

Objective: Understand the financial environment in which patient organisations operate

Financial sustainability is essential for patient organisations, which must balance mission-driven activities with the need to generate adequate revenue. Patient organisations are increasingly looking beyond traditional donations and government grants to ensure their long-term financial stability. Financial sustainability not only helps maintain operations but also strengthens the organisation's ability to respond to unforeseen challenges and changes in funding sources (Cairns & Hodge, 2021). Diversifying income portfolios is one of the most effective strategies for achieving this sustainability.

Patient organisations can however be restricted in opportunities for funding due to the funding environment, external influences on the policy environment, and/or their population reach.

There needs to be a fundamental shift in how patient organisations are perceived - moving from the outdated view of them as mere 'charities' relying on financial support to recognising them as essential investments in the health system infrastructure. These organisations play a critical role in providing vital resources and driving policy improvements that directly impact healthcare outcomes. By supporting patient organisations as key players in the healthcare ecosystem, governments and stakeholders can foster more sustainable, patient-centered healthcare systems that address the real needs of communities. This shift in perspective would not only enhance the efficiency of healthcare delivery but also ensure that patient organisations are empowered to continue their invaluable work, contributing to the broader goal of improving public health.

This paper provides a discussion on how patient organisations navigate the challenges of diversified funding, the benefits this approach offers in ensuring both financial resilience and mission alignment, and the external environment that drives the opportunities that patient groups have to seek funding.

The Importance of Financial Sustainability

Financial sustainability for patient organisations is essential to ensuring that these groups can deliver on their social missions, particularly in the face of shifting external funding landscapes. Research by Kearns and Finch (2021) underscores that patient organisations must adopt a long-term approach to financial stability, focusing on diversified income sources to prevent over-reliance on any single donor or government fund. Effective financial management and diverse income strategies allow organisations to better navigate economic downturns, political changes, and health crises like the COVID-19 pandemic.

Patient organisations often face a dual challenge of operating under stringent budget constraints while simultaneously adapting to an environment of increasing demand for services (Giovannini et al., 2022). As government funding becomes less predictable, patient organisations need to innovate and embrace financial models that offer consistent, flexible revenue streams to maintain operations and expand their reach.

Diversifying Income Portfolios

Diversification of income sources allows patient organisations to mitigate risks associated with reliance on a single funding stream. Various strategies have been proposed to build more resilient financial portfolios in nonprofit organisations, each offering unique advantages and challenges. Below are the key income streams used by patient organisations.

Individual Donations and Fundraising

Individual donations remain one of the most important revenue streams for patient organisations. However while individual giving has remained stable, its growth rate has slowed, with donors becoming more selective in the causes they support (Hill et al. 2022). Therefore, patient organisations have needed to enhance their fundraising strategies

by adopting methods such as digital campaigns, online crowdfunding, and donor loyalty programs. Online platforms have proven effective in reaching a larger pool of smaller donors, which can contribute to a more sustainable income base (Fulton et al., 2021).

One of the significant challenges faced by patient organisations working with rare diseases or conditions that lack government or industry interest is the limited availability of funding and resources. Many rare diseases affect small populations, which often results in a lack of commercial incentive for pharmaceutical companies to invest in research and development. Without substantial government funding or industry support, these diseases may be overlooked, leaving patients with few treatment options and little advocacy. Patient organisations in these fields often bear the burden of raising awareness, conducting research, and providing support services without the substantial backing that larger, more common diseases receive. Rare disease patient organisations may struggle to secure government grants, as rare diseases do not always meet the criteria for large-scale public health funding, and industry involvement is scarce due to the limited market for treatments. This lack of attention leads to a cycle where the needs of patients remain unmet, and progress on developing treatments or improving care is slowed. For these charities, diversifying income sources and building strong partnerships with other like-minded organisations is crucial to navigating these challenges, but it remains an uphill battle given the financial and institutional constraints.

Corporate Partnerships and Sponsorships

Corporate social responsibility (CSR) has emerged as a key area of focus for many patient organisations, which have begun developing partnerships with private sector companies to generate revenue and raise awareness for their causes. A 2023 study by Sandford and Lee found that corporate sponsorships and cause-related marketing initiatives could provide a steady income stream, particularly when aligned with a charity's mission (Sandford & Lee, 2023). However, it is important for patient organisations to critically assess the ethical implications of corporate partnerships, as potential conflicts of interest may arise when corporate sponsors influence charitable agendas (Zimmerman et al., 2021).

