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National Patient Organisation Network (NPON)

2025 Conference Report

The National Patient Organisation Network (NPON) convened in Brisbane in July 2025 under the theme “Sustainability for Equity.” The central focus was on strengthening patient organisations so that they remain resilient, effective, and credible advocates in the face of rising demand and limited resources.

The structure of the day was four sessions with a speaker, question time and then workshops with discussions that were structured around four interlinked areas:

1. Leadership in non-profit patient organisations.
2. Efficiencies in operations and collaboration.
3. Code of conduct and organisational culture.
4. Infrastructure and core funding sustainability.

Speakers emphasised that language matters. Referring to people as “consumers” risks depersonalising their experience and is an inherently problematic term. Patients are people with lived diagnoses, and their families are often deeply affected. Advocacy should begin from this recognition, ensuring that representation is not abstract but grounded in *connection, showing up, and amplifying patient experience as evidence*.

There were seven workshop tables, and each table discussed the issues and solutions with a scribe to take notes.

The following are the consolidated notes from each of the eight workshop tables.

Key points

- **Advance planning for consultations:** at least 6–12 months is essential for meaningful patient consultation.
- **Consultation process:** must involve patients and families early, using varied and stringent methods.
- **Leadership:** authenticity, adaptability, accountability, and succession planning are critical.
- **Code of Conduct:** values must be visible in organisational culture, policies, and practice.

- **Efficiency:** collaboration, shared services, structured volunteer management, and IT solutions are core enablers.
- **Infrastructure Funding:** should be reframed as *value-based health investment* rather than “overheads.”
- **Advocacy:** most effective when collective, opportunistic, and rooted in the stringent patient experience data.

Planning, Consultation, and Timelines

One of the strongest themes was the importance of realistic timelines for consultation and planning. Patient organisations reported that they often receive requests for input with inadequate notice, leaving little room to mobilise their members. The group agreed that a minimum of 6–12 months is needed for full consultation cycles, allowing organisations to plan resourcing, secure input, and meet governance requirements. It was noted that in relation to government consultations, these are known in advance as government agencies also need to plan and resource these and there should be no delay in communicating consultation timelines and setting a calendar for consultations.

The key milestones in such a cycle typically include internal planning and scope setting, followed by structured patient and family consultations. These are complemented by stakeholder consultations that extend to clinicians, external partners, and allied organisations. Drafting, internal review, external partner feedback, and quality assurance processes follow before dissemination and advocacy can begin.

Consultation methods should be diverse: surveys to reach wide groups, focus groups and interviews for deeper insights, and workshops or online forums to gather collective perspectives. To deliver these processes, organisations need clinical and consumer advisory groups, communication and IT staff, trained facilitators, and appropriate budget allocations for travel, transcription, and design.

For quality assurance, at least four to six weeks should be set aside to draft, review, and edit documents that incorporate patient perspectives. To manage uncertainty, a contingency buffer of four to six weeks was recommended. This allows for delays caused by low response rates, staff turnover, or changes in government deadlines. Importantly, external partners should be asked to provide sign-off no later than eight weeks before final publication.

Code of Conduct

This session highlighted that patient experiences and data must be central to all submissions. Timelines should balance efficiency with realism:

- 2–3 months for consultation, preparation and submission.
- 6–12 months for response from government (but avoid prolonging uncertainty).

To give weight to submissions, it was noted that collaborative approaches, particularly where multiple patient organisations come together, might be considered.

Best practice for patient organisations includes:

- Prioritising opportunities of greatest value.
- Collaborating where possible, whether via informal partnerships, formal alliances, or using external facilitators.
- Maintaining clarity and consistency in messaging across multiple submissions and government engagements, ideally through a common advocacy platform.
- Balancing written submission work with proactive, ongoing engagement.

Advocacy

Advocacy was described not as abstract lobbying but as humanising patient experience in the eyes of policymakers, media, and the broader community. A respectful approach is necessary: patients should not be overburdened by repeated requests to relive distressing experiences.

Effective engagement strategies include direct meetings with MPs, Ministers, and other leaders. State and federal advocacy require distinct approaches, but both are essential. The formation of alliances was discussed as a way that has amplified impact.

However, the realities of government engagement are often frustrating. Responses are delayed, sometimes piecemeal, and rarely provide a feedback loop. Grants are vulnerable to clawback if funds are not spent within a set timeframe with little flexibility. The most recent department briefing to the health minister was quoted as cautioning against “too many consultations,” arguing that they raise expectations among patients and the public.

