



Checklists

3 Practical checklists for both partners

Use these recommended tools alongside the relevant country chapter. They are not a statement that every item is a legal obligation everywhere. For each item record completed, not applicable or action needed, with an owner and date. Identify whether any requirement comes from law, code, authority or policy.

3.1 Checklist for patient organisations

Decide whether collaboration is right

- ☐ The project supports our mission and the needs of people we serve.
- ☐ We understand the company's objective and intended use of our contribution.
- ☐ We know what decisions our contribution can influence and what is already fixed.
- ☐ Required board, trustee, member or policy approvals have been obtained.
- ☐ We can explain the relationship openly to our community and supporters.
- ☐ We can decline or propose changes without pressure or an unrealistic deadline.

Confirm participation and authority

- ☐ The contracting legal entity and registration details are correct.
- ☐ The signatory has authority and any additional approval is recorded.
- ☐ Our role distinguishes organisational advice, personal experience and consultation findings.
- ☐ Individual engagements, payees and responsibilities are distinguished from organisational work.
- ☐ Any host or intermediary's role in holding funds and accepting responsibility is clear.
- ☐ Relevant foreign-funding, fundraising and cross-border permissions have been checked.

Protect independence and manage interests

- ☐ We retain control of priorities and positions without required endorsement.
- ☐ Drafting, review and final editorial decisions are agreed for each output.
- ☐ Company review has a defined purpose and source.
- ☐ Exclusivity, confidentiality and publication restrictions are understood and assessed.
- ☐ Relevant interests have been identified for disclosure or management.
- ☐ Effects on regulatory, HTA, reimbursement or representative roles have been checked separately.

Check workload and payment

- ☐ Preparation, consultation, meetings, review, administration and follow-up are included.
- ☐ Deadlines allow internal decisions, volunteer availability and changes in health.
- ☐ Accessibility, language, caring, travel and support-person needs have been discussed.
- ☐ Permitted costs and budget exclusions are clear.
- ☐ Payee, amount, currency, invoicing and payment dates are agreed.

- ☐ Upfront costs are manageable or advances/direct arrangements are available where permitted.
- ☐ Individuals understand fees early enough to consider their circumstances and obtain advice.
- ☐ Delay, scope change and cancellation terms address completed work and committed expenses.

Review agreements and administration

- ☐ Document requests are coordinated, proportionate and explained.
- ☐ The agreement reflects purpose, responsibilities, deliverables, funding and timing.
- ☐ Questions on liability, insurance, ownership, confidentiality and termination are resolved.
- ☐ Financial and activity reporting is understood and manageable.
- ☐ Permitted names, logos, materials, channels and duration are agreed.
- ☐ A named company contact and escalation route are available.
- ☐ Required agreements and approvals are complete before substantial commitments.

Protect participants and information

- ☐ Information collection is necessary; anonymous summaries have been considered.
- ☐ Collection, recipients, access, storage, retention and deletion responsibilities are clear.
- ☐ Applicable health-information and international-transfer requirements are assessed.
- ☐ Membership lists are not shared simply because the project is funded.
- ☐ Participants receive understandable information on organiser, funder, use and contacts.
- ☐ Participation, recording and publication choices are distinguished.
- ☐ Stories have been assessed for identifiability beyond names.
- ☐ Any safety role, training, timeline and secure route are understood.
- ☐ Research classification and required approvals are settled before recruitment.

Deliver and close

- ☐ Workload and commitments are monitored; additions are agreed before acceptance.
- ☐ Acknowledgements and disclosures reflect actual involvement.
- ☐ Decisions, expenditure and outputs are appropriately recorded.
- ☐ Outstanding payments and actions have named owners.
- ☐ Participants hear how their contribution was used and why suggestions were not adopted.
- ☐ Retention, deletion and future-use terms are followed.
- ☐ Patient benefit, independence, burden and future improvements are evaluated.

3.2 Checklist for pharmaceutical companies

Establish a legitimate and useful purpose

- ☐ A clear need explains why patient-organisation involvement is appropriate.
- ☐ Intended benefit is realistic and promises are within the project's control.
- ☐ The organisation can shape relevant decisions while they remain open.
- ☐ Personal experience, organisational advice and collective evidence are distinguished.
- ☐ Selection is appropriate and documented for the contribution needed.
- ☐ Both partners agree what a useful result looks like.

