

Objective: To identify some of the considerations external stakeholders need to consider when asking patient organisations to participate in consultation processes

Summary: When approaching a health charity for consultation, external stakeholders should carefully consider the charity's capacity and priorities to ensure their request is both respectful and sustainable. Stakeholders must clearly articulate the purpose of the consultation, how the charity's expertise will be used, and what tangible outcomes are expected, avoiding vague or open-ended demands on staff time.

It is essential to provide sufficient notice, cover reasonable costs of participation where appropriate, and align the consultation process with the charity's mission and ongoing commitments to avoid creating undue burden. Power imbalances should be actively acknowledged and mitigated by sharing decision-making where possible and being transparent about how the charity's input will shape outcomes.

One significant downfall in consultation processes is that stakeholders tend to publish details about a consultation process rather than the impact of the consultation and call this the outcome. Process is important, but it is not an outcome.

Another common challenge is that patient organisations are often participants in the process, rather than being empowered through funding for them to design, implement and manage their own consultation process. Think of the hundreds of thousands of dollars spent to do these when patient organisations would be better placed for this kind of work.

Finally, stakeholders have an ethical obligation to provide timely, specific feedback on how the charity's contributions were used, fostering trust and ensuring the relationship remains mutually beneficial.

Defining roles & setting expectations¹

- **Clarify scope of interaction:** Identify who is being consulted (e.g., people diagnosed with conditions, patient organisations policy makers, health researchers) and define their roles to avoid overlap or tokenism.
- **Agree on levels of engagement:** Engagement can span from outreach to consultation, involvement, collaboration, and shared leadership. External stakeholders should choose the appropriate level based on context and capacity. Patient organisation engagement is not a proxy for direct patient feedback and the two should be distinguished for transparency.

Trust-building and relationship dynamics^{2,3}

- **Be prepared to invest time:** Genuine engagement often requires early contact, iterative dialogue, and trust-building—research in health contexts highlights these as essential if consultation is to be genuine.

Transparency, accountability & conflict of interest ⁴

- **Document and share decision processes:** Use frameworks for healthcare guideline development, clearly reporting stakeholder roles, selection criteria, engagement methods, and conflict management.

¹ Cox, J.G.; Chung, M.; Hamm, J.A.; Zwickle, A.; Cruz, S.M.; Dearing, J.W. Working with Institutional Stakeholders: Propositions for Alternative Approaches to Community Engagement. *Int. J. Environ. Res. Public Health* **2019**, *16*, 4010

² Murphy, J., Qureshi, O., Endale, T. *et al.* Barriers and drivers to stakeholder engagement in global mental health projects. *Int J Ment Health Syst* **15**, 30 (2021). <https://doi.org/10.1186/s13033-021-00458-y>

³ Littlejohns P, Kieslich K, Weale A, Tumilty E, Richardson G, Stokes T, Gauld R, Scuffham P. Creating sustainable health care systems. *J Health Organ Manag.* 2019 Mar 18;33(1):18-34. doi: 10.1108/JHOM-02-2018-0065. Epub 2018 Nov 22. PMID: 30859907; PMCID: PMC7068726.

⁴ Petkovic, J., Magwood, O., Lytvyn, L. *et al.* Key issues for stakeholder engagement in the development of health and healthcare guidelines. *Res Involv Engagem* **9**, 27 (2023). <https://doi.org/10.1186/s40900-023-00433-6>

- **Manage conflicts ethically:** Stakeholders must disclose personal/institutional interests; charities should weigh these against representativeness and bias risk, then implement proportionate solutions.

Ethical engagement & power dynamics^{5,6}

- **Mitigate power imbalances:** Interactions need to be structured to avoid tokenism - this may include shared decision-making, capacity building, and enabling community-led inputs.
- **Recognise diverse knowledge forms:** Combine professional, clinical, experiential, and community knowledge through participatory research methods. Participatory research methods allow for more transparency in process and outcome, enforce ethical practices under the research code of conduct, and promote data being processed without bias or cherry picking.

Goals & mutual benefit⁷

- **Frame stakeholder engagement as reciprocal:** Ensure participants understand how their involvement adds value to both their patient organisation's outputs and their own objectives.
- **Embed evaluation mechanisms:** Predefine success metrics—e.g., feedback integration, relationship quality, learning and evaluate engagement outcomes

Structural considerations & systems alignment

- **Align with sustainability frameworks:** The International Organisation for Standardisation (ISO) develops and publishes international standards for various aspects of technology, scientific testing processes, working conditions, and societal issues. ISO 26000 is a set of principles for social responsibility and can be used in the context of stakeholder consultation including: Accountability, Transparency, Ethical Behaviour, Respect for Stakeholder Interests, Respect for the Rule of Law, Respect for International Norms of Behaviour, and Respect for Human Rights.
- **Institutional audits for fairness:** Use tools from public health literature to evaluate transparency, fairness, legal duties, and equity in how an institution engages and allocates decision-making roles.

Early integration & funder expectations^{7,8}

- **Power dynamics in funding:** Stakeholders must consider power imbalances and ensure predictable, fair resourcing that supports meaningful engagement without undue burden

Co-design and shared decision-making

- **Capture and integrate local expertise⁹:** Recognise community-held contextual insights and operationalise them.
- **Move beyond top-down consultation:** Provide funding for patient organisations to design their own consultation processes on issues of interest as they are often best placed to do this.

⁵ Murphy, J., Qureshi, O., Endale, T. *et al.* Barriers and drivers to stakeholder engagement in global mental health projects. *Int J Ment Health Syst* **15**, 30 (2021). <https://doi.org/10.1186/s13033-021-00458-y>

⁶ Wanyenze RK, Alfvén T, Ndejjo R, Viberg N, Båge K, Batte C, Helldén D, Lindgren H, Mayega RW, Ndeez G, Peterson SS, Nawangwe B, Ottersen OP. Sustainable health—a call to action. *BMC Glob Public Health*. 2023 Aug 3;1(1):3. doi: 10.1186/s44263-023-00007-4. PMID: 39681897; PMCID: PMC11622973.

⁷ Petkovic, J., Magwood, O., Lytvyn, L. *et al.* Key issues for stakeholder engagement in the development of health and healthcare guidelines. *Res Involv Engagem* **9**, 27 (2023). <https://doi.org/10.1186/s40900-023-00433-6>

⁸ Littlejohns P, Kieslich K, Weale A, Tumilty E, Richardson G, Stokes T, Gauld R, Scuffham P. Creating sustainable health care systems. *J Health Organ Manag*. 2019 Mar 18;33(1):18-34. doi: 10.1108/JHOM-02-2018-0065. Epub 2018 Nov 22. PMID: 30859907; PMCID: PMC7068726.

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