CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Australian Patient Organisation Network

ANNUAL REPORT

2020 - 2021

Contents

Introduction + Summary

Background

Australia has a vibrant health charity sector and the Australian Patient Organisation Network (APON) was convened to support the sector and strengthen its impact through collaboration.

In January 2019 the Hon Greg Hunt MP, Federal Minister for Health, Member for Flinders, announced the Patient Pathways program. APON is part of this program where CCDR have been given the task of bringing together the patient organisation community across Australia.

The APON conference occurs annually and is a starting point to bring the community together and develop working networks. All patient organisations and health charities in Australia are welcome to be part of this initiative. Throughout the year, CCDR aim to support the sector so that organisatons are strengthened and so that we have a cohesive and collaborative non-profit sector, that can be leveraged to address common goals.

In the lead-up to the inaugural APON conference in 2019, patient organisations completed a survey that provided information about their current work, what is important to them and future opportunities. This informed the conference program.

A series of workshops was held during the conference where scribes took detailed notes which were displayed on a PowerPoint so that there could be consensus from each group on the final points recorded. The pre-conference survey and results of the conference workshop resulted in an APON program of work. This was then sent to the APON community for comment and then approved by the APON Standing Committee.

APON is hosted by the Centre for Community-Driven Research (CCDR). CCDR's commitment to the community is to facilitate the development of:

- A common agenda
- Shared measurement system(s) and evidence to support actions
- Mutually reinforcing activities
- Communication, network facilitation and as much support as we have capacity to provide and where funding can be sourced

The program of work is based on the challenges, opportunities and recommendations of the patient organisation community. Being an APON member means that you have a place to go as a patient organisation to collaborate, connect and be actively supported. APON membership will be open to patient organisations only, with the program of work facilitating collaboration with key stakeholders. This makes APON your space and a way for patient organisations to address the challenges that are most important to them and their patient populations.

In the program of work, there are some initiatives that are new, some that are new but using and existing platform, and some that CCDR are already working on. The programs that CCDR are already working on have been included to show how some of the challenges identified can be addressed, rather than re-creating new systems. For each challenge, there may be more than one solution, but we ask that we use this program as a starting point for future collaboration across the network.

This report outlines progress of each area of work to date. A high-level report was also presented to the APON Standing Committee. APON Standing Committee members currently include:

Monica Ferrie (Chair), Genetic Support Network Victoria
Agnes Nsofwa, Australian Sickle Cell Advocacy Inc
Anne Wilson, Emerge Australia
Claire Leonard, Liver Kids Australia
Fiona Ellis, HeartKids Limited
Fiona Lawton, Angelman Syndrome Association Australia Inc
Hayley Lethlean, Muscular Dystrophy WA
Melanie Funk, Eczema Support Australia
Rohan Greenland, MS Australia

APON Report 2020-2021

Highlights

A special project looking at the impact of COVID-19 on patient organisations was conducted in lieu of a conference. The project included three online, interactive sessions to touch base with patient organisations and collect information on the challenges they were facing. Two webinars explaining practical aspects of COVID-specific government initiatives were also convened. CCDR also produced a report detailing the impact of COVID-19 on patient organisations and the results were published. This attracted national media coverage and was used as the basis of advocacy with the Federal Government.

A total of 20 webinars and online workshops/brainstorming sessions were held in 2020/2021. CCDR also established an APON newsletter including interviews with APON members and local healthcare professionals.

A registry of patient organisations in Australia has been developed and is updated on an ongoing basis. The register currently holds 451 organisations and can be located at www.cc-dr.org/au/npor

CCDR have developed a system where opportunities for engagement in decisions, funding, collaboration etc. are scanned and collated each month, and then communicated via the APON newsletter/APON webpage

A suite of tools has been developed to help patients and patient organisations understand the health system. Alongside information sheets are PowerPoint presentations and facilitator notes so that patient organisations can run internal or external information sessions on this topic.

The first program evaluation for Patient Pathways is available and represents support provided to 1,245 patients/families. The evaluation is available at www.cc-dr.org/au/pon

The evaluation has resulted in:
- A funding model for continuation of Telehealth nurse positions within patient organisations
- Defined roles and remit for Telehealth nurse positions within patient organisations
- A minimum data set for evaluating impact of Telehealth nurse roles within a patient organisation

CCDR has developed and is testing a protocol to understand how citizens access health services across Universal Health Coverage domains. This will include an online questionnaire and telephone interview and part of the analysis will look at whether stigma has an impact on access to and/or uptake of health services.

Three projects have emerged from APON interest groups. The projects are:

- The Access to medicines and health technology group: Testing questions to understand the impact of a condition/disease on a patient's life.
- Clinical trials and clinical registries, and Research group: Identifying the roles that patient organisations can play to support clinical trials and research
- Health services/Health system and Navigation group: An audit of patient organisations in Australia to understand our contribution to the health system and make it easier for patients to navigate services.

