

## **Section 6: Advocacy activities**

## Summary of NPON advocacy activities

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

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

NPON organisations described the amount of interaction with the PBAC or other government feedback opportunities. In general, following submission there was very little feedback. Approximately 59% of organisations never or rarely received detailed information on how patient representation was used. About 60% sometimes or rarely received detailed information on the impact of patient representation. Approximately half of the organisations were never invited to provide

additional clarifications after the submission period is closed, and 62% of organisations never or rarely were informed of any new policies, guidelines or reports that patient representation contributed to.

### NPON organisations comments about advocacy activities

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

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

#### NPON advocacy activities

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

#### Submissions or representing patients in government feedback

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

## NPON advocacy activities

### Policy and Senate Inquiries

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

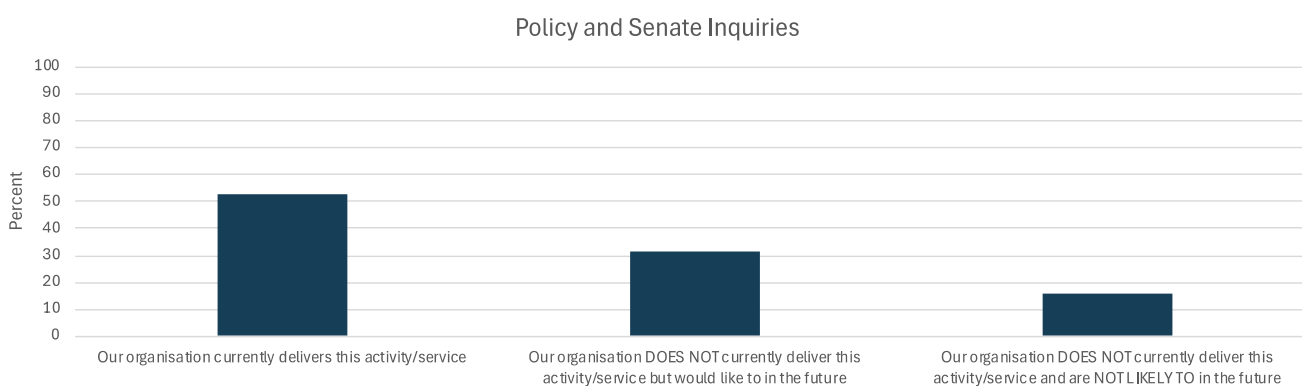
*We are always keen to be involved in submissions and policy updates, but usually have to search for things ourselves, or we chance upon them. It would be great if we were automatically notified or invited to submit. As a small organisation that services the whole country it can be difficult to keep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

### NPON organisations comments about policy and Senate Inquiries

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

**Table 6.1: Policy and Senate Inquiries**

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



**Figure 6.1: Policy and Senate Inquiries**

### PBAC/MSAC submissions & access

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

### NPON organisations comments about PBAC/MSAC submissions & access

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

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

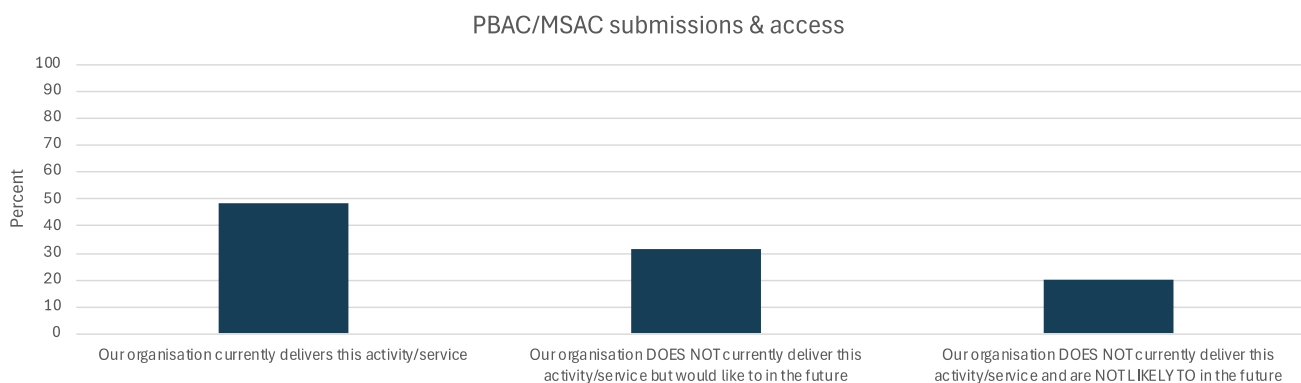
*Leukaemia Foundation supports patient access to emerging therapies and have been active in this space by reaching out to patients for their experiences trialing new medications and therapies. Their experiences are collated as submissions and are provided to regulatory bodies such as the Pharmaceutical Benefits Advisory Committee (PBAC) and Medical Services Advisory Committee (MSAC) to support the*

