

What is patient and family engagement?

Patient and family engagement can be a confusing concept because it has been defined in multiple ways and in various contexts. For SIDM purposes, we can simplify patient and family engagement into two main “types.” The first, which is most well-known, is the idea that patients who are empowered and supported to be active partners in their own diagnostic process (and care), tend to do better and feel better. Therefore, patients and families should be looked to as key members of the diagnostic (and care) team, and involved in decision-making. The other type of engagement focuses not on a given patient’s own diagnostic or clinical management, but rather on drawing from the lived experience of patients and families to improve and design the healthcare system that serves them. This includes participation in designing and delivering educational content at conferences like DEM.

Why is patient and family engagement important?

As the single constant in their diagnostic journey, patients and families are an immense (and untapped) source of data and insight about breakdowns in the diagnostic process and potential solutions for preventing safety events. SIDM believes that patients and families are a critical partner in all diagnostic quality activities including education.

How do I describe patient and family engagement in my submission?

- The key is to be as specific as you can in describing the participation of patient and family faculty in helping to create the workshop and in presenting at the workshop including the content that they will cover, and their responsibilities to create materials.
- If you have existing relationships with patient or family faculty, please list them by name (after they have agreed to be involved).
- If you do not have any connections to specific patient or family faculty, describe the type of patient or faculty members you plan to involve (i.e., “a patient who experienced a near-miss”, “a person with diabetes that was harmed by a delayed diagnosis”). If your submission is accepted, SIDM can help identify patient or family faculty members for your session.
- Finally, if your workshop centers on a project or activity in which patients or family partners have already been involved, you should also describe those activities and contributions.

Sample Patient/Family Faculty Description in a Workshop Submission

In a workshop about learning from errors, the roles of the clinician faculty members are explained (i.e., amount of time, the content they’ll cover), and the session is designed as 3 presentations, culminating in a group discussion and Q&A with the audience. The role of a patient faculty member might look like this:

Jane, a patient who experienced a very serious diagnostic safety event will briefly share her story and using the National Academies of Sciences, Engineering, and Medicine diagnostic process map, identify the key breakdowns in her diagnostic process.

During the discussion, Jane will offer the patient perspective on proposed ideas and solutions for events like hers, providing tangible insights and guidance for learners about the best ways to engage patients and families in diagnostic safety and quality. For example, one of the key solutions to be discussed is care conferences. Jane will share how this can be a crucial step for patients and families, but also outline some of the challenges patients and families may face in making this request, and how clinicians and health systems can reduce those barriers.