The infrastructure has been built to be able to have a central system where patients can register to be involved in research, policy, program development etc., and be connected with researchers, policy-makers, program developers etc. that are seeking patient input. The process is currently being testing in a small pilot project in oncology. The results will be reported and determine whether this can be rolled out at scale or modelled so that individual patient groups can set up their own system.

The focus of the 2021 annual APON conference will be to develop a national campaign to increase awareness of the role and services provided by patient organisations and increase health professional referrals to patient organisations.

Pillar 1: Strengthen Community Actions

Pillar 1

Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities - their ownership and control of their own endeavours and destinies.

Community development draws on existing human and material resources in the community to enhance self-help and social support, and to develop flexible systems for strengthening public participation in and direction of health matters. This requires full and continuous access to information, learning opportunities for health, as well as funding support[1].

Pillar 1: Strengthen Community Actions			
Proposed APON Program Outcome(s)	**Activities**	**Report**	**Indicator**
Outcome 1.1: Maintain APON and support the work of patient organisations who are an integral part of the health system	1.1.1: Convene an APON conference annually

The next APON conference is scheduled for November 2021 in Melbourne. | It was not possible in 2020 to convene a face-to-face conference however a special project looking at the impact of COVID-19 on patient organisations was conducted in lieu of a conference. The project included three online, interactive sessions to touch base with patient organisations and collect information on the challenges they were facing. Two webinars explaining practical aspects of COVID-specific government initiatives were also convened. CCDR also produced a report detailing the impact of COVID-19 on patient organisations and the results were published. This attracted national media coverage and was used as the basis of advocacy with the Federal Government. | |
| | 1.1.2: Develop and implement a system to identify common advocacy platforms to form the basis of discussions at the Annual Conference | 14 online workshops/brainstorming sessions were held in 2020/2021 across the APON interest groups. Each APON interest group identified unique challenges and opportunities, however collectively a common theme that arose was the need to increase awareness of the role of patient organisations in Australia, and what they can contribute to the health system. This theme will be carried forward to the 2021 Annual conference. | |
| | 1.1.3: Develop a registry of Australian patient organisations | A registry of patient organisations in Australia has been developed and is updated on an ongoing basis. The register currently holds 451 organisations and can be located at www.cc-dr.org/au/npor/ | |

---

[1] World Health Organisation. (1986). *Ottawa Charter for Health Promotion: First International Conference on Health Promotion Ottawa, 21 November 1986.* https://www.healthpromotion.org.au/images/ottawa_charter_hp.pdf

Pillar 1: Strengthen Community Actions			
Proposed APON Program Outcome(s)	**Activities**	**Report**	**Indicator**
	1.1.4: Develop a registry of opportunities for engagement in decisions, funding, collaboration etc. and alert system for patient organisations	CCDR have developed a system where opportunities for engagement in decisions, funding, collaboration etc. are scanned and collated each month, and then communicated via the APON newsletter/APON webpage (www.cc-dr.org/au/pon). An alert system is also in place in relation to the Pharmaceutical Benefits Advisory Committee (PBAC) meetings. CCDR export the PBAC agenda when it is released and transfer this into a searchable database so that it is easier for patient organisations to see what is being considered at each meeting.	

Pillar 1: Strengthen Community Actions			
Proposed APON Program Outcome(s)	**Activities**	**Report**	**Indicator**
Outcome 1.2: Increase opportunities for patient organisations – and those that work in them – to be personally and professionally supported in their work	1.2.1: Provide a system for peer-to-peer mentoring and a place for support those working in patient organisations	CCDR placed an open call to all APON members to participate in a patient organisation peer support group (with an external facilitator). The aim of the group was to provide peer-to-peer mentoring and a place for support those working in patient organisations. There was very little uptake of this opportunity and it was discontinued. The APON Standing Committee will discuss this activity and provide recommendations for alternative approaches and/or adjustment of this goal to bring back to the APON community.	

EXCLUSIVE   NATIONAL   CORONAVIRUS PANDEMIC

Health charities struggle to cope under shadow of COVID

For our free coronavirus pandemic coverage, learn more here.

By **Rachel Clun**
July 1, 2020 — 5.22pm

f 🐦 🟢 ✉ | A A A

But to add to the pressure, the CCDR report found these charities were also struggling for money after community fundraisers were put on hold by the national lockdown, putting a question mark over the long-term viability of some of them.

Chief executive of Cystic Fibrosis Australia, Nettie Burke, said that, amid cancelling major fundraisers, charities were loath to ask the community for assistance at a time when many were struggling.

