National Patient Organisation Network Poll: Access to funding for patient experience initiatives

Background

Empowering patient organisations to conduct their own patient experience research is essential for promoting patient-centered care. Patient organisations often have the closest connection to their patient populations and provide valuable insights into their needs and preferences. We recognise that studies have demonstrated that when patients actively participate in research, the findings are often more relevant and reflective of their lived experiences (Carman et al., 2013) and that this approach shifts the power dynamics in healthcare, ensuring that decisions about care are informed by those who experience it firsthand (Domecq et al., 2014).

The issue we raise here is however about empowering patient organisations to lead and innovate in the field of patient experience data collection and reporting, not as a purely academic exercise, but one that directly informs and enhances the quality of life, in a timelier manner. While maintaining a systematic, but not institutionalised, approach, patient organisations can ensure that research is fit-for-purpose and evidence-based, yet flexible enough to adapt to the evolving needs and experiences of the patient community.

Funding patient groups to conduct their own patient experience research is a critical step in ensuring that patient perspectives are meaningfully incorporated into healthcare improvements. Providing financial support allows patient groups to take ownership of the research process, from designing studies to analysing and disseminating findings. Research has shown that when patients are given the resources to lead research efforts, the research is often more aligned with their actual needs, leading to more relevant and actionable outcomes (Carman et al., 2013). Additionally, funding can help overcome barriers such as lack of expertise or access to research tools, empowering patient groups to engage more deeply in patient experience activities. Without appropriate financial resources, patient-led research initiatives may struggle to gain the credibility and scope needed to influence healthcare policy or practice (Domecq et al., 2014, Greenhalgh, T., et al. 2016).

Some of the challenges with academic-led patient experience initiatives is that they can potentially lead to frameworks that do not fully capture the complexities of patient care (Carman et al., 2013). Studies have highlighted that patient perspectives are often inadequately integrated into the development of research methods, resulting in a gap between research findings and real-world application (Domecq et al., 2014). This disconnect can undermine the effectiveness of patient experience research in improving care quality and policy.

Current models of funding are primarily academic led, with patient organisations invited to participate. There is no reason why the opposite isn't possible where patient experience data collection and reporting is led by patient organisation who then invite academic support if it is needed.

To maximise the impact of patient-led research, funding structures should prioritise sustainability and capacity-building within patient groups. This includes not only providing grants for specific projects but also supporting long-term initiatives that develop the skills, infrastructure, and networks necessary for ongoing, patient-led efforts (Simpson et al., 2020). Such funding models encourage the creation of patient-led research networks that can sustain collaborative efforts over time. Supporting patient groups in this way helps to ensure that patient-cantered care remains a priority in healthcare system development, as evidenced by studies indicating that patient-driven research leads to improved healthcare services (Fournier et al., 2018).

A well-funded model that fosters patient organisation-led initiatives, designed and implemented by patient organisations, is essential to advancing patient empowerment and improving healthcare outcomes, and would likely come at a lower economic cost.

NPON poll

A number of patient organisations within the National Patient Organisation Network (NPON) have raised the issue of access to funding to support patient experience data collection and reporting over the past five years.

With the recent Medical Research Future Fund (MRFF) announcement to provide a grant to incorporate patient data into health technology assessment ($16 million available with up to $2 million per grantee), this was an opportunity to connect with NPON members on this issue.

Interested members were polled with 31 patient organisations indicating their views. The results of the poll are below. To note: It was a requirement of the poll that patient organisations responding would be listed for transparency. One NPON member did not want their name listed and this organisation was therefore excluded from the poll responses.

Does your organisation feel that patient organisations should be able to independently apply for the MRFF grant?

	%	n=31
Yes	93.55%	29
No	3.23%	1
Other (Please specify)	3.23%	1

Does your organisation feel that a proportion of this funding should be earmarked for patient organisations to build capacity for them to be able to independently collect patient experience data.

	%	n=31
Yes	96.77%	30
No	3.23%	1
Other	0.00%	0

If you had funding, does your patient organisation feel that you have the internal capacity and expertise to either implement this kind of work or coordinate/lead a team of experts to implement this kind of work?

	%	n=31
Yes	74.19%	23
No	25.81%	8
Other	0.00%	0

The final question was open text for comments. These are presented below:

Patient organisations are literally at the forefront of patient experience and should be supported to conduct this kind of work.

The ongoing challenge lies not only in advancing rare disease research in Australia but also in fostering global collaboration across clinical settings.

The value (in economic, productivity, social and well being terms) of understanding and responding to patient/health consumers needs and delivering patient desired outcomes is well established. Value-based health care is about achieving the best possible outcomes for people receiving care, with the lowest possible use of resources. This is an opportunity to invest in value based health care by supporting patient organisations.

We are already doing a lot of this work unfunded which means we rely on fundraising activities, so this is a precarious way to fund essential work

I believe that gaining traction via MRFF funding by coming together under an umbrella such as the CCDR would be wise as they have the expertise in navigating contracts of this size and also they would bring multiple patient organisations to attain sustainable development for their communities.

