Knowledge Mobilization Planning Guide

Turning research into action for children with rare diseases.

Knowledge Mobilization (KM) is a broad term that covers many different activities involved in sharing and using research findings. For RareKids-CAN, it means making sure what we learn about rare childhood diseases, clinical trials and treatments is shared in ways that families, healthcare providers, researchers, decision-makers, biotech, and industry can use.

This KM Planning Guide supports project teams in turning research into real-world results. It helps create clear messages, reach the right people, choose the best methods, and track impact. By involving families, youth, healthcare providers, decision makers, and people from equity deserving and underserved groups such as Indigenous peoples, racialized communities, people with disabilities, and those living in rural or remote areas, teams can ensure their plans reflect diverse perspectives and make a meaningful difference for the pediatric rare disease community.

Knowledge Mobilization Steps

What knowledge are we sharing?

What research findings, tool, or story are we mobilizing?

How can it be explained in plain language?

Does it address a gap that families, youth, healthcare providers, decision makers, or people from equity deserving and underserved groups have identified? Which groups have identified this need?

Why does this matter?

Why is this knowledge important for people affected by rare disease, and how might its relevance differ across intersecting factors such as race, gender, and socioeconomic status?

What change do we want to see? When identifying the change your project aims to create, consider **whose voices you want to center** and how the work can reflect diverse experiences and priorities (select one or more):

- Empower families (e.g., equip families with knowledge through accessible resources to make informed choices and improve clinical trial processes)
- Improve clinical practice
- Influence policy/funding
- Raise awareness
- Other:

Who is involved?

Who needs to be involved to make sure our knowledge is shared effectively and creates real impact?

At what stage should they be involved (e.g., early design, dissemination, evaluation)?

Who are our “key mobilizers” (e.g., main people or group) that can help promote or advocate for this work?

Collaborators and Key Mobilizers:

- Families and caregivers
- Youth and young adults
- Healthcare providers
- Researchers/research teams
- Policymakers, decision-makers, and funders
- Rare disease organizations and networks
- People from equity deserving and underserved groups*
- Other:

Who are we reaching?

Which audiences need to see, hear, or use this knowledge?

- Families and caregivers
- Patients (children, youth, or young adults living with rare conditions)
- Children and youth
- Healthcare providers and healthcare teams
- Researchers/research teams
- Policymakers
- General public and media
- People from equity deserving and underserved groups*
- Other: (e.g., funders, institutions, biotech, industry)

**for example, Indigenous peoples, racialized communities, people with disabilities, and those living in rural or remote areas.*

How will we share our messages?

What are the preferred formats for the intended audience? See the table below for examples of possible strategies for sharing messages.

Category	Examples and Considerations
Products	Plain language summary, infographic, video, podcast, toolkit
Events	Workshop, meetings, webinar, family forum, policy roundtable, youth panel
Networks	Social media campaign, newsletters, traditional media (e.g., radio, TV)
Academic outputs	Journal publications, scientific posters, conference presentations, reports
Community-driven and traditional approaches	Community-led and traditional methods such as storytelling, sharing circles, and Elder-led teachings, especially meaningful for Indigenous families and communities

Before You Share Messages: Important Considerations

1. Co-Creating with Communities[1,2,3]

Work ***with*** communities to co-create messages that are meaningful and culturally relevant.

- Use community-preferred language and tone.
- Focus on key messages that matter most to families and partners.
- Collaborate with community members to decide which translations or formats will have the greatest impact.

Note*: Communities, including Indigenous and multilingual groups, use many languages and dialects, translation should be guided by community partners.*

2. Inclusive Communication Tips

Apply **equity, diversity, inclusion, and accessibility** principles to every message.

Adapt content, where appropriate and/or feasible, to reflect different cultural contexts and to meet the needs of children and youth with disabilities. Focus on making key messages clear, inclusive, and accessible to all.

Accessibility checklist:[4,5,6]

- Use plain language and clear, uncluttered design (see resource list for more information).
- Add captions or transcripts for videos and audio.
- Provide translations where appropriate.
- Ensure strong visual contrast and readable font sizes.
- Include alternative text for all online images.
- Review reading levels to make sure materials are easy to understand.
- Include an active offer (Duty to Notify) on all print and digital materials, stating that information is available in alternate formats or with communication supports upon request. Place the statement in a visible location (e.g., at the bottom of a document, email, or poster).

✅ These steps make communication inclusive, relevant, and accessible for all audiences.