"The demand for our services and support has increased by nearly 80 per cent while our income has reduced by nearly 70 per cent, so they're frightening numbers," she said.

"They shouldn't feel like we're giving them the support, but we're taking that away from their pocket."

CCDR chief executive Catherine Holliday said the government needed to provide additional funding for the charities, as they were not eligible for funding under the $200 million charity support package because their work was not classed as emergency relief.

"In the health crisis we find ourselves in, patient organisations are stepping up and providing vital services. For many patients, seeking care is an emergency," Dr Holliday said.

Excerpt from Fairfax media coverage of the report on the impact of COVID on health charities

APON Annual Report 2020 - 2021

Pillar 2: Develop Personal Skills

Pillar 2

Health promotion supports personal and social development through providing information, education for health, and enhancing life skills. By so doing, it increases the options available to people to exercise more control over their own health and over their environments, and to make choices conducive to health.

Enabling people to learn, throughout life, to prepare themselves for all of its stages and to cope with chronic illness and injuries is essential. This has to be facilitated in school, home, work and community settings. Action is required through educational, professional, commercial and voluntary bodies, and within the institutions themselves.[1]

Pillar 2: Develop Personal Skills			
Proposed APON Program Outcome(s)	**Activities**	**Report**	**Indicator**
Outcome 2.1: Increase resources for patient organisations to empower their communities to exercise more control over their own health	2.1.1: Repository of tools, resources and a market-place for patient organisations to connect and share	A suite of tools has been developed to help patients and patient organisations understand the health system. Alongside information sheets are PowerPoint presentations and facilitator notes so that patient organisations can run internal or external information sessions on this topic. These are all available at www.cc-dr.org/systems/ CCDR also trialled an online market-place where organisations can share and request tools and resources. This was launched at the start of the pandemic and did not have the traction expected. The APON Standing Committee will discuss this activity and provide recommendations for alternative approaches and/or adjustment of this goal to bring back to the APON community	
	2.1.2: Provide education and support via webinars between annual conferences	20 webinars and online workshops/brainstorming sessions were held in 2020/2021. CCDR also established an APON newsletter including interviews with APON members and local healthcare professionals.	

---

[1] World Health Organisation. (1986). *Ottawa Charter for Health Promotion: First International Conference on Health Promotion Ottawa, 21 November 1986.* https://www.healthpromotion.org.au/images/ottawa_charter_hp.pdf

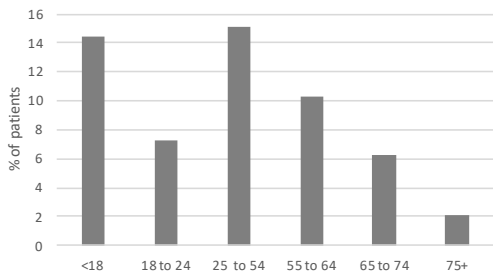| Pillar 2: Develop Personal Skills			
Proposed APON Program Outcome(s)	**Activities**	**Report**	**Indicator**
	2.1.3: Patient Pathways Pilot	The first program evaluation is available and represents support provided to 1,245 patients/families. The evaluation is available at www.cc-dr.org/au/pon The evaluation has resulted in: - A funding model for continuation of Telehealth nurse positions within patient organisations - Defined roles and remit for Telehealth nurse positions within patient organisations - A minimum data set for evaluating impact of Telehealth nurse roles within a patient organisation	
	2.1.4: Framework for Community Engagement	Framework for Community Engagement was being developed by the World Health Organisation and the plan was to adapt this to the Australian setting. The Framework is yet to be released and there is no indication of when it will be released. In 2022, CCDR will conduct a search of existing frameworks and work with APON members to adapt this to the Australian setting. This will include an ethical framework for patient feedback in decision-making.	

Patient Pathways
Telehealth Nurse Service

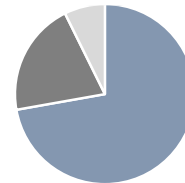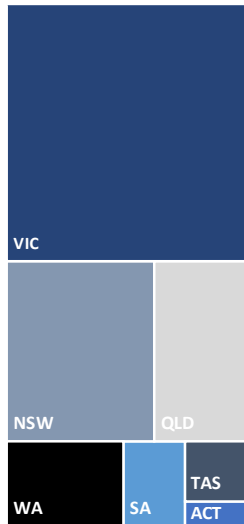**An initiative funded by the Federal Department of Health**

CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Gender

Female   Male

Age

y-axis: % of patients (0 to 16)
x-axis: <18, 18 to 24, 25 to 54, 55 to 64, 65 to 74, 75+

VIC

NSW   QLD

WA   SA   TAS   ACT

Location

- Major Cities of Australia
- Inner Regional Australia
- Outer Regional Australia/Remote