*recommendation of the new therapy to be listed on the Pharmaceutical Benefits Scheme (PBS) or Medicare Benefits Schedule (MBS).*

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

**Table 6.2: PBAC/MSAC submissions & access**

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



**Figure 6.2: PBAC/MSAC submissions & access**

### Health system/service change

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

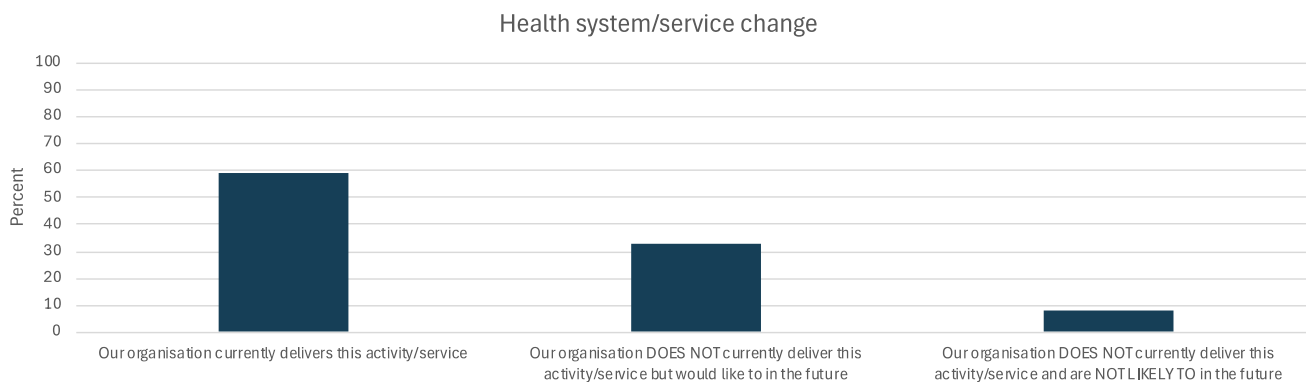
### NPON organisations comments about health system/service change

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

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

**Table 6.3: Health system/service change**

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



**Figure 6.3: Health system/service change**

### Research funding

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

### NPON organisations comments about research funding

*Our main role has been to facilitate research and would like to support clinical trials. Our focus is*

*changing more to the living with the condition to assist our members with their daily activities.*

*We predominantly fund research. Our main challenges are:*

*\* grant applications - not being given feedback to unsuccessful grants*

*\* funding in general - State and Fed government to look favourably at the 'underdogs' in research instead of continually funding the large organisations*

*\* providing patients with information about clinical trials that are being run in Australia are few and far between. We need more availability in Australia.*

**Table 6.4: Research funding**

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



**Figure 6.4: Research funding**

## Access to clinical trials

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

### NPON organisations comments about access to clinical trials

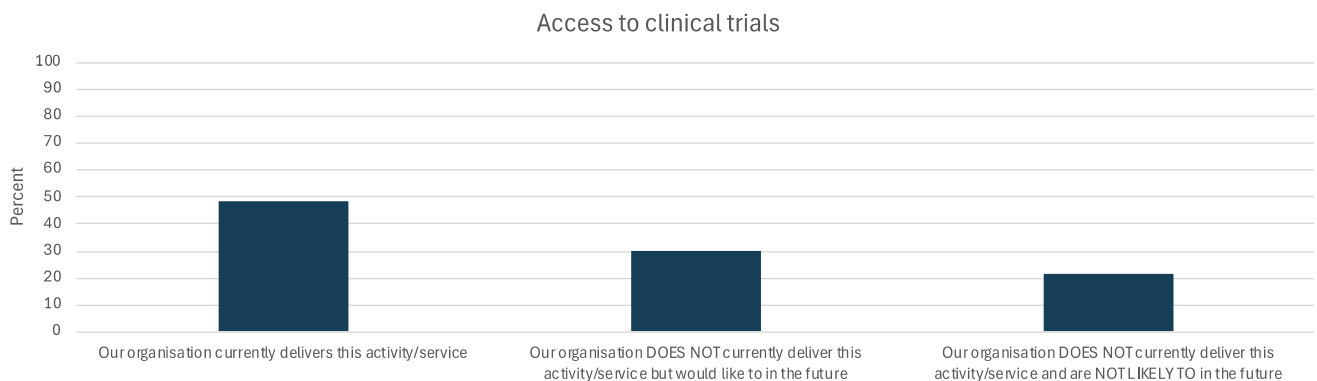
*Limbs 4 Life offers early intervention peer support for people pre or immediately post amputation.*

