Dissemination Guide for Researchers and Family/Patient Partners

Why is this guide important?

Dissemination of a research project extends beyond just study publication. Researchers need to ask themselves: what impact do I want this study to have? In not considering dissemination as an encompassing requirement throughout the research process, audience reach and study impact is limited. This dissemination guide has been developed based on the belief that strategic consideration of how important research insights are shared can ensure maximum impact.

Moreover, early engagement of family/patient partners as knowledge disseminators can result in wider reach to more diverse audiences for research insights. Accordingly, this guide will demonstrate the value of engagement of patient/family partners in strategic dissemination planning and provide guidance around when and where in the research process partnered consideration of dissemination can and should take place.

Who can use this guide?
Any research team and/or family/patient partners conducting research with purposes of knowledge dissemination.

What will this guide help you do?
- Identifying the target audience, channels, and success criteria for dissemination
- Identify the roles of patient/family partners in dissemination throughout the research process
- Promote strategic consideration of who your research would include/engage/resonate with, how this research might impact, and what success looks like

Limitations of this guide
This study was initiated for the purposes of the Family Engagement Course by students with a limited timeframe and all in-kind. The tool developed in this project has not been formally tested but is based on shared knowledge and research from a patient/family partner and researchers with a wide range of experience.

Dissemination Process
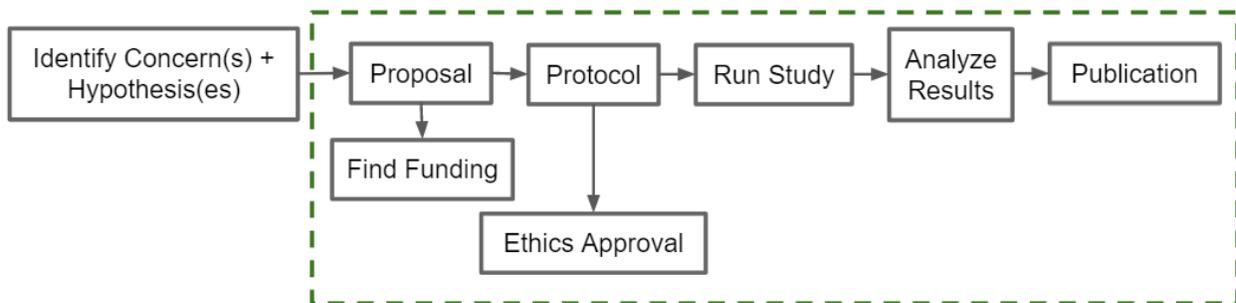
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Step 1: Dissemination Reflection Tool (Appendix 1)
Consider the end goal of your research. Through your research, do you hope to educate others, or influence/impact system change? The dissemination reflection tool will help researchers identify these goals early and will help you distil potential dissemination activities and strategies.

Step 2: Project Planning Tool (Appendix 2)
During the proposal and protocol development phase, patient/family partners are often not recruited and engaged until after the initial proposal development, funding request and award, and Research Ethics Board (REB) approval. However, including Patient/Family Partners in the planning phase of a research project promotes transparency, discussion, and buy-in on the approach which might cut down on disconnects in the process and in the time required for onboarding. Patient/Family Partners' perspectives may also influence decisioning around the goals of the project and consequently the approach to disseminating the research findings.

Dissemination Process
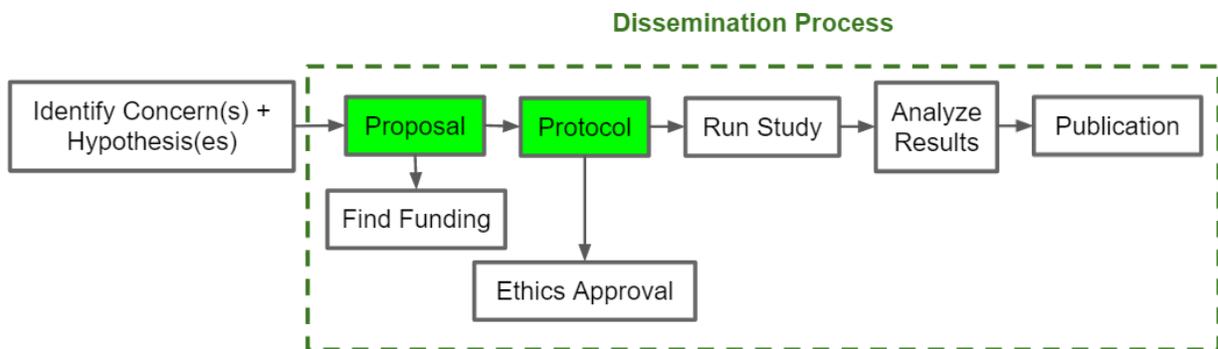
For Patient/Family Partners, goals may include:
- Generating awareness, interest, consensus building, or public action
- Impact/changing behaviour, policy, attitudes, or practice
- Empowering stakeholders
- Knowledge sharing
- Informing future research

