

Objective: To define leadership within patient organisations and our expectations of external stakeholder engagement

Leadership in health charities demands a combination of strategic thinking, ethical integrity, and the ability to inspire and mobilise diverse stakeholders. These leaders must manage complex challenges in healthcare delivery, fundraising, and public trust, often under tight resource constraints.

Leading a patient organisation entails a profound commitment to advocacy, transparency, and strategic financial planning as well as securing resources and creating sustainable revenue streams. This demands deliberate effort and foresight on the part of the NFP leader.

Patient organisations often operate with limited resources. This requires careful allocation across various initiatives such as the provision of services (often free or low cost), the development of information and support resources, awareness campaigns, research funding, and policy advocacy. Additionally, there are constant demands to engage in activities such as supporting the agenda of third parties, which can divert significant resources leading to opportunity costs that may impact other essential services (Baggott & Forster, 2018).

Reliance on private funding can introduce conflicts of interest, potentially compromising the organisation's credibility and the trust of the communities they serve (Ramachandran et al., 2023). Transparency in funding sources and clear communication about financial relationships are crucial to maintaining integrity and public confidence.

Effective leadership in patient organisations requires proactive fundraising strategies, diversification of funding sources, and ethical stewardship of resources. By acknowledging the challenges and actively seeking sustainable financial solutions, leaders can ensure their organisations remain resilient and focused on their mission to support patient communities.

It is not often acknowledged that there is a personal toll in leading small non-profits. Being a leader in the NFP space requires all the same skills and expertise as that of leading a for profit organisation but more. Concepts around leadership by contribution (working behind the scenes to foster collaboration, mentor others, and create lasting positive change) versus leadership by visibility (i.e. creating a strong personal brand) hold unique challenges in the not-profit sector. Yes, you can build your personal brand through your charity work, as long as it's a secondary effect, and not at the expense of the charity's mission, integrity, or public trust. This generally only becomes risky for example where the charity is used to boost a private business or consulting platform, or where there is a clear conflict of interest. This is all part of leadership considerations for those working in patient organisations with the constant balance of organisational versus personal goals and managing potential conflicts.

Below we discuss some of the values we may expect of ourselves and others as patient organisation leaders.

Mission-Driven Strategy

Leaders are expected to align organisational activities with the charity's mission and values, ensuring programs are both impactful and sustainable. Strategic decision-making should prioritise community health needs while remaining adaptable to evolving health trends.

Ethical Stewardship and Accountability

Maintaining transparency and financial integrity is crucial. Leaders must demonstrate responsible use of donor funds and deliver measurable outcomes to preserve public trust. Accountability extends to boards, regulators, and the populations they serve.

Stakeholder Engagement and Communication

Health charity leaders must engage effectively with beneficiaries, donors, healthcare providers, and policymakers. This requires strong communication skills and the ability to build cross-sector partnerships. Active listening and inclusive dialogue are key to meaningful engagement.

Team Leadership and Organisational Culture

Internally, leaders foster a mission-driven, inclusive culture that empowers staff and volunteers. Emphasising diversity, equity, and inclusion improves both team cohesion and service delivery. Strong leaders model the values they wish to instil across the organisation.

Innovation and Change Management

As health challenges evolve, so must the organisations addressing them. Leaders are expected to drive innovation - whether through digital tools, new delivery models, or expanded outreach - and lead teams through change with resilience and clarity.

Advocacy and Public Voice

Often acting as the public face of their organisation, leaders advocate for health equity and policy reform. Their role includes amplifying the voices of underserved communities and influencing public and political discourse on critical health issues.

Types of Leadership and their application

There are many factors that influence the type of leadership required and when to apply it within a non-profit context. Leadership is not static. It must adapt and evolve in response to constantly changing circumstances (that are often volatile, uncertain, complex and ambiguous – VUCA). Many leadership styles have been identified including: Coercive, Authoritative, Democratic, Affiliative, Pacesetter, Coaching. Whilst most leaders gravitate to a preferred style of leadership that aligns with their values, strengths, abilities and personality, within the nonprofit setting it is essential to be able to adapt (often rapidly) leadership style and approach to organise, direct and motivate within a given context.

What leadership should patient organisations model

A part of the role of a patient organisation leader is ensuring politicians and funders support the community-led work of their organisation. It becomes part of the role of patient organisations to model the kind of leadership that is expected from others.

To effectively support patient needs, politicians and funders need to exhibit leadership grounded in empathy, evidence-based policymaking, and long-term commitment to health equity. Ideally, they should prioritise policies and funding models that are inclusive and responsive to the voices of patients, especially those from marginalised communities (OECD, 2021). This includes supporting community-led health initiatives and reducing systemic barriers to care.

Transparent and sustained investment in healthcare infrastructure, prevention programs, and workforce development is essential. Rather than short-term, reactive spending, funders and policymakers must commit to sustained, strategic funding that builds resilience and ensures equitable access to services (WHO, 2025).

Genuine leadership requires accountability. Policymakers must engage in open dialogue with health professionals and the public, using data and patient experience to guide decisions (HLC, 2024). Funders can lead by demanding clear impact metrics from grantees while offering flexibility to adapt to real-time patient needs (Millenson et al 2019).

We expect a certain type of leadership from ourselves as patient organisation leaders, and when we achieve that, we influence others. However all stakeholder need to advocate for and model ethical, inclusive leadership - setting a tone that centres human dignity and patient welfare over political or financial gain (Crutchfield & Grant, 2012).

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