



CCDR+

National Patient Organisation Network (NPO)

Draft work plan

**Development of a code of conduct for
patient organisations**

Phase 1 – Initiation & Scoping (Months 1–2)

Objectives: Clarify purpose and secure buy-in.

- Define scope: behaviour, governance, transparency, conflict-of-interest, patient duty of care.
- Establish a working group
- Develop a project charter: aims, principles, expected outputs, roles.
- Map existing codes (e.g. other professional bodies, clinical bodies).

Phase 2 – Stakeholder Consultation 1 (Months 3–4)

Objectives: Gather broad input on needs and expectations.

- Conduct consultations (surveys, focus groups, interviews).
- Engage patients, clinicians, researchers, government, and industry for perspective.
- Identify priority issues: integrity, inclusivity, respectful comms, governance, lived experience, professional balance.
- Document key values and risks from consultations.

Phase 3 – Drafting the Framework (Months 5–6)

Objectives: Translate consultation into draft principles.

- Draft Code of Conduct framework (values, standards, enforcement, training).
- Identify whether there is a need to include sections for staff, boards, volunteers.
- Prepare plain-language patient-friendly summary.
- Internal review by working group and NPON leadership.

Phase 4 – Stakeholder Consultation 2 (Months 7–8)

Objectives: Test and refine draft.

- Circulate draft Code to patient org members, families, and external stakeholders.
- Collect feedback via:
 - Online survey (4–6 weeks).
 - Webinars/roundtables for discussion.
 - Interviews.
- Pay particular attention to equity and inclusivity concerns.

Phase 5 – Revision & Piloting (Months 9–10)

Objectives: Strengthen Code and trial adoption.

- Revise draft based on feedback.
- Select 5–6 pilot patient organisations to test implementation.
- Develop tools and resources:
 - Induction checklists.
 - Conflict-of-interest forms.
 - Templates for board reporting.
- Collect pilot organisation feedback on usability.

Phase 6 – Finalisation (Months 11–12)

Objectives: Produce government- and sector-ready Code.

- Refine Code of Conduct following pilot feedback.
- Conduct legal/ethical review to ensure compliance.
- Translate into accessible formats (easy-read, infographic, training slides).
- Prepare implementation guide for patient organisations.

Phase 7 – Adoption & Launch (Months 13–14)

Objectives: Secure sector uptake and visibility.

- Secure NPON endorsement.
- Launch Code at national meeting or event.
- Share with government, peak bodies, and funders to increase credibility.
- Provide training sessions for leaders and volunteers.
- Establish annual review process to keep Code relevant.