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Evaluating parent-led research: the power of partnership and arts-based knowledge mobilization

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Abstract

Background Effective knowledge mobilization (KM) and meaningful partnerships can improve research relevance, quality, and impact. While guidance for effective KM tool development and successful research partnerships exists, practices are not consistently described or evaluated. To address this gap, we applied a mixed-methods approach to (i) describe and evaluate a set of tailored KM tools and (ii) assess parent-partnership, within a study on caregiver recruitment networks.

Methods A custom survey, distributed to participants of the primary study, was used to evaluate KM tools. The Public and Patient Engagement Evaluation Tool 2.0© survey, and a facilitated discussion, was used to evaluate research partnership. Evaluations were conducted in year two of the two-year project. Quantitative data were analyzed descriptively. Qualitative feedback underwent directed content analysis followed by inductive analysis. Data were integrated during analysis and interpretation.

Results KM tool evaluation: Participants reported that their views were adequately reflected in each KM tool, and they were likely to recommend the tools to others. Important messaging, clarity, and visual appeal were noted as positive features across tools. The lay summary and tip sheets were concise, easy to read, yet still full of information. The painting series was described as engaging and emotionally evocative, prompting reflection on one's personal experience and drawing out feelings of "hope, partnership, and a journey". Participants provided tangible feedback on missed messages in the KM tools, or where additional emphasis or clarification was needed to support accuracy. Partnership evaluation: All team members were satisfied with their involvement. Data within the category of "What went well" highlighted knowledge gained, and personal and team-level qualities (humility, balance, honesty, positivity). The category of "What could be improved" drew attention to systemic barriers to sustained partnership (time, finances, and logistics), and lack of diversity within the team.

Conclusions Involving primary participants in KM tool evaluation ensured message accuracy and highlighted the unique power of arts-based KM to evoke emotional resonance. Future research should consider integrating arts-based methods to complement traditional KM tools to enhance engagement with research findings. High

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partner satisfaction suggests that strong relational foundations can mitigate common logistical pitfalls in research partnerships.

Plain English summary

Parent-partnership in research, and the need for tools to share research findings, are recognized as important parts of conducting meaningful and impactful research. In a previous study our team, which includes parent partners and researchers, explored the experiences of parent partners who have been asked to use their personal networks to help recruit for research. Based on what we learned from the parent partner participants, we then created tools to share these insights with more people. These tools included a plain language summary, tip sheets for both researchers and for parent partners, and three paintings with write-ups that linked to the three themes uncovered in the study. We then developed a study to evaluate (i) what participants thought of each of the knowledge sharing tools, and (ii) how our team of researchers and parent partners worked together. These evaluations are the focus of the current paper. The feedback that participants provided on the knowledge sharing tools indicated that the lay summary and tip sheets were concise, easy to read, yet still full of information. The painting series was described as engaging, encouraging reflection, and evoking feelings of “hope, partnership, and a journey”. Participants provided feedback on key messages that were missed in the tools as well as where additional emphasis and clarification was needed. This feedback helped us correct and improve these information sharing methods before we released them to the public. We discovered that all research team members were satisfied with their involvement in the collaboration. Our team found that having humility, balance, honesty, and positivity went well when working together. Areas for improvement included time, finances (e.g., compensation), and logistics (e.g., role clarity, decision making). When research teams conduct evaluations on knowledge sharing and partnerships, the team can improve their research outputs and teamwork. We share our findings to encourage other teams to build evaluations into their projects, with the goal of enhancing partnerships and research impact.

Keywords Patient and public involvement (PPI), Integrated knowledge translation (iKT), Arts-based knowledge mobilization, Parent-led research, Research partnership evaluation, PPEET 2.0, Co-design

Background

Meaningful involvement of people with lived and living experience as partners within research teams (herein referred to as partnership) is becoming more common across research disciplines, in part due to the work of patient and public involvement organizations and research funding agencies who have developed strategies and tools to encourage partnership-based research [1–5]. There are numerous recognizable benefits to research partnership, including more feasible and relevant research, and improvements in knowledge mobilization (KM) planning and products that increase the likelihood of research finding its way back to interested parties [6–10]. In this way, research partnership and KM are inextricably interrelated. Partnership informs and supports timely and relevant research and effective KM can also meet an important engagement goal of patient/public partners. Indeed, high-quality KM is a primary mechanism through which lived experience is transformed into real-world impact.

