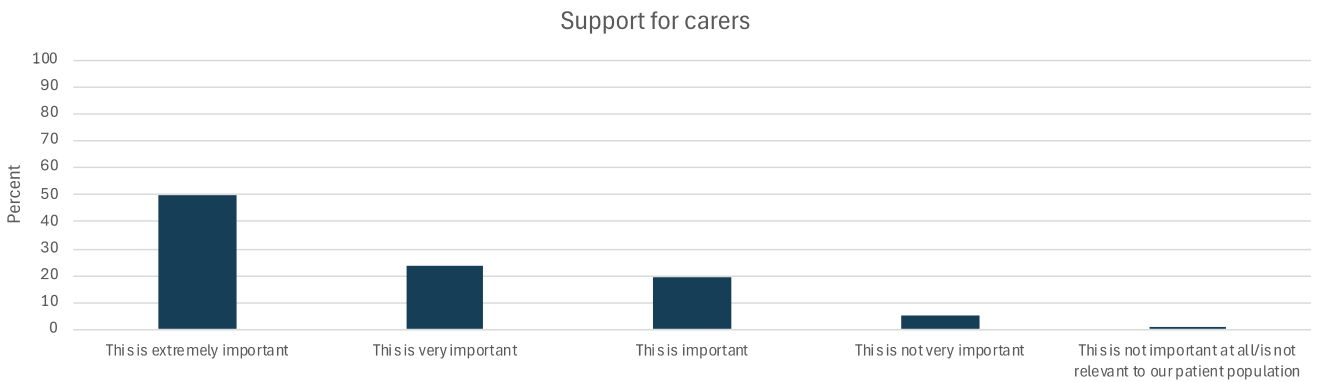


Figure 14.11: Importance of access to support for carers

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

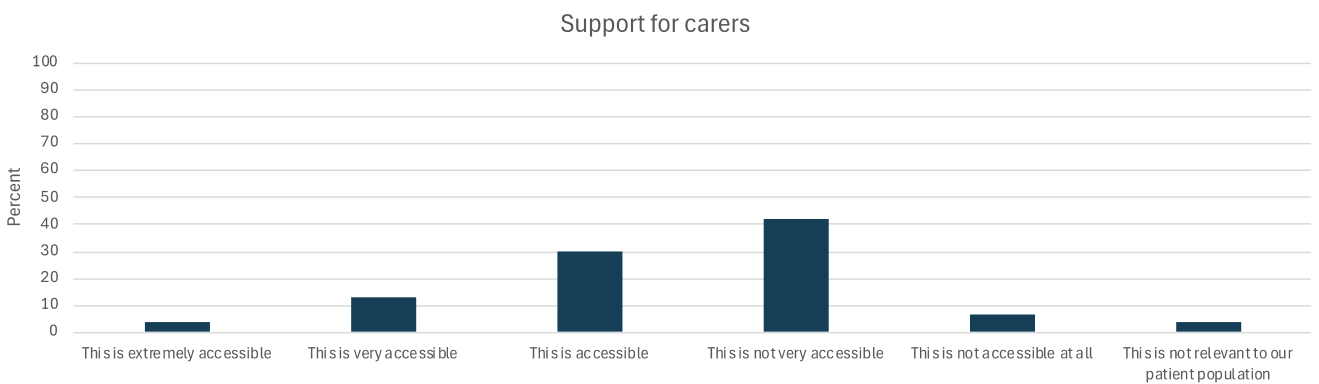


Figure 14.12: Accessibility of support for carers

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

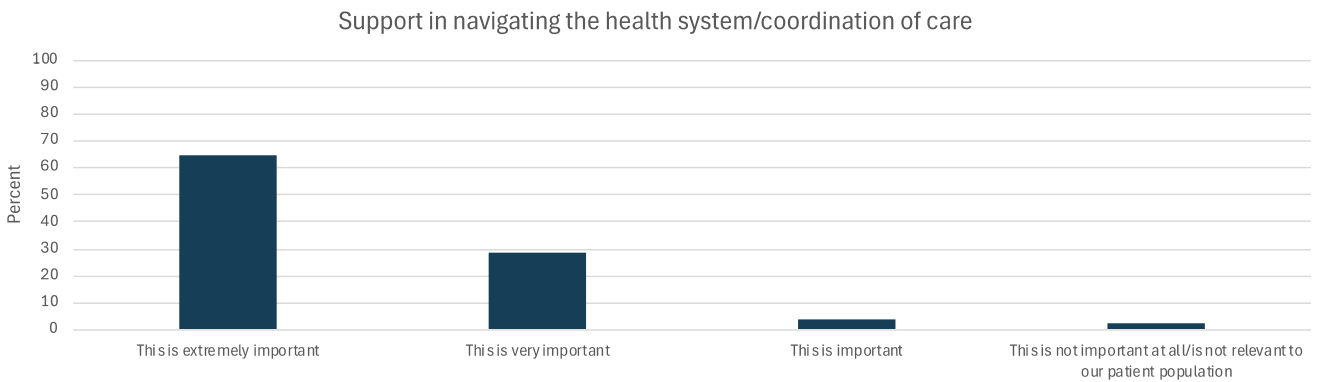


Figure 14.13: Importance of access to support in navigating the health system/coordination of care