Socioeconomic status

Lower to medium	33.49
Higher	36.71
Unknown	29.80
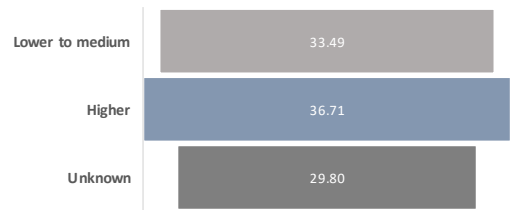
Access to Patient Pathway services over time

y-axis: % of patients (0 to 35)
x-axis: Q3 2019, Q4 2019, Q1 2020, Q2 2020, Q3 2020
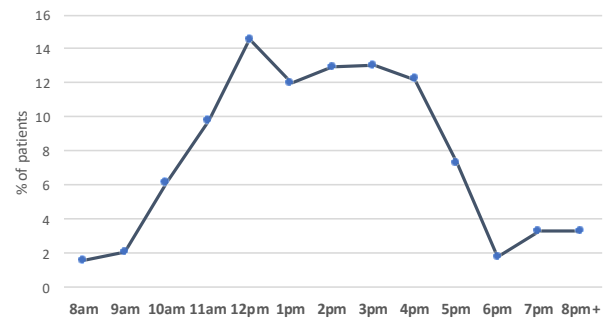
Time of day patients access Patient Pathway services

y-axis: % of patients (0 to 16)
x-axis: 8am, 9am, 10am, 11am, 12pm, 1pm, 2pm, 3pm, 4pm, 5pm, 6pm, 7pm, 8pm+

7867

Number of concerns across all patients

1245

Number of patients accessing Patient Pathways

95

Average minutes per patient

6.32

Average number of concerns per patient

9247

Total number of nurse-led interventions and referrals

7.43

Interventions per patient

Patient Pathways
Telehealth Nurse Service

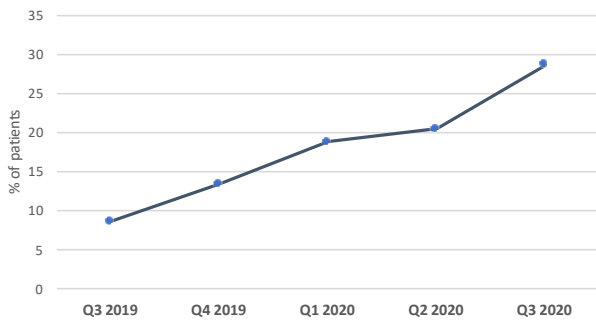An initiative funded by the Federal Department of Health

CENTRE FOR COMMUNITY-DRIVEN RESEARCH

1. Treatment options
2. Disease management
3. Psychological/social support

Most common requests for information

Ongoing chronic disease management

Most common point of clinical pathway when entering Patient Pathways service

873
Number of symptom management assessments

840
Number of clinical trial status assessments

771
Number of pain management assessments

704
Number of multidisciplinary team assessments

773
Number of primary care assessments

849
Number of home status support assessments

774
Number of palliative care assessments

Partner Organisations

Crohn's & Colitis AUSTRALIA — making life more liveable

Cerebral Palsy Support Network

eating disorders victoria

emerge australia

MDDA — Metabolic Dietary Disorders Association

mito⁺ FOUNDATION

Maddie Riewoldt's Vision.

pancare FOUNDATION

SAVE OUR SONS DUCHENNE FOUNDATION

Tuberous Sclerosis Australia

genetic alliance australia

Syndromes Without A Name

gsnv — Genetic Support Network Victoria

GENETIC AND RARE DISEASE NETWORK

CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Pillar 3: Create Supportive Environments

Pillar 3

Our societies are complex and interrelated. Health cannot be separated from other goals. The inextricable links between people and their environment constitutes the basis for a socioecological approach to health. The overall guiding principle for the world, nations, regions and communities alike, is the need to encourage reciprocal maintenance - to take care of each other, our communities and our natural environment. The conservation of natural resources throughout the world should be emphasized as a global responsibility.

Changing patterns of life, work and leisure have a significant impact on health. Work and leisure should be a source of health for people. The way society organizes work should help create a healthy society. Health promotion generates living and working conditions that are safe, stimulating, satisfying and enjoyable.

