Section 7: 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	Self care interventions
• 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	• 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

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

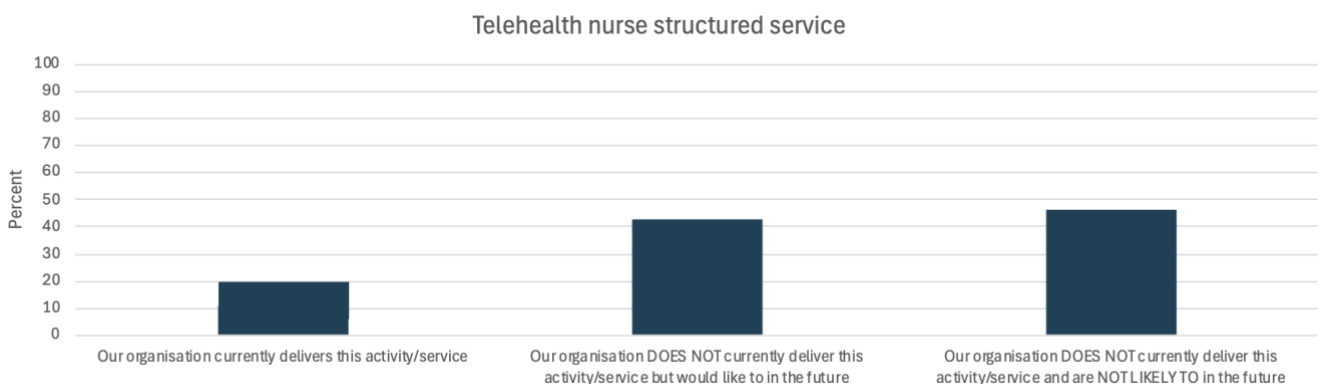| Telehealth nurse structured service (This means a virtual clinic or case management service where patients need to make an appointment to talk with a nurse)	n=80	Percent
Our organisation currently delivers this activity/service	20	25.00
Our organisation DOES NOT currently deliver this activity/service 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 guidance for f2f groups

Table 7.3: Face-to-face support groups

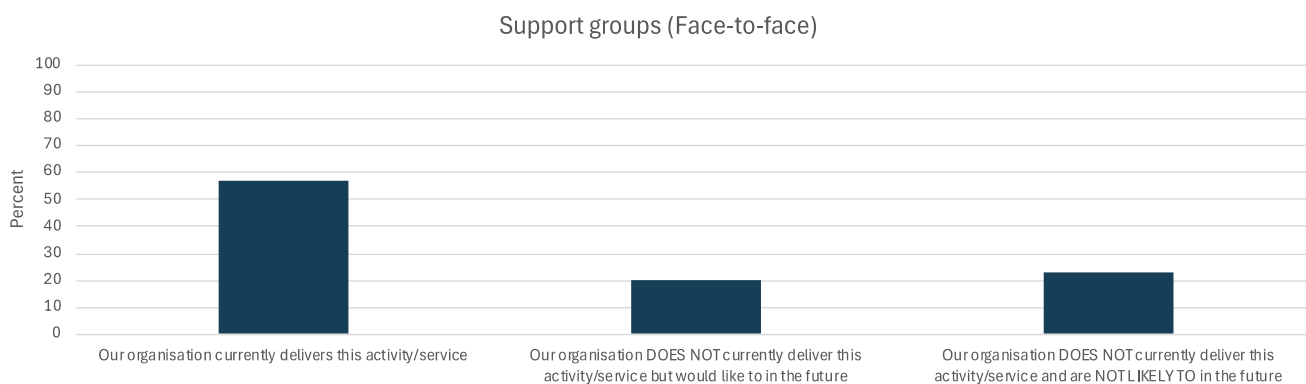| Support groups (Face-to-face)	n=83	Percent
Our organisation currently delivers this activity/service	47	56.63
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	17	20.48
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY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

Support groups (Face-to-face)

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

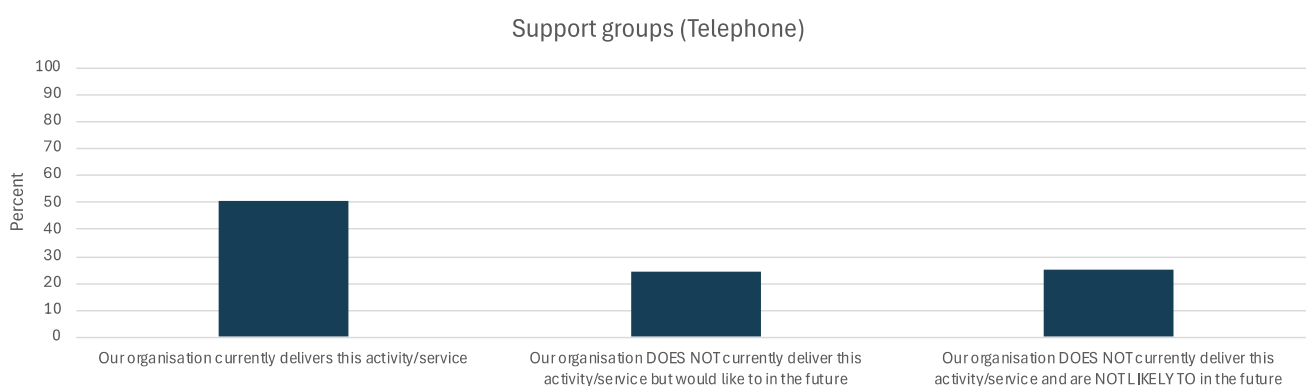| Support groups (Telephone)	n=83	Percent
Our organisation currently delivers this activity/service	42	50.60
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	20	24.10
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY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

