



Introduction

Amplify Impact: Patient Organisation Sustainability
& Health Equity

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The policy problem

Health charities, patient associations, community-controlled organisations and other nonprofit providers occupy a distinctive position within contemporary health systems. They often bridge the gap between formal clinical services and the practical, social and informational needs experienced by patients, families and communities. Their contribution may include peer support, navigation, health education, prevention, advocacy, outreach, research participation and the development of trusted relationships with populations poorly served by conventional institutions. Yet the public value of these activities is not always captured by standard measures of service throughput, clinical activity or short-term expenditure. A funding system can therefore be transparent and administratively orderly while still failing to sustain the community organisations on which equitable access depends.

This distinction provides the rationale for evaluating government support not simply in terms of the availability of grants, but in terms of the design, accessibility, flexibility and distributive effects of the funding environment.

Community participation as a substantive funding principle.

The theoretical foundations of community-first funding extend beyond consultation. Arnstein (1969) distinguishes symbolic participation from forms of citizen influence that redistribute decision-making power. Applied to grantmaking, this means that asking communities to comment on an already designed funding program is not equivalent to involving them in defining priorities, assessing applications or determining what constitutes success. Bovaird (2007) similarly conceptualises co-production as an arrangement in which public service users and communities contribute actively to the design and delivery of services. Together, these perspectives imply that a program should be evaluated by the authority communities exercise over decisions, rather than by the number of consultation events undertaken. A government agency may demonstrate extensive engagement activity without demonstrating that

community preferences have changed its funding allocations.

The empirical case for meaningful engagement

Community engagement is not solely a normative commitment; it has an empirical public-health rationale. In a meta-analysis of interventions involving disadvantaged groups, O'Mara-Eves et al. (2015) reported positive pooled effects for health behaviours, health consequences, self-efficacy and social support, although the evidence did not identify one universally superior engagement model. This qualification matters: engagement is not an automatic intervention, and its value depends on design, relationships, context and implementation. Community-based participatory research also emphasises reciprocal knowledge production, with community members contributing to the formulation of questions, interpretation of evidence and development of responses (Wallerstein & Duran, 2010). A funding framework informed by this literature should examine whether lived experience is accepted as evidence, whether participation is resourced and whether community feedback can meaningfully alter decisions.

Nonprofits as health-system infrastructure

Nonprofit organisations are frequently funded as deliverers of discrete activities rather than recognised as institutions requiring continuing investment. However, service quality depends on organisational capabilities that are not always visible in project budgets: governance, workforce supervision, digital infrastructure, data protection, finance, evaluation, community representation and reserves. Lecy and Searing (2015) describe a nonprofit starvation cycle in which pressure to minimise overhead can encourage underinvestment in the infrastructure necessary for effective delivery. Their analysis is particularly relevant to government contracts that specify extensive performance obligations but provide limited support for management and indirect costs. The apparent efficiency of low overhead can be misleading when costs are shifted to unpaid volunteers, philanthropic donors or the future financial stability of the provider.

Funding quality and economic efficiency

From a health economics perspective, the relevant unit of analysis should include the total resources required to generate an outcome, not only the amount transferred by a funder. Application preparation, duplicate reporting, cash-flow financing, grant renewal and compliance all consume real resources, even when those costs are excluded from the public budget. Short funding cycles can create repeated transaction costs, inhibit workforce retention and discourage investment in evaluation or service improvement. Conversely, flexible multi-year arrangements may reduce administrative duplication and allow organisations to adapt to changing needs, although such benefits should be tested rather than presumed. The economic assessment should therefore distinguish direct program costs, indirect organisational costs, funder administration, applicant burden and the opportunity costs borne by patients and communities.

Accountability without administrative overload

Public funding requires accountability, but accountability is multidimensional. Ebrahim (2003) identifies reporting, evaluation, participation, self-regulation and social audits as different mechanisms and highlights the tendency for upward accountability to funders to overshadow accountability to communities. Ebrahim (2005) further warns that a narrow emphasis on short-term rule compliance can displace organisational learning and long-term mission. This literature supports a proportionate approach in which reporting is calibrated to funding value and risk, and in which communities have opportunities to judge whether programs meet their priorities. A larger volume of reporting should not automatically be interpreted as a higher standard of accountability. A stronger test is whether information improves decisions, protects public resources and supports meaningful learning.