By engaging Patient/Family Partners in the planning phase of a project, they are empowered to start considering project impact through knowledge mobilization strategies, opportunities, and challenges that researchers may not think of. As well, the identification of audiences and respective strategies and channels to reach these audiences may impact the budget requirements of a project, so discussing and identifying opportunities in advance of funding requests is important to ensure sufficient resource allocation to develop knowledge outputs for dissemination.

Step 3: Findings Analysis Tool (Appendix 3)
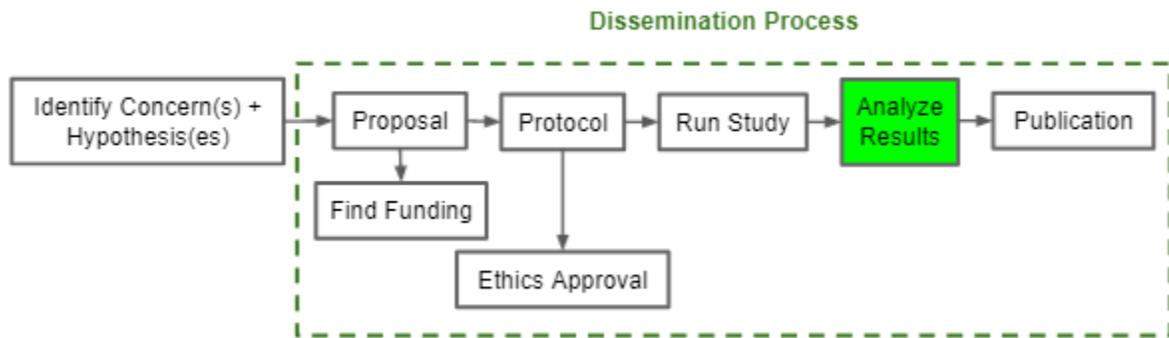
Patient/Family Partners are often not included in assessment of research results. This limits strategic discussions that includes perspectives and insights from end-users that might lead to optimizations of dissemination planning to target audiences, channels, and formats for better alignment. There is an opportunity to leverage the reactions and insights of Patient/Family Partners in response to expected and unexpected research findings to ensure optimal impact in how the results are shared and to whom.

Step 4: Dissemination Plan (Appendix 4)
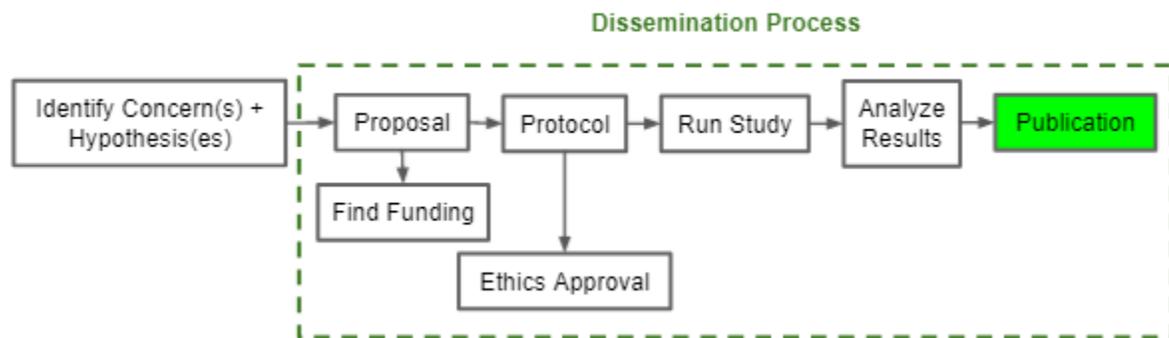
The ultimate goal in research is often to publish in an academic journal. These scientific insights can get lost to many audiences, including potential end-users. Patient/Family Partners can be strong advocates for implementation, which can drive policy and system change. In addition, Patient/Family Partners may be aware of relevant and innovative dissemination channels and formats that researchers may have overlooked. Thus, strategies for dissemination can (and should) be shaped with Patient/Family Partners to help ensure uptake - especially if results are relevant to the Patient/Family Partner audience.