As a small volunteer-run organisation it would cause increased stressors and therefore become a non-sustainable effort.

In our experience, too often collected patient data used by researchers and the medical profession still rarely includes meaningful insights from the key people - patients. We take this opportunity to encourage government to include a patient-focused and patient-driven approach to data collection. To efficiently facilitate this, we recommend funding a suitable collective patient organisation such as the National Patient Organisation Network (NPON) to assist patient groups build capacity in patient data collection. The aim would be to develop data collection systems that are robust, standardised, quantitative as well as qualitative regarding experience, and useful for researchers, medical and allied health professionals, patients, patient groups, and policymakers. Inclusion of such patient data would provide low-cost but highly valuable insights.

Embedding patient data within a research solution is a critical component of our research strategy and data design. Muscular Dystrophy Australia securely holds valuable patient data that has the potential to become meaningful within a MRFF funding model in partnership with Institutes. The inclusion of NFP's into the MRFF funding of patient experience data serves to protect the patient, housed within an ethical, compliant NFP governance and relationship management framework that is a core business of NFP's, enabling Institutes to focus on their core business of research, creating impact across clinical trial preparedness, patient recruitment and ongoing data analysis for research purposes. By working with NFP's as a key stakeholder, the MRFF will stimulate public/private and philanthropy partnerships that deliver end-to-end solutions, enabling trusted NFP's to continue to manage the patient relationship, which can often be complex and time-consuming for an Institute to establish, manage and maintain the governance, human resources and systems framework. The MRFF holds the power to enable Institutes and NFP's to keep to their core business, utilise their assets, and together, make an impact sooner.

I ticked no as I don't believe many patient organisations (and specifically ours) have the capacity for such projects - ie, not registered research organisations with capacity for ethics review, storage, oversight, library access, legal teams and alike. I do believe there are ways to prioritise the expertise in patient organisations and that these should be explored further. From my experience sometimes the inclusion of consumers or patient organisations in MRFF studies is simply tokenism/box ticking and that should be investigated - there should be follow up to see if the aims for consumer involvement and sharing of power was achieved - particularly when reported as codesign studies. I do believe there should be funding to build capacity in patient organisations and organisation led activities to collect data should be supported, but I'm not sure this is the stream/program for it. I also recognise that other patient organisations may have capacity that we don't so there may be vastly different views (something that sounds with to research, too!).

We have a significant amount of data that we require in order to do a submission to the MSAC. We however have no funding and so can't make headway.

Inclusion of Patient Organisations in all research work. Dedicated funding for specific cancers to enable equity of funding for cancers other than the main stream.

We believe that patient organisations have the ability to lead research efforts in this area, through projects like the Mito Stories Project. This project exemplifies how patient organisations are best placed to gather, analyse and share insights rooted in lived experience through a formal research framework. While we recognise the benefits of an academic approach to addressing this challenge, it is essential that this is accompanied by a demonstrated commitment to resourcing patient organisations for their contributions. Patient organisations are uniquely positioned to connect with their communities and ensure that the research remains truly patient-centred.
Adequate funding and support would enable these organisations to take on leadership roles and contribute meaningfully in a sustainable way across multiple HTA decisions.

NPON organisations that responded

Angelman Syndrome Association Australia
Ankylosing Spondylitis Victoria Inc.
ausEE Inc.
Australian Addison's Disease Association Inc
BEAT Bladder Cancer Australia
Cataract Kids Australia
CF Together (Cystic Fibrosis Community Care)
Charcot-Marie-Tooth Association Australia Inc
CHARGE Syndrome Australasia
Childhood Dementia Initiative
Children's Tumour Foundation
Cystic Fibrosis QLD
Eczema Support Australia
HAE Australia
Hidradenitis Suppurativa Australia
ITP Australia and New Zealand
Leukaemia Foundation
Lipoedema Australia
LiverWELL
Miracle Babies Foundation
Mito Foundation
Pain Australia
Muscular Dystrophy Australia
Muscular Dystrophy NSW
Musculoskeletal Health Australia
NeuroEndocrine Cancer Australia
SATB2 Connect
The Addisons Disease Association Of Australia
The Immune Deficiencies Foundation of Australia (IDFA)
Through the Unexpected
Tourette Syndrome Association of Australia

References

Carman, K. L., et al. (2013). Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Affairs, 32*(2), 223-231.

Domecq, J. P., et al. (2014). Patient engagement in research: a systematic review. *BMC Health Services Research, 14*(1), 89.

Fournier, L. S., et al. (2018). Patient-centered care: why and how. *Canadian Family Physician, 64*(6), 415-417.

Greenhalgh, T., et al. (2016). Patient and public involvement in research: a brief overview of the evidence and practice. *Public Health, 137*, 41-47.

Simpson, M., et al. (2020). Sustaining patient and public involvement in research: a practical framework. *Journal of Patient Experience, 7*(5), 662-671