
Patient Expert Engagement with Hospitals

Listening to the voice of the customer and the end-user is critical for hospitals to develop services that match the right expectations and that deliver health outcomes. This implies that throughout the patient journey, from first entry into a hospital until the end of the treatment, patient insights can contribute to improve practices and lead to better outcomes and quality of life. It is evident that patients are not experts in medicine or hospital care, but they know probably more about what it means to live with their disease and treatment than the hospital expert. The care and services should be designed to address patient needs.

Patient organisations offer the collective knowledge of all their members and can be represented by trained Patient Experts who can talk on behalf of their patient community. Even if the systematic and early engagement with patients may make the process more complex, at the same time it also ensures an increase in effectiveness and value generation.

The question often asked is how these patient experts can engage with hospitals to create meaningful collaborations¹. This paper tries to give an overview of the different types of patient engagement throughout the care pathway.

This overview was developed early 2022 with patient organisations who are member of the Patient Expert Center, together with representatives from six hospitals active in Belgium. We added a number of services based on recent literature².

The list of patient engagement topics should serve as a general guideline of possibilities, rather than interactions that are cast in concrete. The list of engagements is not limited to the services identified below, and the services should also be adapted to the specific need of the moment.

We identified six major categories for interaction

1. Research
2. Patient Pathway Design
3. Patient Education & Literacy
4. Quality of Care
5. Staff Education & Culture
6. Governance

Within these major categories we try to identify the “*Areas of Engagement*”. As much as possible, we also specify the “*Nature of the Engagement*” – i.e. the more tactical interaction - and the “*Level of Engagement*”. This last topic identifies how deeply involved the patient experts are with the collaboration. For this, we use the model designed by the University of Maryland³. Although this was set up for use in clinical trials, the basic concept can also be used for other areas of engagement.

¹ “Lack of skill and negative beliefs among providers were patient engagement barriers”, according to recent research (Liang L, Cako A, Urquhart R, et al. Patient engagement in hospital health service planning and improvement: a scoping review. *BMJ Open* 2018), which can only further emphasise the need for trained Patient Experts.

² Gagliardi, A.R., Martinez, J.P.D., Baker, G.R. *et al.* Hospital capacity for patient engagement in planning and improving health services: a cross-sectional survey. *BMC Health Serv Res* **21**, 179 (2021)

³ University of Maryland Center of Excellence in Regulatory Science and Innovation (CERSI), Assessing Meaningful Patient Engagement in Drug Development a Definition, Framework, and Rubric (2015)



Patient Role	Examples	Engagement Level
Partnership role	<ul style="list-style-type: none"> • Patients provide a priori and continuous consultation on outcomes of importance, study design, etc. • Patients are paid investigators or consultants • Patients have a governance role; patients have "a seat at the table" 	High
Advisor role	<ul style="list-style-type: none"> • Patients serve as advisory committee members or provide <i>a priori</i> consultation on outcomes of importance and study design, but have no leadership role or governance authority 	Moderate
Reactor	<ul style="list-style-type: none"> • Patient input is collected distally through surveys, focus groups or interviews, but patients are not consulted directly or a priori on such things as study design and outcomes of importance • Patients are asked to react to what has been put before them rather than being the origin of the concepts of interest 	Low
Study subject	<ul style="list-style-type: none"> • Patients are recruited or enrolled as study subjects, but are not asked for input, consultation, or reaction 	None

1. Clinical Trials

Research prioritisation

a. Trial Design

Even if most clinical trials are designed at international level, it is important to gain insights from patients in different countries, including Belgium. Patient Experts can be in international panels. And because Belgium is an important country for clinical research, it is also critical that patients actively participate in the design of the studies.

The most important areas of engagement are

- Understand patient needs
- Identification of endpoints & patient-relevant outcomes (PROMs/PREMs)
- Identification of patient preferences (PREFER⁴)
- Discussion on benefit/risk & value
- Feedback to patients involved

In order to obtain these patient insights both qualitative and quantitative data are needed.

Qualitative data can be obtained through a first focus group session to scope the project and understand the full context of patients living with the disease, followed by more detailed patient questionnaires and the final discussion of the questionnaire with preferably the same group of patients to identify the commonalities and differences among patients. The process will also address current issues with the standard-of-care, expectations for innovation, prioritisation of needs and preferences, weighing of the different parameters used to evaluate outcomes, including benefits, risks and value.

It is also essential to organise feedback to the patient organisation and to the patients ultimately enrolled in a study.