This step allows researchers to re-address the dissemination plan. Consider the activities and strategies outlined in the initial considerations and optimize based on the final insights and inputs.

Appendix 1: Research Planning with Patient/Family Partners - Dissemination Reflection Tool

This tool will guide Researchers and Patient/Family Partners in considerations of what impact they want the dissemination of their research insights to have and the various strategies to achieving this impact.

Consider the end goal of your research. Through your research, do you hope to educate others, or influence/impact system change? Reflect, and check off appropriate goals. Identifying these goals early will help you distil potential dissemination activities and strategies.

Identify the Ultimate End Goal(s) of the Research	
Education	Systems Change
☐ Generate awareness ☐ Generate interest ☐ Impact/change attitudes ☐ Empower stakeholders ☐ Knowledge sharing ☐ Inform future research	☐ Generate consensus building ☐ Generate public action ☐ Impact/change behaviour ☐ Impact/change policy ☐ Impact/change practice
Potential (non-exhaustive) Dissemination Activities and Strategies	
• Social Media • News Article • Information Blogger • Conferences • Video • Report • Infographs • Journal Article • Podcast • Webinar • Website	• Press conference • Developing champions • Meetings with lawmakers/members of parliament • Petitions • Town Halls • Social Media • Shared Governance • Communities of Practice • ThinkTanks • Lobbying

Appendix 2: Project Planning Tool

Project planning involves creating hypotheses, protocol writing and identifying resource considerations. For each of these activities, you'll want to consider input from both the research team, and Patient/Family Partners. It's useful to fill this table out separately, and then compare/contrast results as a full team to determine the best course of action. For each activity, we've provided dissemination-specific reflection questions.

	Patient/Family Partners Input	Research Team Input
Hypothesis Generation		
Are hypothesis results expected to result in a finding that can be disseminated? If not, how can we modify the hypothesis?		
Protocol Development		
Consider the evidence perspectives of your target audience. What do they consider 'meaningful evidence'?		
How will the research protocol help (or hinder) reaching the target audience?		
What are the roles and resources needed to support dissemination?		
Resource Considerations		
What will be the cost needed for dissemination in order to ensure an adequate (and often wide) reach? Consider costs for: ● Personnel ● Human resources ● Marketing ● Honoraria		
How will dissemination impact		

the project timeline?		
How will dissemination impact bandwidth? Are there other initiatives or events which may impact teams members ability to disseminate the results?		
Consider additional dissemination costs associated with the following personnel: ● Trainees ● Primary Investigator ● Research Coordinator ● Parents ● Family Partners		

Appendix 3: Findings Analysis Tool

Patient/Family Partners can help to interpret and provide feedback on research findings. Specifically, they are able to help contextualize the findings in light of their lived/living expertise. Have research team members extract key results, highlighting unexpected findings, and allow Patient/Family Partners to help contextualize and explain potential reasons why those findings may exist. Doing so will help you frame the research findings for maximum and real-world relevance during dissemination, thus increasing uptake.

Research Finding Interpretation		
	Research Finding	**Patient/Family Partners Reflection on Finding**
Finding #1:		
Finding #2:		
Finding #3:		

Appendix 4: Dissemination Plan

Take all that you have learned from your engagement with Patient/Family Partners throughout the research process, and re-address the dissemination plan. Consider the activities and strategies outlined in the initial considerations and optimize based on the final insights and inputs. Reflect on the following questions to develop a plan.

Dissemination Plan	
Questions:	**Answers:**
What are the key insights and messages from the research?	
Who are the audiences and what do you want them to do?	
How will these key insights and messages resonate with the target audience?	
How will these key insights and messages work to generate education or drive system change?	
What strategies or channels will you use to disseminate the key insights and messages?	
How will you ensure the continued use/relevance of your key insights and messages after the end of the research project?	