Systematic assessment of the health impact of a rapidly changing environment - particularly in areas of technology, work, energy production and urbanization - is essential and must be followed by action to ensure positive benefit to the health of the public. The protection of the natural and built environments and the conservation of natural resources must be addressed in any health promotion strategy.[1]

Pillar 3: Create Supportive Environments			
Proposed APON Program Outcome(s)	**Activities**	**Report**	**Indicator**
Outcome 3.1: Increase opportunities for all patients and the community to access everything that the health system has to offer	**3.1.1: Create a mechanism to ensure that equitable access is addressed in each of the APON activities and program of work**	The opportunity to join a 'vulnerable populations interest group' was offered to the APON community. There was not enough interest to go ahead with this interest group. The APON Standing Committee will discuss this activity and provide recommendations for alternative approaches and/or adjustment of this goal to bring back to the APON community.	
Outcome 3.2: Reduce the impact that stigma has on the way that patients and their families experience the health system	**3.1.2: Develop research question(s) to implement across a range of disease areas in relation to the impact of stigma in vulnerable populations**	CCDR has developed and is testing a protocol to understand how citizens access health services across Universal Health Coverage domains. This will include an online questionnaire and telephone interview and part of the analysis will look at whether stigma has an impact on access to and/or uptake of health services. This project is commencing in July 2021.	

---

[1] World Health Organisation. (1986). *Ottawa Charter for Health Promotion: First International Conference on Health Promotion Ottawa, 21 November 1986.* https://www.healthpromotion.org.au/images/ottawa_charter_hp.pdf

Universal Health Coverage: The experience of citizens in Australia

Universal Health Coverage (UHC) is implemented through a range of policies that intend to ensure that citizens have access to preventative, treating, curative, rehabilitative and palliative services. However, for all of the policies, frameworks, interventions and initiatives, we need to ask how well are ordinary people able to access services and are there indications of quality and affordability?

The Centre for Community-Driven Research (CCDR) will conduct a program to understand how citizens experience UHC in their everyday lives. We will do this through a structured interview using a protocol that we have recently developed for this purpose. The protocol crosses the UHC domains of promotion - prevention - cure/treatment - rehabilitation and palliative care, with the cross-cutting themes of access, quality and affordability.

We anticipate that the results of the program will provide insights into aspects of UHC that are implemented equitably, and those that lead to inequity including those that experience stigma. Once these strengths and weaknesses are identified, we can then trace-back to the policies being implemented and discuss the positive and negative impact on UHC.

CCDR successfully applied for an arms-length grant from GSK Australia to implement this protocol in Australia.

Pillar 4: Reorient Health Systems

Pillar 4

Our societies are complex and interrelated. Health cannot be separated from other goals. The inextricable links between people and their environment constitutes the basis for a socioecological approach to health. The overall guiding principle for the world, nations, regions and communities alike, is the need to encourage reciprocal maintenance - to take care of each other, our communities and our natural environment. The conservation of natural resources throughout the world should be emphasized as a global responsibility.

Changing patterns of life, work and leisure have a significant impact on health. Work and leisure should be a source of health for people. The way society organizes work should help create a healthy society. Health promotion generates living and working conditions that are safe, stimulating, satisfying and enjoyable.

Systematic assessment of the health impact of a rapidly changing environment - particularly in areas of technology, work, energy production and urbanization - is essential and must be followed by action to ensure positive benefit to the health of the public. The protection of the natural and built environments and the conservation of natural resources must be addressed in any health promotion strategy.[1]

Pillar 3: Reorient Health Systems			
Proposed APON Program Outcome(s)	**Activities**	**Report**	**Indicator**
Outcome 4.1: Increase engagement between patient organisations, decision-makers, key health agencies and stakeholders to ensure that the needs of the individual - as a whole person - are addressed in health programs , research and policies	4.1.1: Develop working groups within APON, and engage relevant key health agencies across the areas of**: - Access to medicines and health technology (including PBAC, MSAC, TGA) - Research (NHMRC, MRFF) - Clinical trials and clinical registries - Health services/Health system and Navigation - Digital health (My health record and emerging technologies) - Vulnerable populations - Vulnerable issues (special issues addressing stigma, palliative care, pain management and mental health)	14 interest group webinars/workshops have been held. There has not been enough interest in the vulnerable populations interest group so this one did not go ahead. The Clinical trials and clinical registries, and Research groups have amalgamated, as have the Digital health and Health services/Health system and Navigation groups. Three projects have emerged from the interest groups and additional information about these projects is provided below. The projects are: The Access to medicines and health technology group: Testing questions to understand the impact of a condition/disease on a patient's life. Clinical trials and clinical registries, and Research group: Identifying the roles that patient organisations can play to support clinical trials and research Health services/Health system and Navigation group: An audit of patient organisations in Australia to understand our contribution to the health system and make it easier for patients to navigate services.	

