

#### **Summary of NPON support services**

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Data was collected from NPON members in 2024 about programs and outreach to regional and rural populations, Aboriginal and Torres Strait Islander, people from a non-English speaking population, low income and/or homeless people, and LGBTQ+ populations,

Outreach programs were most commonly delivered to regional and rural populations (n=22, 26.51%). There were 7 organisations (8.43%) that offered outreach to non-English speaking background populations, 5 organisations (6.02%) that offered outreach to low income and/or homeless populations, and two organisations that each provided outreach to Aboriginal and Torres Strait Islander populations (2.41%), and LGBTQ+ populations (2.41%).

Specific programs were most commonly delivered to regional and rural populations (n=15, 18.07%). There were 8 organisations (9.64%) that offered specific programs for non-English speaking background populations, 3 organisations (3.61%) that offered specific programs for Aboriginal and Torres Strait Islander populations, two organisations that each provided specific programs for low income and/or homeless populations (2.41%), and LGBTQ+ populations (2.41%).

NPON organisations reported that all programs have a component that addresses the following: regional and rural populations (n=36, 43.37%), Aboriginal and Torres Strait Islander populations (n=17, 20.48%), non-English speaking background (n=16, 19.28%), LGBTQ+ populations (n=15, 18.07%), and low income and/or homeless populations (n=14, 16.87%).

### NPON organisations comments about support services

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.

We are in the process of developing a program plan which includes hiring a Health Promotion Officer.

We provide each patient with access to their own Specialist Cancer Navigator for personalised clinical, emotional, financial and practical support throughout their diagnosis, treatment and beyond.

The ATSI population are greatly impacted by T2 diabetes and inturn amputation resulting from this disease. We have been looking into ways that we can assist with greater education and access to information to support those members of our community.

We utilise interpreter services when necessary to ensure that we are able to deliver adequate support and intervention to those who come from a non english speaking background. We are in the process of translating our reading materials and support guides so they are more accessible to those who don't speak English as their first language.

Our services are truly personalised. We have provided letters to government agencies for housing, healthcare cards, etc. If a person has an issue related to their NF then we are willing to support them in whatever is needed. It can be hard for people to explain the impacts of NF so we always aim to provide assistant to low income populations where required.

Regional and rural populations	Low-income and/or homeless populations
27% offer outreach programs	6% offer outreach programs
<ul> <li>18% delivers specific programs</li> </ul>	<ul> <li>2% delivers specific programs</li> </ul>
• 43% all programs have a component that addresses	• 17% all programs have a component that addresses
this population	this population
Aboriginal and Torres Strait Islander populations	LGBTQ+ populations
<ul> <li>2% offer outreach programs</li> </ul>	2% offer outreach programs
<ul> <li>4% delivers specific programs</li> </ul>	<ul> <li>2% delivers specific programs</li> </ul>
• 20% all programs have a component that addresses	18% all programs have a component that addresses
this population	this population
Non-English speaking background populations	
8% offer outreach programs	
<ul> <li>10% delivers specific programs</li> </ul>	
• 19% all programs have a component that addresses	
this population	

#### **Regional and rural populations**

## Regional and rural populations: Outreach programs

There were 22 organisations (26.51%) that offered outreach programs for regional and rural populations, 28 organisations (33.73%), do not offer this at the moment but would like to in the future, and 33 organisations (39.76%) do not offer this and are unlikely to offer it in the future.

## NPON organisations comments about regional and rural populations

We don't have the resources to provide enough of the services we currently provide so we couldn't even contemplate expanding them.

Our regional program is no longer funded.

Breast Health Education programs into regional Australia.

Outreach, peer connection (in person and online) to young breast cancer patients in regional Australia.

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.

Focus group recently conducted on rural and regional people in our community. There is no registry in Australia on hereditary cancer patients so its hard for us to understand where these people are but we do know they have trouble accessing genetic counselling and high risk screening.

