Strengthening the Capacity and Capability of the
Rare, Genetic and Undiagnosed
Conditions Sector in WA

Gap Analysis Report and Recommendations

Ensuring long term sustainability of the Rare, Genetic, and Undiagnosed Conditions Sector in WA

June 24, 2021

Strengthening the Capacity and Capability of the
Rare, Genetic and Undiagnosed
Conditions Sector in WA

ConnectGroups
helping support groups & individuals

Contents

1. Executive Summary

ConnectGroups Support Groups Association WA Inc. (peak body for Peer Support Groups in WA) was engaged in January 2021 by the Department of Health's Office of Population Health Genomics (OPHG) to inform the Department as to the capacity and capabilities of the Rare, Genetic, and Undiagnosed Conditions Non-Governmental Organisation (NGO) Sector, the actions required to ensure its long-term sustainability, and to provide the relevant recommendations for future action. To this effect, ConnectGroups established an effective and accessible consultation process to enable all Groups to provide input across multiple platforms, including a digital survey tool, written surveys, alongside virtual and face-to-face Consultations. For the purposes of the Report, 'Groups' are defined as Peer Support Groups, small community-based organisations, and NGOs.

Capacity is defined as *the extent to which a Group or sector can support those living with a Rare, Genetic, or Undiagnosed condition and their families; how many people it can support, how frequently it can provide such support and for how long this support is sustainable given its current resources, including funding, staff, and volunteers*.

Most Groups in the Sector experience limitations in the number and range of support services they can provide in Western Australia (WA) as well as in the number of people they can support. These gaps in capacity are largely due to staffing, volunteer, and funding constraints, alongside a lack of accessible training which has a significant, but notably smaller impact. Support services were also markedly reduced in regional, rural, and remote areas, the primary cause of service delivery gaps in these areas were limitations in resources (including funding, staff, and volunteers), ability to respond to local demand, digital skills, and public awareness of Groups.

Capabilities are defined as *the nature and quality of the services a Peer Support Group, NGO, or sector can provide; an assessment of the programs, systems, skills, and knowledge available that can be leveraged to support those living with a Rare, Genetic, or Undiagnosed condition and their families*.

The main limitations in the capabilities of this Sector are related to its ability to raise awareness of the condition(s) and deliver in-person meetings, peer support, education and advocacy. A majority of Groups also experienced difficulty in minimising turnover of volunteers, who account for a significant part of the Sector's workforce.

Groups also identified gaps within the Health System that affect their capacity and capabilities. The lack of awareness of each Rare condition among medical professionals, the lack of recognition and support for conditions across the system, and resource constraints (including funding, staff, and volunteers) were identified as relevant shortfalls.

While these gaps affect many Groups in their Sector regardless of size, the Report illustrates that small Groups, including peer Support Groups, are disproportionately affected by shortcomings in capabilities and capacity. In view of these capabilities and capacity gaps, and on behalf of the Sector, the Report provides eight (8) key Recommendations:

<u>Recommendation 1:</u> *Establish a WA-based Centralised Model for the service delivery, quality control, and oversight of the Rare, Genetic, and Undiagnosed conditions Sector.*

<u>Recommendation 2:</u> *Provide a sustainable, open, and equitable Grants Program that has the capacity to increase over time so that new Groups can be supported as they arise.*

<u>Recommendation 3:</u> *Promote awareness of Groups and of the Rare, Genetic, and Undiagnosed Conditions that they target among individuals with these Conditions, medical professionals, Health Care Providers, and the general public.*

Recommendation 4: *Influence improvement in the quality of care that health professionals provide to individuals with Rare, Genetic, and Undiagnosed conditions.*

Recommendation 5: *Establish a specialised Training and Development Program to promote self-sufficiency within the Sector.*

Recommendation 6: *Identify adequate resourcing to meet the demands for service delivery in regional, rural, and remote areas of WA.*

Recommendation 7: *Influence the inclusion of Rare and Undiagnosed conditions in the National Disability Insurance Scheme (NDIS) model.*

Recommendation 8: *Undertake a holistic and culturally safe approach of investigation and action to ensure that the needs of First Nations Australians who have Rare, Genetic, or Undiagnosed conditions are met.*

2. Background

The project was titled *"Strengthening the Capacity and Capability of the Rare, Genetic and Undiagnosed Conditions Sector in WA"* to communicate the WA Health Department's outcome of *"determining the capacity and capabilities of the NGO sector in WA that look to support those in the community living with Rare, Genetic and Undiagnosed conditions and their families, what are the capability gaps and identifying what ongoing training and support is needed to help address the current gaps in service"*. To achieve this measurable outcome, an initial environmental scan was conducted across a four-month period in consultation with the Office of Population Health Genomics (OPHG) *(Report 1- Capacity and Capabilities)*.

275 Groups were invited to participate in the environmental scan, of which 50 completed the full survey. 98% of these respondents represented Genetic conditions, 70% represented Rare conditions, and just 2% represented Undiagnosed conditions. 20% of the Groups indicated that their services extended to Aboriginal and Torres Strait Islander peoples or Culturally and Linguistically Diverse populations, however culturally-appropriate services were not apparent and only 2 Groups delivered culturally-secure information to their members.

Key findings of the environmental scan indicated that the Sector could support more people if required to *(82% of Groups had this capacity)*. However, they did not have the capacity to increase the frequency of support services *(with just 36% of Groups reporting this capacity)* or have the capacity to service those in regional, rural, and remote areas *(43% did not service remote areas at all)*. The environmental scan did not assess limitations in the range of services that the Sector could deliver. Instead, this topic was a subject of subsequent Gap Analysis, and is described in the present Report.

The most common capabilities of Groups in the Sector (*'email support', 'raising awareness', 'Zooms', 'Facebook group', 'peer support',* and '*information for members'*) were oriented towards the delivery of support, information, and advocacy both to and on behalf of individuals accessing their services. Additional key capabilities of Groups in the Sector- ('*staff training'* and *'minimisation of volunteer turnover'*) were intended to maintain and improve their current service delivery and to ensure their long-term sustainability. These capabilities reflected the objectives of Groups within the Sector well, and were represented in a diagram, seen below *(Figure 1)*.

Figure 1: **Main capabilities identified by environmental scan**

Objective: "Support members and improve their quality of life"

CAPABILITY CATEGORY 1:
Support

- Peer support:
  - *Email*
  - *Zooms*
  - *Facebook group*
  - *Mentoring*
  - *Connecting families*
- Practical, financial, and medical support
- Information and advocacy

Objective: "Educate the general public and members"

CAPABILITY CATEGORY 2:
Information

- Condition information
- Health system information
- Education of general public
- Delivery through:
  - *Website*
  - *Email*
  - *Facebook group*
  - *Conferences*
  - *Newsletters*

Objective: "To advocate for and empower members"

CAPABILITY CATEGORY 3:
Advocacy

- Public awareness promotion
- Advocacy to government and the health system
- Research
  - *Participation*
  - *Promotion*
- Patient registries that can be used in research

Figure 1 (continued): **Main capabilities identified by environmental scan**

CAPABILITY CATEGORY 4:

Maintenance and improvement of current service delivery to ensure long-term sustainability

- **Strategies to retain volunteers:** *respect, personal engagement, involvement in decisions, positive expectations and positive feedback*
- **Training for staff and volunteers:** *Zoom, Facebook group management, in-person meetings, peer support, public relations and social media*

The findings of the environmental scan provided a fundamental understanding of the Sector and were used as a framework during subsequent gap analysis to better understand the Sector's limitations in capacity and capabilities. The findings of the gap analysis are described in this Report, in alignment with the OPHG outcome of recognising *"capability gaps"* and *"identifying… ongoing training and support (that) is needed for the WA NGO sector that support those living with Rare, Genetic and Undiagnosed conditions to help address the current gaps in service."*