The practical advice offered by experienced leaders was consistent: perseverance and timing are critical, face-to-face engagement is most effective, and patient experience using strong methodologies for data collection is the most powerful advocacy tool. It was also noted that there are times where we do ‘everything right’ yet still may not be successful.

Collaboration and Mergers

Collaboration was presented both as a necessity and a challenge. The merger of Arthritis NSW and QLD was highlighted as a case study. Initiated during the COVID era, the process took three years, beginning with shared services such as HR, IT, and webinars before progressing to a formal merger. Trust between boards was built gradually, resulting in a stronger governance framework, unified financial management, and a significantly expanded patient reach.

The reflections from this case emphasised that mergers require substantial time and financial investment but should be reframed as strategic growth rather than organisational failure. Patients ultimately benefit from more integrated care and a broader reach of services.

Barriers remain, particularly in federated models such as Motor Neurone Disease organisations, where national integration is difficult. Personality clashes, organisational egos, and uneven maturity across organisations also hinder collaboration. The lessons learned point to starting small - with shared projects and IT systems - while seizing opportunities when political or funding contexts shift in favour of cooperation.

Leadership

The plenary explored what makes an effective leader in a patient organisation. Core traits identified included empowerment, trustworthiness, accountability, collaboration, reliability, transparency, goal orientation, adaptability, self-awareness, passion, and intuition.

Leadership in the not-for-profit space must be authentic and adaptable, capable of balancing personal values with the mission of the organisation. A duty of care is essential in dealing with patients and stakeholders.

The challenges are well known. Founder’s Syndrome - where leaders struggle to let go beyond a time that supports a flourishing organisation – remains common and is an understandable human response. There is also a risk of co-dependency, where personal identity becomes entwined with the cause. While lived experience is invaluable, it does not automatically translate into leadership capability; governance and business skills are also needed. Many groups struggle with succession planning, particularly where leadership is voluntary. It was noted this is also because a lack of funding may be a barrier to succession, with a founder being the only one willing to sacrifice to keep an organisation going.

Governance practices that can support strong leadership include trained and diverse boards, documented codes of conduct, active succession planning, and mentoring.

Leadership Characteristics

This discussion identified universal leadership traits required for success:

- Vision and influence.
- Continual learning.
- Ambition and restlessness (always striving to do better).
- Integrity, trust, and ethics.
- Resilience.
- Self-awareness.
- Understanding and empathy, especially for patients and beneficiaries.

For all organisations, passion and adaptability were seen as essential. For organisations, cultural leadership becomes critical: the ability to create a team that grows beyond the founder or CEO, and the capability to understand corporate basics such as governance, compliance, and operations.

Code of Conduct

Developing and living by a code of conduct was described as central to organisational integrity. A code builds trust with patients, clinicians, funders, and government by setting behavioural standards for staff, volunteers, and board members.

The core values should include integrity, transparency, inclusivity, accountability, respectful communication, and a strength-based, empowering culture.

In practice, this means having clear constitutions and governance documents, investing in training (from governance basics to accidental counsellor skills), enforcing conflict-of-interest policies (particularly around pharma partnerships), and ensuring transparency in both decision-making and finances.

The risks of neglecting conduct include personality conflicts, over-reliance on lived experience without governance checks, and failure to adequately protect patients' duty of care.

Infrastructure and Core Funding

Participants highlighted the persistent challenge of funding infrastructure, defined as the operational costs that keep organisations running—salaries, office space, IT, insurance, legal compliance, governance processes, and volunteer management.

These costs are often excluded from grants, with funders preferring to support projects. Smaller organisations are especially vulnerable, with too many CEOs across fragmented groups leading to inefficiencies.

To justify infrastructure spending, organisations should demonstrate social and economic impact. Transparent reporting is also crucial, through regular treasurer updates, newsletters, social impact reports, and clear financial breakdowns.

Strategies include diversifying income streams, combining government funding with sponsorships, fundraising, and pro bono support. Income generation activities, such as Cystic Fibrosis Queensland's bookshop, can offset costs. Partnerships with universities and corporates provide additional stability.

The case of Cystic Fibrosis Australia illustrated these principles. Facing $800,000 in debt, the organisation restructured, sold unsustainable assets, downsized its office, and introduced new revenue streams. Market-based salaries were introduced to attract skilled staff, transforming its financial sustainability. It was noted that this is not possible in many small organisations where staff may be voluntary or only be able to afford small salaries and they should not be judged for this.

