Representing Diverse Patient Perspectives

A practical checklist for patients, advocates, researchers and organisations

Purpose: Use this guide to include different experiences and be honest about whose views are represented.

Meaning: Representation means bringing perspectives into a discussion. One person or group cannot speak for every patient.

1 Map whose views are missing



- ☐ Consider age, ethnicity, language, disability, income and location, alongside diagnosis, disease stage and access to care. Ask who is absent. [1]

2 Reach beyond familiar contacts



- ☐ Work with trusted community partners. Offer clear invitations through different routes and allow time to build relationships. [1]

3 Remove practical barriers



- ☐ Agree accessible formats, interpretation, flexible timing and ways to contribute offline or remotely. Budget for expenses and support. [1, 2]

4 Make room for different voices



- ☐ Use plain language and agreed discussion rules. Offer spoken, written or supported contributions. Check who gets heard and who influences decisions. [1, 2]

5 Explain whose views you bring



- ☐ Distinguish personal experience from feedback gathered from others. Explain how views were collected and avoid claiming a mandate you do not have.

6 Keep differences visible



- ☐ Record disagreement and less common views. Do not force a single patient position or assume silence means agreement. [1]

7 Protect choice and privacy



- ☐ Ask permission before sharing stories or identifying details. Explain use of contributions. People should not have to disclose sensitive experiences to be heard.

8 Report back and review gaps



- ☐ Explain what changed and why. Ask contributors whether the process felt inclusive. Record missing perspectives and agree how to reach them next. [2]

KEY POINTS: Seek different experiences. Reduce barriers. Keep disagreement visible. Acknowledge gaps.

Guidance informed by [1, 2], not a validated checklist. Group feedback does not establish how common a view is across all patients.
Privacy, consent, payment and participation rules vary by country. Local legal and clinical details require expert verification.

Sources (UK research guidance; adapt to local arrangements)

[1] NIHR: Being inclusive in public involvement in health and care research https://www.nihr.ac.uk/being-inclusive-public-involvement-health-and-care-research

[2] UK Standards for Public Involvement https://sites.google.com/nihr.ac.uk/pi-standards/standards