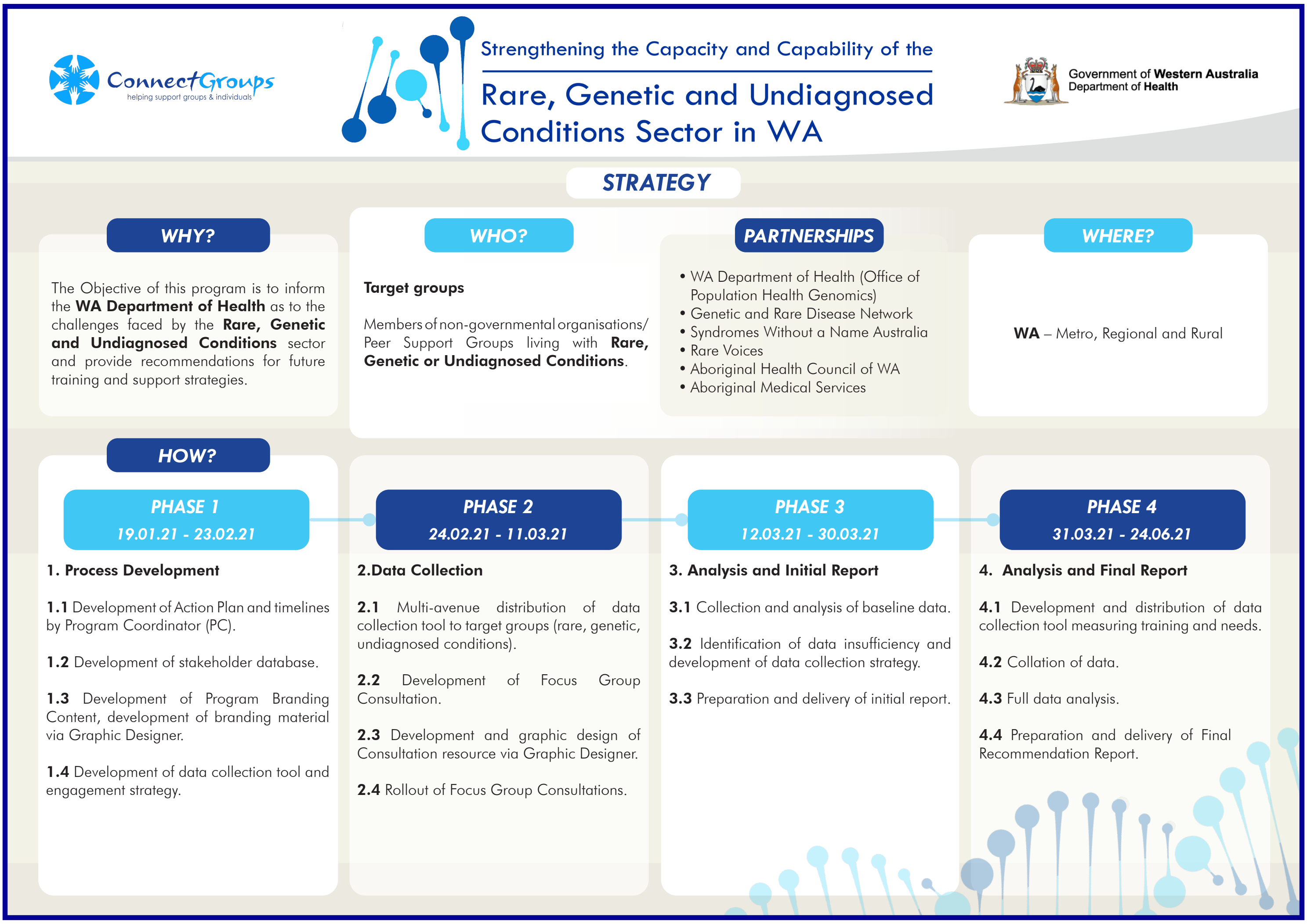
It needs to be noted that concurrently, the OPHG also engaged Social Ventures Australia (SVA) to consult the Sector in the co-design of a System Navigation Service pilot. The program recognised that many individuals who live with Rare, Genetic, and Undiagnosed conditions did not have access to system navigation support services and this program was considered synergistic to ConnectGroups' scope.

3. Methodology

A strategy *(Figure 2*, page 7*)* was created to outline the project's parameters and to ensure the program itself was clearly understood by all stakeholders. This tool was referred to throughout the Program but was considered flexible to the development of stakeholder needs.

The methodology of this project had a consistent and intentional focus on consultation, grass-roots level discussion, and the opportunity for Groups to engage at different levels depending on their requirements, abilities, and available time. The Report drew on data from an online survey of the Sector, Virtual Sector Consultations, and a face-to-face Sector Consultation. These data collection tools were designed and operated in close collaboration with representatives from the OPHG. The resultant dataset was an amalgamation of qualitative and quantitative components, and this multifaceted approach was reflected in the data analysis.

Figure 2: **Project Strategy**



ConnectGroups
helping support groups & individuals

Strengthening the Capacity and Capability of the
Rare, Genetic and Undiagnosed Conditions Sector in WA

Government of **Western Australia**
Department of **Health**

STRATEGY

WHY?

The Objective of this program is to inform the **WA Department of Health** as to the challenges faced by the **Rare, Genetic and Undiagnosed Conditions** sector and provide recommendations for future training and support strategies.

WHO?

Target groups

Members of non-governmental organisations/ Peer Support Groups living with **Rare, Genetic or Undiagnosed Conditions**.

PARTNERSHIPS

- WA Department of Health (Office of Population Health Genomics)
- Genetic and Rare Disease Network
- Syndromes Without a Name Australia
- Rare Voices
- Aboriginal Health Council of WA
- Aboriginal Medical Services

WHERE?

WA – Metro, Regional and Rural

HOW?

PHASE 1
19.01.21 - 23.02.21

1. Process Development

1.1 Development of Action Plan and timelines by Program Coordinator (PC).

1.2 Development of stakeholder database.

1.3 Development of Program Branding Content, development of branding material via Graphic Designer.

1.4 Development of data collection tool and engagement strategy.

PHASE 2
24.02.21 - 11.03.21

2.Data Collection

2.1 Multi-avenue distribution of data collection tool to target groups (rare, genetic, undiagnosed conditions).

2.2 Development of Focus Group Consultation.

2.3 Development and graphic design of Consultation resource via Graphic Designer.

2.4 Rollout of Focus Group Consultations.

PHASE 3
12.03.21 - 30.03.21

3. Analysis and Initial Report

3.1 Collection and analysis of baseline data.

3.2 Identification of data insufficiency and development of data collection strategy.

3.3 Preparation and delivery of initial report.

PHASE 4
31.03.21 - 24.06.21

4. Analysis and Final Report

4.1 Development and distribution of data collection tool measuring training and needs.

4.2 Collation of data.

4.3 Full data analysis.

4.4 Preparation and delivery of Final Recommendation Report.

4. Findings

This section provides a thorough and detailed analysis of the data gathered throughout the course of the project.

4.1 Summary of Key Gaps in Capacity and Capabilities

4.1.1 Capacity Gaps

Gap analysis indicated capacity limitations in the number and range of services that Groups can provide in WA, particularly in regional, rural, and remote WA. 78% of Groups wish to provide more services in WA than they are currently able to. The primary factors contributing to these capacity constraints are a lack of volunteers or staff (91% of Groups), a lack of funding (85% of Groups), and a lack of skills or training (26% of Groups). Another significant issue was the geography of WA.

