

Partnering with Patients and Families

Partnering with patients in the planning, design and delivery of healthcare services is an important way to improve care quality and accountability in the system.

Person and Family Engagement has been identified as one of the drivers for quality improvement in the ‘Framework for Improving Quality in our Health Services’.ⁱ The framework provides a strategic approach to improving quality in the health service.



Supporting patients, families and communities to collaborate as equal partners in service design and delivery of care is a key component of Person and Family Engagement.

The 2014 Report of the Roundtable on Consumer Engagement in Patient Safetyⁱⁱ describes patients as being the extra sets of eyes and ears that should be integrated into the safety processes of all healthcare organisations. Patients often have insights into the processes of care that healthcare staff may lack because they are focusing on getting the job done. Patients bring new, innovative approaches and offer unique perspectives to decisions about their own health and treatment, to care design processes in their local health organisations, or to the bigger policy decisions that shape the healthcare system.

What partnering with patients and families mean?

Partnering with patients and family members refers to:

- The knowledge, skills, ability and willingness of patients to manage their own and family members’ health and care;
- The culture of the health care organisation that prioritises and supports partnering with patients and family members;

- The active collaboration between patients and providers to design, manage and achieve positive health outcomes.

Our goal is to achieve the highest level of engagement possible and to move towards more collaborative models that are based on shared decision making and supporting and enabling patients and families to become true partners in service planning, design and improvement.

| Levels of Engagement ⁱⁱⁱ | Methods |
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| <ul style="list-style-type: none"> • Informing – providing information that addresses concerns or assists in understanding problems, alternatives, opportunities or solutions. One way communication only. | <ul style="list-style-type: none"> ➤ Information leaflets/fact sheets ➤ Press releases ➤ Public health announcements |
| <ul style="list-style-type: none"> • Consulting – getting feedback to help inform a decision or determine a direction to take. This level of engagement is required when we need to listen to the patient perspective to inform decision making at the stage where policies or programme decisions are still being shaped. | <ul style="list-style-type: none"> ➤ Interviews ➤ Focus groups ➤ Questionnaires/surveys ➤ Reference groups ➤ Listening sessions ➤ Public meetings/forums |
| <ul style="list-style-type: none"> • Involving – working with patient representatives to ensure that the patient voice is understood and considered. A two way information exchange takes place and patient representatives have an interest in the issue and will be directly affected by the outcome. Involving encourages discussion among all stakeholders. | <ul style="list-style-type: none"> ➤ Workshops ➤ Patient Councils ➤ Membership of working groups/governance committees |
| <ul style="list-style-type: none"> • Collaborating – partnering with patient representatives in all stages and aspects of the decision making process, including agenda setting, development of alternatives and identification of solutions. | <ul style="list-style-type: none"> ➤ Patient experience advisors ➤ Experience based co-design ➤ Shared decision making ➤ Peer support |
| <ul style="list-style-type: none"> • Empowering – patients identify issues, solutions and actions. System empowers and supports them. | <ul style="list-style-type: none"> ➤ Patient directors ➤ Centre for patient leadership |



Enablers for partnering with patients and families

- Having leaders who are knowledgeable and committed to partnering with patients and families
- Designating staff member(s) with knowledge and skills as lead(s)
- Creating variety of ways in which patients/families can contribute in meaningful ways to decision making
- Recruiting patients/families continually
- Investing in orientation and training for staff and patients/families to develop trusting relationships
- Supporting the development of patient and family leaders
- Providing on-going support and mentoring
- Evaluating using process and outcome measures
- Celebrating accomplishments and efforts

Checklist to consider before partnering with patients and families^{iv}

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| 1. Why do you want to partner with patient representatives in this project? |
| 2. At what stage are you in your project/working group, etc.? <input type="checkbox"/> Planning <input type="checkbox"/> Implementation <input type="checkbox"/> Evaluation Bringing patient representatives at the start of the project or working groups creates opportunities for true collaboration and better relationships and participation. |
| 3. What inputs is your project/initiative seeking from patient representatives? Refer to levels and methods of engagement on P.2 of this document. |
| 4. Are there specific objectives related to partnering with patient representatives in your work that need to be met? If yes, ensure that these are reflected in the Terms of Reference. |
| 5. Will patient representatives need any information in advance or throughout the process to engage effectively? If yes, ensure that this information is available in easy to understand, plain English and any terminology is clearly explained. Allow enough time for patient representatives to consider the information and ask questions in advance of getting involved in the project/group. |
| 6. Will any training/background information on the work of your group be provided to patient representatives prior to the first meeting? |



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| <p>7. Nominate someone on your group who could act as a “mentor” to patient representatives, someone who patient representatives could liaise with and who could provide support to them.</p> |
| <p>8. How many patient representatives would you like to involve in your committee/project/initiative? For representation on working groups/committees it is recommended to have more than one patient representative.</p> |
| <p>9. Are there any specific criteria for patient representatives (i.e. skills, past experience or other) to participate in the work of your group/project ?</p> |
| <p>10. Consider if engagement opportunity is:</p> <ul style="list-style-type: none"><input type="checkbox"/> One time event<input type="checkbox"/> Short term (few meetings over a limited time, e.g. 3 to 6 months)<input type="checkbox"/> On-going (longer term commitment – up to one year)<input type="checkbox"/> On-going (longer terms commitment from one to three years) |
| <p>11. How will patient representatives be expected to participate? Provide options for participation:</p> <ul style="list-style-type: none"><input type="checkbox"/> In person<input type="checkbox"/> Teleconference<input type="checkbox"/> Webinar<input type="checkbox"/> Other |
| <p>12. Please note that you must cover travel expenses, as well as any out of pocket expenses incurred by patient representatives for the purposes of engagement. More information on reimbursing expenses to patient representatives is available from the following link: http://hse.ie/eng/about/Who/QID/Person-Family-Engagement/ResourcesQID/Policy-for-the-reimbursement-of-service-user-expenses-2017.pdf</p> |

ⁱ ‘Framework for Quality in our Health Service: Part 1 Introducing the Framework. 2016 <https://www.hse.ie/eng/about/who/qid/framework-for-quality-improvement/framework-for-improving-quality-2016.pdf>

ⁱⁱ ‘Report of the Roundtable on Consumer Engagement in Patient Safety’ 2014, National Patient Safety Foundation’s Lucien Leape Institute.

ⁱⁱⁱ International Association for Public Participation 2014. IAP2’s a Public Participation Spectrum

^{iv} Adapted with permission from Vancouver Coastal Health’s “How to Engage Patient and Public Advisors: A Guide for Staff.”