⁴ PREFER is a European initiative to identify patient preferences during drug development processes and approval. More information can be found here: <https://www.imi-prefer.eu>



b. Participation in Ethics Committee

The Ethics Committees of hospitals require the presence of a patient representative. Very often, it is difficult to find patients who are sufficiently knowledgeable to evaluate the methodology and set-up of clinical trials. It is therefore important for both the hospital and patient organisations to develop the proper training and framework for the patient representative to have meaningful input at the Ethics Committee meetings.

c. Trial Recruitment

Patient organisations can participate in the recruitment process of a trial, by reviewing the recruitment strategy and materials but also by disseminating the recruitment itself to the members of the organisation or through their communication channels.

Typical patient engagement processes include:

- Recruitment strategy & materials – this can be done in collaboration with the investigators and will largely depend on the type of disease, its incidence and facility of identifying potential candidates. Depending on the situation, patient testimonials (videos, apps, ...) can be used to highlight the value of participating in trials, but also the caveats and eligibility. Flyers and posters should be reviewed by patient experts. Some patient organisations also announce via their websites or social media when trials start recruiting.
- Lay person summary – the materials presented to the patients to explain the trial itself, what it entails and how it will be set up, with all consequences for the patient should be explained in easy-to-understand language. Patient Experts should review the final material.
- Informed Consent Forms – the enrolled patients should understand what they are signing. Most informed consent forms are very legal (complete and accurate) but lack communications value (clarity). A good '*informed consent form*' starts with a one-page summary with the key messages.
- Dissemination of results – once the study has been completed, or when it is discontinued, patients should be informed of the result of the study in an easy-to-understand language. Patient organisations can assist the company with the reviewing of the materials.

d. Monitoring Tools

- a. Patient Diary – developing a patient diary to complete during the trial is the most common tracking tool about the quality-of-life of patients.
- b. Digital applications – the diary can also be set up as an app, with the additional advantage that it can be linked to other smartphone metrics such as physical activity and tools such as pill-coach.

e. Choosing to participate in clinical trials

The patient choice of whether to participate in a clinical trial should be based on well-informed decisions. Patient organisations and hospitals can design a process to enable the decision to participate, in collaboration with the medical team and the family doctor. The patient should also be fully informed on all the relevant clinical research studies that may be suited for his or her situation, even if this study is conducted in another hospital.



We also refer to the more elaborated format designed at European level⁵ for medicines development, as depicted in the following graph, but it can also serve as inspiration for other research areas.

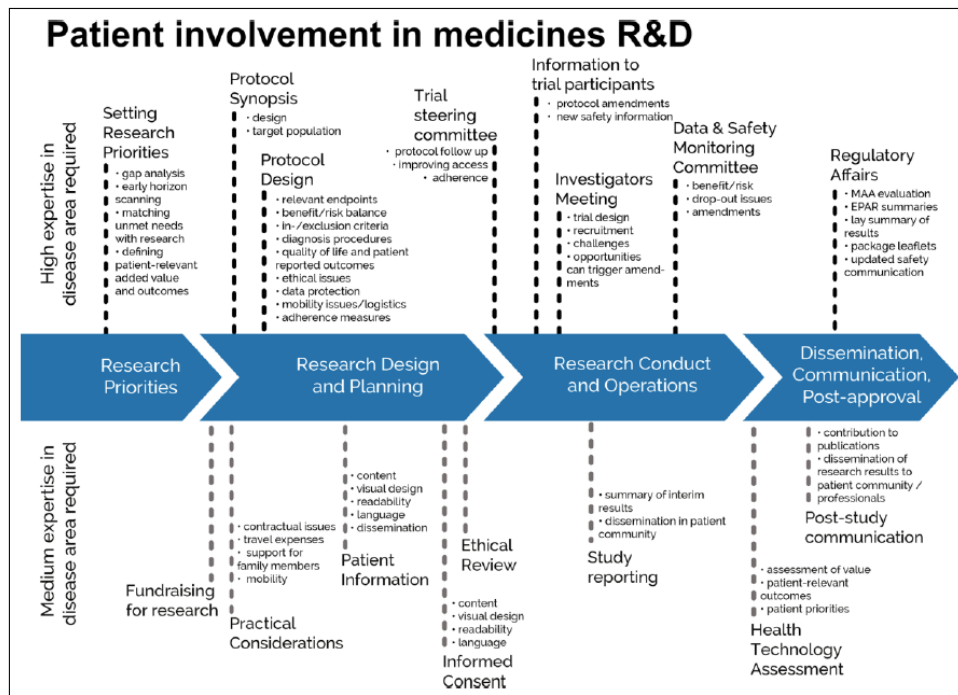


Figure 3. Practical roadmap for patient involvement in medicines R&D.