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

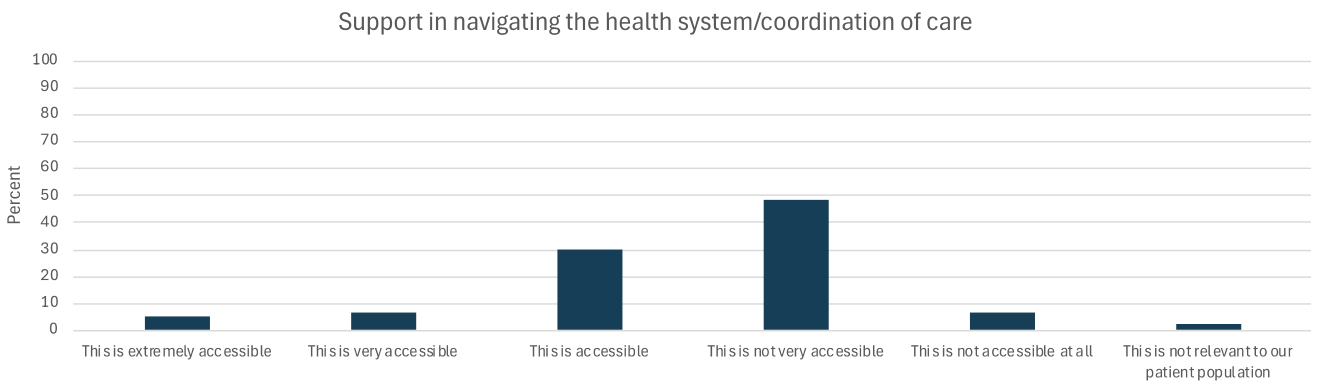


Figure 14.14: Accessibility of support in navigating the health system/coordination of care

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 community, 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

