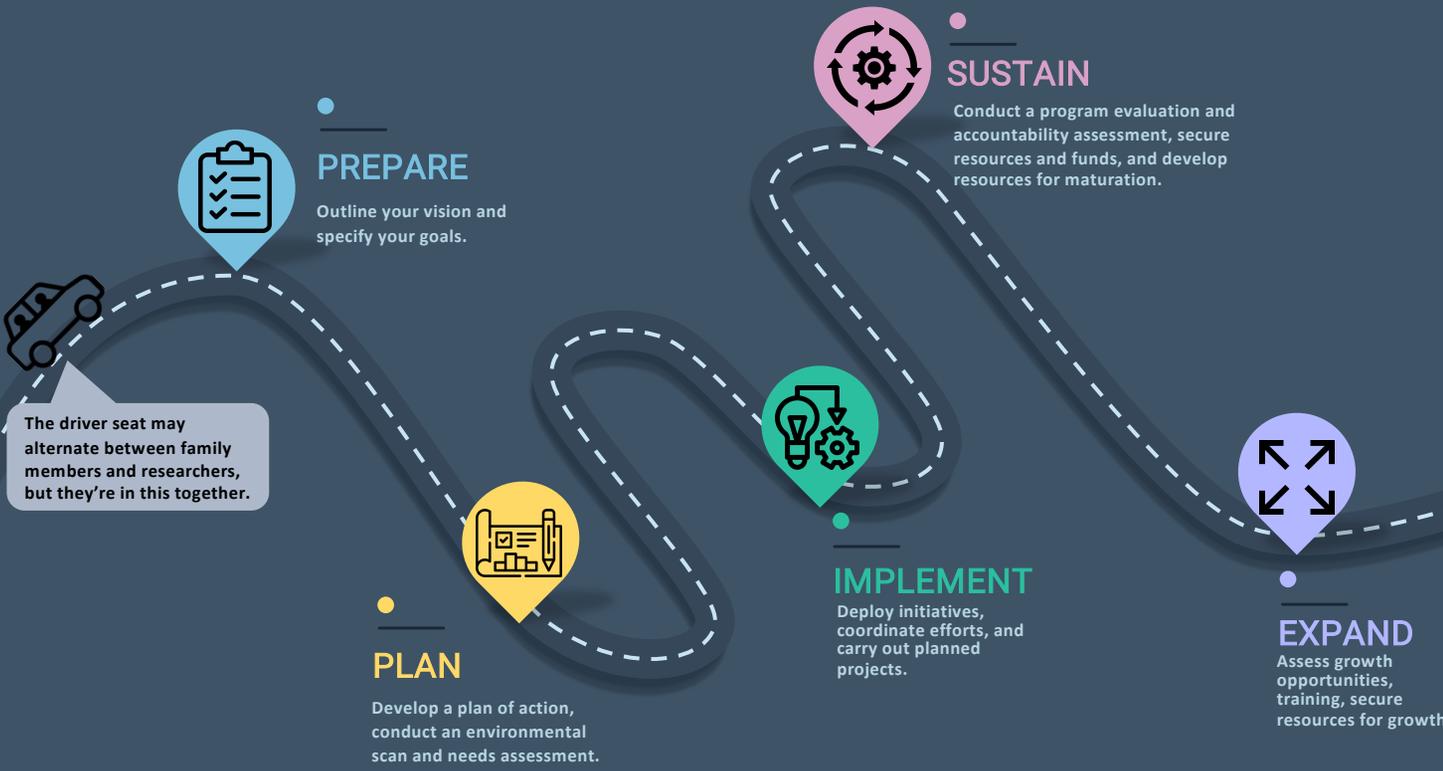


Establishing Institutional Family Engagement in Research (FER) Programs: A ROADMAP



Rationale: FER seeks to forge mutually beneficial outcomes between lived experience, research, and clinical expertise. This requires an authentic and sustainable partnership between those with experience and those with expertise. This is not easy, and the road to develop comprehensive programs and an institutional culture that is conducive to FER is paved with many obstacles. It is not surprising, then, that while many guidelines and resources exist, only a handful of institutions have reached a high level of FER maturity and successful integration.

Who should use the roadmap: This roadmap provides high-level guidance to guide institutions (e.g., research centers, hospitals, clinics) to develop or expand their FER programs and activities.

How to use the roadmap: Simply follow the 5 steps and refer to the table below. It is critical that the FER program establishment is done in partnership between researchers, family members, patients, and the institution's executives.

Expected Outcomes: This will have a direct impact on the institutions themselves, as well as on researchers, families, and patients, who will benefit from building capacity within their institutions and thus form authentic and effective partnerships.