Support groups (Telephone)

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 guidance 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

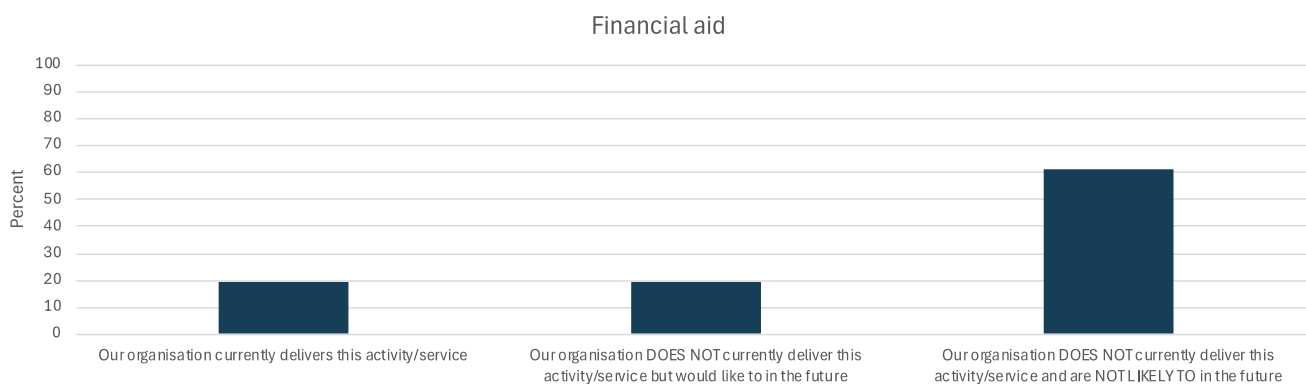| Financial aid	n=83	Percent
Our organisation currently delivers this activity/service	16	19.28
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	16	19.28
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future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

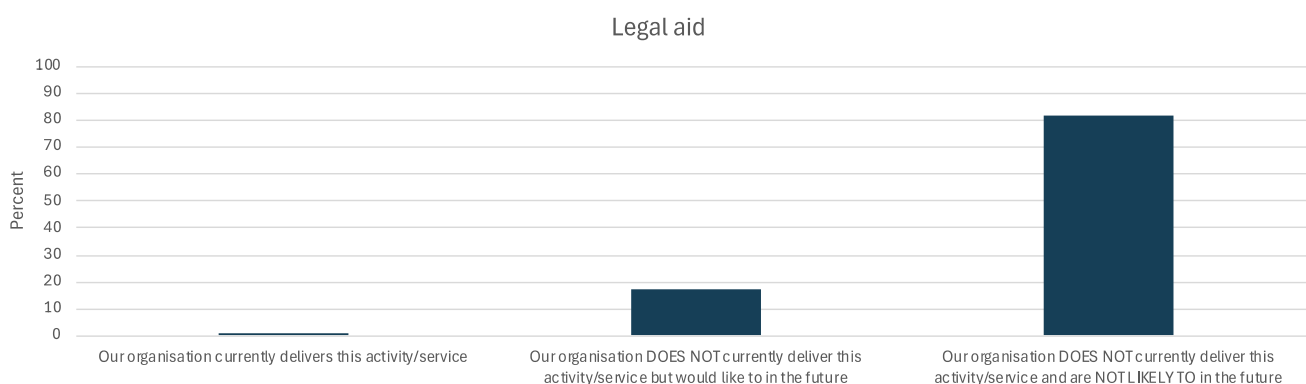| Legal aid	n=82	Percent
Our organisation currently delivers this activity/service	1	1.22
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	14	17.07
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	67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