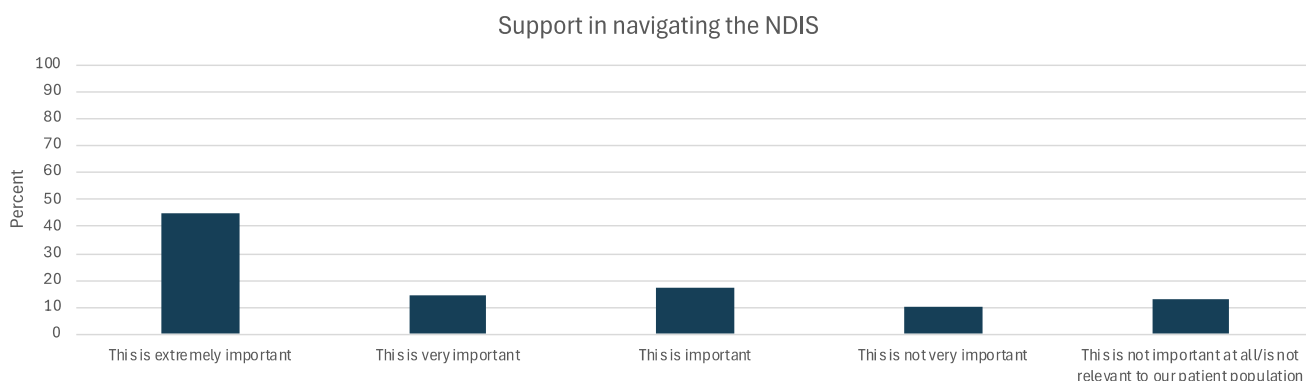


Figure 14.15: Importance of access to support in navigating the NDIS

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

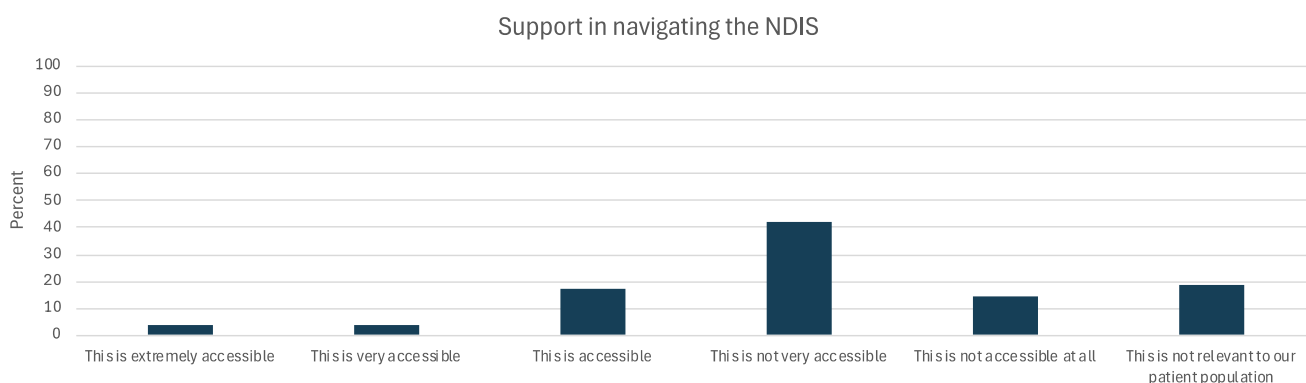


Figure 14.16: Accessibility of support in navigating the NDIS

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 would 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

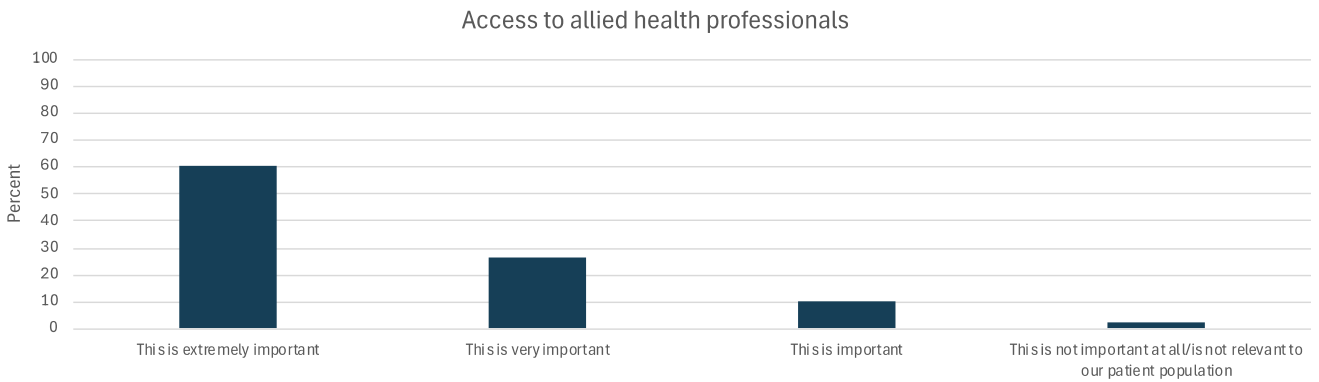


Figure 14.17: Importance of access to allied health professionals

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

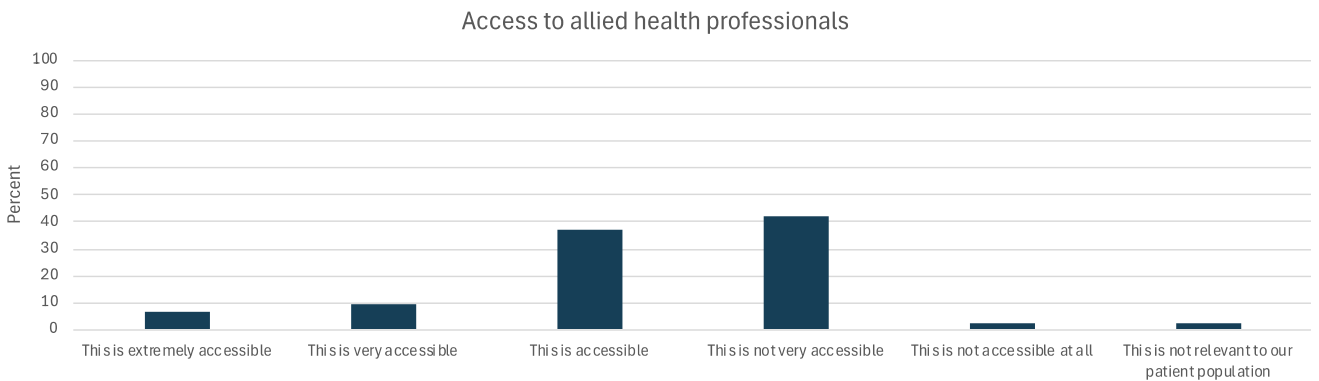


Figure 14.18: Accessibility to allied health professionals

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 organisation (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 someone who understands the condition and we invite members to recommend any that have been 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

