



Practical tips for patient engagement

Turning the community's practical tips about what to do and not to do when developing and delivering patient engagement into an actionable and easy to use checklist.



Shared purpose

DOs

- ✓ Set up partnerships to identify top research priorities
- ✓ Allow additional time for meetings with key stakeholders
- ✓ Discuss and agree together with partners on the shared purpose for your partnership/collaboration and check that the purpose is still appropriate over the duration of the project

DON'Ts

- ✗ Do not present a long list of aims and objectives using technical language
- ✗ Do not treat partners as mere reviewers of your goals for the collaboration



Respect and accessibility

DOs

- ✓ Consider participants with long-term conditions and cater to their needs
- ✓ Consider travel burden and other barriers to join F2F meetings and offer other ways to participate
- ✓ Provide regular breaks and refreshments in meetings
- ✓ Consider how much time and in which formats patient partners might need to review material prior to meetings
- ✓ Ensure that patients have a way and dedicated time to give regular feedback on project progress
- ✓ **Tip:** Make compensation/contracts as simple as possible for patients

DON'Ts

- ✗ Do not keep one format of engagement for all participants irrespective of their needs
- ✗ Do not create 9 to 5 meetings when patients with long term conditions are involved
- ✗ Do not provide reading material last minute, share documents and slides in advance allowing enough time for people to read



Representativeness of stakeholders

DOs

- ✓ Specify in the beginning what is the target population for the project in order to be able to define the representativeness of project partners
- ✓ Take measures to ensure that stakeholders are able to engage meaningfully by facilitating interactions between them



Representativeness of stakeholders

DOs

- ✓ Always try to have more than one patient or patient engagement representative on a committee allowing them to support each other
- ✓ Involve the patients themselves in addition to carers to ensure the patient's voice is heard
- ✓ Try to expand your range of stakeholders beyond the “usual suspects”
- ✓ Try to be as inclusive as possible in the populations you consult with

DON'Ts

- ✗ Do not assume having one group of patients to be representative of all patients in the disease area



Roles and responsibilities

DOs

- ✓ Discuss and agree with your project partners of the roles and responsibilities throughout the project
- ✓ Outline and mutually agree on what is the commitment, expectation and accountability of each partner
- ✓ Define points of contacts for additional support for partners if needed
- ✓ **Tip:** Think about having project terms of reference (ToR) or similar document so that all participants understand their role and can also refer to the ToR to understand the project goal etc

DON'Ts

- ✗ Do not always use the same patient as patient engagement representative for all projects
- ✗ Do not assume that patients are able or okay to stay in a long term role without flexibility, but rather build in interim checkpoints to make sure they are still comfortable in the roles defined in the beginning



Capacity and capability for engagement

DOs

- ✓ Organise pre-meeting with patient engagement representatives to discuss the agenda and cater to their concerns and needs
- ✓ Have a standing agenda item to invite comments from the patient or patient engagement representatives and other project partners
- ✓ Discuss with project partners to find out if there is a need for capacity building throughout the project e.g. ask them to self-assess their engagement preferences and the need for support
- ✓ If possible, provide training and/or resources for patient representatives on project processes, and training on how to work with patients for other partners
- ✓ **Tip:** Tailor the training according to the needs of the patients and representatives or co-produce this with the help of patient organisations or other patient engagement facilitators



Capacity and capability for engagement

DON'Ts

- ✗ Do not invite patients and patient representatives to an annual report meeting only
- ✗ Do not include patient representatives only for a limited section of the meeting
- ✗ Do not assume that patient partners are ready to discuss whatever topic, but rather ask and adapt to their needs to ensure that their input is mutually valuable
- ✗ Do not assume that only patient partners need capacity building and support, others might as well in order for them to ask the right questions or to engage in a meaningful way



Transparency in communication and documentation

DOs

- ✓ Co-create a transparent communication plan throughout and beyond the project - it should include a mutually agreed process and format for feedback loop, internal and external dissemination topics and channels, frequency, etc
- ✓ Consider the documentation needs of the project in the beginning: e.g. pre-read before meetings, follow-up notes, evaluation of experience, other mid and long term documentation needs
- ✓ Involve patient engagement representatives in the content and style of all patient-facing documents
- ✓ Involve patient engagement representatives in all publications from the project
- ✓ **Tip:** Make sure to update the participants after the project is finished and let them know how their involvement made a difference

DON'Ts

- ✗ Do not just presume that patient engagement representatives will not contribute to the technical peer-reviewed publications
- ✗ Do not expect to only receive feedback and updates from the patient and other partners but also proactively reach out to all who were involved



Continuity and sustainability

DOs

- ✓ Try to have a succession plan for longer projects so patient engagement representatives can handover their responsibilities in case they can no longer contribute
- ✓ Discuss and consider together with partners the sustainability of the project and its outcomes already in the beginning of the project, not in the end
- ✓ Consider how the project or its processes or outcomes can be applied outside of the therapeutic/geographic area or outside of its current scope - how can others benefit from the lessons learned?

DON'Ts

- ✗ Do not have a single patient engagement representative
- ✗ Do not treat the partnership with patients as a single “one-and-done” thing, but nurture the partnership even after the project ends



Other general tips

DOs

- ✓ It's integral to build relationships with patients and help them understand the project
- ✓ A multi-stakeholder approach gives the best overview of the questions, providing a variety of different perspectives and making it easier to prioritize the key findings
- ✓ It is important to allow enough time to plan and identify the right participants
- ✓ An introduction session is very beneficial in ensuring that patient volunteers understood everything and felt free to ask any questions as the project progressed
- ✓ It is beneficial to create a long term, self-standing and frequently meeting advisory board that a research team can "tap in" and involve throughout the project.
- ✓ Measure progress within teams to ensure employees are also accountable to make patient engagement happen (in a pharma company)
- ✓ Plan your project carefully with the flexibility to respond to potential challenges
- ✓ Consider guidances and support from organised patient organisations that can help in the planning and execution of multi-stakeholder projects