Government Grants

While government funding remains a key revenue source for some organisations, others make the strategic decision to not take government funding due to the conflict of interest and contractual obligations which advocacy responsibilities are traded in accepting government funding.

The availability of government grants for health-related charities fluctuates, and there are few grants where 100% of costs are covered, with many grants resulting in a financial loss to charities.

There are also very few government grants that patient organisations are eligible when compared to other parts of the health sector, and where there are grants available they are not earmarked for patient organisations who then need to compete with research institutes, hospitals and universities. As an example, there are 98 registered administering institutions under the National Health and Medical Research Council (NHMRC) which gives eligibility to apply for grants. Within the 98 administering institutions, there are three that are patient organisations (Cancer Council NSW, Queensland and Victoria). Where open grants are then available through the Department of Health and Aged Care, there is no requirement for organisations to register as administering institutions, however there are no pools of funding earmarked for patient organisations, even when the purpose of the grant is intended for community-based support. This has been observed a number of times particularly in the rare disease space where grants intended for patient support has not reached patient organisations, rather they have been awarded to academic groups that already have the advantage of access to NHMRC funding as well.

Industry sponsorships

In Australia, the Medicine's Australia code of conduct provides the guidelines for interactions between industry and health-related stakeholders including patient organisations.

The Code is designed to ensure ethical conduct, transparency, and appropriate relationships between the pharmaceutical industry and health professionals, promoting responsible interactions in areas such as marketing,

sponsorship, and provision of information. The Code is regularly updated to reflect changes in regulatory and ethical standards, aiming to maintain public trust and ensure that the industry's activities prioritise patient welfare and safety.

While there is no verification process to ensure accuracy and compliance, Medicine’s Australia publish a list reporting financial support and/or significant direct/indirect non-financial support to patient organisations, as self-reported by pharmaceutical companies.

The pharmaceutical industry gives significant funding to patient organisations, providing much needed program funding, often where no other funding opportunities are available. In 2023, the reported amount of funding from industry to patient groups was \$9,075,421. Industry therefore has influence on which disease areas are a priority for support as funding tends to align with their therapeutic interests.