Pillar 4: Reorient Health Systems			
Proposed APON Program Outcome(s)	Activities	Report	Indicator
	4.1.2: Develop a central system where patients can register to be involved in research, policy, program development etc., and be connected with researchers, policy-makers, program developers etc. that are seeking patient input.	The infrastructure has been built to be able to do this and the process is currently being testing in a small pilot project in oncology. The results will be reported and determine whether this can be rolled out at scale or modelled so that individual patient groups can set up their own system.	■

The Access to medicines and health technology group: Testing questions to understand the impact of a condition/disease on a patient's life

Members of the access to medicines and services interest group participated in an online workshop. Participants were asked to Imagine that nothing exists in relation to community/patient feedback and engagement in health technology assessment (HTA), i.e. that there is no community portal and no mechanism for feedback. This aimed to get participants to think outside of and not be constrained by the current system.

As a starting point, participants were asked 'What questions would you ask patients and families to understand what everyday life is like for them?' (The answers to these questions would be used to educate decision-makers on the impact of the disease/condition).

The second thing participants were asked is to think about their patient community and their everyday life. What are some of the things that would improve their quality of life? (This question aims to be demonstrative of quality of life and also lead us to develop a set of values important to patients and families.)

When responding to the question, we asked for a 'statement' and an 'impact'. For example: If our patients could have better upper arm strength, they would be able to prepare their own meals and do light housework. This would improve their quality of life as they would be able to be more independent.

From the workshop we have a preliminary list of questions that are important to the community in the context of HTA. The project that we will take forward it testing and validating the questions (via telephone interview). The question validation process includes 1) making sure the questions make sense to participants and result in responses that fit the question, and 2) making sure we can trust the data in different settings. We aim to test the questions in participants across a range of disease areas (rare disease, chronic disease, oncology, autoimmune disease, disabilities) and a range of demographics (age, location, education, ethnicity, socioeconomic status).

CCDR has also conducted workshops with international stakeholders (Health Technology Assessment agencies and health economists) from Canada, USA, UK, Australia, Netherlands, South Africa and Taiwan to add to the community's questions and CCDR will commence consolidating and testing questions with patients.

CCDR successfully applied for an arms-length grant from AstraZeneca Australia to conduct this project.

Clinical trials and clinical registries, and Research group: Identifying the roles that patient organisations can play to support clinical trials and research

Members of the clinical trials and research interest group participated in an online workshop. They were asked to imagine that there is a non-profit research grant round through the government (for example through the Medical Research Future Fund).

As a starting point, they were asked what kind of research they would like to conduct (for example to evaluate and build the evidence in relation to peer support programs or collect patient experience data to inform decisions). Participants were then asked to think about clinical trials and how their organisations had been involved in clinical trials in the past. They were asked to list the unique roles that patient organisations play in clinical trials.

The final question participants were asked was in relation to eligibility criteria. Every research grant program has eligibility criteria, but what would a patient organisation need to have in place to conduct research internally, that is fit-for-purpose for the type of research they are interested in?

From the workshop we have a preliminary list of research areas and clinical trial support that patient organisations are interested in. As a next step, CCDR will conduct additional consultation with the broader APON network to 1) consolidate this list and, 2) for the types of research and clinical trial support activities that result from this work, conduct some research to analyse the cost and resources needed.

This will result in a community-driven approach research and if a subsequent funding pool is made available through the government, it will provide the community with the independence to conduct research activities and clinical trial support activities that are important to them and their communities.

CCDR successfully applied for an arms-length grant from AstraZeneca Australia to conduct this project.

Health services/Health system and Navigation group: An audit of patient organisations in Australia to understand our contribution to the health system and make it easier for patients to navigate services.

This interest group participated in a workshop to discuss the kinds of services provided by patient organisations e.g. connect patients with specialist care, homecare services or mental health support, open up opportunities to participate in and clinical trials, provide information and advocacy.

CCDR has developed a patient organisation register and as a next step, will seek funding to conduct a more formal audit of patient organisations in Australia. An audit methodology has been developed to identify patient organisations and the next step would be to work with the APON community to agree on the classifications that we need to use to characterise the contribution of patient organisations to the health system. Classifications would be things like Telehealth services, information services, support groups, advocacy, research (funding), research (conducting internally) and so on.

This work is aligned with the overarching goal of APON to increase awareness of the work patient organisations do and their contribution as part of the health system. This will help patient organisations articulate their value and to use this as the basis of grant and funding applications in the future. The tools resulting from this will also make it easier for patients to navigate the services available to them through patient organisations.

Funding has not yet been secured to conduct the audit.

Pillar 5: Build Healthy Public Policy

Pillar 5

Our societies are complex and interrelated. Health cannot be separated from other goals. The inextricable links between people and their environment constitutes the basis for a socioecological approach to health. The overall guiding principle for the world, nations, regions and communities alike, is the need to encourage reciprocal maintenance - to take care of each other, our communities and our natural environment. The conservation of natural resources throughout the world should be emphasized as a global responsibility.

Changing patterns of life, work and leisure have a significant impact on health. Work and leisure should be a source of health for people. The way society organizes work should help create a healthy society. Health promotion generates living and working conditions that are safe, stimulating, satisfying and enjoyable.

