

Section 9: Information and education

Summary of NPON information and education services

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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

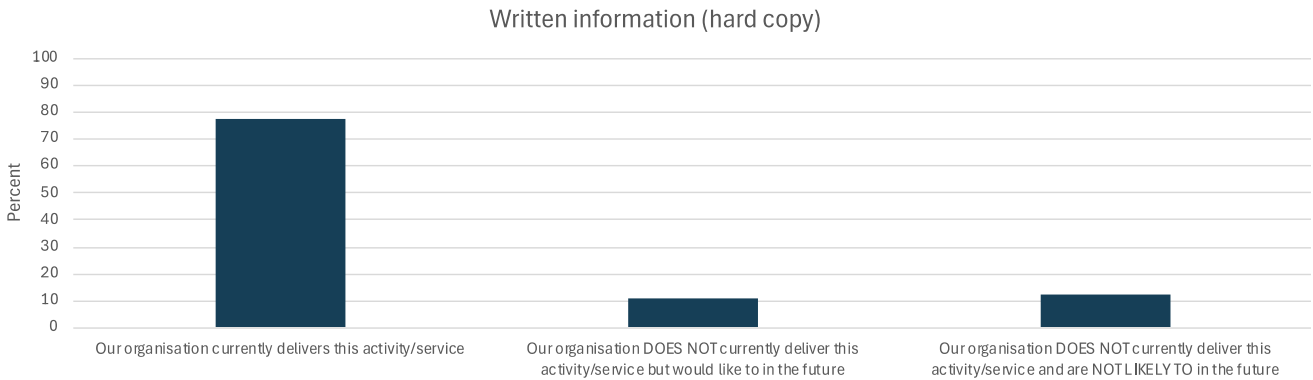


Figure 10.2: Written information (hard copy)