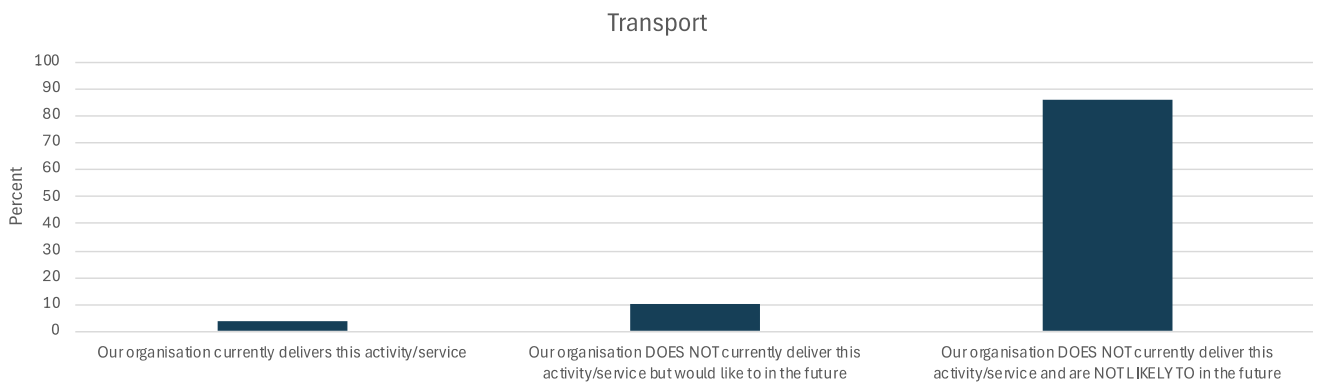| Transport	n=79	Percent
Our organisation currently delivers this activity/service	3	3.80
Our organisation DOES NOT currently deliver this activity/service but would like to in the future	8	10.13
Our organisation DOES NOT currently deliver this activity/service and are NOT LIKELY TO in the future	68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

Figure 7.8: Transport

Self-care interventions

Self-care interventions 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

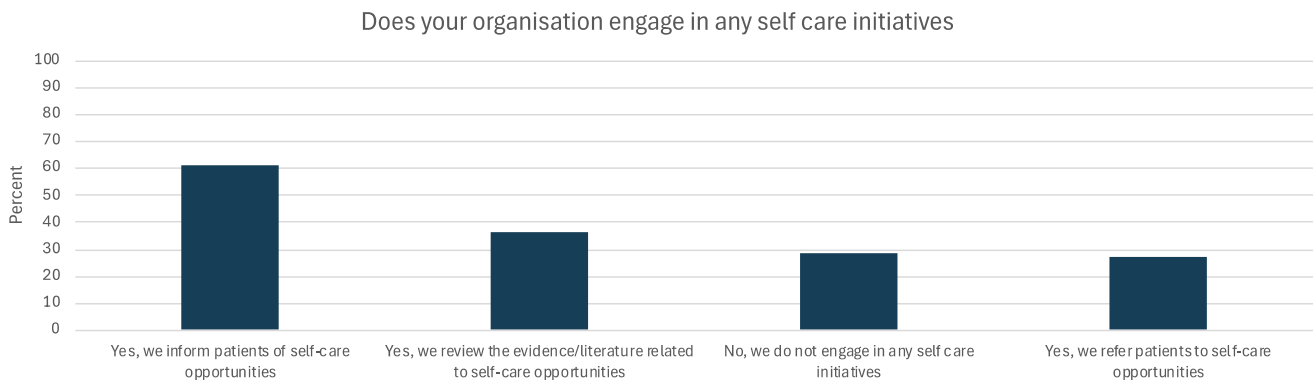| Does your organisation engage in any self care initiatives	n=69	Percent
Yes, we inform patients of self-care opportunities	42	60.87
Yes, we review the evidence/literature related to self-care opportunities	25	36.23
No, we do not engage in any self care initiatives	20	28.99
Yes, we refer patients to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

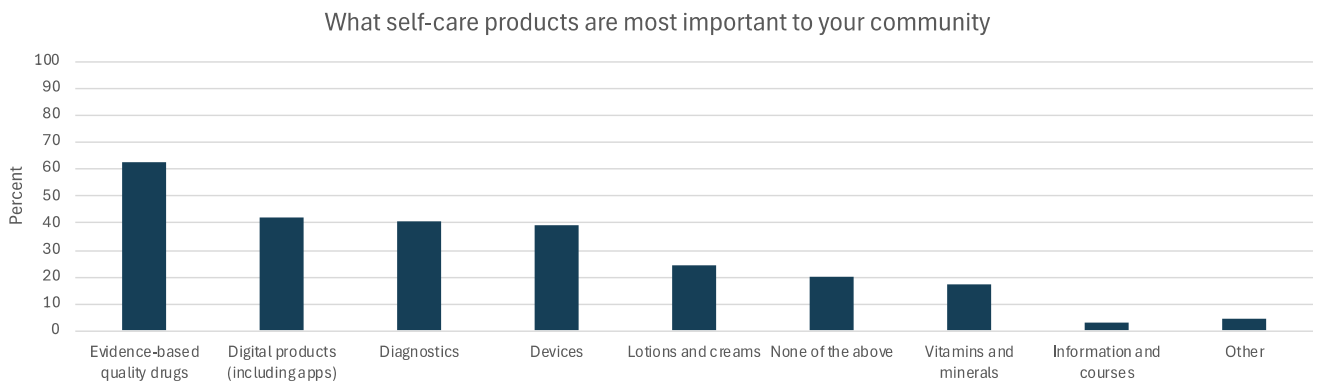| What self-care products are most important to your community	n=69	Percent
Evidence-based quality drugs	43	62.32
Digital products (including apps)	29	42.03
Diagnostics	28	40.58
Devices	27	39.13
Lotions and creams	17	24.64
None of the above	14	20.29
Vitamins and minerals	12	17.39
Information and courses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

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