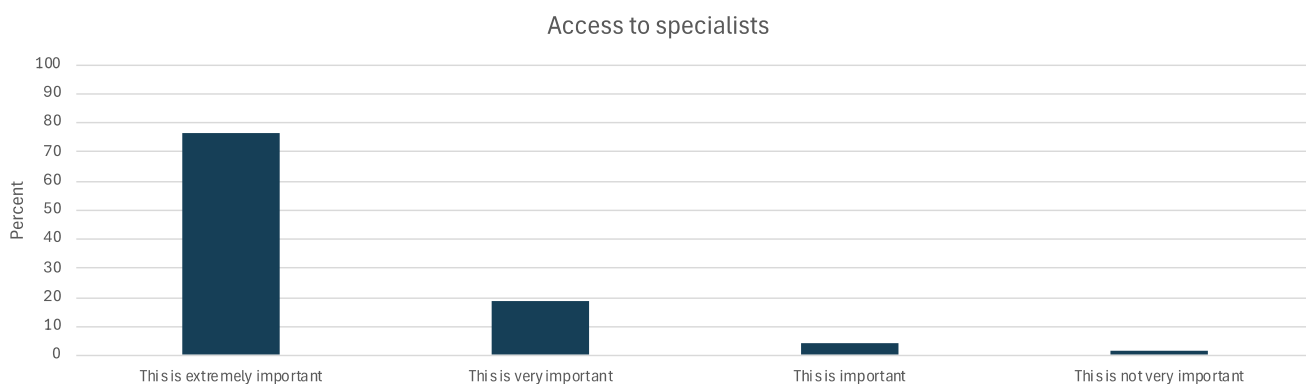


Figure 14.19: Importance of access to specialists

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

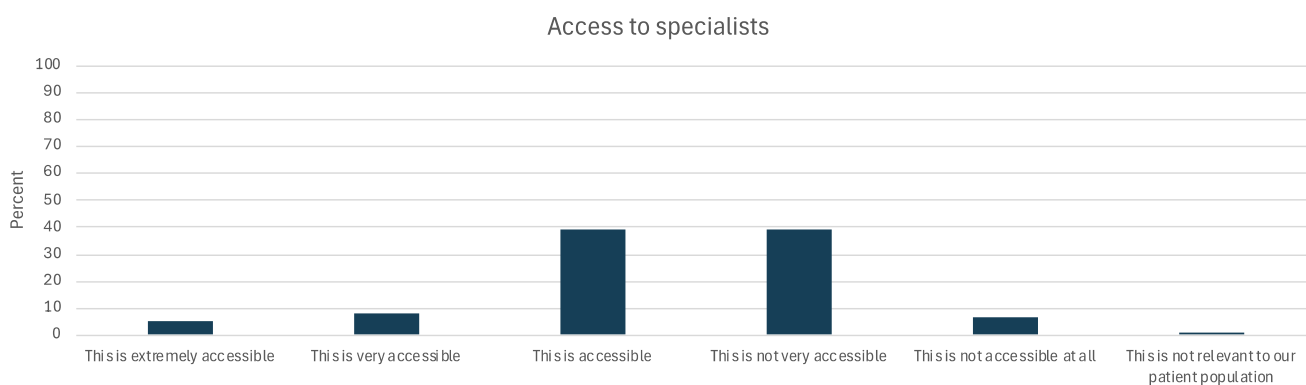


Figure 14.20: Accessibility to specialists

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%).

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%).

Accessibility to earlier diagnostic tests

Access to earlier diagnostic tests was extremely or very accessible to 9 organisations (11.84%),