### We are currently delivering:

- 1. face-to-face meetings with specialist healthcare professionals in regional/rural locations.
- 2. all brochures/resources are downloadable from our website
- 3. offer a scholarship specific to this audience to our annual patient conferences

Table 13.1: Regional and rural populations: Outreach programs

Outreach programs	n=83	Percent
Our organisation currently delivers specific activities/services for this population	22	26.51
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	28	33.73
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	33	39.76

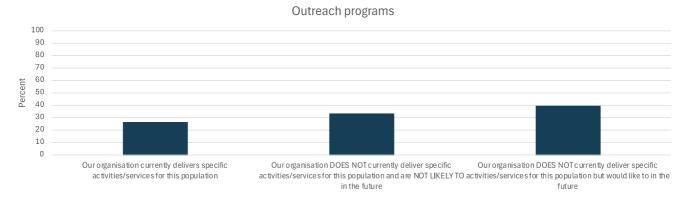


Figure.1: Regional and rural populations: Outreach programs

#### Regional and rural populations: Specific programs

There were 15 organisations (18.07%) that offered specific programs for regional and rural populations, 24 organisations (28.92%), do not offer this at the moment but would like to in the future, and 44 organisations (53.01%) do not offer this and are unlikely to offer it in the future.

# NPON organisations comments about regional and rural populations

Some services are delivered in regional areas however more funding and resources needed to expand and meet the need.

We would like to establish a Telehealth counselling service specific to voice disorders for

rural and remote people. Have submitted for funding unsuccessfully.

Approx 30% of our patients are from Regional/Rural/Remote Australia, we currently do not have specific programs that cater to them but engage with them via telehealth nursing & via our Online Patient/Carer/Grief Support groups (relies on good internet which they may not have)

Awareness and Symptoms brochures to targeted regional/rural areas via community centres and GP clinics.

Rural and regional workforce development programs and forums that bring together organisations and community to focus on identifying and addressing local challenges, issues, opportunities.

Table 13.2: Regional and rural populations: Specific programs

Specific programs for this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	15	18.07
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	24	28.92
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	44	53.01



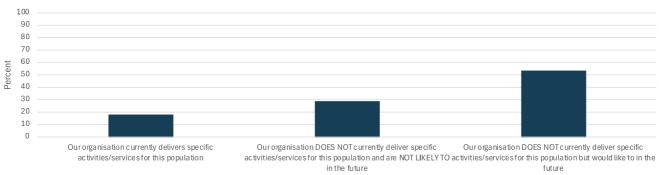


Figure.2: Regional and rural populations: Specific programs

## Regional and rural populations: All programs have a component that addresses this population

There were 36 organisations (43.37%) that offered all programs have a component that addresses regional and rural populations, 17 organisations (20.48%), do not offer this at the moment but would like to in the future, and 30 organisations (36.14%) do not offer this and are unlikely to offer it in the future.

### NPON organisations comments about regional and rural populations

All infirmation we deliver is available to all. We do not deliver physical services.

We serve populations around the country, which includes remote and regional people. As our services are often delivered by phone or online or through email via resources, a significant portion of our work serves these communities, as they are often the least connected to specialist clinical services.

All our Peer to Peer support is offered online and is available to anyone Australia wide. Our annual conference is also offered to everyone Australia wide.

No specific programs directly designed for solely rural and remote but all of our healthcare professional and patient support programs are available to and promoted to people in these locations.

All our programs have digital elements and so are able to be delivered in all locations.

For health professionals we will offer CPD education, guidelines, evidence based content and in-practice programs. These would be run via virtual platforms.

Patient peer support programs and helpline are available to rural and remote individuals as these are phone services.

Kidney bus holiday dialysis service allows people from rural areas to travel and have a holiday.