To continue to advance the science and practice of both KM and research partnership, it is key that efforts in both arenas are adequately reported on, including detailed descriptions of practices and structured evaluations [7, 11, 12]. Describing how research partners and project participants inform KM planning can highlight the unique contributions of people with lived experience

and other team members to the final KM products. These types of reports can also provide a template for others to apply in their partnerships and projects. Wherever possible, the use of existing evidence-informed planning and evaluation tools can help achieve consistency in how KM and partnership are enacted, described, and evaluated [7]. Similarly, evaluating research partnerships can help teams understand how the partnership was experienced by various team members or member groups, so that teams can learn and improve practices within a given project and for future projects [6, 8]. For this, there is a growing body of evaluative tools to choose from [7], however, there remains a knowledge gap around how they are applied in niche contexts like parent-led research partnerships. Reporting on partnership practices and evaluations can also inform existing literature on processes, outcomes, and impacts of research partnerships [7, 8, 12].

Our multidisciplinary team previously conducted a study to understand caregiver perspectives on being asked to use their personal networks for research recruitment (here-in referred to as the primary study) [13]. The primary study was co-led by parent researchers who conceptualized the project and were partners in every stage of the research. The primary study aimed to address a gap in knowledge and resources by developing KM tools. Recognizing that KM and parent-led partnership were

methodologically essential to the primary project, the current study was developed to evaluate both of these project components. In this paper we aim to: (i) describe the development and participant evaluation of a set of tailored KM tools, and (ii) provide a description and evaluation of research partnership within the primary study about caregivers' experiences using personal networks for research recruitment.

Methods and data analysis

In the following sections we briefly describe the primary study (full publication elsewhere [13]), to provide context for the evaluations we conducted. We then present the methodology for the current study in two parts; Part A: KM tool development and evaluation and Part B: Partnership evaluation.

Context: the primary study

The research question for the primary study originated from a discussion between the parent co-leads of this work (CC, LK). Both individuals had previous involvement as members of research teams, but they had different approaches, perspectives, and experiences related to sharing recruitment material through their personal networks. Noting a lack of guidance on this topic in the literature for parent/caregiver research partners, they decided to embark on a research project to explore this further. The parent co-leads connected with and invited the academic team members into a partnership to investigate the question further. A protocol was co-developed, and the team secured a grant to support participant honorarium and a small stipend for the parent co-leads. Additional funds were secured to support a part-time research coordinator and an undergraduate student researcher to further support the project. From the onset, team members agreed to equal decision-making capacity for the parent and academic partners; beyond this no formal governance structure was developed.

Study participants of the primary study included fifteen caregivers (defined to include biological, adoptive, kinship, and foster parents, as well as legal guardians) with research partnership experience. Data for the primary study was collected by parent co-leads through interviews and focus groups and analyzed thematically [14]. Three main themes were derived from the data: *Motivations*, *Authentic Partnership*, and *Learned Decision Making*. Though the research question was focused on using personal networks for research recruitment, each theme included broad perspectives about caregiver research partnership, as well as specific perspectives related to research recruitment through personal networks.

The KM tool development and assessment and partnership evaluation that are reported on here were conducted in year two of the two-year project. Evaluations were led

by the undergraduate student researcher, with guidance and supervision from the other team members. Ethical approval for this study was received by the University of Manitoba Health Research Ethics Board (HS24672 [H2021:077]).

Part A: KM tool development and evaluation - methods

The research team planned a priori to develop three KM tools to share the findings of the study with two or more audiences. There was early consensus that one tool would be a lay summary of the research findings, which would allow for sharing of the findings with the study participants as part of the member checking process, and serve as a participant-approved template for other knowledge mobilization tools (e.g., presentations, publications). The format for the other two was selected through an iterative process, guided by The SickKids KT Planning Template[©] and further supported through team discussion and an informal assessment of the skills of team members (Table 1) [15]. As a result, the team decided to develop a set of tip sheets (one for researchers, one for parents) and an arts-based KM product that leveraged the talents of our student researcher (series of paintings and write-ups, depicting the main themes of the study) (Fig. 1a-c). The student researcher also met with KM experts local to our institution, who collectively had expertise in patient engagement, marketing, and knowledge mobilization theory and practice. These consultants viewed early drafts of tools and provided advice to help ensure the intended messages were clearly portrayed, especially in the paintings.