2. Patient Pathway Design

The second category determines how patient pathways can be designed for each disease from first diagnosis to end of treatment. For hospitals this is a critical element in the multidisciplinary treatment of patients. It includes how patients are informed on their disease and its treatment, which interventions are needed and how often, how patients are monitored, how patients can interact with the hospital when they have questions.

Based on the input of patients, areas for improvement can be achieved, and best practices introduced for the entire patient pathway. The Pathway Design can also include the mapping of all the areas of attention that patients need to work with, and to develop a task division between the medical team (more the clinical aspects), the quality team of the hospital and the patient organisation (non-clinical aspects). Hospitals and patient organisations can work in full complementarity so that the needs of patients during treatment are fully covered. It is of the essence to include patient experts treated in other hospitals to be able to discuss various options of approach.

The following items were identified

- a. Mapping of the full patient pathway for both inpatient and outpatient settings
 - a. **Full Patient Journey & Care Pathway** description, with the overview of all clinical and non-clinical interventions, moments for information-sharing, consultation and decision, involvement of specialised expertise. Interesting models have already been designed that could be used as template⁶.

⁵ Geissler et al « Improving Patient Involvement in Medicines Research and Development: A Practical Roadmap, In Therapeutic Innovation & Regulatory Science, 2017

⁶ Richter, Peggy & Schlieter, Hannes. (2021). Patient Pathways for Comprehensive Care Networks - A Development Method and Lessons from its Application in Oncology Care. 10.24251/HICSS.2021.455.



- b. **Decision-tree** with therapeutic options/timings/location and other elements
- c. **Shared Decision-Making Process (SDM)** is one of the most critical aspects in the relationship between patient and the medical team: *“It involves choosing tests and treatments based both on evidence and on the person’s individual preferences, beliefs and values. It makes sure the person understands the risks, benefits and possible consequences of different options through discussion and information sharing”*⁷. Interesting guidelines have been developed over the years, and we can recommend the NICE Guidelines and materials in this respect. Shared Decision-Making has also been incorporated as a basic patient right in the European Code of Cancer Practice⁸.
- d. **Patient Reported Outcomes Measures (PROMs)** and **Patient Reported Experience Measures (PREMs)**. Both PROMs and PREMs are essential to assess the outcomes and Quality of Life of patients during and after treatment, but their collective insights can be used for improving the day-to-day practice in the hospital. Patient experts can participate in the design of questionnaires, the weighing of the importance of the various elements in the questions, the wording, frequency and use of the questionnaires.
- e. **Improvement of hospital services.** This can be general in approach or disease-specific. Patients can provide useful insights to the quality team of the hospital to improve all processes, healthcare and other services: *“Service design can be a process of improving customer participation in the iterative cycle of design, testing, measurement, and redesign by considering customer experiences, and thereby creating better value”*⁹.
- f. Agreement for **patient follow-up** after discharge.

b. Patient Navigation

Patients and their families have to find their way in the healthcare system. Hospitals have some basic information, but not all information. In order to ensure that patients get the full benefit of all the healthcare and social services that exist in our country, it is useful for the hospital and the patient organisation to make the inventory of possible services within a disease area. Some hospitals already have “case managers” who can assist patients for any question they may have, but that is rarely sufficient. Patient navigation can include services such as a specialised dietician, psychological support, physical re-education, home nursing, but also reimbursement of home adaptations, transport to the hospital, social and professional counseling, etc. Many of those services are not medical, but patients who are fully supported are also more likely to have better quality of life and health outcomes.

Both hospital and patient organisation can develop

- a. Inventory of all patient support services (inpatient and outpatient)
- b. Agree on task division between hospital and patient organisation
- c. Design Patient Navigator Training Programmes
- d. Function as Patient Navigators

⁷ Shared Decision-Making Guidelines of the National Institute of Care and Excellence, UK, 2022

⁸ European Cancer Organisation : European Code of Cancer Practice: <https://www.europecancer.org/2-standard/85-the-code-shared-decision-making>

⁹ DonHee Lee - A model for designing healthcare service based on the patient experience, International Journal of Healthcare Management, 2017



3. Patient Education & Literacy

Before diagnosis, few patients are familiar with the disease and its treatment, let alone with their implications and consequences. The information provided during the initial consultations is often limited, incomplete and results in even more questions than answers. The availability of information sources such as internet are not always helpful, providing complex information, information not suited to the situation of the individual seeking it, erroneous, outdated or even deliberately misleading. Furthermore, living with a disease or undergoing treatment has many consequences that the medical staff in a hospital are not aware of or cannot easily understand. We therefore recommend to have a complementary approach in which both hospital and patient organisation agree on the basic information needs and to develop information materials.