Table 13.3: Regional and rural populations: All programs have a component that addresses this population

All programs have a component that addresses this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	36	43.37
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	17	20.48
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	30	36.14



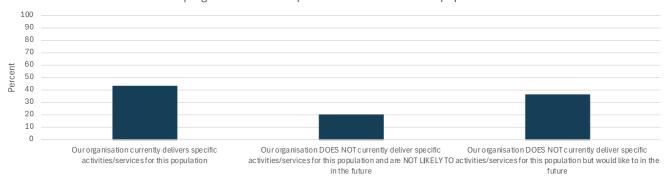


Figure.3: Regional and rural populations: All programs have a component that addresses this population

#### **Aboriginal and Torres Strait Islander populations**

# Aboriginal and Torres Strait Islander populations: Outreach programs

There were 2 organisations (2.41%) that offered outreach programs for Aboriginal and Torres Strait populations, 46 organisations (55.42%), do not offer this at the moment but would like to in the future, and 35 organisations (42.17%) do not offer this and are unlikely to offer it in the future.

# NPON organisations comments about Aboriginal and Torres Strait Islander populations

Support and assistance currently provided to First Nations people with existing programs.

Leukaemia Foundation does have and provides dedicated information and resources for First Nations people.

We would never consider doing this ourselves but definitely work with indigenous communities and indigenous led projects and hope to increase this in the future.

We are developing an education program - The Science Within Us in partnership with an indigenous education organisation for delivery in indigenous communities by indigenous teachers.

Table 13.4: Aboriginal and Torres Strait Islander populations: Outreach programs

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Outreach programs	n=83	Percent
Our organisation currently delivers specific activities/services for this population	2	2.41
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	46	55.42
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	35	42.17

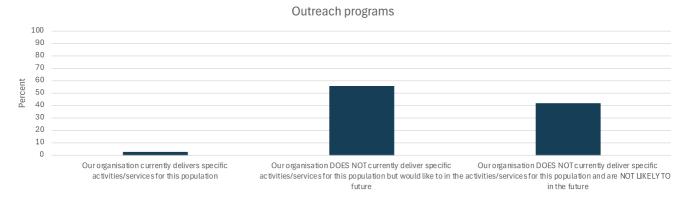


Figure.4: Aboriginal and Torres Strait Islander populations: Outreach programs

# Aboriginal and Torres Strait Islander populations: Specific programs

There were 3 organisations (3.61%) that offered specific programs for Aboriginal and Torres Strait populations, 46 organisations (55.42%), do not offer this at the moment but would like to in the future, and 34 organisations (40.96%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about Aboriginal and Torres Strait Islander populations

Difficult to get engagement from these populations but slowly increasing awareness & trust by having culturally safe care provided by telehealth nurse

Pilot program developed in partnership with ACCHO's to deliver community led health promotion activities in viral hepatitis. Development of resources and materials specifically designed for Community. LiverLine helpline and app

Table 13.5: Aboriginal and Torres Strait Islander populations: Specific programs

Specific programs for this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	3	3.61
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	46	55.42
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	34	40.96

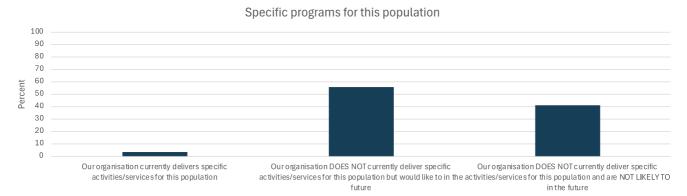


Figure.5: Aboriginal and Torres Strait Islander populations: Specific programs

### Aboriginal and Torres Strait Islander populations: All programs have a component that addresses this population

There were 17 organisations (20.48%) that offered all programs have a component that addresses Aboriginal and Torres Strait populations, 41 organisations (49.40%), do not offer this at the moment but would like to in the future, and 25 organisations (30.12%) do not offer this and are unlikely to offer it in the future.