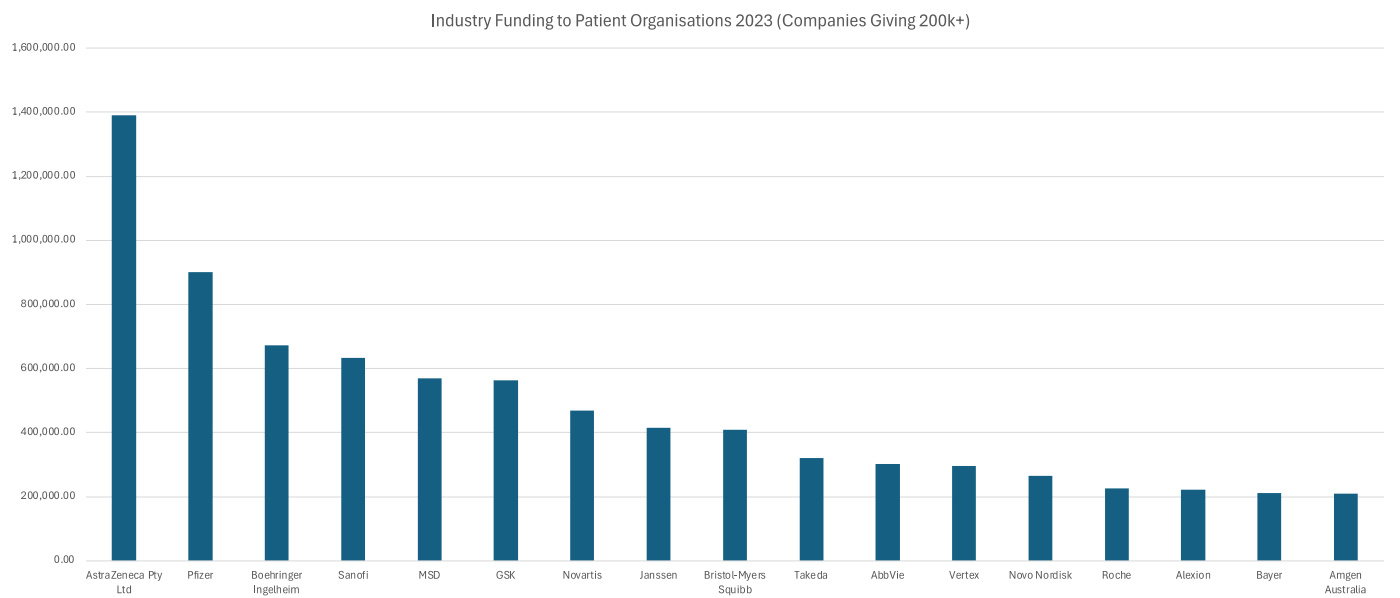
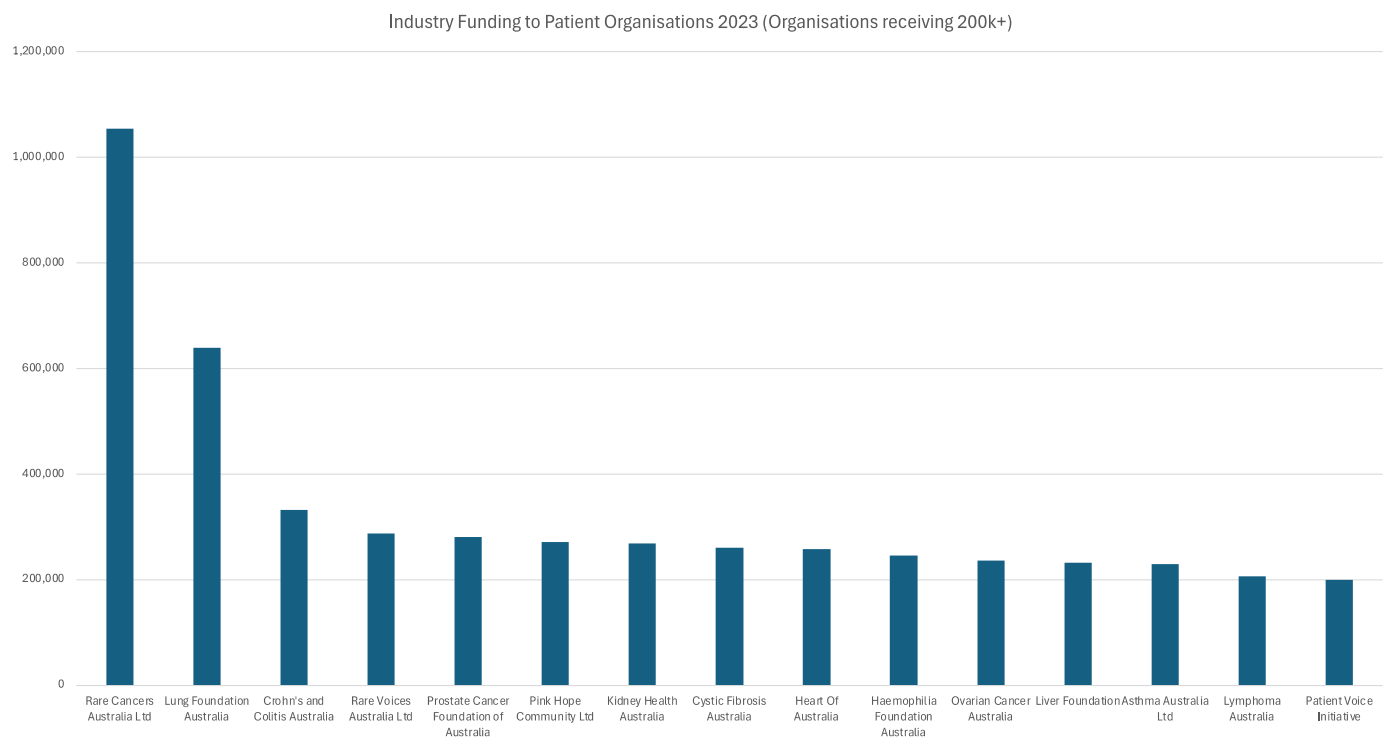


Table 1: Funding reported by companies in 2023 giving 200K+¹



¹ Source: <https://www.medicinesaustralia.com.au/code/transparency-reporting/health-consumer-organisation-support-reports/member-company-reports/>

Table 2: Funding received by patient organisations in 2023 giving 200K+ ¹

Earned Income and Social Enterprises

Social enterprises offer patient organisations an innovative avenue to earn revenue while remaining mission-driven. Recent research by Hernandez and Davis (2022) highlights how charities have successfully integrated social enterprise models, such as health-related product sales, fee-for-service models, and retail operations, to generate earned income. For example, a patient organisation might establish a community wellness program or a clinic offering health services on a sliding scale to generate income. According to the same study, social enterprises provide a steady and reliable source of income that can be reinvested into the charity's mission, ensuring long-term sustainability.