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

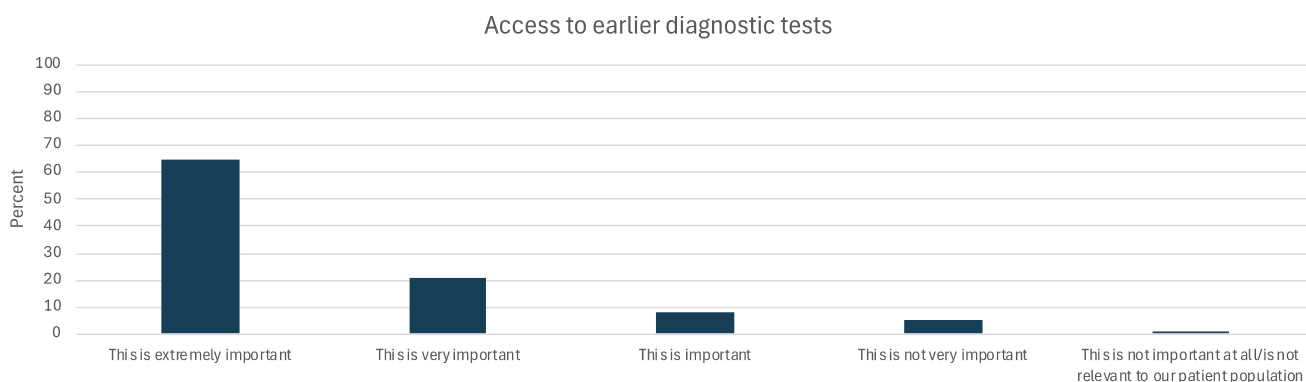


Figure 14.21: Importance of access to earlier diagnostic tests

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

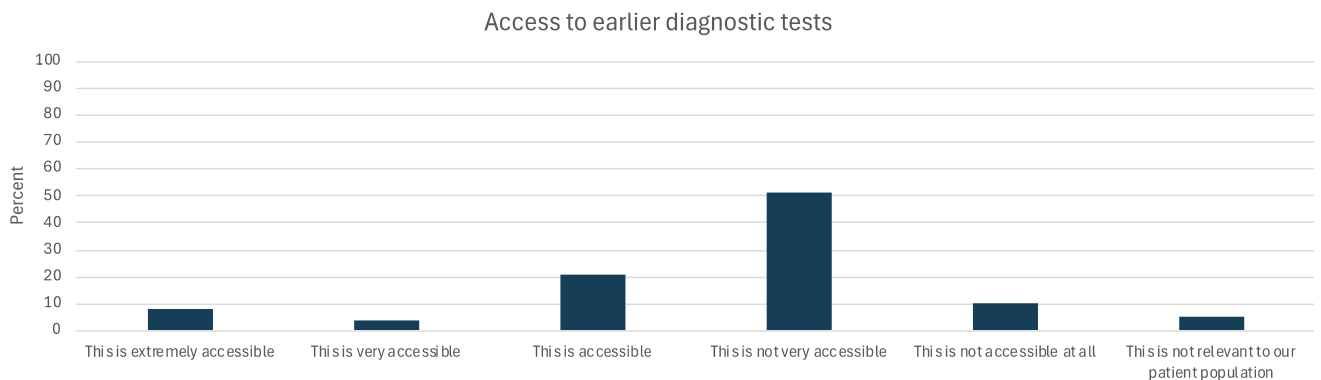


Figure 14.22: Accessibility to earlier diagnostic tests

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

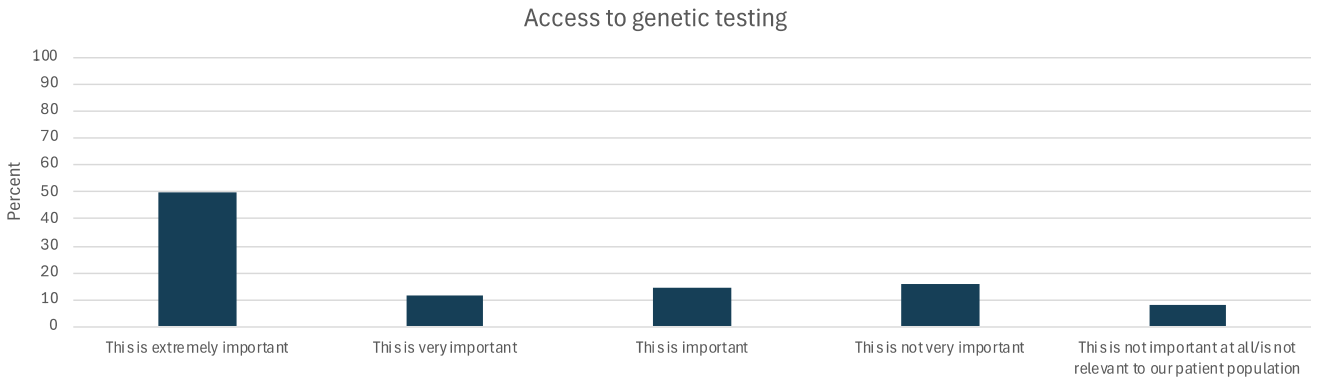


Figure 14.23: Importance of access to genetic testing

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

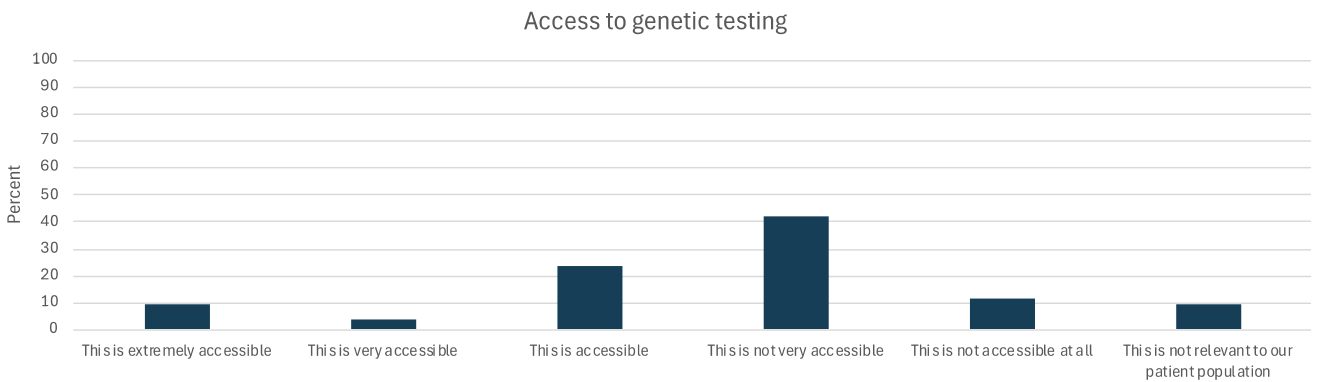


Figure 14.24: Accessibility to genetic testing

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.