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

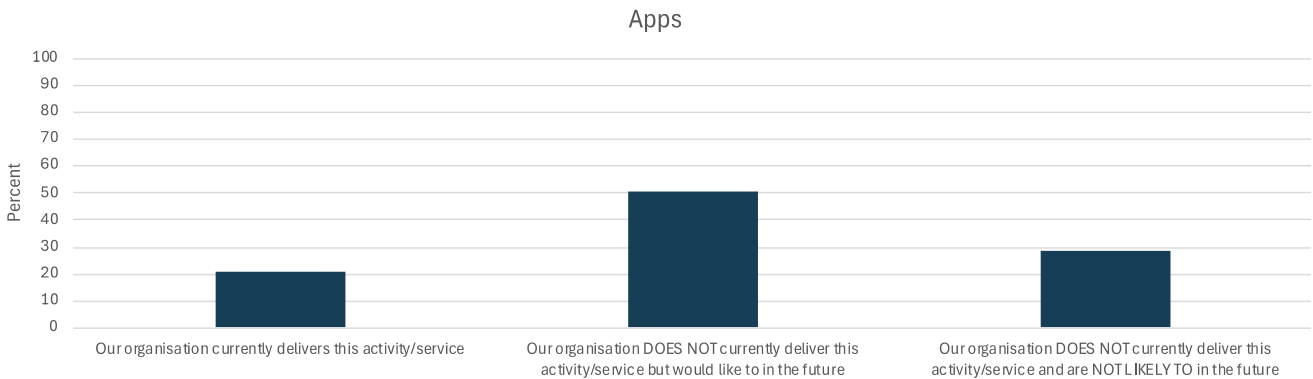


Figure 10.3: Apps

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

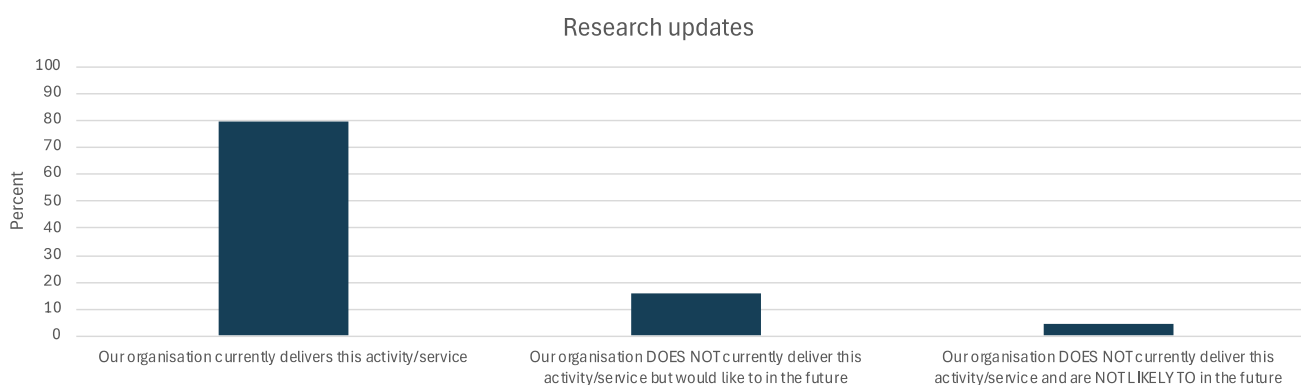


Figure 10.4: Research updates

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

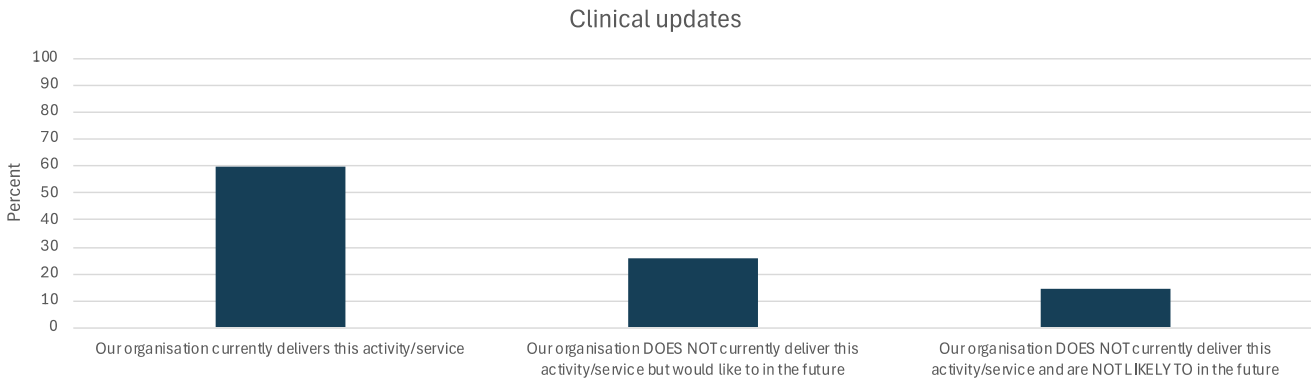


Figure 10.5: Clinical updates

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

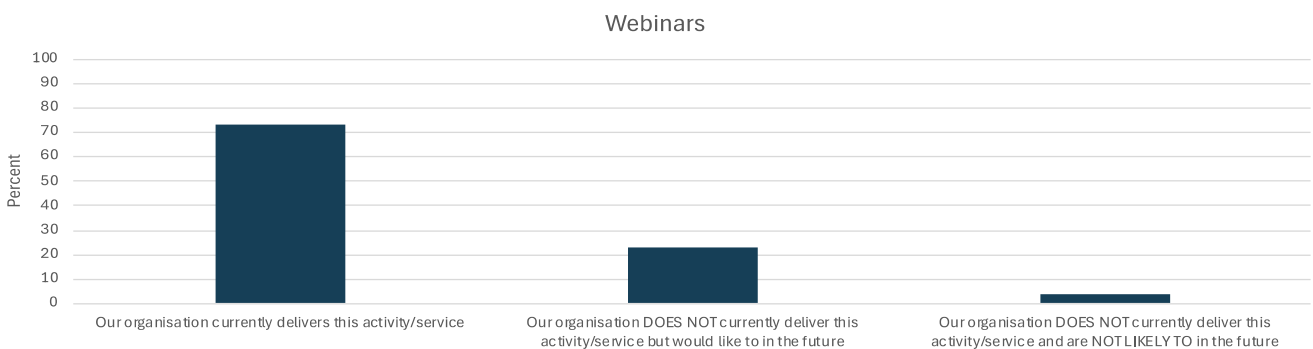


Figure 10.6: Webinars

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

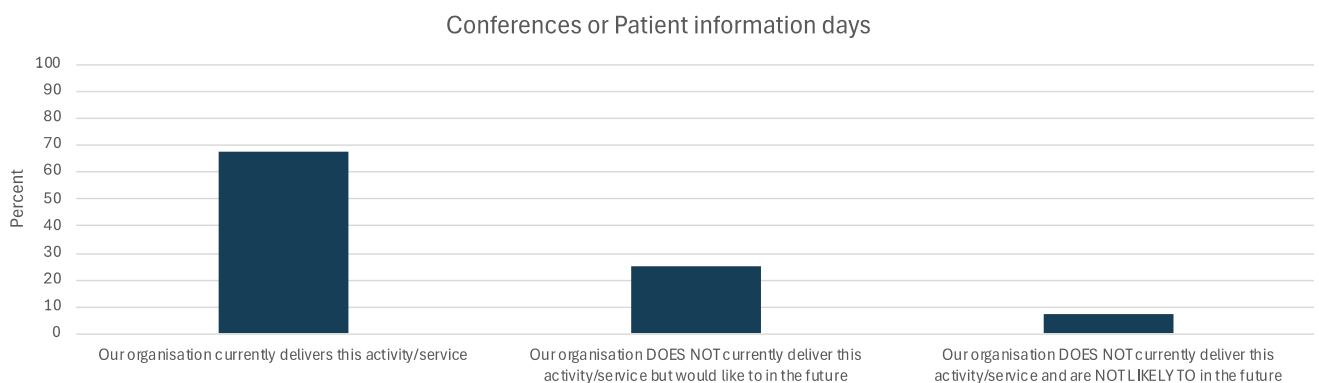