91% of Groups lack staff or volunteers	**26%** of Groups lack skills/training
85% of Groups lack funding	

4.1.2 Groups' ability to meet set measurable outcomes

78% of Groups were successful in achieving some of their intended measurable outcomes, while the rest reported success in achieving all their intended measurable outcomes. High quality organisational strategies and management, strong demand, and sufficient resources contributed to the success of these Groups. Poor organisation strategies and management, limitations due to the rarity of conditions, insufficient resources (including funding, staff, and volunteers), COVID-19, and systemic barriers (e.g. lack of government support and recognition of the value of Groups) emerged as preventative factors to success. Most Group leaders were concerned with the capacity of their Sector.

4.1.3 Capabilities Gaps

Capabilities gaps were also identified, mainly in raising awareness (60% of Groups wanted to deliver this service) and delivering in-person meetings (54% of Groups), peer support (51% of Groups), education of Group members and Health professionals (49% of Groups), and systemic advocacy to government (45% of Groups). These services are predominantly oriented towards improving the quality of life of individual Group members. Most Groups experienced difficulty when attempting to minimise turnover of volunteers, with 86% of the Groups relying on their volunteers to deliver services.

4.1.4 System Gaps

Gaps in the health system were also identified, and comprised limited awareness and understanding of the Groups, their services and the conditions they target, lack of condition-specific support or recognition (including through the NDIS), lack of information provided by health professionals including at time of diagnosis, and insufficient funding directed towards treatment of Rare, Genetic, and Undiagnosed conditions. Groups wanted increased awareness and support from health organisations to advocate for specific conditions and to collaborate and link with healthcare providers.

4.1.5 Ongoing Funding and Training Needs

One third of Groups (32%) did not receive any funding. Of those that did receive funding, the most common sources of funding were community fundraisers of donations (82%) and grants (71%). Primary funding needs were identified around operational expenses (61% of Groups required funding in this area), administrative support (51% of Groups), development of resources (44% of Groups- *e.g. information booklet*), education (44% of Groups), and website upkeep or design (42% of Groups).

One quarter of Groups indicated that they needed funding for volunteer training and that increased training would allow them to deliver more services and supports in WA. Popular training needs included preparation of grant applications (63% of Groups indicated interest), engaging stakeholders (57% of Groups), governing (50% of Groups), raising awareness (48% of Groups), and connecting individuals with systems (45% of Groups).

4.1.6 Recommendations

Identification of these gaps and further grass-roots level consultation on strategic solutions lead to the emergence of eight (8) evidence-based Recommendations. The detail of these is provided in Section 5.

All the Recommendations brought forward in the Report were derived from qualitative and quantitative data gathered at a grass-roots level. Broadly, the Recommendations speak to a WA-based Centralised Model, a Grants Program, awareness promotion, the quality of care provided by health professionals, a specialised Training and Development Program for the Sector, strategies to address the drop-off in support services in regional, rural, and remote areas, inclusion in the NDIS model, and the needs of First Nations Australians.

The following data analysis reveals a strong, vibrant, and growing Sector with key limitations in funding, specialised training, and public awareness, and the need for a high-quality centralised system to address these gaps. Group leaders have contributed a significant amount of their limited time to this project and in many cases have demonstrated an eagerness to share more. They look forward to seeing the outcomes of this and other projects in which they have participated, and to this effect infographic dashboards have been included as Appendices to the present the Report (Appendices 2-4). With the right support, the Rare, Genetic, and Undiagnosed Conditions NGO Sector will continue to thrive in WA and could become an international model that leads the way in its management and support of those living with all Rare, Genetic, and Undiagnosed conditions and their families.

4.2 Data Analysis

This Section summarises the data collected from the following avenues: 1) online survey of Groups; 2) online Sector Consultations; and 3) face-to-face Sector Consultations.

4.2.1 Group characteristics

Among the Groups that responded to the online survey:
- 98% targeted Genetic Conditions, 70% Rare Conditions and 2% Undiagnosed Conditions
- 66% operated nationally, with 16% operating locally / state-wide only
- 71% received funding of some kind, 29% received no funding at all
- 67% were primarily volunteer-based, with a further 22% partly volunteer-based
- 93% had a primary objective of *"supporting members and improving their quality of life"*

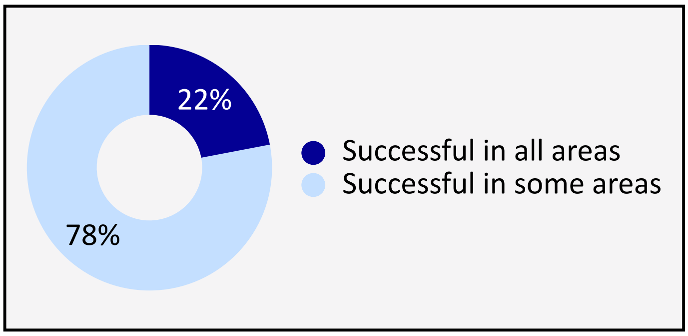
Among the 12 Group representatives that attended virtual Sector Consultations:
- 100% targeted Genetic Conditions, 75% Rare Conditions and 0% Undiagnosed Conditions
- 70% operated nationally, with 20% operating locally / state-wide only

Among the 13 Group representatives that attended the Face-to-face Sector Consultation:
- 100% targeted Genetic Conditions, 85% Rare Conditions and 0% Undiagnosed Conditions
- 50% operated nationally, with 50% operating locally / state-wide only

4.2.2 Groups' ability to meet set measurable outcomes

Respondents were asked to assess how successful their Groups had been in achieving their individual service delivery objectives.

No Groups indicated that they were *"not at all successful"*, 78% of Groups indicated that they were *"successful in some areas but not others"*, and 22% indicated that they were *"successful in all areas"*.



Subsequently, each respondent was asked to reflect on why their Group had achieved the level of success that it had. Due to the varying levels of success in the Sector, some respondents explained factors that limited Group success, while other respondents explained factors that enabled Group success.

> *"From the very start we have personally engaged with our members (by) listening to their feedback and stories."*

> *"We are a small organisation with no government funding (so) some of our objectives that can have the greatest impact… can be difficult to achieve."*

Qualitative analysis was conducted on these responses, and the following themes were identified:

Table 1: **Qualitative themes pertaining to reasons for success**

Organisational strategies and management

Groups that experienced high levels of success credited the quality of their Group's management as the main reason, specifically citing their:

- Use of peer support
- Leverage of partnerships *(e.g. other Groups, Government, medical professionals, and researchers)*
- Adaptability of Group
- Experience of Group
- Group knowledge, expertise, and passion
- Clear, achievable goals
- Capacity to listen to members

Resources

Group success was enhanced by sufficient resources, including:

- Motivated and skilled staff and volunteers
- Sufficient funding levels
- Funds that allow them to offer affordable membership to individuals

Strong demand

Other Groups credited their success to the significant demand for their services. In some cases, this demand for peer support was enhanced during the COVID-19 pandemic.

> *"We had a good structure and setup from the beginning. We are highly motivated and also have a strong skillset."*

Table 2: **Qualitative themes pertaining to barriers to success**

Organisational strategies and management

Small Groups predominantly cited high-level operation and management of their Group as a barrier to its success, mainly through:

- Poor strategic planning *(predominantly the smaller grass-roots organisations)*
- Burden of governance
- Lack of group skillset *(including knowledge and experience)*

Lack of resources
Insufficient resources posed a barrier to meeting key outcomes, especially through:

- Limiting capacity to deliver services (lack of funding)
- Preventing establishment and/or increase of workforce
- Subject to risk of high volunteer turnover
- Subject to restraints of health conditions of group members that perform staff or volunteer roles

Limitations due to rarity of conditions
Some barriers to success were specific to Rare conditions only, and included:

- Lack of awareness
- Lack of demand
- Lack of effective referral pathways *(e.g. from medical professionals to Groups)*

Systemic barriers
Characteristics of the Health System imposed some barriers on Groups, through a:

- Lack of government support
- Lack of medical system recognition of work conducted by Groups

COVID-19
The COVID-19 Pandemic caused a number of Groups to overhaul their model of support completely, and challenged other Groups' members, staff, and volunteers to learn how to engage virtually.