Patients who do understand their disease have better health outcomes. They are more compliant, more aware of their own role in obtaining success, more engaged in contextual aspects such as physical activity, nutrition, social participation, etc. In order for patients to be fully informed, it is good standard practice to direct patients to a disease-specific patient organisation to provide the full picture of what it means to live with the disease.

The following items have been identified.

a. Identification of information needs

The first inventory can be based on desk research developed by the hospital and the patient organisation. This can be further expanded based on

Nature of the engagement

- Medical minimum information
- Focus Group sessions
- Help desk statistics
- Surveys
- Patient interviews

b. Collaboration Agreement on Patient Information post-diagnosis

- Testing patient understanding after consultation (Teach-Back Method)
- Design patient education programs
 - One-on-one education (including emotional and psychological support)
 - Group education and information sessions (for instance on intimacy & sexuality, on living with a stoma, on how to cope with disease progress, ...)
- Education materials
 - International review of patient education materials (there is a not very efficient tendency to re-invent the wheel in every hospital and in every country)
 - Develop information or communication aids
 - Review of materials
 - Testing of messages, materials, and technology (apps, website, ...)
- Task division between hospital and the patient organisation

4. Quality of Care

To improve the quality of care, the following services have been identified.

- #### a. Preparation for consultation & mediation
- Patient organisations can assist patient to articulate the questions they have after being diagnosed. Patients are not always active participants in the consultation, or are sometimes afraid to ask certain questions. It can also



happen that patients are not satisfied with the services received, or not convinced about the treatment suggested. Patient organisations can then also participate in the process of coming to the right choices.

Activities can include

- i. Identification of questions to ask
- ii. Helping understand perspectives & needs
- iii. Develop patient satisfaction or experience instruments
- iv. Patient safety materials, discussions and the licence to "Speak Up"¹⁰.

b. Improvement of service delivery

All hospital services are always open for improvement. Patient organisations and hospitals can work together in this area.

- i. Identification of critical services
- ii. Exit Interview Questionnaire
- iii. Focus Group Sessions

In Flanders, the Vlaams PatiëntenPlatform (VPP) and het Agentschap Zorg & Gezondheid, conduct the survey on quality indicators in Flemish hospitals. VPP gives the best hospitals the award of "Patiëntvriendelijk Ziekenhuis", based on the actual experience of patients and on the quality of the information provided on the websites of the hospitals.

- c. Peer support** – Some patient organisations are present in the hospitals to provide services to patients. This can include the provision of basic information, listening to patients, providing basic support, but it can also include entertainment activities for young patients or just keeping them company.
- d. Innovation** – hospitals are open to innovation in service delivery. Patients and patient organisations can participate with the hospitals in designing innovative new approaches that will facilitate healthcare delivery and outcomes.

Examples include:

- i. The development of specific tools to improve the service, eg Virtual reality in pediatric setting and operating theatres
 - ii. The design information tools, e-health systems, remote monitoring tools, patient diaries, ... (apps, digital)
- e. Help desk** – both patient organisations and hospitals receive general questions by patients about their disease. It may help to align their respective Q&As and to align how to interact during crises situations¹¹.
- f. Quality Audits** – Based on the literature, the following items for patient engagement have been identified:
- Develop strategic or operating plans for quality and safety
 - Develop quality criteria/indicators
 - Design or plan specific quality improvement projects
 - Conduct or execute quality improvement projects

¹⁰ The global **Speak Up!** programme was developed by the Joint Commission of Medicare and Medicaid in the United States, but in the meantime implemented in more than 70 countries, providing tools to medical teams and patients to speak up if they have questions, concerns, or feel inappropriately treated.

¹¹ During the Covid-19 pandemic, patients could not get through to the call centers of the hospitals because of overload, and the help desks of patient organisations were insufficiently informed to help patients further about how to proceed. It would be good to have agreements about joint statements and collaborative approaches between the help desks of both patient interfaces.



- Implement changes emerging from quality improvement projects
- Audit a clinical or hospital service
- Design healthcare staff/professional data collection instruments to inform audit
- Develop patient data collection instruments to inform audit
- Design improved clinical services based on audit findings
- Plan or conduct patient interviews/focus groups to inform audit
- Develop the format/content of audit reports
- Review audit data
- Plan for or participate in accreditation
- Plan or conduct executive walkabouts

5. Staff Education & Culture

Hospitals put great store in their patient-centric culture. To have a patient-centric culture, it is critical to have strong patient engagement and strong patient focus in all activities of hospital. The active role of patient experts can help develop this internal culture for all management principles and employee engagement.