To facilitate evaluation of the KM tool package, all participants of the primary study received the lay abstract, tip sheets, and photos of the paintings along with their corresponding write-ups. After viewing these materials, participants were asked to complete a custom 9-item anonymous survey (KM Tool Evaluation Survey Additional File 1; Survey Monkey[®]). Questions and response options were informed by the SickKids KT Planning Template[©] and included questions focused on three broad areas: (i) participants' overall satisfaction with each tool, (ii) how useful the tools would be to meet the team-identified KM goals, and (iii) how useful the tools would be for various audiences. Questions were repeated for each of the three tools, with the response options of: Not at all useful, Somewhat useful, Very useful, Extremely useful, Unsure.

Survey responses were collected between July 28th to August 18th, 2022. Data was exported into Microsoft Excel for organization and analysis. Responses to limited choice questions were analyzed using descriptive statistics and directed content analysis was used with open text responses. Recommendations for changes to the tools were compiled so they could be considered by the

Table 1 Summary of SickKids KT Planning Template responses for KM tool development

SickKids KT Planning Template Section	Resources	Tip Sheets	Paintings and Write-ups
	Lay Summary		
Target audiences	Parent/patient partners Researchers Public	Parent/patient partners Researchers	Parent/patient partners Researchers Public
KT goals	Generate awareness Share knowledge Inform decision-making Inform research(ers)	Generate awareness Share knowledge Inform decision-making Inform research(ers)	Generate awareness Share knowledge Inform decision-making Inform research(ers)
Main message	Summary of the study methods and results to highlight the three main themes of <i>Motivations, Authentic Partnership, and Learned Decision Making</i> .	There is limited information about caregivers' perspectives on using their personal networks to share study information. A series of tips for caregiver partners and researchers can help inform discussions and decision-making.	Like the lay summary, the three main themes of the study were shared; however, with the arts-based format, the goal was to allow people to interact emotionally, or reflexively with the themes, and derive their own message from the work.

team. Representative quotes were selected where they added further meaning to the evaluation findings.

Part B: partnership evaluation - methods

Participation in the partnership evaluation was optional, and open to all research team members. Evaluation was conducted using an adapted version of the Public and Patient Engagement Evaluation Tool (PPEET) 2.0©. The PPEET was developed in 2011, through a cross-Canada collaboration focused on evaluating the impacts of patient and public engagement within organizations [16]. PPEET 2.0© was released in 2018 [8] and while developed with organizational evaluation in mind, the PPEET has and continues to be used to evaluate the impact of patient/public engagement within research teams [9, 10]. The PPEET has received high scores on composite measures of scientific rigour (80%), patient and public perspective (80%), comprehensiveness (100%) and usability (80%), and has high construct validity ($r = 0.70$; 95% CI 0.63, 0.75) for clinical practice guideline development, using validation questions that align closely with the purpose of our engagement efforts [7, 17, 18].

Module B (Background, Parts A-D) of the PPEET was selected for use, which was developed for evaluation of on-going or long-term engagement initiatives. The PPEET module for long-term engagement has been designed such that it can be administered once or at multiple time points of the engagement initiative. The PPEET was administered once to all six team members at the end of the primary study (June 24 to July 4, 2022), using SurveyMonkey®.

As per guidance within the PPEET manual, minor adaptations were made to PPEET questions to ensure applicability to the study and team [19]. The original

four domains of PPEET Module B were maintained: (i) Communication and supports for participation, (ii) Sharing your views and perspectives about being a member of this research team, (iii) Impacts and influence of the engagement initiative, and (iv) Overall experience. Questions were added within domains to elicit further feedback on topics that had come up in past team discussions (e.g., amount of time spent on the project, whether the individual's role on the project changed from how it had initially been defined, team diversity, and decision-making practices). Team members were asked to self-identify with one of three roles (parent-partner researcher, academic researcher, research assistant/research student). Demographic questions were asked to facilitate discussion within our team, however, are not reported on here due to small sample size. The PPEET survey, with adaptations, was pre-tested by the student researcher and an academic researcher prior to distribution.

Preliminary analyses were conducted by the team's student researcher paired with an academic researcher. Responses to the PPEET limited choice questions were analyzed using descriptive statistics. Likert-scale based PPEET questions that were responded to with 100% (6/6) of team members indicating Agree or Strongly agree were grouped into the category of "What went well" for further analysis and discussion. The remaining questions (those receiving at least one response of Neither agree or disagree, Disagree, or Strongly disagree) were grouped into the category of "What could be improved".