Equality, equity and access to public funding

A central analytical distinction is between formal equality and substantive equity. A grant scheme may offer every eligible organisation the same form, deadline, matching requirement and reporting schedule. Nevertheless, these common rules impose

different burdens on a large national charity, a volunteer-run patient group and a small community-controlled provider. Established organisations can spread administrative costs across programs and maintain professional grant-writing and evaluation teams. Emerging organisations may have strong community trust but little financial history, limited unrestricted reserves and incomplete datasets. Consequently, apparently neutral assessment criteria may favour organisational maturity rather than community need. Community engagement evidence indicates that context and participation matter in addressing disadvantage (O'Mara-Eves et al., 2015; Wallerstein & Duran, 2010). An equitable funding system should therefore test whether applicants can realistically participate, rather than treating published eligibility as sufficient proof of access.

Rare conditions and populations with small numbers

The equity question is especially acute for rare diseases, uncommon conditions and geographically dispersed patient communities. Conventional value-for-money indicators often reward the number of beneficiaries reached or the cost per participant. These measures can undervalue organisations serving small populations where the severity of need is high, specialist services are scarce, families bear substantial navigation burdens or there is no alternative source of reliable information and peer support. Such groups may also lack the epidemiological data, fundraising base and local concentration required by standard grant criteria. An equity-sensitive framework should consider the absence of substitutes, consequences of unmet need, cross-jurisdictional coordination and the fixed costs of maintaining a credible national organisation. This is not an argument for exempting rare-condition programs from evaluation, but for choosing measures that reflect their actual social and economic contribution.

Why international comparison is useful

International comparison can reveal institutional design choices that may be difficult to recognise within a single national system. The seven-country project examines Australia, New Zealand, the United States, Canada, the United Kingdom, Singapore and India across transparency, accessibility, funding quality,

timeliness and reliability, equity, proportional accountability and operational enablement. The jurisdictions differ in government structure, health financing, civil-society regulation and the relationship between public agencies and nonprofit providers. Such variation permits structured comparison of mechanisms—including grant portals, commissioning, indirect-cost rules, core funding, capability programs and differentiated reporting—without assuming that a policy can be transferred unchanged between contexts. The audit scores are provisional documentary assessments of system design, not causal estimates of program effectiveness or independently validated international rankings.

The proposed assessment framework

The project uses a seven-dimension country audit, scored from zero to three per dimension, for a maximum of 21 points. This is supplemented by a more detailed program-level self-assessment intended for government agencies, program administrators and independent funders. The two tools serve different purposes: the national audit maps the enabling environment, while the program assessment examines concrete practices within a particular funding mechanism. Both place community leadership, organisational sustainability and equity alongside conventional transparency and accountability criteria. Importantly, scores should be accompanied by narrative explanation and a documented evidence register. The numerical total is a summary of judgement, not a substitute for understanding why specific groups benefit or are excluded.

Health economics contribution and research direction

The longer-term research agenda is to determine whether alternative funding designs improve value for

money when a broader societal and distributional perspective is adopted. Relevant outcomes include administrative time, staff turnover, payment delays, service continuity, community participation, access among underserved populations and organisational resilience. Evaluation could compare application and compliance costs across funding models, examine whether advance payments reduce financial stress, and test whether multi-year full-cost grants improve continuity relative to short-term restricted awards. Distributional analysis would examine whether reforms benefit small organisations and rare-condition communities rather than merely increasing aggregate grant efficiency. This work should distinguish observed associations from causal effects and seek to validate the proposed assessment scales before treating score bands as external standards.

Study rationale and significance

The underlying proposition is that health funding arrangements shape both what nonprofit organisations do and which communities can obtain representation. Funding decisions may reinforce existing capacity by rewarding established providers, or they may strengthen overlooked community infrastructure by adjusting for unequal starting conditions. A comprehensive assessment must therefore consider not only whether a funding opportunity exists, but whether communities influence its purpose, whether providers receive the full resources needed to deliver it and whether accountability supports learning as well as compliance. By combining international policy comparison, organisational analysis, community participation theory and health economic evaluation, this project seeks to develop a practical evidence base for funding systems that are efficient, sustainable and responsive to the needs of communities with the least institutional power.

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