Establish applicable requirements

- ☐ Support, sponsorship, services, research, communications and assistance are classified.
- ☐ Entities, participants, locations, audiences and information flows are mapped.
- ☐ Operative sources, effective dates and transitional provisions are checked.
- ☐ Law, codes, authority requirements and policy are labelled correctly.
- ☐ Foreign-funding, fundraising, banking and other special permissions are resolved.
- ☐ Material uncertainties have owners and are resolved before dependent activity.

Understand organisational governance

- ☐ The legal entity and authorised signatory are confirmed.
- ☐ Nonprofit, charity, tax and donation-receipt status are distinguished.
- ☐ The timetable allows organisational and member approvals.
- ☐ Relevant funding conditions and policies have been discussed.
- ☐ Documents have defined purposes and appropriate alternatives are considered.
- ☐ Capacity is assessed directly rather than inferred from country or size.

Preserve independence

- ☐ Funding does not require company or medicine endorsement.
- ☐ Commissioned outputs and independent communications are distinguished.
- ☐ Review requests and unresolved editorial decisions have a clear process.
- ☐ Confidentiality, exclusivity and publication restrictions are proportionate and assessed.
- ☐ Names and logos are used only as authorised.
- ☐ Official submissions remain under organisational control.

Make participation feasible

- ☐ Budget includes permitted preparation, consultation, accessibility and follow-up.
- ☐ Local cost restrictions have been checked before offers are made.

- ☐ Remuneration has a documented basis and any limit is properly attributed.
- ☐ The intended organisational or individual payee is agreed early.
- ☐ Advances, direct booking or practical payment arrangements address upfront barriers.
- ☐ Participants are asked what support they need without unnecessary disclosure.
- ☐ Cancellation and changes address completed work and committed costs fairly.

Coordinate approval and contracting

- ☐ One accountable owner coordinates teams and organisation contact.
- ☐ Requests are consolidated and current information reused where appropriate.
- ☐ Dependencies are explained before preparation, recruitment and publication.
- ☐ Review estimates are realistic and delays communicated promptly.
- ☐ The agreement is understandable and reflects the final activity.
- ☐ Substantial work is not requested without clear approval and payment status.
- ☐ Agencies understand responsibilities, oversight and escalation.

Assess communications and transparency

- ☐ Purpose, content, audience, distribution and company involvement are assessed together.
- ☐ Patient membership and expertise are not treated as professional qualifications.
- ☐ Restricted and public materials, access controls and reuse are distinguished.
- ☐ Personal-story permission does not replace advertising review.
- ☐ Reportable support, services and in-kind contributions are identified.
- ☐ Public descriptions and correction routes are explained before agreement.
- ☐ Acknowledgement neither conceals support nor implies wider endorsement.

Protect information and establish safety arrangements

- ☐ Need, recipients, access, security, retention and transfers are mapped.
- ☐ Privacy roles and legal grounds are assessed separately from the collaboration contract.
- ☐ Participant information and recording/publication choices are clear.
- ☐ Identifiable information and membership-list requests are minimised.
- ☐ Safety classification reflects the actual activity and role.
- ☐ Training, instructions, timelines, secure routes and follow-up contacts are ready.
- ☐ Research classification and relevant approvals are documented.
- ☐ New questions, uses, participants and outputs trigger reassessment where needed.

Close responsibly

- ☐ Deliverables, invoices and outstanding commitments are reconciled.
- ☐ Disclosures match the final arrangement.
- ☐ Participants receive meaningful feedback, including limits on adoption.
- ☐ Information is retained or deleted as agreed, including by providers.
- ☐ Future use of stories, materials and names stays within permission.
- ☐ Both partners evaluate benefit, burden, accessibility and improvements.

3.3 Joint readiness check

Stage	Confirm together
Accept funding or sign	Purpose, authority, requirements, independence, budget and terms are understood.
Begin preparation	Approval status, preparation payment and cancellation treatment are clear.
Recruit	Roles, support, participant information, payments and approvals are ready.
Collect information	Privacy, safety and research arrangements are complete and understood.
Publish	Content assessment, acknowledgements, permissions and channels are confirmed.
Make official input	Eligibility, independence, declarations, format and deadline are separately checked.
Close	Payments, disclosures, feedback, records and retention actions have owners.

These checklists are recommendations developed for this guide. Supporting sources are identified in the principles and country chapters; they do not establish identical obligations in every market.