Amplify Impact Fund

An innovative idea discussed was the Amplify Impact Fund. This fund would enable patient organisations to focus on patient support rather than administration by providing centralised back-office services.

The fund would be an entity, administered independently but co-designed with patient organisations, offering services such as:

- CRM systems, IT, HR, finance (bookkeeping, reporting, receipting).
- Legal and company secretarial support.
- Policies, procedures, and strategic planning.
- Contact centre functions, including AI-driven chat functions and triage.
- Marketing, social media, and website support.
- Central research, patient information development and project support.

An expert pool of consultants would also provide limited hours of free advice on governance, government advocacy, and collaboration. Sub-funds could support collaboration, research administration, or provide emergency stabilisation support for organisations in distress.

Eligibility would be limited to ACNC-registered organisations with turnover under $2 million, with larger groups able to participate for a fee below market rates. No money would flow directly to organisations; instead, the value would be in freeing time, money, and energy for patient outcomes. A pilot model involving 10 organisations was proposed.

> "We call on all patient organisations to extend the same care and support to one another as we give to the patients we represent."

Efficiencies in Practice

Efficiency gains were explored across multiple dimensions. Opportunities include natural collaborations, shared services (finance, IT, HR), outsourcing specialist tasks, integrating volunteers and students, and embracing remote or virtual working models.

Yet risks are real: personality clashes, misaligned values, and uneven organisational capacity can derail collaboration. The recommendations were to begin with a needs analysis, pilot small, shared projects, adopt common governance templates, and frame collaborations as “bundled problems” that government is more likely to fund.

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The National Patient Organisation Network is hosted by the Centre for Community-Driven Response

Registered delegates

TABLE 1

Helen Jentz	MSK Australia (Facilitator)
Suki Sun	Scribe
Alex Green	Arthritis Movement
Sarah Gray	ausEE Inc.
Kate Legg	Scleroderma Australia
Ryan Ginard	Minderoo
Julie Andrews	HCF

TABLE 2

Petrina Fraccaro	Cystic Fibrosis Queensland (Facilitator)
Eliza Cowan	Scribe
Debbie Singh	Palliative Care Queensland
Madelene Rich	CHARGE Syndrome Australasia
Toni Catton	Mito Foundation
Kylie Pussell	Miracle Babies Foundation
Jim Toohey	Carers Queensland
Radhika Arunkumar	Her Heart

TABLE 3

Carolyn Dews	The Immune Deficiencies Foundation of Australia (IDFA) (Facilitator)
Nujhat Mubarrat	Scribe
Meredith Cummins	Neuroendocrine Cancer Australia
Victoria McCulloch	ozED Australian Ectodermal Dysplasia Support Group
Sandi Rodiger	Epilepsy Queensland
Ash Webb	QENDO
Rachael Nowak	Beigene
Kelly Oldham	Cerebral Palsy Support Network

TABLE 4

Adam Lynch	BEAT Bladder Cancer Australia (Facilitator)
Darlene Balanag	Scribe
Agness M Nsofwa	Australian Sickle Cell Advocacy Inc
Catherine Stace	Muscular Dystrophy Australia
Lisa Moore	CMT Australia
Maria Kemper	22q
Kathlene Jones	Prader-Wili Research Foundation of Australia
Helena Sfelagis	GSK