Challenges of Diversification

Despite the advantages of income diversification, there are inherent challenges that patient organisations must overcome. As organisations seek to integrate new funding streams, they often encounter administrative, financial, and ethical complexities. For example, managing multiple revenue streams can strain resources, requiring specialized staff, technology, and reporting systems (Cairns & Hodge, 2021). Additionally, ethical concerns can arise when organisations accept funding from sources that may not align fully with their core mission, or where contractual agreements conflict with their core mission. It can be difficult for patient organisations to maintain their independence and remain focused on their mission, while managing the financial pressures they may face.

Another significant challenge is the potential for mission drift. As patient organisations pursue diversified income streams, they may inadvertently shift focus from their core mission to meet the demands of funders or donors. Research by Healy and Smith (2022) emphasizes the importance of maintaining alignment between financial strategies and organisational values, suggesting that patient organisations regularly assess their funding sources to avoid losing sight of their mission. Likewise, funders need to be asking whether their needs are truly meeting the needs of patient populations if patient organisations are being placed in a difficult position.

Responsibility of funders

The responsibility of funders in the healthcare sector is fundamentally rooted in ensuring that their financial contributions align with the needs of patients and the broader community, rather than being driven by their own interests or agendas. In the context of patient organisations, funders - whether they are government agencies, private donors, corporations, or foundations - must recognize that their primary role is to support the fulfillment of patient-centered goals. This means that funding decisions should prioritise the well-being of individuals who rely on these organisations for care, support, and resources, rather than advancing the interests of the funders themselves.

Funders must also be aware of the ethical implications of their contributions. For instance, when funders impose strict guidelines or conditions on the use of their funds that do not align with the organisation's mission or the specific needs of patients, they risk undermining the integrity of the charity's operations. The health of patients and communities should always come first in funding decisions, with an emphasis on funding programs that address the most pressing and under-resourced health challenges. If a funder's priorities are misaligned with patient needs, this can result in a diversion of resources from where they are most needed, ultimately detracting from the charity's effectiveness in improving health outcomes.

Additionally, funders have a responsibility to ensure transparency and accountability in how their donations or investments are used. They should engage in a collaborative approach with patient organisations to understand the local context and patient needs. This means actively listening to the feedback from health professionals, service users, and community stakeholders to make informed decisions about where funds can make the most difference. In doing so, funders not only contribute to the sustainability of patient organisations but also ensure that their investments create meaningful, long-term impacts for patients, rather than serving as a tool for personal or corporate gain.

Infrastructure and core funding for patient organisations

Unrestricted grants are a critical source of funding for many organisations, providing flexibility in how funds are used without being tied to specific projects or programs. Likewise the ability to include administrative costs so that a financial loss is not incurred is also important. However, unlike other parts of the health system, such as primary care and hospitals, which receive substantial government funding for infrastructure, patient organisations have no dedicated infrastructure funding, despite being an important part of the health system. Primary care services, for example, are supported by government-funded programs that cover operational costs such as staff salaries, facilities, and equipment. Similarly, hospitals receive public funding to maintain their infrastructure, ensure ongoing operations, and provide essential services. In contrast, patient organisations—despite being an integral part of the healthcare system—are typically left to secure funding for their core operational needs, such as staff salaries, office space, and technology, through grants or donations. Unrestricted grants, while valuable, are often the only means through which these organisations can cover their essential overheads, yet these are not routinely offered, and the lack of dedicated infrastructure funding places a significant burden on their ability to sustain operations and effectively provide services for patients.

6. Conclusion

Financial sustainability is essential for patient organisations to fulfill their missions effectively and adapt to a constantly changing funding landscape. Diversifying income portfolios—through a combination of individual donations, corporate partnerships, earned income, social impact investments, and government grants—allows patient organisations to reduce their dependency on single revenue sources, enhancing their resilience and long-term viability. However, the process of diversification requires careful management to ensure that financial strategies align with the charity's mission and ethical principles, and it is also the responsibility of funders to ensure their programs are aligned with patient needs.

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