At the same time, it is equally important for medical staff to learn about the challenges of diseases for patients in their daily lives. Umbrella patient organisations and disease-specific patient organisations can provide value in this respect.

The following items were identified:

- a. Education on the value of patient engagement
 - Deliver presentations about patient engagement activities/impact
- b. Educating on the patient pathway
 - Overview of complexity of living with the disease (including home situation)
 - Understanding the diversity within the patient population
 - Understanding the services that patient organisations provide
 - Communicating with the patient and the family
 - Provide patient engagement orientation or training to healthcare staff, professionals or executives
 - How to deal with complementary and alternative medicine?
- c. Installing a culture of patient-centricity – this can be done by reviewing the current practices, and to ensure that they are fully integrated in the Quality of Care and Patient Pathway Design as described above.
- d. Develop healthcare worker training curricula
 - Review healthcare worker performance
 - Establish healthcare worker competencies (eg how to speak at patient level)
 - Member of the selection committee for new healthcare workers

6. Governance

The last priority topic that was identified was patient engagement and patient participation in the governance structure of the hospital and hospital departments. It is obvious that this cannot be done by disease area, but it is essential that the patient representatives are also actual patients, preferably with training so that they understand the healthcare system and so that they can speak on behalf of all patients.

The following items were identified:

- a. Patient representative in governance structures
 - Members of quality committees



- Members of hospital management committees
 - Members of advisory panels, councils or networks
 - Members of project teams
- b.** Care unit organisation, improvement of hospital service delivery

In conclusion

The list of patient engagement above is just an overview of possibilities.

Hospitals that are interested in taking this a step further should either contact the patient organisation active in the disease they want to set up an initiative or with the Patient Expert Center. We will then come with a proposal based on a more substantial briefing on the topic for which patient engagement is sought.

Further reading

General

- Toolkit for Patient Organisations on Patient Empowerment, European Patient Forum, 2017
- The Added Value of Patient Organisations, European Patient Forum, 2017
- Declaration on Patient-Centred Healthcare, International Alliance of Patient Organisations, 2006
- Marguerite Friconneau et alii - Le patient-expert - Un nouvel acteur clé du système de santé, Médecine/Sciences, 2019
- Eva Marie Castro – Nieuwe Collega's in de Zorg : Ervaringsdeskundigen in het Ziekenhuis, Lannoo, 2019
- Advancing Models of Patient Engagement: Patient Organizations as Research and Data Partners, Milken Institute, 2019

Hospital Care

- Maria-José Santana et al - Measuring patient-centred system performance: a scoping review of patient-centred care quality indicators, BMJ Open, 2019
- Elysia Larson et al - When the patient is the expert: measuring patient experience and satisfaction with care, Bull World Health Organ 2019
- Op Weg naar Persoonsgerichte Zorg, Qualicor Europe, 2019
- DonHee Lee - A model for designing healthcare service based on the patient experience, International Journal of Healthcare Management, 2017
- Glenn Robert et al - Patients and staff as codesigners of healthcare Services, BMJ 2015
- Lidewy Eva Vat - Transforming the health research system: Embedding Patient Engagement in Decision-Making, University of Amsterdam, 2021
- Yvonne Bombard et al - Engaging patients to improve quality of care: a systematic review, Implementation Science (2018)
- Laurel Liang et al - Patient engagement in hospital health service planning and improvement: a scoping review, BMJ Open, 2018
- Anna R. Gagliardi et al - Hospital capacity for patient engagement in planning and improving health services: a cross-sectional survey, BMJ Open, 2021
- G. Ross Baker - Evidence Boost: A Review of Research Highlighting how Patient Engagement Contributes to Improved Care, Canadian Foundation for Healthcare Improvement, 2014

Shared Decision-Making

- Glyn Elwyn et al. - Shared Decision Making: A Model for Clinical Practice, Journal of General Internal Medicine, 2012
- NHS England – Shared Decision-Making, 2019



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- Hanna Bomhof-Roordink et al - Key components of shared decision-making models: a systematic review, *BMJ Open*, 2019
 - Arwen Pieterse et al - Patient explicit consideration of tradeoffs in decision making about rectal cancer treatment: benefits for decision process and quality of life, *Acta Oncologica*, 2019
 - Arwen Pieterse - Shared Decision Making and the Importance of Time, *JAMA*, 2019
 - Arwen Pieterse - Alles wat u moet weten over gedeelde besluitvorming – Een Investering van Arts en Patiënt in Betere Zorg, *Medisch Contact*, 2017