> *"We sometimes just do not have the expertise nor funds to do what we would like."*

It is worth noting in this analysis that the reasons given for success focus on factors internal to the organisation, such as good organisational strategies and management rather than resources and demand.

To the contrary, reasons given for non-success focus more heavily on external factors, with more mentions of limited resources and systemic barriers and fewer mentions of organisational strategies or management.

4.2.2.1 Strategies to increase ability of Groups to meet set measurable outcomes

When asked to brainstorm potential strategies to increase the number of Groups that felt they were "successful in all areas", Group Leaders' responses centred around four key themes:

Table 3: **Qualitative themes pertaining to strategies to increase ability of Groups to achieve measurable outcomes**

Increased resources
Ensuring that all Groups have adequate resources was a clear solution, including through:

- Increased Government funding
- Increased funding through non-Governmental avenues

Increased opportunities in training and development

By understanding how to set achievable measurable outcomes and strategies to deliver them, Group success could be improved. To this effect, Group leaders mentioned the importance of:

- Training opportunities
- Improving Groups' ability to clearly communicate available support and set realistic Group goals
- Increased experience and expertise

External support

Success could be enhanced through support from key stakeholders, including:

- Acknowledgement of the value of Groups by Government
- Access to researchers
- Promotion of awareness of Groups by Health Care Providers

Collaboration within the sector

- Collaboration between Groups based in WA
- Collaboration with Groups based in the Eastern States

4.2.3 Barriers to Service Delivery in WA

4.2.3.1 Factors preventing Service Delivery in WA

93% of the Groups surveyed operated within WA, of these Groups, 78% indicated that they would like to provide more services and supports in WA than they currently did.

These 43 Groups who wished to provide more services in WA were subsequently asked to identify the factors preventing them from doing so. Upon conducting basic qualitative analysis, primary barriers could be identified from that dataset:

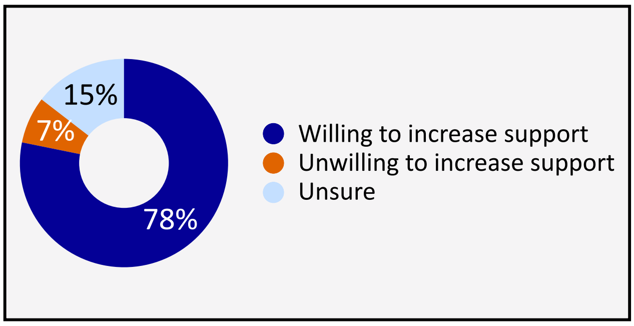


Table 4: **Qualitative themes pertaining to factors preventing increased services and supports in WA**

Funding

Specific areas that were mentioned as lacking funding included:

- Outreach programs into new areas *(e.g. regional, rural, and remote areas)*
- Paid staff members
- Appropriate venues for meetings
- Stand-alone WA offices
- Ability to travel interstate (for Groups that are not based in WA)
- Operational activities

Resources

Respondents that mentioned a lack of resources referred to staff, volunteer, and funding constraints.

Time

Limited time available to paid staff and external volunteer commitments impacted the level of service delivery. This theme relates to staffing.

Staffing

Respondents cited a lack of sufficient paid staff but also a lack of sufficient active volunteers and board members.

Geographical

Specific characteristics of Western Australian and Australian geography posed additional barriers, including:

- Distance of organisational base from WA
- Dispersion of individuals across a State as large as WA makes it difficult to bring people together
- Cost of interstate travel means work must be done remotely
- Lack of specific knowledge of the State
- Distance from pharmaceutical companies (in Eastern States) prevents WA-based Groups from being able to conduct, advocate for, or benefit from research

COVID-19

The COVID-19 pandemic halted face-to-face support and prevented staff travel to WA.

Quantitatively, respondents were asked in a multiple-choice format to further identify factors that prevent them from providing all of the services and supports that they would like to provide in WA. The primary barriers were a lack of staff or volunteers, a lack of funding, a lack of skills or training, and a lack of demand.

91% of Groups lack staff or volunteers	**26%** of Groups lack skills/training
85% of Groups lack funding	**11%** of Groups lack demand

Other barriers to increasing provision of support in WA, which were all specifically cited by fewer than 10% of respondents, included lack of awareness of the Group and its services, rareness of the condition, lack of members, personal health issues, and organisation size.

Four Groups, however, did not operate in WA. Three of these Groups indicated that they would like to do so. When these Groups were asked to identify factors preventing them from delivering services in WA, two indicated *"funding"* difficulties. One each indicated *"knowledge"*, *"access to specialists"*, and geographical factors that make it difficult to *"reach out"*, to *"communicate with hospitals"*, and to be sure of *"where patients/families are".*

4.2.3.2 Factors preventing Service Delivery in regional, rural, and remote WA

Report 1 identified a shortfall of Service Delivery in regional, rural, and remote areas of WA, which were serviced by 78% (regional areas) and 52% (remote areas) of Groups. In Consultations of the Sector, key Group leaders were asked to identify the causative factors of this regional, rural, and remote 'drop-off'. Basic qualitative analysis indicated key themes (see Table 5).

Table 5: **Qualitative themes pertaining to factors preventing Service Delivery in regional, rural, and remote WA**

Limited resources

Respondents cited a lack of paid staff and volunteers as well as a general lack of resources and funding.

It was also mentioned that staff and volunteers live with or care for loved ones with Rare, Genetic, or Undiagnosed Conditions and must attend to their own or their loved one's health, and that managing volunteers imposes an additional burden on Group leaders.

Lack of expertise

Areas requiring expertise include:

- How to use technology to connect virtually
- Knowledge of contacts in rural areas

Lack of awareness and demand

Reduced demand for Groups' services was caused by:

- Lack of demand from regional, rural, and remote individuals
- Lack of awareness of the condition
- Lack of external advocacy support
- Limited referral of individuals to the organisation

Uncontrollable factors

Some barriers that were mentioned were uncontrollable but could be addressed through alternative solutions. These factors included:

- Geographical constraints
- Few spread out individuals
- In-person services are preferred to virtual support, but require more funding

4.2.3.3 Strategies to increase Service Delivery in regional, rural, and remote WA

Group leaders were also asked to brainstorm potential strategies to reduce regional, rural, and remote drop-off. These strategies largely responded directly to each of the main causative factors.

Table 6: **Qualitative themes pertaining to strategies to increase service delivery in regional, rural, and remote WA**

Increase resources

The importance of human and financial resources was emphasised by Groups, with specific reference to:

- Sustainable funding
- Staff/volunteers in rural areas
- Small grants program
- Insurance funding to allow volunteering

Increase use of technology
The facilitation of virtual support was expected to meet the needs of regional, rural, and remote members, especially through:

- Virtual Support Groups
- Training for staff and volunteers on use of video meeting services (e.g. Zoom)
- Funding for video meeting equipment
- Telehealth and other accessibility options for individuals with Rare, Genetic, and Undiagnosed conditions

Groups acknowledged, however, that connecting face-to-face was necessary to build long-term relationships.

Increase awareness and demand
Strategies to increase demand for services comprised internal strategies and external support, especially:

- Promotion of Peer Support Groups
- Staff or volunteers in rural areas
- Referral pathway that involves Groups *(i.e. Health professionals that refer their patients to Groups)*
- Support from health organisations to advocate for individuals with Rare, Genetic, and Undiagnosed conditions

Increase collaboration
Groups understood the utility of working together to overcome the limitations of small Group size, suggesting:

- A collaborative rural outreach program with resource pooling
- Shared knowledge between Groups about regional, rural, and remote areas
- Direction of queries within the Sector from regional, rural, and remote areas to a central office phone line

4.2.4 Capacity Gaps

In the Sector Consultations, Group leaders were presented with estimates of the Sector's Capacity and were asked to identify whether they believed the current Capacity of the Sector was reassuring or concerning.

