

Models of Patient/Family Engagement for Improvement Work

Model of Engagement	Advantages	Disadvantages	Scope: Local/Network Level
Advisors embedded on QI teams – at least 2 (3-4 is ideal) patient/parents serve on and attend regularly scheduled improvement team meetings with staff and participate on a regular basis	<ul style="list-style-type: none"> The purest form of engagement, this is the only model which allows for our patients to inform the process on an ongoing basis. Allows for insights to be heard in real time that may surprise staff and could potentially reduce time spent on PDSAs that they know from experience may not be worthwhile 	<ul style="list-style-type: none"> Can be challenging to identify parents available during the day, when meetings are often scheduled Requires orientation of advisors to Improvement Science Requires orientation of staff to benefits of having advisors in the room, and ways to welcome and engage them in the process Can be challenging to coordinate schedules 	<ul style="list-style-type: none"> Local level
Family/Patient Advisory Council Chronic Care Advisory Group Group of patient/parent advisors with experience in chronic and acute care (but perhaps not your specific disease). Group meets regularly to meet the needs of the larger strategic initiative of the local hospital	<ul style="list-style-type: none"> Provides the broadest range of input from advisors with a wide range of clinical experiences Meets regularly and is typically facilitated by local hospital staff The structure is built – the QI team brings their work to their table No recruitment, screening or orientation is needed Feedback broad based – may not be based on your specific work which can be extremely beneficial 	<ul style="list-style-type: none"> Requires QI team to be able to “pull out” topics which need to be informed by patient advisors. May potentially lose insights which only frequent users can provide by not having them present at all meetings May not include members with your specific chronic disease No ongoing relationship with this group – therefore there may be no way to get feedback between sessions on specific questions / follow up – one time shot Need to learn process for getting on their agenda Feedback broad based – may not be based on your specific work 	<ul style="list-style-type: none"> Local Level
Customized Focus Group/Task Force Group of patients and parents of patients from specific clinical arena which	<ul style="list-style-type: none"> Provides feedback from a larger group with a great deal of specific experience Less frequent meetings so can be scheduled at the convenience of the 	<ul style="list-style-type: none"> Will not gain the perspective of “non-users” of your system, losing the perspective of newly diagnosed (unless this population specifically recruited) Requires staff be able to “pull out” topics which need to be informed by patient advisors. May 	<ul style="list-style-type: none"> Local Level

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gathers “as needed” to inform your work (6 – 8 is ideal).	advisors and staff	<p>potentially lose insights which only frequent users can provide by not having them present at all meetings</p> <ul style="list-style-type: none"> • Can be difficult to keep the group engaged for the duration of your improvement work (months/years) • Requires ongoing communication with the group and feedback to the group in between sessions – CANNOT FORGET THEY EXIST 	
Social Media Facebook, Exchange, Twitter etc	<ul style="list-style-type: none"> • Ideal for parents/patients who travel here for care and/or cannot attend mtgs. • Ideal to get feedback in between regularly scheduled sessions • Can be added to any enrich any of the other models above 	<ul style="list-style-type: none"> • On its own, may not provide for people to interact and build from others’ ideas 	<ul style="list-style-type: none"> • Local/Network levels
Survey	<ul style="list-style-type: none"> • Can be customized to your work • Quick response time • Can promote to a wide population of people for large number of responses • Can provide platform for anonymous feedback 	<ul style="list-style-type: none"> • No opportunity to build on conversations and ask follow up questions • One time shot 	<ul style="list-style-type: none"> • Local/Network levels
Learning Session takeaways Conversations/breakout sessions/presentations by and with patient and parent advisors	<ul style="list-style-type: none"> • Can be very relevant and connected to your work in real time • Can learn from follow up questions and dialogues that have taken place with other teams and advisors 	<ul style="list-style-type: none"> • May not be customized to your particular site • Time frame of discussions dictated by others • Advisors may not represent your site 	<ul style="list-style-type: none"> • Network level
Network wide virtual	<ul style="list-style-type: none"> • Broad base input from advisors 	<ul style="list-style-type: none"> • No face to face contact 	<ul style="list-style-type: none"> • Network Level

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advisory group Advisors representing participating sites commit to regularly scheduled conference calls to address topics brought by individual sites. This functions as a “virtual” advisory group/focus group.	representing a range of sites <ul style="list-style-type: none"> Logistical arrangements taken care of by project team staff Immediate feedback and ability to ask follow up questions in real time 	<ul style="list-style-type: none"> Limited long term follow up possibilities QI team must be able to pull out the “right” questions to be asking the group – advisors have no input on what has happened before/after the session 	
Action Period Calls Advisors embedded on calls can inform topics as requested	<ul style="list-style-type: none"> Logistical/administrative issues are handled by Network Project Team staff members Real time conversations and allows for follow up questions 	<ul style="list-style-type: none"> Extremely time limited as agendas are already often quite full Can be challenging to develop comfortable conversation on APC Agenda topics in control of Project Team Staff 	<ul style="list-style-type: none"> Network