

Section 11: Clinical trials and research

Summary of clinical trials and research

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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

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

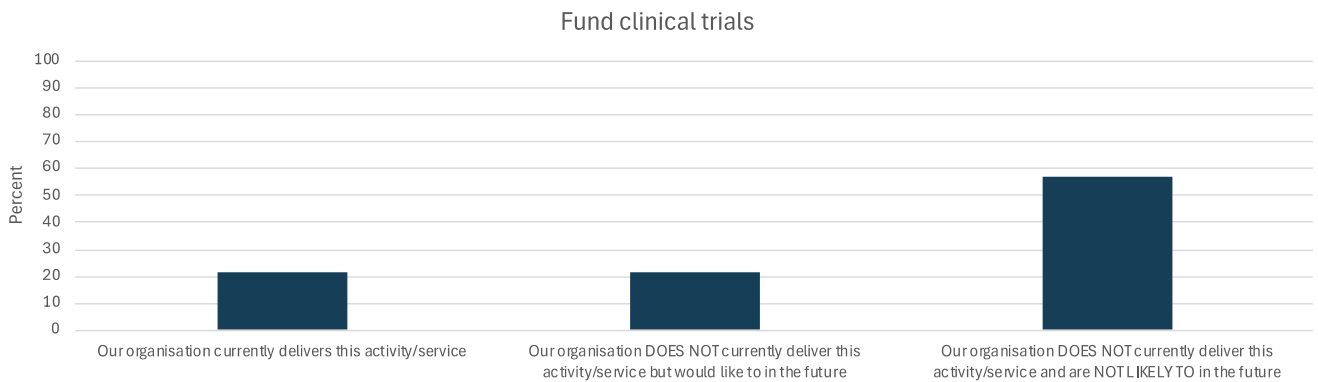


Figure 11.1: Fund clinical trials

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.

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.

NPON organisations comments about directing patients to clinical trials

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

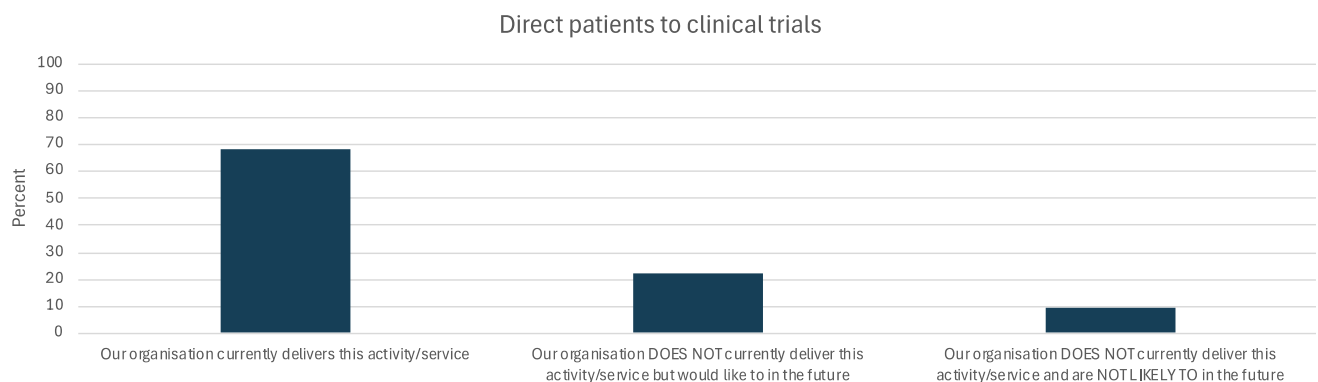


Figure 11.2: Direct patients to clinical trials

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

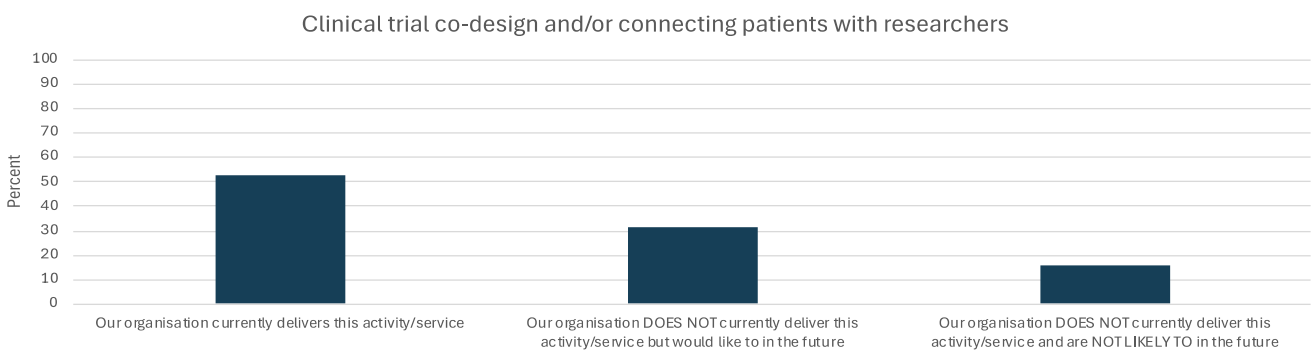


Figure 11.3: Clinical trial co-design and/or connecting patients with researchers