Only one attendee at the Sector Consultations indicated that they were reassured by the current capacity as members were already contacted at a sufficient frequency, all other participants, however, indicated that the current capacity of the Sector was <u>concerning</u>. Basic qualitative analysis of these sentiments was conducted, and the following themes were identified:

Table 7: **Qualitative themes pertaining to concerns surrounding current Sector capacity**

Current capacity is limited by a lack of resources
Few, inequitably distributed resources were cited as limitations to Sector capacity, with particular concerns around:

- Insufficient staff and volunteers to deliver services
- Insufficient support for staff or volunteers
- Inequitable funding (i.e. less funding for smaller Groups) limits Sector capacity, particularly that of small Groups
- Lack of funding limits the capacity of the Sector as a whole

Service delivery could be improved if Sector capacity was increased

Most Group leaders expressed concern about the limited capacity of their Sector, as its limitations have serious impacts on their members. Improved Sector capacity would allow:

- More individuals to be supported
- Service gaps to be addressed
- Groups to be accessible in a more timely manner

Sector has unused potential that should be addressed

The environmental scan indicated that 82% of Groups had the capacity to support more people. This was a cause for concern for Group leaders who mentioned that:

- More individuals could be supported if this unused potential was addressed
- This unused potential could be fully utilised if there was more awareness of Groups

Responses regarding specific limitations in capacity

While Groups had a general concern for their Sector's capacity, they also voiced concerns about its specific limitations, including the fact that:

- The sector does not have the capacity to access medical professionals
- Capacity is limited by a lack of NDIS support or access
- Groups are not able to cater for all the multi-faceted needs that their members have

Capabilities remain limited

A component of Group leaders argued that the capacity of their Sector would not be sufficient until the capabilities of the Sector were improved.

> *"(There is a) lack of resources and support from the government to run the service delivery (in regional, rural, and remote WA)"*

> *"(Pharmaceutical industry) funding does not pay for salaries so (Groups) can have great resources but no paid time"*

4.2.5 Capabilities Gaps

4.2.5.1 Future service needs

Respondents were asked to indicate which services and supports they would like to provide or increase provision of in WA. The most common services desired, and the corresponding proportion of Groups who wanted to deliver them, were:

1. Raising awareness of Groups and Conditions	60%
2. In-person meetings	54%
3. Peer support	51%
4. Education of health professionals	49%
5. Education of members	49%
6. Systemic advocacy to government	45%

Other services that many Groups hoped to deliver in the future included *“Events”* (36%), *“Advocacy for individual members”* (34%), *“Activism for research”* (34%), *“Public relations or social media”* (31%), and *“Help to access medical treatments”* (31%). In fact, all of the multiple-choice options in this question were selected by at least 3 Groups.

During the Sector Consultations, Group leaders were asked to provide their insight as to why these services emerged as the most desired for the future. Their responses were analysed to identify the following themes:

Table 8: **Qualitative themes pertaining to reasons behind future service needs**

Desired services focus on quality of life

Group leaders desired services that intended to improve their members’ quality of life, because:

- Quality of life is a focus of Groups
- Quality of palliative care is important
- Peer support reduces loneliness

Increased awareness of Rare conditions will improve individuals’ quality of life

Groups that chose ‘raising awareness for Rare conditions’ as a route to improve quality of life believed that:

- Organisations would find it easier to collaborate with and link to good Health Care Providers
- Increased awareness of Rare conditions is a sector-wide effort

Increased awareness of Groups will improve individuals’ quality of life

Groups that chose ‘raising awareness for Groups’ as a route to improve quality of life believed that:

- Individuals would have a better understanding of the services available to them
- Reaching more individuals would allow Groups to help as many people as possible
- Groups would allow new individuals more constant support across the entire disease journey

Educational services are based on member feedback

Groups that chose ‘education of medical professionals’ as a future service need had heard from their members that they were:

- Dissatisfied with medical professionals
- Not given sufficient information when diagnosed

Desired services reflect a drive to continue and improve upon common current services

A component of Group leaders indicated a need to improve existing capabilities and argued that the services desired for the future were reflective of the services delivered today.

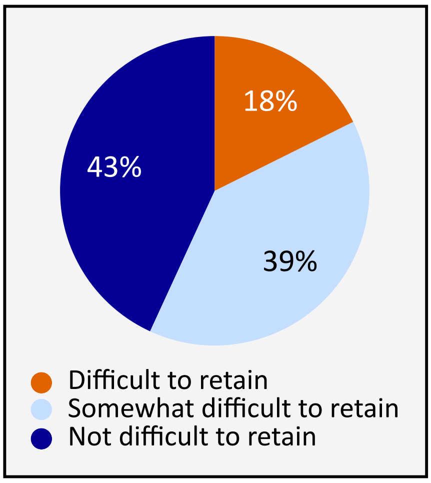
> *“We all want to reach more people- that is (our) purpose- to help as many and improve lives”*

4.2.5.2 Volunteer turnover

Respondents to the online survey were asked to assess their ability to retain volunteers. While 43% of respondents indicated that they had not had any difficulty, the remaining majority indicated that they had experienced some difficulty in minimising turnover of their volunteer base.

Qualitatively, difficulties cited included *"volunteer burnout and churn"*, lack of *"dedicated"*, *"motivated"* and *"willing"* volunteers, and lack of volunteers to take over *"leadership roles"* such as *"President, Secretary or Treasurer".*

> *"Increasing demands on a 100% volunteer organisation (cause) burnout and stress. Working full time and volunteering pretty much full time is not sustainable."*



4.2.5.3 Strategies to address capabilities gaps

Participants at the Sector Consultations were asked to identify strategies to ensure that the services they desired would be provided in the future. Basic qualitative analysis identified the following themes in their responses:

Table 9: **Qualitative themes pertaining to strategies to ensure provision of desired services in the future**

Funding
A handful of responses referred to their Groups' need for increased funding and three (3) Groups mentioned a specific need for funding to promote Groups affordably.

Resources
One Group referred to their need for resources and another mentioned a specific need for paid staff and volunteers.

Training
Two Groups mentioned their need for training of any kind, and others proposed specific topics:

- Managing burn out
- Pitching your organisation
- Reducing stigma of support

Increasing the sustainability of the Sector
'Future-proofing' was considered a goal of the Sector to ensure the continued delivery of its services.

4.2.6 System Gaps

4.2.6.1 System Gaps that can be addressed by Groups

Groups were asked to identify the Gaps that they could address in the Health System. Their responses were analysed to identify recurrent themes (see Table 10).

Table 10: **Qualitative themes pertaining to system gaps that Groups can address**

Limited awareness of Groups, their services, and the conditions they target

Groups believed that they could address the lack of awareness in several key Groups, including:

- Health professionals
- The general public

Lack of support for the condition

Groups identified a lack of condition-specific support or condition recognition in the Health System.