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

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

**Table 6.5: Access to clinical trials**

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



**Figure 6.5: Access to clinical trials**

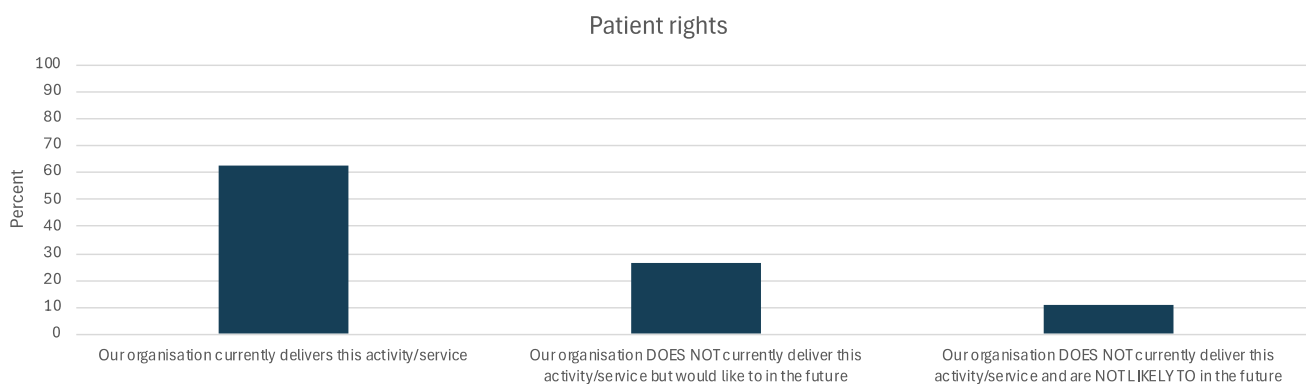
## Patient rights

Almost 63% organisations (n=52, 62.65%) took part in patient right advocacy, and approximately a

quarter (n=22, 26.51%) do not currently offer this but would like to in the future. About 10% of organisations (n=9, 10.84%) do not offer this service and are unlikely to in the future.

**Table 6.6: Patient rights**

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



**Figure 6.6: Patient rights**

### PBAC or submitting feedback to the government

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

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

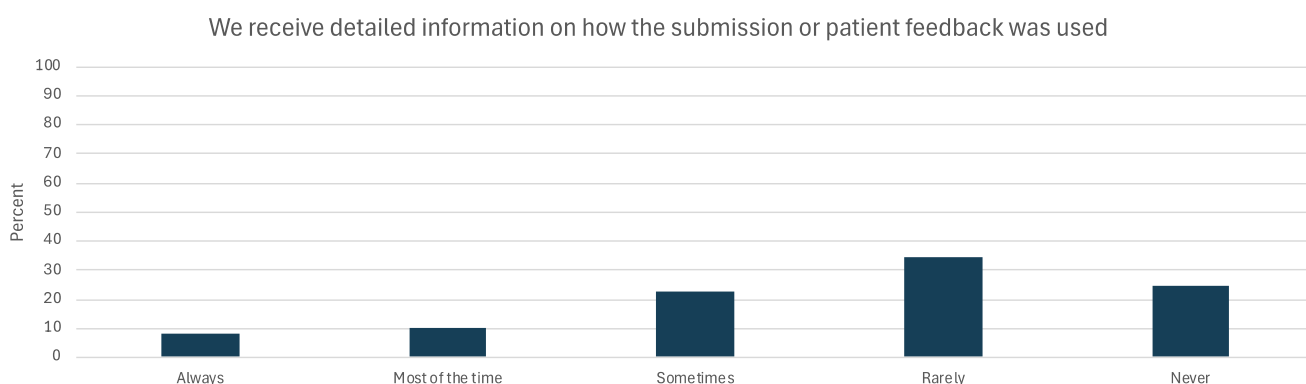
#### NPON organisations comments about receiving detailed information on how the submission or patient feedback was used

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

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

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

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



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

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

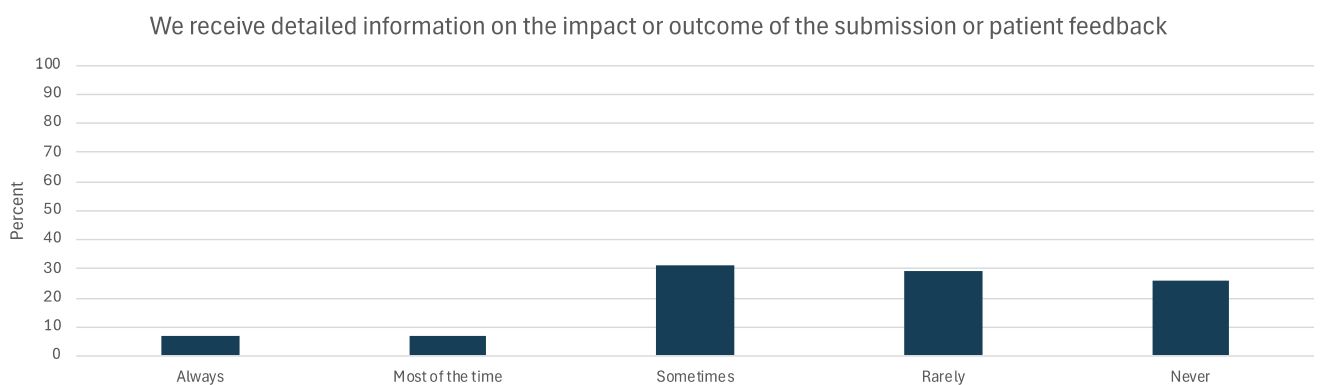
Detailed information about impact or outcomes of the submission or patient feedback was given to 8 organisations always or most of the time (13.11%), given sometimes to 19 organisations (31.15%), and given rarely or never to 34 organisations (55.74%).