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

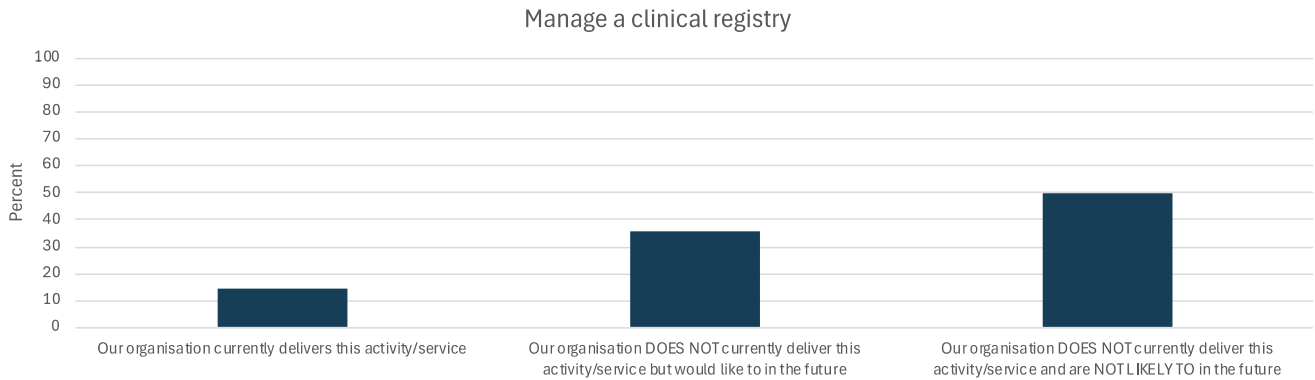


Figure 11.4: Manage a clinical registry

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

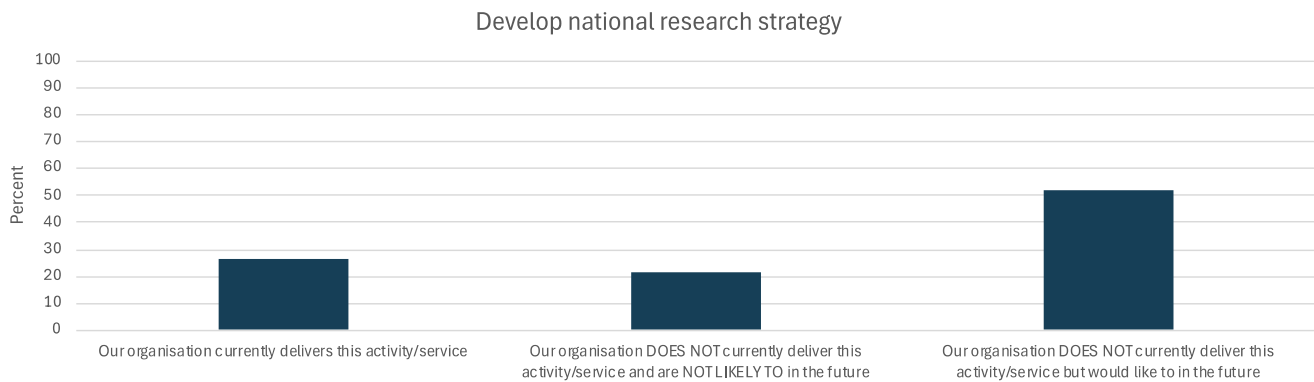


Figure 11.5: Develop national research strategy

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 activities (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