Systematic assessment of the health impact of a rapidly changing environment - particularly in areas of technology, work, energy production and urbanization - is essential and must be followed by action to ensure positive benefit to the health of the public. The protection of the natural and built environments and the conservation of natural resources must be addressed in any health promotion strategy.[1]

Pillar 5: Build Healthy Public Policy			
Proposed APON Program Outcome(s)	**Activities**	**Report**	**Indicator**
Outcome 5.1: Provide the evidence to inform key policy and funding decisions, based on the experience and needs of patients	5.1.1: Develop health program and research impact measures that reflect the values that are important to patients and patient organisations	As a first step, the result of the access to medicines and health technology group: Testing questions to understand the impact of a condition/disease on a patient's life, will inform this activity. The responses that patients provide will be analysed from a values perspective. These will then be taken back to the APON Standing Committee to discuss next steps for further consultation with the APON community.	
	5.1.2: Prospective research methodologies and pilots to test best practice community engagement systems in various contexts including health technology assessment, health services, research and community-based programs	Evaluation and pilots are core to all of the APON program of work. This is evidenced by the projects that have resulted from the interest groups as well as this annual report.	
This is existing CCDR work included in the APON program of work to acknowledge that it was raised by the APON community but included to avoid duplication.	5.1.3: Develop and validate levels of evidence for patient experience, patient feedback and real-world data	This is in progress. A group of patient organisations participated in a workshop to scope the different kinds of evidence generated to identify the kinds of evidence that are used in patient feedback and real-world data generation. As a next step, CCDR will need to secure funding to take this work forward.	
This is existing CCDR work included in the APON program of work to acknowledge that it was raised by the APON community but included to avoid duplication.	5.1.4: PEEK repository of patient experience and expectation data and integration of this data into decision-making processes	CCDR have tested the feasibility of routine collection of both qualitative and quantitative data. This is the Personal Experience, Expectations and Knowledge program (PEEK) and CCDR hold the largest repository of systematic patient interview data in the world.	

---

[1] World Health Organisation. (1986). *Ottawa Charter for Health Promotion: First International Conference on Health Promotion Ottawa, 21 November 1986.* https://www.healthpromotion.org.au/images/ottawa_charter_hp.pdf

Develop and validate levels of evidence for patient experience, patient feedback and real-world data

Stream 1:
In the first session of the workshop, the Committee discussed the general principles of patient experience evidence, that is what should be considered when developing patient evidence. The principles identified included:

• Geographically and demographically balanced
• Evidence developed is holistic, that is it encompasses diagnosis, treatment, information, communication, support and care
• Acknowledges the practical considerations that are important to patients and their families
• Has transparency in recruitment or engagement strategies used to develop the evidence (inclusion/exclusion criteria, intervention)
• Provides evidence of patient needs

To differentiate between patient experience data and patient/patient organisation engagement, a discussion was then held in relation to the principles of patient organisation engagement. The following principles were identified and demonstrate what patient organisations expect/require in order to gain feedback from their patient population in a meaningful way:
• Resourcing
    • Proposals should include a budget to support non-profit organisations if that this is part of the recruitment or engagement strategy
    • Alternatively, there needs to be a pool of money for non-profit organisation to apply to to support recruitment or engagement of patients
• Demonstrate some understanding of the patient organisations working in the disease area and rationale for selecting/not selecting to work with specific groups
• Evidence of patient and/or patient group consultation at all stages of development to promote the highest level of translation possible
• Demonstrates a plan for recruitment/engagement of the patient community that it is geographically and demographically diverse
• Provides evidence of patient need: What is the patient-driven challenge that has been identified?

The main focus of the first session was to build a hierarchy of evidence in relation to patient experience data (just as there are levels of evidence for clinical data).

The Committee discussed and listed the type of data that is available to them and ranked these in relation to the principles of patient experience data previously discussed. A ranking exercise was conducted in the context of diseases that had large populations and those that had small populations or were rare diseases.

Table 1 below is the draft ranking of levels of evidence for patient experience data, with I being the most valued and IX being the least valued.