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

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

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

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



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

**Invited to provide additional clarifications after the submission period is closed**

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

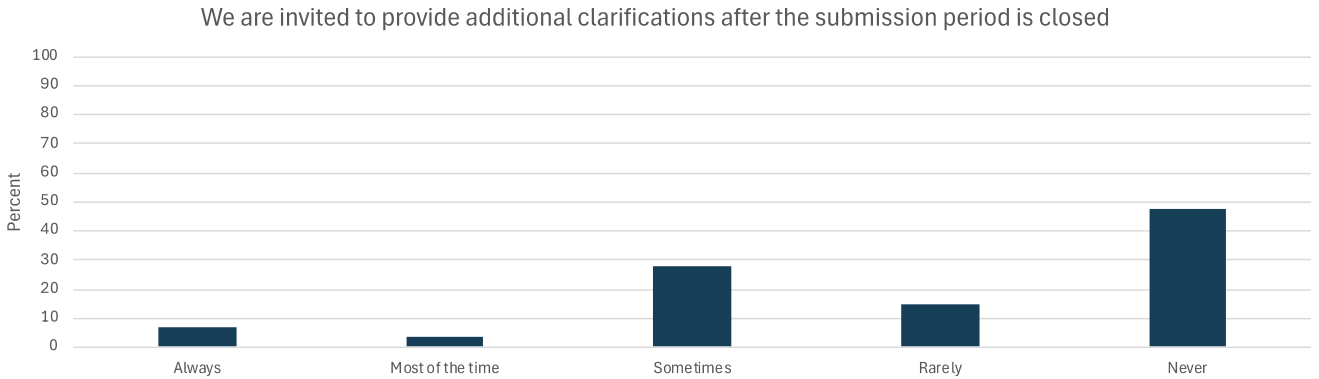
**NPON organisations comments about being invited to provide additional clarifications after the submission period is closed**

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



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

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



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

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

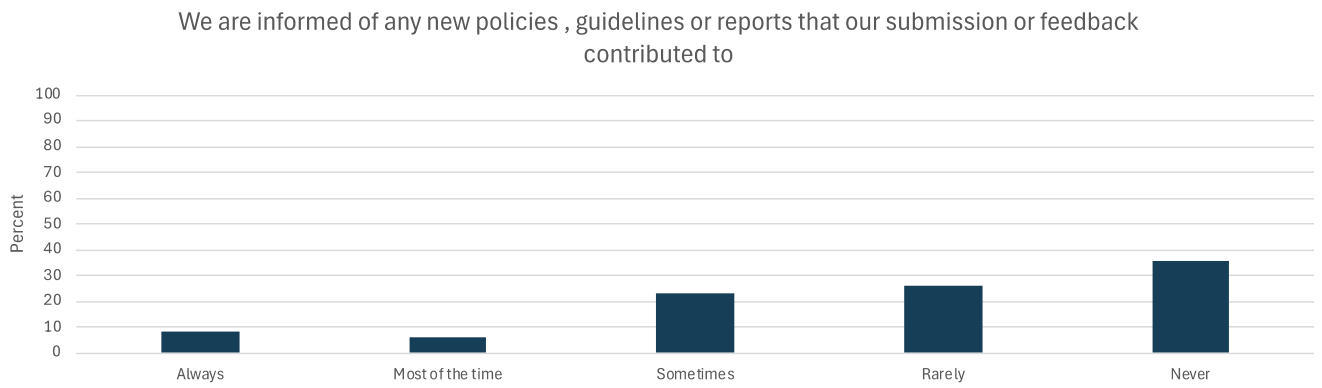
There were 9 organisations (14.75%) that were always or most of the time informed of any new policies, guidelines or reports that our submission or feedback contributed to, while 14 organisations (22.95%) were sometimes informed, and 38 organisations (62.30%) were rarely or never informed.

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

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

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

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



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