System-wide limitations

Groups argued that they provided support where the Health System did not, largely due to:

- Limited funding for their target condition
- Lack of recognition of their target condition under the NDIS
- Insufficient Medicare support for their target condition
- Lack of government support for their target condition

Gaps in understanding of the condition

Groups indicated that they provided individuals with an understanding of the condition in cases where they did not properly understand it, largely due to:

- Insufficient provision of information to patients by medical professionals
- A lack of research

Respondents were also asked to identify the strategies they could take to address these gaps:

Table 11: **Qualitative themes pertaining to Group strategies to address system gaps**

Aid with system navigation

Groups argued that they played an important role in:

- Connection to services and system navigation
- Acting as a service hub
- Providing NDIS support

Provision of supplementary support to individuals and carers

Groups emphasised that they provide necessary non-healthcare services to individuals with Rare, Genetic, and Undiagnosed conditions, including:

- Peer support
- Information
- Individualised support
- Empowerment
- Rural/regional support
- Mental health program for Carers and people with Rare, Genetic, and Undiagnosed conditions

Collaboration and connection across the system

Building on their role as system navigators, Groups noted that they provide:

- Connection to services
- Collaboration with medical professionals on behalf of individuals
- Collaboration with government and NGOs on behalf of individuals

Education and training

Groups serve as educators of key stakeholders in individuals' lives by providing:

- Information for individuals
- Education of health professionals
- Education of the public
- Advocacy to individuals, Carers, and health professionals

> *"We find gaps, find needs and we address those gaps and needs by working directly with government, health departments and other relevant stakeholders."*

> *"We provide an important opportunity for families and individuals of this Rare syndrome to come together and learn from one another… You cannot be what you cannot see."*

4.2.6.2 System gaps that threaten Groups

Respondents were also asked to identify gaps that they believed could lead to the *"winding down"* of their Group. Their responses were analysed to identify recurrent themes:

Table 12: **Qualitative themes pertaining to system gaps that threaten Groups**

Lack of resources

As emphasised throughout the Report, a lack of resources presented a serious threat to Groups, with Groups reporting insufficient:

- Funding
- Staffing or volunteers
- Time
- Training
- Government support

Gaps related to Rare conditions

For Groups that target Rare conditions, additional risks arise due to a lack of awareness of their Group or its services causing reduced demand.

Other gaps

- Geographical factors (see Table 4 for limitations imposed by WA geography)
- COVID-19 (see Table 4 for limitations imposed by the COVID-19 Pandemic)

> *"(We) feel extremely unvalued and our voice ignored and unheard. (There is a) complete lack of funding or support from the government"*

4.2.7 Ongoing funding and training needs

4.2.7.1 Areas requiring funding

A lack of funding and other resources emerged as a repeated theme across the consultation, 85% of Groups indicated that a lack of funding prevented them from delivering basic and a wider range of services and supports across WA. The importance of ascertaining the specific areas that required funding was understood, and questions were asked to this effect throughout data collection. 5% of Groups indicated that they were *"happy with (their) current level of funding"*. Among the remaining Groups, the following areas were most commonly selected as funding needs:

1. Operation expenses*	61%
2. Administrative support	51%
3. Resource development *(e.g. info booklet)*	44%
4. Education (of Health professionals and members)	44%
5. Website upkeep or design	42%
6. Research	33%
7. Financial support for members	31%
8. Volunteer training	26%

While the majority of Groups required funding to pay for *"operational expenses"*, it was acknowledged that this phrase is vague and provided little insight into specific funding needs. As such, Group Leaders at the Sector Consultations were invited to develop a definition:

> *** Operational expenses:** any expense that allows for the continued *"day to day running of the organisation"*, including *"wages, rent, phone lines, printing, parking (including for hospital visits), fuel, loss of wages, administrative expenses, insurance, and funding to pay someone to run the organisation"*

The exact type of *"research"* that required funding was also somewhat unclear. Throughout the Consultations, however, Group Leaders referred primarily to funding for academic research not conducted by Groups (mainly with the intention to discover new treatments). It is also clear, however, that some Groups have a research focus themselves and conduct their own research, which also requires funding.

The remaining areas were all selected by fewer than 25% of Groups, and included *"venue hire"* (21%), *"insurance"* (19%), and *"governance"* (14%). Six Groups highlighted their specific funding needs, including an *"annual national meeting"*, *"potential clinical trials"*, *"travel expenses"*, and *"community service programs"*.

4.2.7.2 Areas requiring training

26% of Groups indicated that increased training would allow them to deliver more of the services and supports that they wanted to deliver in WA. Questions were posed across all the data collection tools to identify the specific areas in which Staff and Volunteers required training.

1. Preparing grant applications	63%
2. Engaging stakeholders	57%
3. Governing	50%
4. Raising awareness of Group and condition	48%
5. Connecting individuals with system	45%
6. NDIS	44%
7. Fundraising	43%
8. Providing mental health support	43%
9. Facilitating Groups	43%
10. Navigating systems	39%

Other training areas that were selected by at least one quarter of Groups included *"peer support"* (34%), *"advice on patient rights"* (34%), *"system advocacy"* (34%), *"public relations or social media"* (32%), *"education of individuals and health professionals"* (32%), *"help to access treatment"* (32%), *"cultural awareness"* (32%), *"referral to clinical trial opportunities"* (30%), *"advocacy for individual members"* (29%), *"conflict resolution"* (29%), *"helping others with system navigation"* (29%), and *"events"* (27%).

Groups in the Sector were interested in many training options and each had their own unique training needs. When given the opportunity to provide their own custom response, five (5) Groups indicated that they could not provide a response to the question, for example because they were a *"facilitator"* or *"peak body"*. Two Groups indicated a need for training in specific areas of administration and raising awareness. Additionally, 23% of Groups indicated in a previous question that while they did not link to or own a patient registry, they wanted to know more about patient registries.

In addition, drawing on the qualitative findings, training opportunities could be welcome in the following areas: managing burnout, pitching your organisation, leveraging partnerships, attracting Board members and building sustainability.

4.2.7.3 Strategies to ensure funding and training needs are addressed

With key funding and training needs identified, strategies were developed in consultation with the Sector to ensure that training and funding would be provided to the Groups that required it. In the Sector Consultations, leaders of key Groups brainstormed on this topic and the following themes were identified:

Table 13: **Qualitative themes pertaining to strategies to ensure funding and training needs are addressed**

Central Organisation

Groups shared interest in registering with a Central Organisation that also provides:

- Sustainable Sector grants
- Resources and training

Improving small Groups' ability to secure funding

Small Groups with few staff and volunteers lack the time, and in some cases the expertise, to secure funding. These Groups would benefit from:

- Governance training
- Discounted or free training
- Transparency of Government funding and training

Securing new funding and training sources

Groups understood that seeking new avenues for funding and training would be beneficial, suggesting:

- Peer to peer training
- Corporate volunteering
- Philanthropy
- In-kind support
- Pro-bono

Equitable access to training and funding for smaller Groups

Groups noted the importance of ensuring that funding and training is affordable and not too time-consuming to access. Expensive training and lengthy application processes for funding disadvantage small Groups.

> *"(We need) a central Rare (organisation) who manages grants for (the) sector, operational and sustainable funding, training, and resources."*

4.2.7.4 Strategies to ensure Groups are aware of available funding and training

A need was identified to guarantee that Groups understood the training and funding options available to them. As part of the Sector Consultations, leaders of key Groups were asked to discuss the strategies that could be implemented to this effect, and the following themes emerged:

Table 14: **Qualitative themes pertaining to strategies to promote awareness of available funding and training**

Central Organisation and collaboration within the Sector

Groups noted that a Central Organisation that facilitated Sector collaboration would be helpful, mentioning the:

- Importance of any solution being WA-based but nationally and internationally collaborative
- Need for ConnectGroups to assist the Sector
- Value of support and networking opportunities
- Value of regular meeting by representatives from each Group (e.g. monthly)

Announcements of funding and training
Poor awareness of funding and training disproportionately affects Groups that are time-poor. Groups indicated the importance of:
- Funding and training announcements via email and newsletters
- Information about non-Government funding
- State or national awareness campaigns
- Ensuring funding and training is transparent and equitable
- Enduring that small Groups are not disadvantaged by lengthy application processes

4.2.8 Summary of key themes and additional thoughts

The final question in the online Survey and Sector Consultations invited participants to share any thoughts they had not yet shared regarding their Sector. The themes that emerged upon qualitative analysis summarised many of the themes identified throughout the consultation but did introduce some novel points.