Figure 10.7: Conferences or Patient information days

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

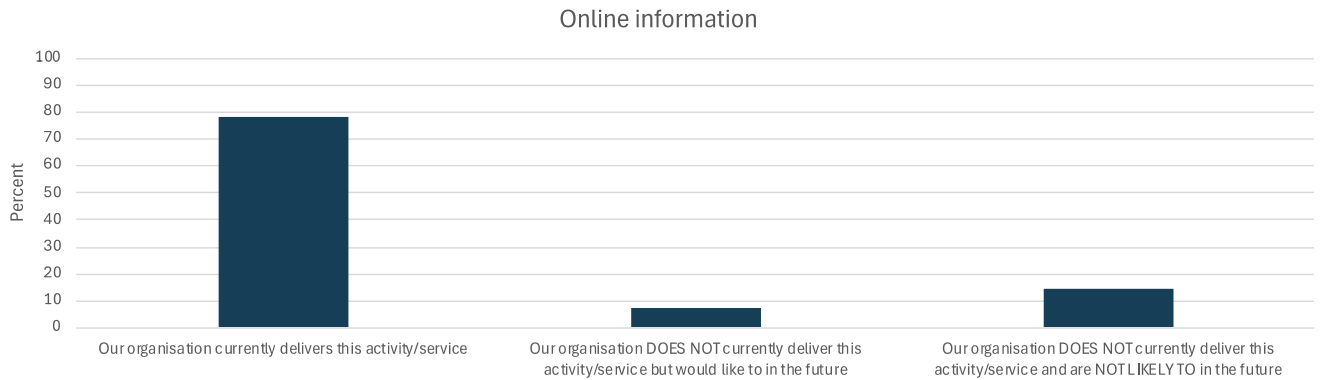


Figure 10.8: Online information

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 providers 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

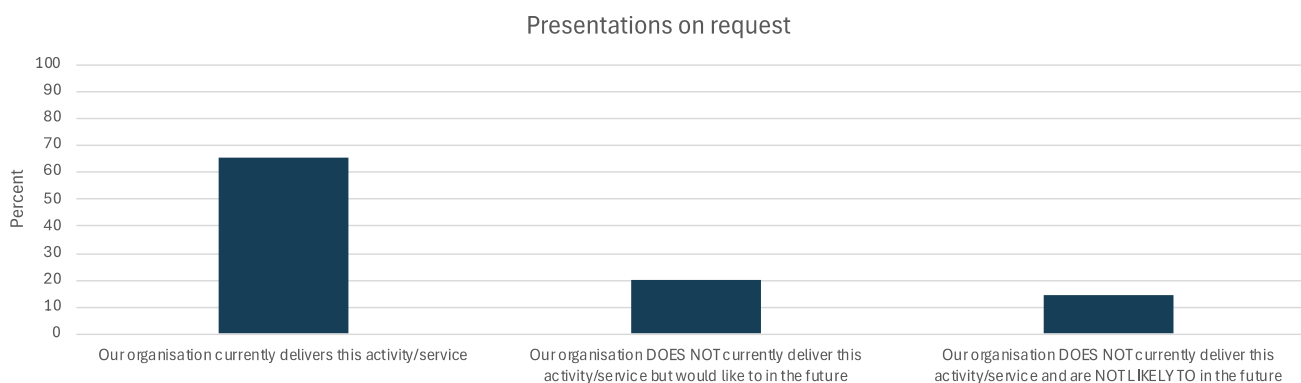


Figure 10.11: Presentations on request

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

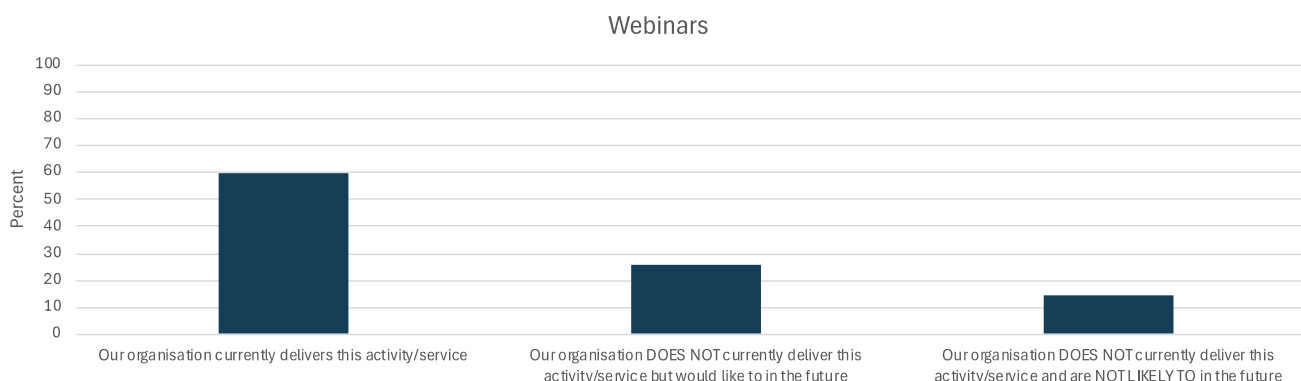


Figure 10.11: Webinars

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 Clinical 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