Prior 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

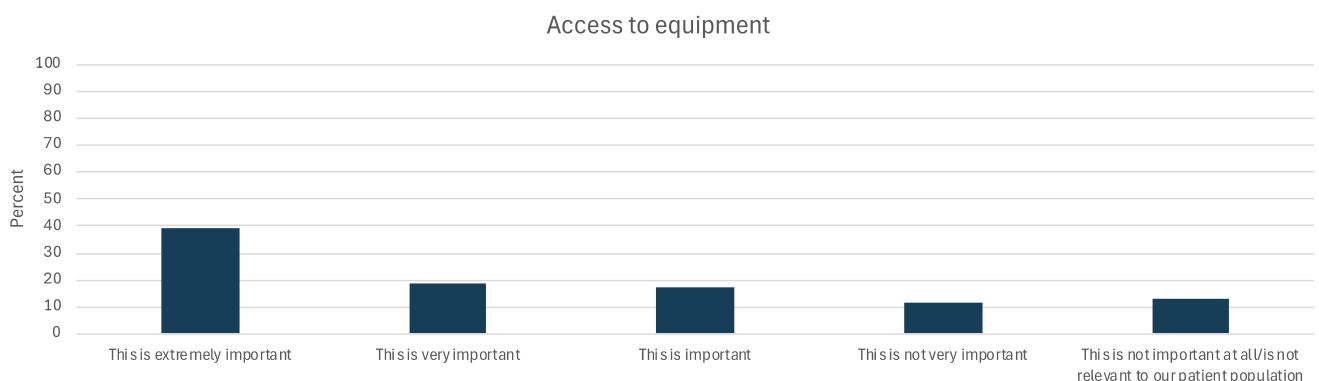


Figure 14.25: Importance of access to equipment

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

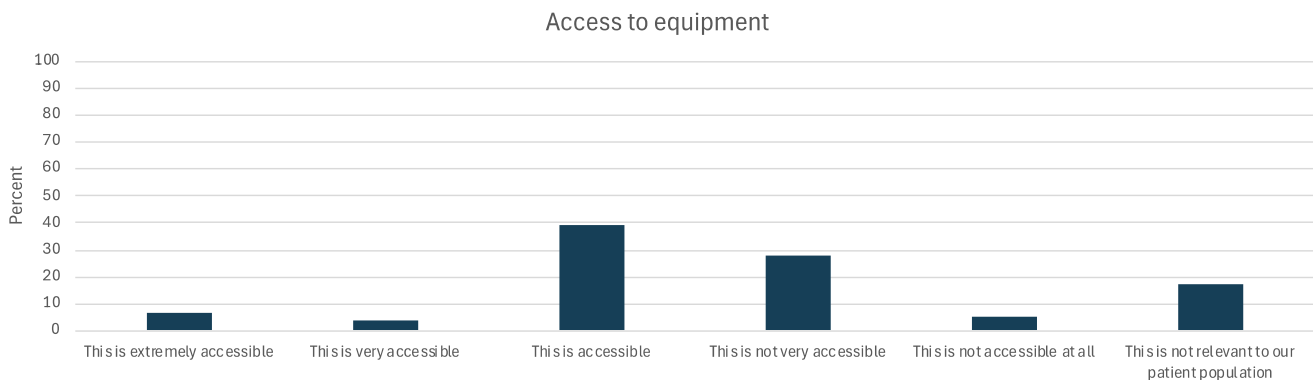


Figure 14.26: Accessibility of equipment

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 improving the health outcomes of musculoskeletal 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 its 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

