National Patient Organisation Network: Discussion Paper 1
Health Charity Sustainability

Objective: Understand the concept of sustainability in the context of health charities and what trade-offs we are willing to make

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In the health sector, we often hear about the need for trade-offs, that is, the process of weighing the benefits and risks of evidence, resources and needs to make the best possible choice. Since no option is perfect, individuals, healthcare providers, and policymakers must often balance competing factors. This is no different for patient organisations that need to make decisions to ensure their sustainability while meeting the needs of patients, often with limited resources.

Financial sustainability versus growth

Balancing financial sustainability and growth is a challenge for patient organisations of all sizes. Financial sustainability ensures that organisations have stable, longer-term funding to provide essential services and support patients. This often requires diversifying revenue streams, managing expenses efficiently, and building financial reserves to weather economic downturns. The latter however is often a luxury for small to medium organisations where the reality is that funding is often project-to-project basis and year-by-year.

Growth however is not just about expansion or reserves, but about enhancing impact. This might be improving service quality, and/or driving innovation through a reallocation of resources. However, growth must be strategic and sustainable, aligning with the patient organisation’s mission rather than overstretching resources or aiming for financial growth, just for the sake of it or without a complementary plan on how patients will benefit from additional funds.

Another trade-off that patient organisations face is between helping as many people as possible today or maintaining financial reserves to support future patient needs. In this context, we need to remember what the core purpose of a patient organisation is, and that is to improve patient outcomes, whether through direct support, research, or advocacy. Holding reserves ensures the charity can continue its mission during, however, excessive reserves may mean fewer resources are allocated to urgent patient needs in the present and can affect whether an organisation is fulfilling its purpose. The challenge lies in finding the right balance.

Effort versus Impact

Effort and impact are not mutually exclusive; however, they do not always align. In an ideal scenario, increased effort would always lead to greater impact, but this is not always the case. A patient organisation can put in significant effort - such as organising large-scale awareness campaigns or extensive fundraising initiatives - without necessarily achieving a proportional impact on patient outcomes. Conversely, some initiatives may require relatively low effort but generate high impact, such as providing direct financial assistance to patients in need.

Another challenge is predictability. As an example, a patient organisation may collate feedback from patients that indicates patients want more support groups. Efforts can be made to design and implement this, but that doesn’t ensure uptake, and the impact of that effort may be lost. Unfortunately, it’s not always a case of build it and they will come.

Balancing effort and impact also involves making strategic choices about where to allocate resources. Addressing challenges in the health sector effectively requires a collaborative approach, where patient organisations work alongside each other and other stakeholders to identify and tackle systemic issues. Rather than acting in isolation, charities should ask: What is the underlying health system issue that needs to be addressed, and who else is facing the same challenge? If patient organisations are going to address an issue, we all need to be considering what patient populations the issue needs to be fixed for.

Capacity versus competence

Patient organisations often face challenges with capacity. This should never be confused with a lack of competence.

Capacity and competence are both critical factors in the effectiveness of patient organisations, but they serve different roles. Capacity refers to the resources available - funding, staff, volunteers, infrastructure, and time - that enable a patient organisation to carry out its mission. Without sufficient capacity, even the most well-planned initiatives may struggle to reach their full potential.

Simply having resources is not enough either; patient organisations must also have the competence - the skills, knowledge, and strategic expertise - to use those resources effectively. A charity with a large budget but lacking in leadership, strategic planning, or specialised expertise will likely fail to deliver meaningful impact.

Many patient organisations are very well planned with sophisticated processes to allocate resources and plan annual programs of work. This however can be a delicate balance for small organisations where capacity - not competence - can be strained when patient organisations are asked, often without notice, to participate in external evaluations, consultations or policy development.

Capacity has an impact on equity with well-funded patient organisations having more capacity to advocate and participate in decision-making processes. They also tend to represent larger populations who are more likely to be selected to participate. Hand-picking groups to participate in decision-making creates an imbalance in representation and drives a culture of exclusion. This selective involvement risks reinforcing existing disparities, as certain patient communities - especially those with lower visibility, fewer financial resources or divergent perspectives - may be left out of important policy discussions.

External priorities versus community priorities

In patient organisations, there is often a tension between external priorities such as those set by government agencies, funders, or the broader healthcare system, and the specific needs of the communities they serve. External priorities may focus on broader health trends, national policies, or areas that are deemed to have the most widespread impact, such as chronic diseases or high-profile health issues. While these priorities can attract funding and support, they might not always align with the unique, immediate concerns of patient communities, particularly for underserved diseases. As a result, patient organisations may face challenges in securing funding for programs that are crucial for their specific populations but fall outside of the established priorities of larger funders.

Community priorities are deeply rooted in the experiences, needs, and challenges faced by the patients and families served by the organisation. These priorities often focus on providing targeted support, addressing gaps in care, or funding research that directly impacts a patient population. If the response to a funding request - derived from the needs of patients – is that it does not align with the priorities or the strategic interests of a funder, we need to be questioning whose priorities are misaligned. This misalignment not only limits resource allocation but can also lead to frustration and inequity in how healthcare needs are met. The entities making funding decisions often hold significant privilege, as their choices can shape which patient groups receive support, potentially prioritising certain causes over others based on their own perspectives, values, or other interests, which may not fully reflect the needs of all communities.

Competition versus community spirit

Competition often drives individuals and organisations to strive for success, push boundaries, and innovate. While it can lead to growth, it can also create a mindset of scarcity. In such an environment, collaboration and mutual support can take a back seat, with organisations prioritising their own advancement over collective well-being. The emphasis on competition may foster an atmosphere of rivalry, rather than one of empathy, kindness and cooperation, potentially undermining the very reason a patient organisation exists.

Sharing resources and intellectual property can greatly enhance a spirit of cooperation and community within patient organisations. However, it’s crucial to strike a balance between collaboration and ethical conduct. While sharing can foster growth and progress, it's essential to avoid crossing ethical boundaries, such as presenting another's work as your own or failing to properly recognise the original source. It’s important to also reflect on the limits of the good faith principles that many patient organisations operate by that are regularly tested, for example, shifting contract expectations that result in increased resources and costs to the patient organisation, or the provision of professional services by patient organisations without compensation. Being a non-profit doesn't mean that intellectual property and resources aren't valuable or don't deserve protection; they are essential assets that support the organisation's mission and should be respected.

This is all part of how we treat each other through kindness, respect, and collaboration so that we can build stronger, more inclusive communities where success is shared, rather than viewed as a limited resource. When launching a new advocacy campaign, project, or initiative, a question that is not often asked is whether our drive to reach our objectives comes at the detriment of another patient group or population. It’s a difficult acknowledgement but there does need to be an awareness that when we declare our patient population as the top priority, we are implicitly diminishing the importance of others. This may be the most significant trade-off that we need to work to change.