This resource was created as part of the McMaster University, CanChild, and Kids Brain Health Network Family Engagement in Research Certificate of Completion Program. Icons from Freepik, Kiranshastry and itim210. Copyright © 2021 (Jean-Christophe Bélisle-Pipon, Kimberly Courtney, Shelley Frappier, Alison Howie). All Rights Reserved.



Phase	Step	What to do
Prepare	Vision & goals	State the ultimate purpose of developing or expanding FER capacity in the institution and specify the goals that should be pursued.
Plan	Develop a plan of action to achieve stated goals	Identify specific objectives to be achieved, including metrics and timeline.
		Assess how the intended efforts and initiatives can be leveraged using the institution's resources. Seek buy-in and participation from the executive level.
		Develop an organizational chart to determine the composition of the committee. Ensure equal partnerships between all parties (e.g., families, executives, researchers, clinicians).
		Define how progress will be measured, who will be responsible for measuring it, and how milestones can be measured against the defined timeline.
	Environmental scan and needs assessment	Assess the institutional willingness to change research practices.
		Identify the most effective approaches to achieving the stated goals and accessible resources.
		Develop a plan to obtain new resources or leverage existing ones where required.
Equip	Ensure that the current institutional processes, policies, and structures enable and nurture patients and families to be part of the governance structure.	
	Educate, prepare, and empower families, clinicians, and healthcare leaders to partner effectively together.	
Implement	Deploy	Deploy pilot initiatives that respond to the goals and vision and have high probability to be scaled-up more broadly.
	Coordinating efforts	Continuously assess the balance between research-driven and family-driven involvement as well as the ability of the projects to meet the expectations and interests of both the researchers and the community of families involved.
		Ensure coordinated efforts in a coherent and meaningful way and strive to develop a sense of community and recognition.
		Ensure provisions to enable meaningful engagement that weave research expertise and experiential knowledge.
		Ensure that families and stakeholders are supported and compensated throughout the process.
		Ensure that there are peoples to act as family leaders and facilitators (e.g., coordinators/knowledge brokers) and that their hiring criteria includes a preference for selecting family members or former patients with lived experience in the hospital setting with a good network among the family and patient community.
	Carry out	Co-create research proposals with patient and families and work with them on designing and implementing studies that answer the questions that matter most to them.
		Conduct research projects that support patient and family engagement—by patients, families, clinicians, administrators, and other health professionals—within various healthcare settings.
		Partner with patients and families to design process and outcome measures to identify outcomes of most interest to patients and families.
		Continuously assess milestones achievement and goals through quantitative and qualitative metrics and track progress in the annual reporting. Ensure that return-on-investment metrics are assessed and allow to track outcomes, experiences of care, and costs into research on patient and family engagement efforts.
Develop a strong web presence, build awareness, and spread communication about your program through various platforms. Network with other sites, share best practices, and troubleshoot problems together.		
	Look beyond the peer-reviewed literature for ways to disseminate results and information. Share results via blogs, consumer-friendly fact sheets, and social networks.	

Phase	Step	What to do
Sustain	Evaluation	Assess whether goals have been achieved, resources where sufficient and mechanisms and practices have been adequately implemented.
		Survey involved all stakeholders, especially families and patients. Identify and prioritize areas for improvement.
	Accountability	Evaluate whether the accountable persons have fulfilled their responsibilities (including researchers, families, executives, clinicians).
		Develop an evidence-based plan to ensure that everyone fulfills their roles and responsibilities as well as to facilitate organizational changes needed to nurture authentic and effective FER initiatives.
		Make data and information transparent to promote organizational accountability for quality and safety and to enable patients and families to be active in their health and healthcare.
	Secure resources and funds	Secure the resources needed to maintain operations allowing to move from a pilot mode to having FER included in the institution's standard practices and operations.
	Maturation	Co-develop a plan to achieve sustainability of FER practices by involving all stakeholders.
		Seek out engagement researchers to champion the value of the patient/family voice in their research.
		Create measures and conduct research to improve care, facilitate changes in processes, and assess the relationships among engagement, experiences, and outcomes.
		Enable a continuous feedback loop from family/patient partners to ensure they feel meaningfully engaged and are receiving enough time and guidance to contribute to goals achievement.
Provide training opportunities and guiding documents that foster patient/family knowledge and confidence in their role and viewpoints.		
Expand	Assess growth opportunities	Identify growth opportunities aligned with the vision and goals.
	Training	Train the people who will be able to sustain and continue what has been developed. Ensure that all new people who join the institution are trained, whether they are researchers, patients/families, clinicians or executives.
	Secure resources for growth	Secure the resources needed to expand operations.
		Add additional roles for family leaders, knowledge transfer, research ethics, selection committee for hiring new peoples (including researchers, executives, clinicians and family/patient members).
	Network with other sites still in development, share resources, and mentor them as they grow.	