Table 15: **Qualitative themes pertaining to additional thoughts on the Sector**

Positives
A component of Groups indicated that the management of Rare, Genetic, and Undiagnosed conditions in WA is satisfactory. Sector Consultation attendants were also thankful for the opportunity to collaborate.

Lack of recognition of the condition
Groups reiterated the impact that a lack of condition recognition has on their work, including the:
- Lack of recognition from Government
- Lack of recognition from the Health System
- Lack of recognition under the NDIS
- Poor adherence of Rare conditions to traditional labels and requirement of needs-based treatment

Limitations in resources
Groups summarised the constraints they experienced due to limitations in resources, especially in funding, training, staff, and volunteers.

Under-targeted problems in the Sector
Groups also introduced or reiterated a variety of problems they had observed in the Sector, including:
- The need for research into Rare and Undiagnosed Conditions
- Groups being unaware of the support available to them
- Mental health problems for individuals with Rare, Genetic, and Undiagnosed conditions
- Increase benefits for individuals in the Eastern States of Australia relative to WA
- Barrier that the geography of WA imposes
- Sector needs for collaboration to improve equity, governance, and training
- Lack of Health professionals that understand Rare conditions and poor communication between Health professionals
- Lack of an up-to-date database of Groups, Health Providers and other available supports

Comments related to project stakeholders

A number of Groups made reference to the stakeholders (*i.e. ConnectGroups, WA Department of Health, Groups)* of this project specifically, with Groups mentioning:

- Flaws in the survey tool (respondent confusion or fatigue, as described in Report 1)
- Interest in ConnectGroups support
- The need for a peak body for Rare, Genetic, and Undiagnosed conditions sustained by WA Department of Health
- The Groups involved in this project are diverse and have different but equally important issues

"WA sets a great example for Rare disease management."

"We are very fortunate in WA to have one of the better state systems from Genetic testing to treatments that are covered here but not in other states"

"We have also been glad over the years to be part of ConnectGroups and to have a… display stall at your events."

5. Recommendations

Eight recommendations have been identified following the consultation process. The aim of the intended recommendations is to ensure the longevity of a much-required Sector which is providing valuable services to individuals and families living with Rare, Genetic, and Undiagnosed conditions. It is important to acknowledge, however, that there are nuances in the needs of each individual Group. By contrast, Groups share common concerns, and it is these common themes that the following recommendations seek to address.

"There is a spectrum of (Groups) from very small Groups… to larger ones. Often the issues faced (by these Groups) are different but still very real."

"We all seem to have common themes and issues."

Recommendation 1:

Establish a WA-based Centralised Model for the service delivery, quality control, and oversight of the Rare, Genetic, and Undiagnosed conditions Sector.

A 'one-stop shop' would be the most effective strategy to ensure this Sector's needs are continuously monitored and strategically addressed. In this case, a Centralised Model refers to a single key Organisation representing the Rare, Genetic and Undiagnosed Conditions Sector providing information, training, and services required. The Organisation would maintain quality control by ensuring that service delivery is current and relevant. The Model would also conduct oversight of the Sector, by implementing strategies to review and monitor its support services. This function would help Groups to identify and mitigate risk, ensure due diligence, and achieve set measurable outcomes. It would also provide necessary insight to deliver targeted collaborative activities between Groups with the aim of addressing emergent service delivery gaps.

The key role of this Centralised Model would include, but need not be limited to, awareness promotion of Groups and conditions, provision of a first point of contact for newly diagnosed individuals and their family members, maintenance of an up-to-date database of Groups, operation of a centralised phone line, development and delivery of specialised training to meet the needs of the Sector, provision of networking and peer support opportunities for individuals, family members, and Groups, information sharing as to accessibility to Government and non-Government grants, provision of free or low-cost resources to Groups *(i.e. human, operational, and administrative resources)*, facilitation of collaborations and partnerships with organisations based in the Eastern states and internationally to improve equity of support across Australia, establishment of an annual forum for Groups in the Sector, delivery of seminars and awareness training for Health professionals, and establishment of a small grants Program providing small injections of funding to address capacity building of individual Groups. The establishment of this model would be instrumental in the delivery of Recommendations 2-8.

> **Recommendation 2:**
> **Provide a sustainable, open, and equitable Grants Program that has the capacity to increase over time so that new Groups can be supported as they arise.**

Evidence suggests a well-funded Grants Program that Groups could tap into would significantly improve the long-term capacity and capabilities of the Sector and enable the smaller emerging Groups to remain sustainable. This Recommendation is partly based on the fact that 87% of Groups cited funding as a primary barrier to improving their support services. Funding Sustainability was mentioned across all data collection methods to allow Groups to *"continue (the) breadth of services required"*. The necessity of an Open Grants Program was indicated by the 63% of Groups that cited day-to-day running costs including ability to pay wages, cover insurance costs, and rent as a primary funding need. The importance of an Equitable Grants Program was illustrated by 30% of respondent Groups, who were entirely unfunded and, in some cases, felt *"unvalued… ignored and unheard"*. 18% of the Groups surveyed were established in the last five (5) years, highlighting the annual emergence and trend of new Groups in the Sector and exemplifying the need for a Grants Program that draws on an increasing funding pool.

- **2.1 *Provide Sustainable Funding.***
  Once funded by the Program, Groups should be confident that their funding will continue if they meet clearly articulated targets. These targets could be defined on a case-by-case basis by the Department of Health, a Central Organisation, or the Groups themselves. This would allow for better long-term planning and continued breadth of service delivery in the Sector.

- **2.2 *Provide Open Funding.***
  The main funding needs of this Sector are not oriented towards project delivery. Any Grants Program for this Sector would deliver the most benefit by allowing Groups to use funding as they see fit.

- **2.3 *Provide Equitable Funding.***
  An equitable Grants Program that deliberately reflects smaller Groups would allow these Groups to expand their service delivery, increasing the support available to people who live with Rare Conditions.

- **2.4 *Provide Increasing Funding.***
  An equitable Grants Program should seek to identify and support new Groups as an avenue to maintain its sustainability and equity of funding. To meet the increasing demands of a growing Sector, a needs-analysis would need to be implemented on the Program's funding pool every three years.

Recommendation 3:
Promote awareness of Groups and of the Rare, Genetic, and Undiagnosed Conditions that they target among individuals with these Conditions, medical professionals, Health Care Providers, and the general public.

- **3.1** ***Promote awareness of Rare conditions.***
  Increased awareness of Rare conditions would allow for faster diagnosis times and improved treatment. It would also increase the capacity of Groups to link their members to Health professionals and specialists.

- **3.2** ***Promote awareness of Groups.***
  Increased awareness of Groups, particularly in regional, rural, and remote areas, would allow them to provide more individuals with constant support throughout their journey. An awareness program would also allow individuals to better understand all the services available to them and may be useful in addressing the reduced level of service delivery in regional, rural, and remote areas.

Recommendation 4:
Influence improvement in the quality of care that health professionals provide to individuals with Rare, Genetic, and Undiagnosed conditions.

- **4.1** ***Promote multi-disciplinary support for Health professionals who are caring for individuals with Rare, Genetic, or Undiagnosed conditions.***
  Health professionals play an integral part in the health plan of those people with Rare, Genetic, and Undiagnosed conditions. Multi-disciplinary efforts should be undertaken to support doctors and specialists in their care for these individuals. Educational seminars, increased communication among Health professionals, improved communication with patients, and better support for Health professionals is needed.

- **4.2** ***Facilitate and promote collaboration and mutual learning between Health professionals and Groups.***
  Health professionals and Groups could both benefit from increased collaboration, by educating, training, and strengthening one another through mutual learning to provide better support for people with Rare, Genetic, and Undiagnosed Conditions. These collaborative efforts could be facilitated and promoted by the WA-based Centralised Model.

Recommendation 5:
Establish a specialised Training and Development Program to promote self-sufficiency within the Sector.