TABLE 5

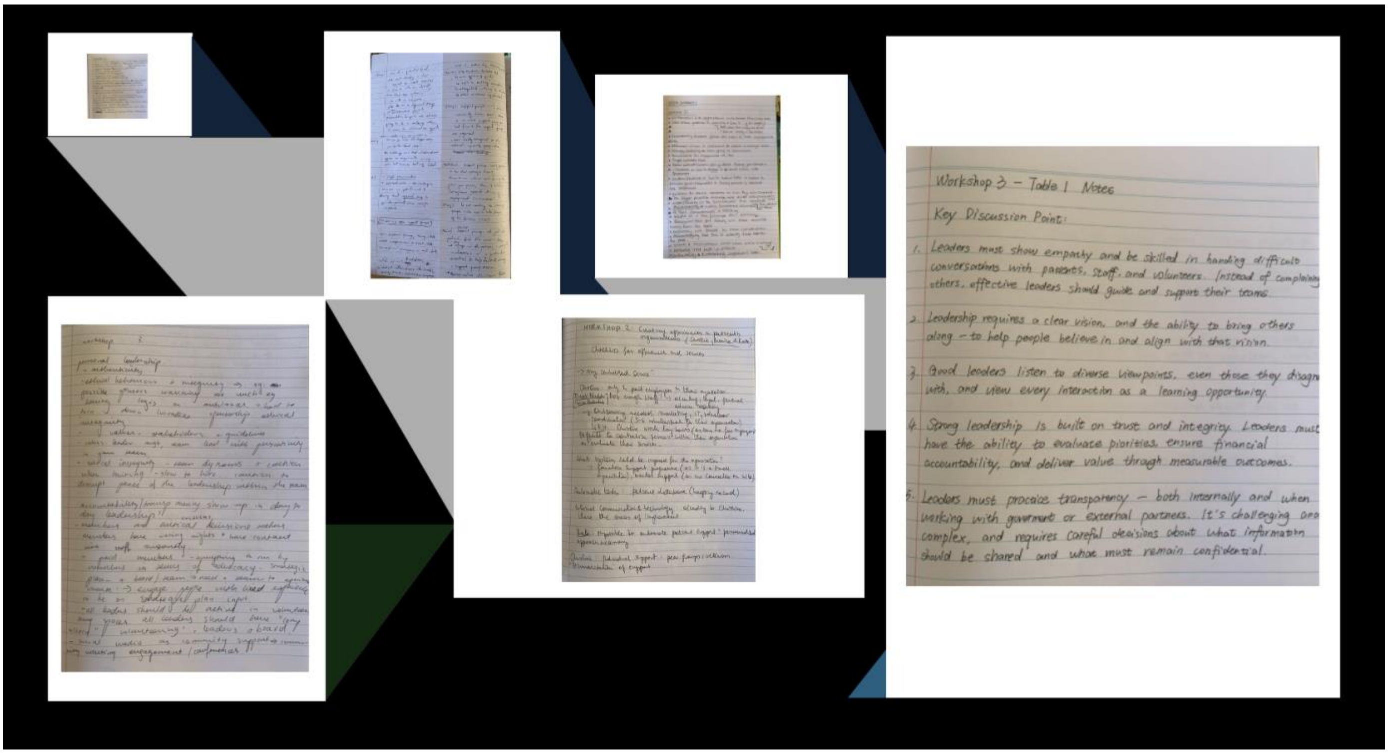
Dalal Baumgartner	SATB2 Connect (Facilitator)
Natasha Singh	Scribe
Chris Walker	Parenteral Nutrition down Under Inc
Jennifer Mocker	Cystic Fibrosis Queensland
Emmy O'Neill	Transplant Australia
Lysandra Callahan	Angelman syndrome Association Australia
Brooke Howard	Novartis
Gavin Marshall	Sjogrens Australia

TABLE 6

Kate Holliday	CCDR (Facilitator)
Sylwia Turlej	Scribe
Christine La Rose	BEAT Bladder Cancer Australia
Jo Armstrong	Cystic Fibrosis Australia
Louise O'Neill	Palliative Care Queensland
Leonie Hogarth	Epilepsy Queensland
Linda Foran	Vertex
Jess Taylor	QENDO

TABLE 7

Jackie Gambrell	Tuberous Sclerosis Australia (Facilitator)
Penny Deavin	Muscular Dystrophy Queensland
Jude Kalman	Eczema Support Australia
Robert Bird	ITP Australia New Zealand
Rachelle Panitz	So Brave
Daria West	Sjogrens Australia
Alistair Beasley	Miracle Babies Foundation
Jasmine Ranken	Cleft Connect Australia
Adriana Grillo	Novartis



Workshop 3 - Table 1 Notes

Key Discussion Point:

1. Leaders must show empathy and be skilled in handling difficult conversations with patients, staff, and volunteers. Instead of complaining others, effective leaders should guide and support their teams.
2. Leadership requires a clear vision, and the ability to bring others along - to help people believe in and align with that vision.
3. Good leaders listen to diverse viewpoints, even those they disagree with, and view every interaction as a learning opportunity.
4. Strong leadership is built on trust and integrity. Leaders must have the ability to evaluate piorities, ensure financial accountability, and deliver value through measurable outcomes.
5. Leaders must practice transparency - both internally and when working with government or external partners. It's challenging and complex, and requires careful decisions about what information should be shared and what must remain confidential.

During the conference, 109 pages of notes were taken by the following scribes. We thank them for their time and contribution. We also thank NPON members who were table facilitators