## NPON organisations comments about Aboriginal and Torres Strait Islander populations

We are actively looking to develop programs specifically for First Nations populations. Currently, we have guidelines, patient and health professional resources available for First nations peoples and all our general programs include components that address first nations kidney health

Table 13.6: Aboriginal and Torres Strait Islander populations: All programs have a component that addresses this population

All programs have a component that addresses this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	17	20.48
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	41	49.40
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	25	30.12

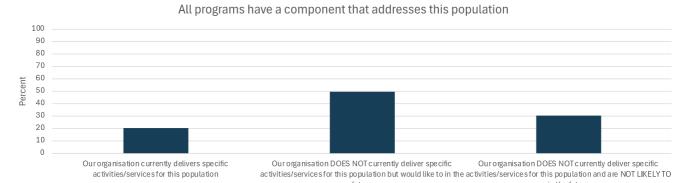


Figure.6: Aboriginal and Torres Strait Islander populations: All programs have a component that addresses this population

#### Non-English speaking background populations

## Non-English speaking background populations: Outreach programs

There were 7 organisations (8.43%) that offered outreach programs for non-English speaking background populations, 35 organisations (42.17%), do not offer this at the moment but would like to in the future, and 41 organisations (49.40%) do not offer this and are unlikely to offer it in the future.

### NPON organisations comments about non-English background populations

Resources, information and events to engage NESB communities and support access to viral hepatitis information, testing and care is developed and distributed. We work in partnership with community leaders and/or community organisations as well as local health units. Many resources provided in language. LiverLine helpline and app.

Table 13.7: Non-English speaking background populations: Outreach programs

Outreach programs	n=83	Percent
Our organisation currently delivers specific activities/services for this population	7	8.43
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	35	42.17
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	41	49.40

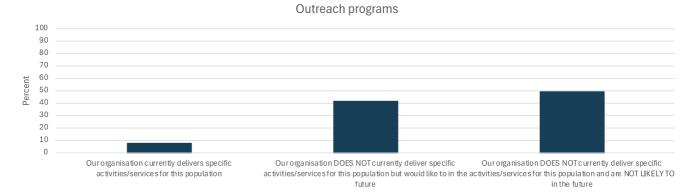


Figure.7: Non-English speaking background populations: Outreach programs

## Non-English speaking background populations: Specific programs

There were 8 organisations (9.64%) that offered specific programs for non-English speaking background populations, 42 organisations (50.60%), do not offer this at the moment but would like to in the future, and 33 organisations (39.76%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about non-English background populations

Funded and supported a project that printed brain tumour information in several different languages.

Our website and online information hub is about to be linked with an inclusion/accessibility tool that will allow readers to access our website and select different languages, text to voice, vision support and many other tools.

Table 13.8: Non-English speaking background populations: Specific programs

Specific programs for this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	8	9.64
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	42	50.60
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	33	39.76



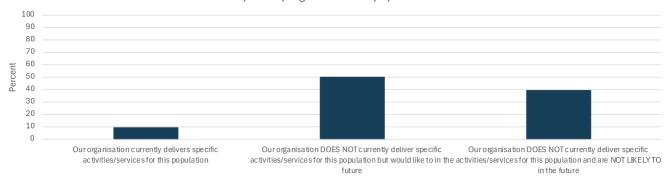


Figure.8: Non-English speaking background populations: Specific programs

Non-English speaking background populations: All programs have a component that addresses this population

There were 16 organisations (19.28%) that offered all programs have a component that addresses non-English speaking background populations, 42 organisations (50.60%), do not offer this at the moment but would like to in the future, and 25 organisations (30.12%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about non-English background populations

Support and assistance currently provided to NESB populations with existing programs and services. Leukaemia Foundation does have numerous resources translated in non-English languages.

The only thing we can offer is for a family from a non-English speaking background who needs information about Fragile X is to offer to engage the TIS service interpreter to assist our Counsellor with the meeting or query.