The development and implementation of a specialised Training Program would encourage self-sufficiency and increase the skillset of the Sector. In the first instance, the Program should focus on five key areas: ‘Grant Applications, Availability of Funding and Fundraising’, ‘Stakeholder Engagement and Raising Awareness’, ‘Recruitment and Retainment of Volunteers’, ‘Supplementary Support- NDIS and Mental Health’ and ‘Group Operation- Governance, Strategic Planning, Facilitation, and System Navigation’. The Training Program should be available to Groups (and those in the Sector without a Group) either free or at low cost. Also see Recommendation 6.3 Training in the effective use of technology.

> **Recommendation 6:**
> **Identify adequate resourcing to meet the demands for service delivery in regional, rural, and remote areas of WA.**

Ensuring adequate resourcing will allow strategies to be put in place addressing the service delivery gaps in regional, rural, and remote areas.

- **6.1** ***Provide funding for service delivery in regional, rural, and remote areas of WA.***
  A portion of funding to be allocated to regional, rural, and remote activity.

- **6.2** ***Increase awareness of Groups and conditions in regional, rural, and remote WA.***
  A collaborative Rural Outreach approach.

- **6.3** ***Deliver training in the effective use of technology.***
  Training to enable Groups to establish, build, and run virtual components or equivalents of their current services in order to broaden their reach.

> **Recommendation 7:**
> **Influence the inclusion of Rare and Undiagnosed conditions in the National Disability Insurance Scheme (NDIS) model.**

Group capacity is limited by a lack of NDIS recognition of Rare and Undiagnosed conditions. There is demand for needs-based support rather than diagnosis-based support.

> **Recommendation 8:**
> **Undertake a holistic and culturally safe approach of investigation and action to ensure that the needs of First Nations Australians who have Rare, Genetic, or Undiagnosed conditions are met.**

First Nations people were not sufficiently represented in the consultation as many of their needs as individuals with Rare, Genetic, or Undiagnosed conditions are addressed alongside other health concerns through Aboriginal Medical Services (AMS's) rather than through Groups that specifically target these conditions.

It is important to note that Aboriginal and Torres Strait Islander peoples are affected by these conditions, sometimes disproportionately. 81% of Australia's diagnoses of a Rare Condition called Rheumatic Heart Disease, for example, are among Indigenous Australians [1].

It is crucial that the WA Department of Health undertakes a holistic approach to assess and improve the ability of AMS's to support individuals with any condition. An individual-level approach may also be of benefit and could involve identifying First Nations people who have Rare, Genetic, and Undiagnosed conditions and assessing the support they receive as individuals. These efforts should be Aboriginal-lead and culturally safe.

6. Conclusion

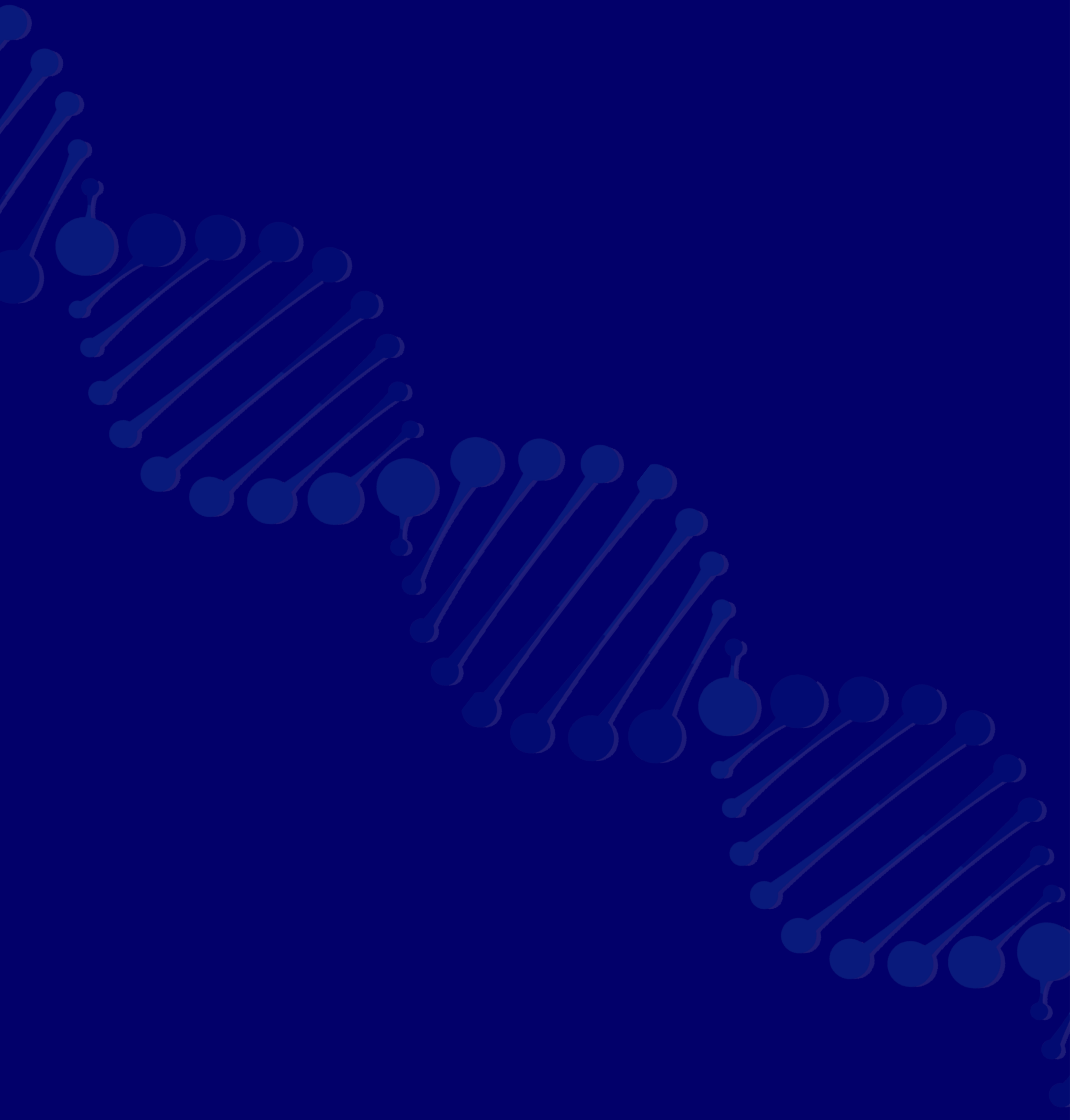
WA's Rare, Genetic, and Undiagnosed Conditions NGO Sector is a strong, vibrant, and growing Sector. Extensive grass-roots level consultation with the Sector indicated key limitations in funding, specialised training, and public awareness. It is apparent that the Sector is interested in contribution to policy and reform and seeks further collaboration with clinical models. To achieve these outcomes, there is a requirement for the establishment of a one-stop Centralised Model- a single key Organisation representing the Rare, Genetic, and Undiagnosed Conditions Sector that enables access to training, funding, and other Sector-wide services including patient referrals, health professional training, and awareness promotion. These strategies will ensure long-term sustainable growth of the Sector's capacity and capabilities.

7. Bibliography

1. Australian Institute of Health and Welfare. (2021). *Acute rheumatic fever and rheumatic heart disease in Australia, 2015-2019* (p. 2). Australian Government.

8. Appendices

1. Report 1- *Capacity and Capabilities*
    Section 9.1- *Formal Group Database*
2. Infographic Dashboard 1- *Capacity of Groups*
3. Infographic Dashboard 2- *Capabilities of Groups*
4. Infographic Dashboard 3- *Gaps, training, and support*



Strengthening the Capacity and Capability of the
Rare, Genetic and Undiagnosed
Conditions Sector in WA

ConnectGroups
helping support groups & individuals