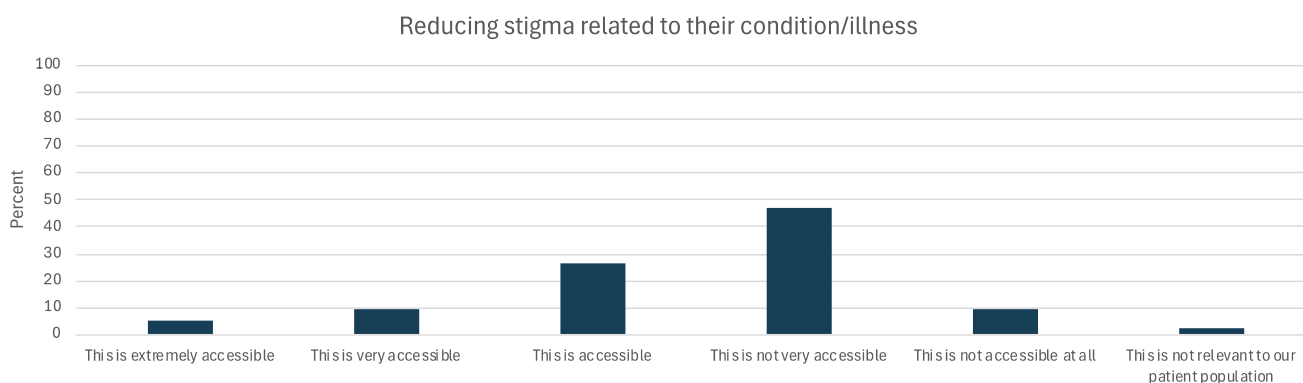


Figure 14.27: Accessibility of reducing stigma related to their condition/illness