Table 13.9: Non-English speaking background populations: All programs have a component that addresses this population

All programs have a component that addresses this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	16	19.28
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	42	50.60
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	25	30.12



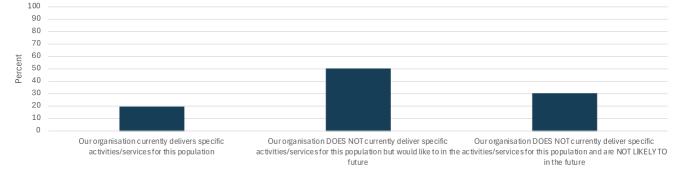


Figure.9: Non-English speaking background populations: All programs have a component that addresses this population

#### Low income and/or homeless populations

### Low income and/or homeless populations: Outreach programs

There were 5 organisations (6.02%) that offered outreach programs for low income and/or homeless populations, 29 organisations (34.94%), do not offer this at the moment but would like to in the future, and 49 organisations (59.04%) do not offer this and are unlikely to offer it in the future.

## NPON organisations comments about low income and/or homeless populations

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

Resources, information and events to engage these communities and support access to viral hepatitis information, testing and care is developed and distributed. We work in partnership with community leaders and/or community organisations as well as local health units. LiverLine helpline and app.

Table 13.10: Low income and/or homeless populations: Outreach programs

Outreach programs	n=83	Percent
Our organisation currently delivers specific activities/services for this population	5	6.02
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	29	34.94
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	49	59.04

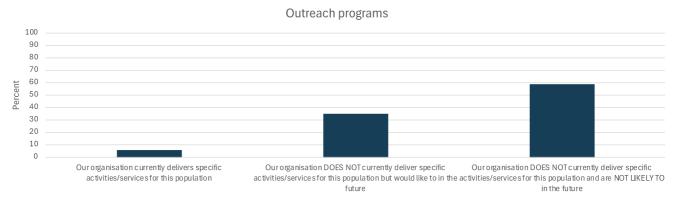


Figure.10: Low income and/or homeless populations: Outreach programs

# Low income and/or homeless populations: Specific programs

There were 2 organisations (2.41%) that offered specific programs for low income and/or homeless populations, 33 organisations (39.76%), do not offer this at the moment but would like to in the future, and 48 organisations (57.83%) do not offer this and are unlikely to offer it in the future.

Rare Cancers Australia provide financial assistance and support to patients including those who come from a low-income population. Rare Cancers Australia understands the impact a cancer diagnosis can have on an individual's financial situation and the associated toxicity of trying to find money to cover your expenses. Our financial support packages are tailored to individuals and can assist with fuel, groceries and utilities, transport and medication costs.

Table 13.11: Low income and/or homeless populations: Specific programs

Specific programs for this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	2	2.41
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	33	39.76
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	48	57.83

Specific programs for this population

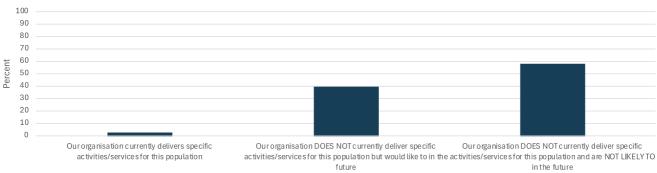


Figure.11: Low income and/or homeless populations: Specific programs

Low income and/or homeless populations: All programs have a component that addresses this population

There were 14 organisations (16.87%) that offered all programs have a component that addresses low income and/or homeless populations, 30 organisations (36.14%), do not offer this at the moment but would like to in the future, and 39 organisations (46.99%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about low income and/or homeless populations

Our services support everyone regardless of socioeconomic backgrounds

Support and assistance currently provided with existing programs and services.

Table 13.12: Low income and/or homeless populations: All programs have a component that addresses this population

All programs have a component that addresses this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	14	16.87
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	30	36.14
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	39	46.99



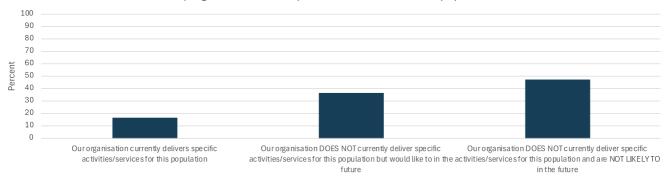


Figure.12: Low income and/or homeless populations: All programs have a component that addresses this population

#### **LGBTQ+ populations**

#### **LGBTQ+ populations: Outreach programs**

There were 2 organisations (2.41%) that offered outreach programs for LGBTQ+ populations, 31 organisations (37.35%), do not offer this at the moment but would like to in the future, and 50 organisations (60.24%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about low income and/or homeless populations

Resources, information and events to engage these communities and support access to viral hepatitis information, testing and care is developed and distributed in partnership with other community and health organisations.