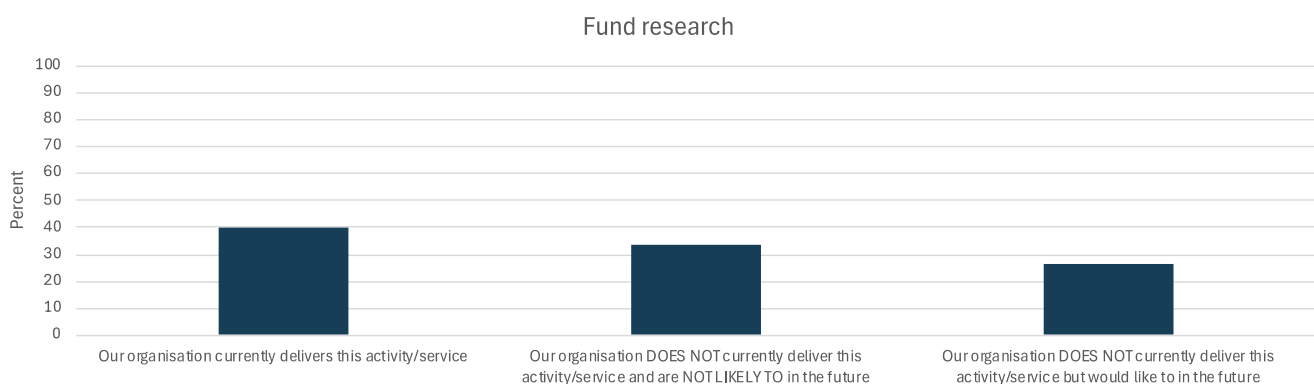


Figure 11.6: Fund research

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

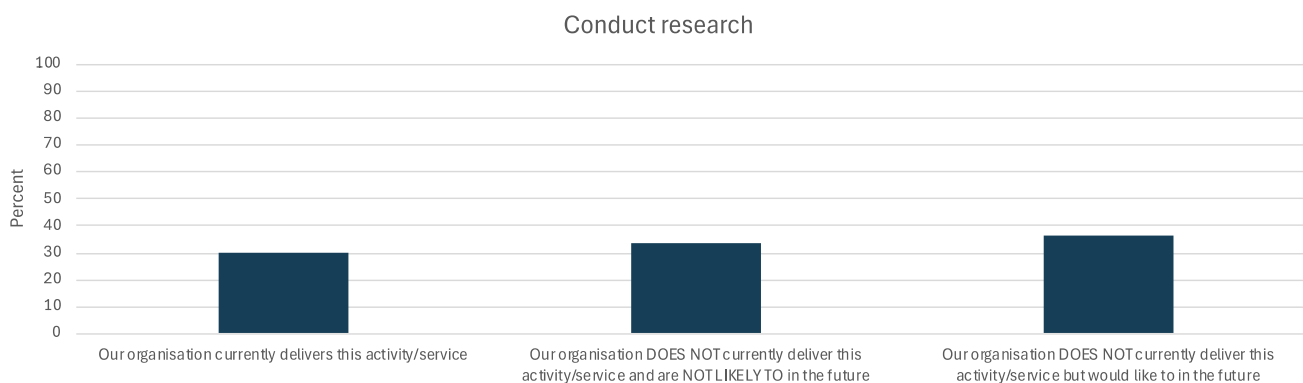


Figure 11.7: Conduct research

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

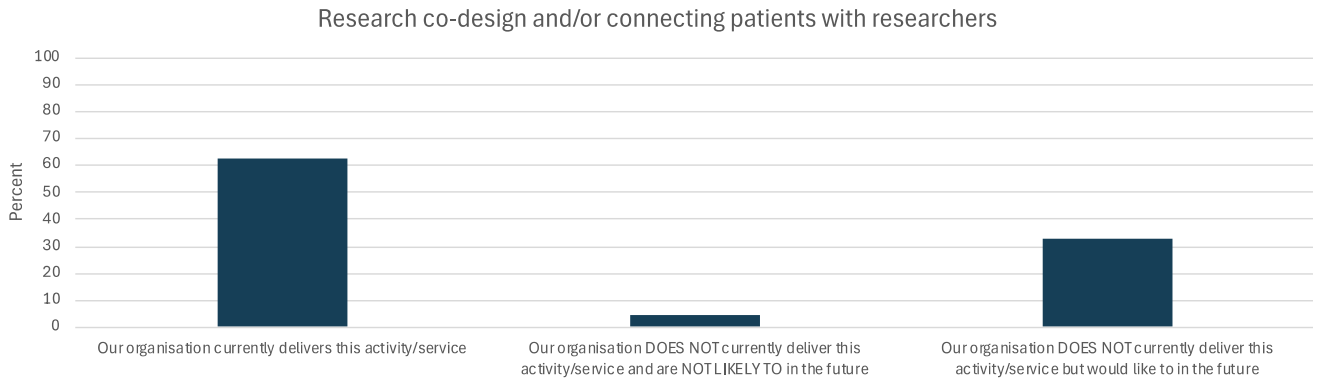


Figure 11.8: Research co-design and/or connecting patients with researchers