Level of Evidence	Large population	Small population/Population sub-group
I	Questionnaire/Structured Interview (mixed methodology)	Questionnaire/Structured Interview (mixed methodology)
Ii	Structured Interview	Structured Interview
III	Questionnaire (Validated)	Focus group (multiple with diversity)
IV	Focus group (multiple with diversity)	Individual comments (With transparency)
V	Individual comments (With transparency)	Unstructured/Semi-structured interview
VI	Unstructured/Semi-structured interview	Focus group (single)
VII	Questionnaire (Not validated)	Individual comments (Without transparency)
VIII	Focus group (single)	Questionnaire (Validated)
IX	Individual comments (Without transparency)	Questionnaire (Not validated)

The Committee then discussed the broad influences on developing good quality patient experience data, that is, what makes a difference to the quality of the information. This included:

a. Who is participating in the patient experience research
Patient population (Characteristics, demographics, size, disease stage etc.)

b. Who is conducting the patient experience research
Level of expertise consistent with what you are trying to achieve. This includes:
•Ability (technical) and ("soft skills")
•Driver and motivation (transparency)
•Objectivity vs subjectivity

The Committee felt it was important to separately discuss the use of case studies. To this end, it was agreed that case studies provide the context of the situation. These should be used to clarify or complement other data to provide the narrative of the data, but are not necessarily representative of the patient population.

Stream 2: Transparency
The challenges in transparency that were addressed in the second session were in relation to the lack of information provided to patient organisations when being asked to provide feedback. This might be feedback in the context of research, policy, health service development or health technology assessment.

The Committee developed a set of questions that they felt needed to be answered in order to provide informed comments in order to aid transparency (noting that for full transparency, the group requesting feedback needs to provide some form of response to the patient organisation in relation to their understanding of the feedback and how the feedback has been incorporate in their decision-making) :

•How were patients involve in the development? Tell us the story of the development.
•Patients are not their disease: How does this treatment/program/policy/test/device improve the overall quality of life of the patient? Do you have evidence of this?
•Who is the submission/project for? i.e. is there a sub-group that will benefit (more/specifically) or is it the whole patient population?
•What type of clinical data is being used to support this submission?
•What type of patient data is being used to support this submission? (Patient-driven question? Patient reported outcomes?)
•Efficacy: what does this treatment/device/research/project/policy do for patients?
•How is it better or different to the current situation?
•What are the practical/holistic/emotional considerations in relation to the proposed change?
•What is the burden of treatment? How is it administered/impact/accessed?
•What are the practical implications including for example travel, time, recovery etc.? Burden of process/time required?
•What are the other treatment options/research/programs etc. currently available?

Stream 3: Meaningful dialogue with decision-makers

Throughout the workshop, the challenges in relation to funding in the non-profit sector arose. It was identified that there are no avenues of funding available for projects that aim to support patients in the health system or for core activities of non-profit organisations. To this end, the Committee agreed that a key message to decision-makers would need to be to demonstrate the value of the non-profit sector and what the health sector would look like in the absence of patient organisations. The overall aim would be to advocate for a pool of funding that patient organisations could apply to in order to support their critical work. It was proposed that this be the key message to the Minister for Health.

Pillar 6: Moving Into The Future

Pillar 6

Our societies are complex and interrelated. Health cannot be separated from other goals. The inextricable links between people and their environment constitutes the basis for a socioecological approach to health. The overall guiding principle for the world, nations, regions and communities alike, is the need to encourage reciprocal maintenance - to take care of each other, our communities and our natural environment. The conservation of natural resources throughout the world should be emphasized as a global responsibility.

Changing patterns of life, work and leisure have a significant impact on health. Work and leisure should be a source of health for people. The way society organizes work should help create a healthy society. Health promotion generates living and working conditions that are safe, stimulating, satisfying and enjoyable.

Systematic assessment of the health impact of a rapidly changing environment - particularly in areas of technology, work, energy production and urbanization - is essential and must be followed by action to ensure positive benefit to the health of the public. The protection of the natural and built environments and the conservation of natural resources must be addressed in any health promotion strategy.[1]

Pillar 6: Moving Into The Future			
Proposed APON Program Outcome(s)	**Activities**	**Report**	**Indicator**
Outcome 6.1: Increase visibility and leverage the position of patient organisations in Australia, as professional partners who work with patients in the settings of their everyday life	6.1.1: Develop a national campaign to increase awareness of the role and services provided by patient organisations, and increase health professional referrals to patient organisations	This activity is yet to commence however it is the focus of the 2021 APON conference. An expression of interest has been opened to public relations and government relations agencies to provide pro-bono support to the APON community to develop the messaging around a national campaign.	
	6.1.2: Develop a system to classify patient organisations according to the services they provide	This activity has cross over and is aligned with the Health services/Health system and Navigation group where an audit of patient organisations in Australia to understand our contribution to the health system and make it easier for patients to navigate services. The audit will be the first step in classification of activities conducted by patient organisations. The next step addressing this activity will be to work with the APON community to see if there are overarching classification to distinguish in a positive way different types of patient organisations for example those that focus on research, those that focus on support and information and those that include a broader range of services and activities.	

---

[1] World Health Organisation. (1986). *Ottawa Charter for Health Promotion: First International Conference on Health Promotion Ottawa, 21 November 1986.* https://www.healthpromotion.org.au/images/ottawa_charter_hp.pdf