Table 13.13: LGBTQ+ populations: Outreach programs

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Outreach programs	n=83	Percent
Our organisation currently delivers specific activities/services for this population	2	2.41
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	31	37.35
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	50	60.24

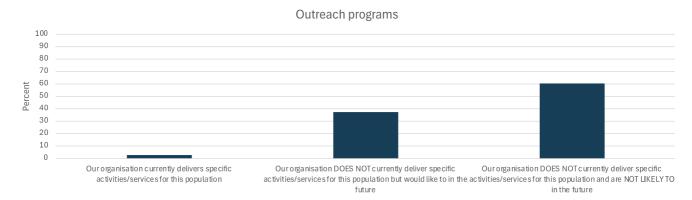


Figure.13: LGBTQ+ populations: Outreach programs

#### **LGBTQ+ populations: Specific programs**

There were 2 organisations (2.41%) that offered specific programs for LGBTQ+ populations, 33 organisations (39.76%), do not offer this at the moment but would like to in the future, and 48 organisations (57.83%) do not offer this and are unlikely to offer it in the future.

NPON organisations comments about low income and/or homeless populations

Focus group recently conducted for this group of people.

Table 13.14: LGBTQ+ populations: Specific programs

Specific programs for this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	2	2.41
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	33	39.76
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	48	57.83

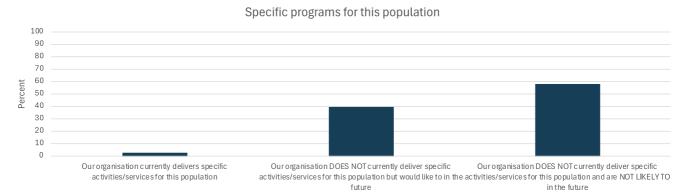


Figure.14: LGBTQ+ populations: Specific programs

# LGBTQ+ populations: All programs have a component that addresses this population

There were 15 organisations (18.07%) that offered all programs have a component that addresses LGBTQ+ populations, 31 organisations (37.35%), do not offer this at the moment but would like to in the future, and 37 organisations (44.58%) do not offer this and are unlikely to offer it in the future.

# NPON organisations comments about low income and/or homeless populations

Our service and support is inclusive of all populations. So we don't have targeted LGBTQ+

programs, but we ensure that ever person with NF feels welcome.

We do not have resources to address this population alone, so we integrate this into most programs or work specifically with a client to ensure we provide culturally appropriate support.

We do not currently have programs specifically for this audience but do include some general information within standard programs. We are trying to ensure that all our materials are appropriate and inclusive.

Table 13.15: LGBTQ+ populations: All programs have a component that addresses this population

All programs have a component that addresses this population	n=83	Percent
Our organisation currently delivers specific activities/services for this population	15	18.07
Our organisation DOES NOT currently deliver specific activities/services for this population but would like to in the future	31	37.35
Our organisation DOES NOT currently deliver specific activities/services for this population and are NOT LIKELY TO in the future	37	44.58



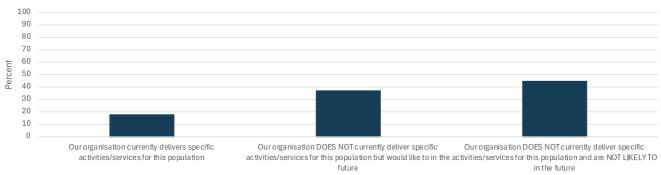


Figure.15: LGBTQ+ populations: All programs have a component that addresses this population