3. Trauma-Informed and Culturally Safe Storytelling[7,8,9,10]

Trauma-informed and culturally safe storytelling means sharing stories in ways that **honor people's experiences**, **protect their emotional wellbeing**, and **respect cultural identity and context**. It recognizes that some individuals and communities may have experienced trauma or mistrust in healthcare or research systems.

In practice, this means:

- Obtain informed consent before sharing stories and/or knowledge (e.g., medicine teachings).
- People can withdraw at any time.
- Give individuals the chance to review and approve quotes, images, or materials before publication.
- Ensure people have control over how their identities and experiences are represented.
- Avoid sensationalizing or retraumatizing narratives.

Many stories about rare diseases include experiences of medical trauma or mistrust in systems. Storytelling should always be guided by **choice**, **consent**, and **respect** for those sharing their experiences.

Resources and Timing

What resources (e.g., budget, time, people, tools) do we need to share our messages effectively and reach the right audience?

When is the best time to reach this audience?

Resource Planning Tip

When planning your resources, consider supports that promote **accessibility**, **cultural safety**, and **trauma-informed practice**:

- **Accessibility:** Budget for captioning, plain language editing, translation, and adapted formats.
- **Cultural safety:** Include time and funds to co-develop materials with community partners following local guidelines (e.g., welcoming spaces, food, honoraria) and, where appropriate, translate key messages into Indigenous or other relevant languages.
- **Trauma-informed practice:** Set aside resources for honoraria for storytellers, time for informed consent and review, and supports for debriefing or follow-up.

These considerations help ensure your KM efforts are inclusive, respectful, and sustainable.

How will we measure success?

How will we measure success in reaching our audiences, sharing our messages, and achieving the impacts we planned?

Review the table below for examples of how to track success across key areas such as reach, usefulness, impact, and equity.

Area	Focus	Example Indicators
Reach	Who we engaged and how widely our messages were shared	Number and type of audience engaged (e.g., website visits, downloads, social media engagement, event attendance, participant demographics)
Usefulness	Whether audiences found the knowledge helpful, relevant, or empowering	Feedback forms, post-event surveys, interviews, focus groups
Impact	Evidence that knowledge influenced care, advocacy, or policy change	Changes in clinical practice, references in policy documents, advocacy outcomes, families reporting greater confidence in decision-making
Equity	Extent to which efforts were inclusive, accessible, and power-sharing	**Representation:** Which groups are we not reaching? **Accessibility outcomes:** Were materials understandable across literacy and language levels? **Power-sharing:** Were families or community partners co-authors or decision makers in dissemination activities?

Reflection

What worked well in our KM efforts?

What could be improved next time to better share our messages and reach our audiences?

How did our partners and audiences experience being part of this process, both logistically and emotionally?

- Did our process unintentionally exclude or burden certain groups?
- How did we ensure cultural safety, equity, and respect throughout dissemination?
- Were partners given opportunities for emotional reflection or debriefing, especially if previous trauma may have been triggered?

How are families, youth, and community partners being compensated, credited, or acknowledged for their input and contributions?

How are different forms of knowledge, such as lived experience, cultural teachings, and community narratives, being recognized, validated, and integrated into our KM plan?

For support with developing your Knowledge Mobilization plan for your RareKids-CAN project, connect with: Megan Bale-Nick, Knowledge Broker, megan.balenick@umanitoba.ca

Want to expand your understanding of knowledge mobilization? Explore these resources:

- Research Impact Canada – national network with KM courses, guides, and training.
- SickKids Knowledge Translation Program – practical, health-focused knowledge translation online training and resources (e.g. plain language checklist).
- KT Canada – national network offering seminars, summer institutes, and knowledge translation tools.
- National Health Services Health Information – health literacy toolkit, including resources on plain language, readability, design.
- Centre for Healthcare Innovation Knowledge Nudge – information on knowledge translation and patient engagement, from a health research and healthcare perspective.
- Clinical Trials Ontario Participant Experience Toolkit – practical guidance for participant-centered clinical trial research.
- IMPACT Clinical Trial Knowledge Mobilization and Communication Skills – online learning module.
- Queen's University Equity, Diversity, and Inclusion in Research – online learning module.
- Trauma Informed Engagement Publications:
  - Moving towards a more inclusive patient and public involvement in health research paradigm: the incorporation of a trauma-informed intersectional analysis
  - Valuing All Voices: refining a trauma-informed, intersectional and critical reflexive framework for patient engagement in health research using a qualitative descriptive approach

This resource was developed by the Knowledge Synthesis and Mobilization Sub-platform with support from the Patient and Family Engagement and Equity, Diversity, Inclusivity, and Indigeneity Sub-platforms and is available in alternate formats upon request.

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