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

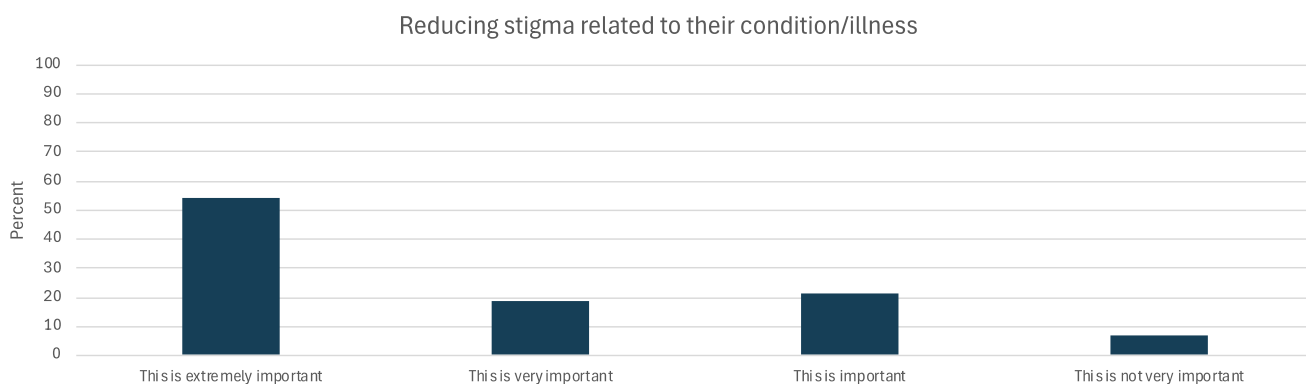


Figure 14.28: Importance of reducing stigma related to their condition/illness

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

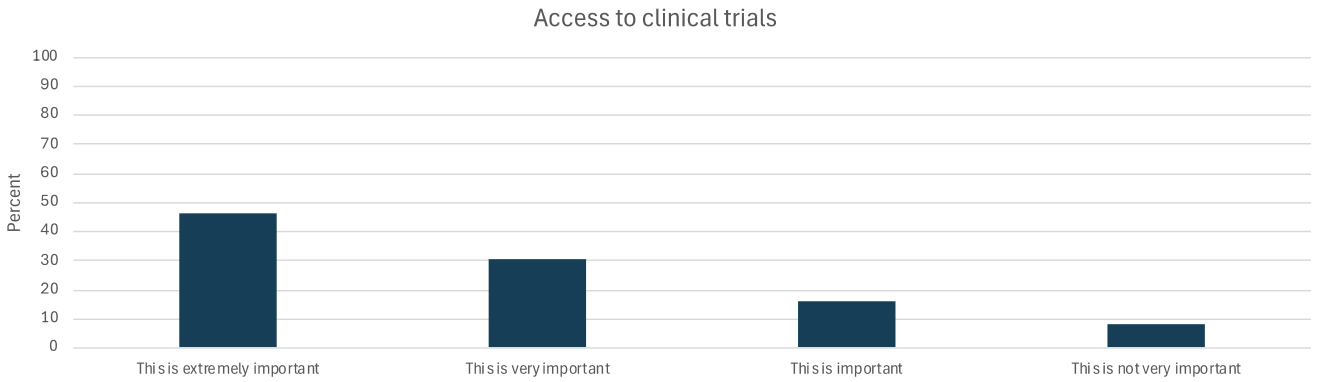


Figure 14.29: Importance of access to clinical trials

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

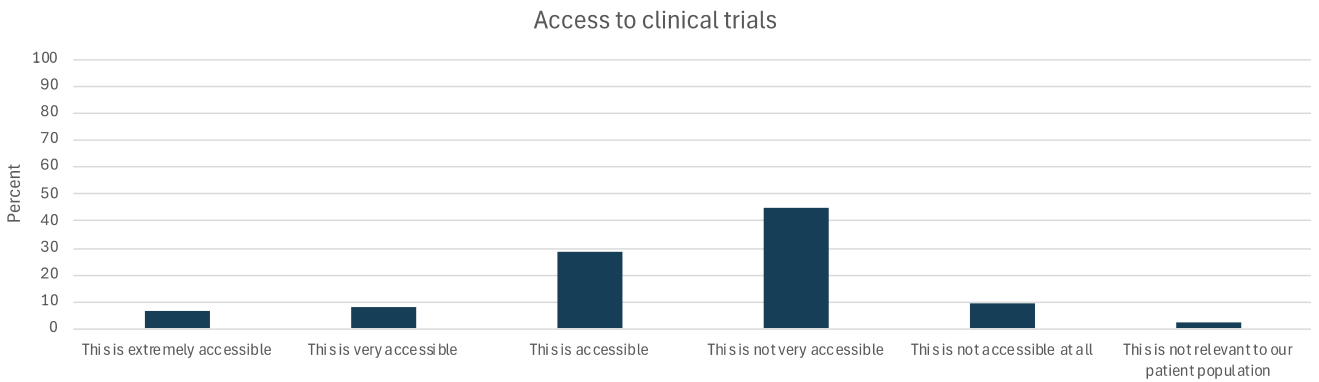


Figure 14.30: Accessibility of clinical trials

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

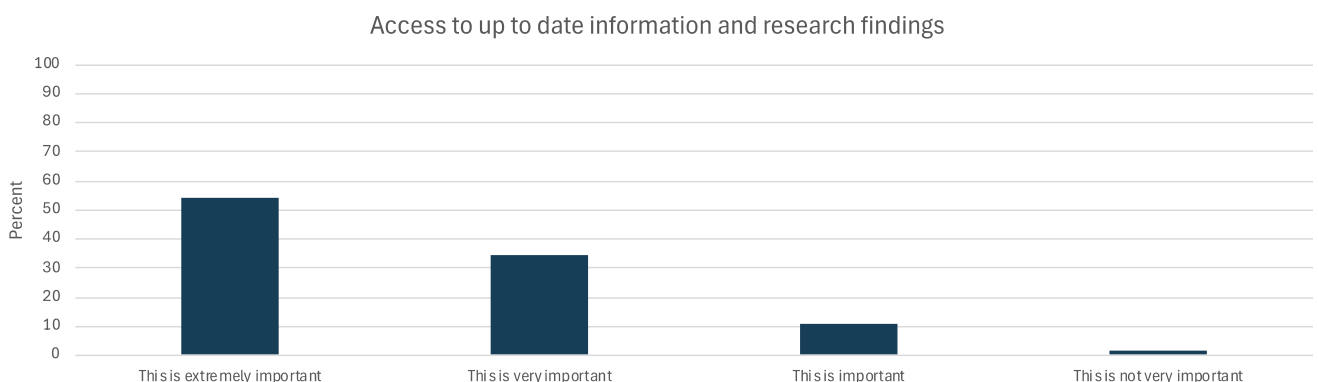


Figure 14.31: Importance of access to up to date information and research findings

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

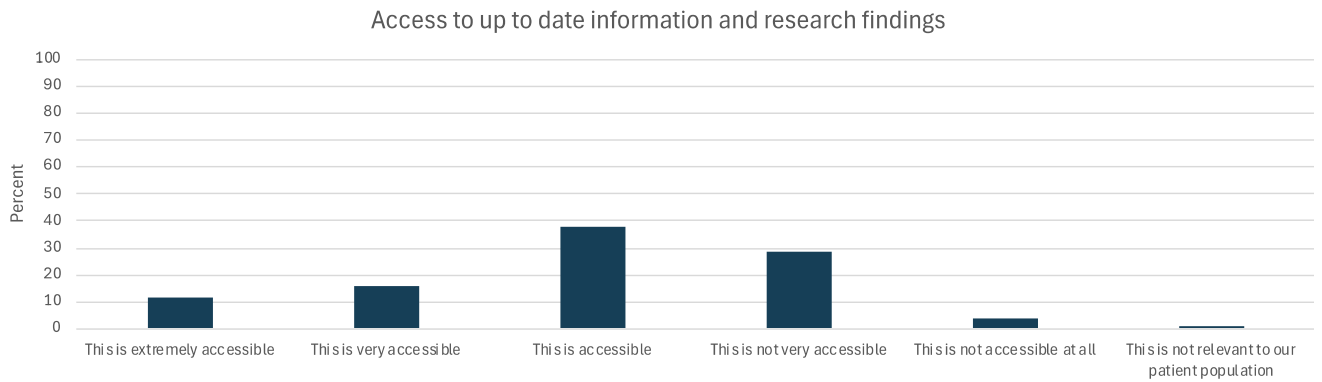


Figure 14.32: Accessibility of up to date information and research findings