Open text responses were analyzed using directed content analysis. This process began deductively by organizing responses into the above broad categories of "What went well" and "What could be improved". In this step, data remained anchored to the PPEET domain. Next,

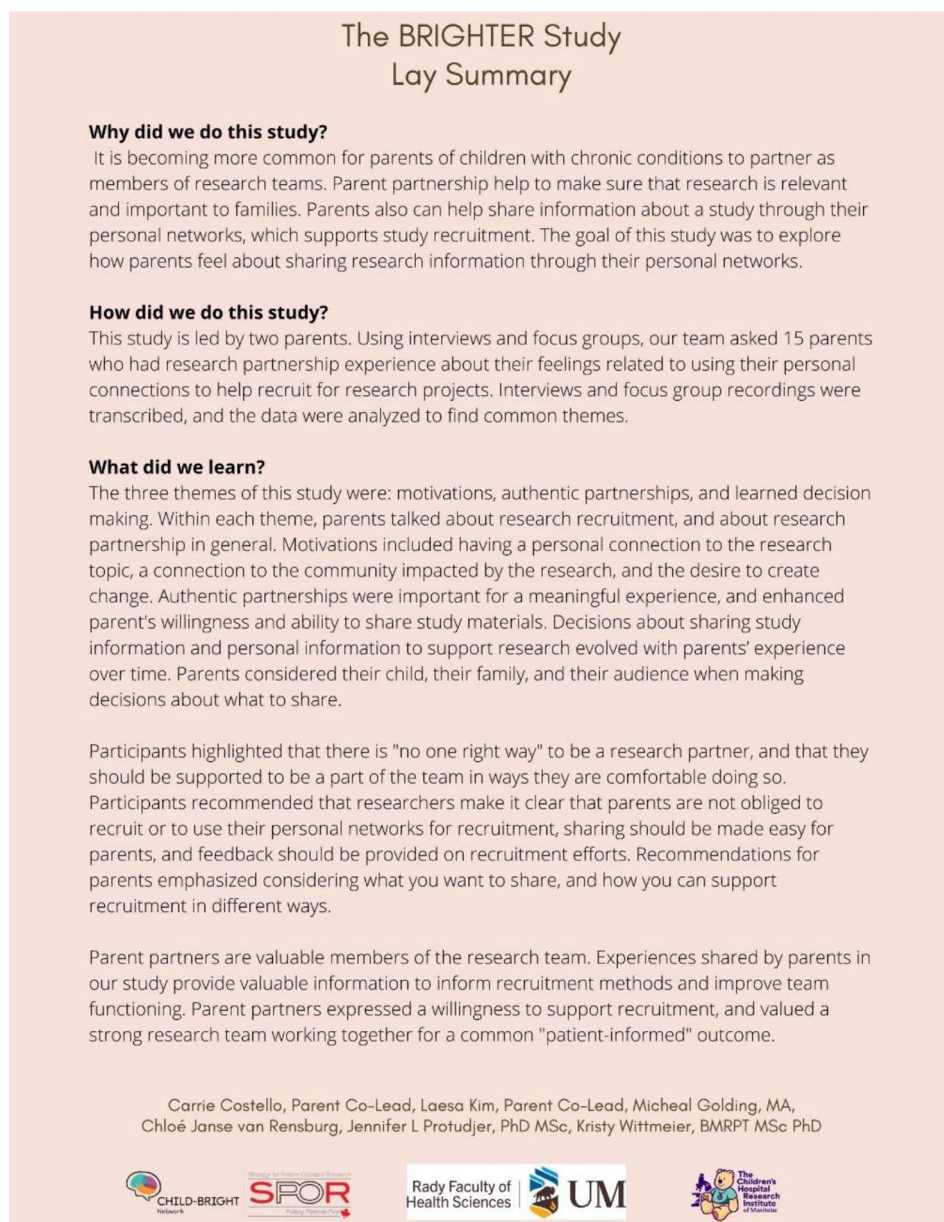


Fig. 1 a. BRIGHTER study – Lay Summary. **b.** Tip sheets. Legend: The panel on the left depicts the tip sheet for parent-partners, while the panel on the right contains the document aimed at researchers. **c.** Art-based research summary. Legend: This figure depicts a series of paintings and write-ups that we used to convey the results of a research study examining the experiences of parent-research partners

responses were inductively analysed to identify sub-categories [20]. Member-checking was used to validate and further interpret the findings. To accomplish this, PPEET results were summarized and shared for discussion during a team meeting. Notes were taken during the discussion by the student researcher and an academic researcher team member to further enhance trustworthiness and were incorporated into the analysis. Results were presented back to the team for final input and review. Representative quotes from survey responses or team discussion were selected to provide further context.

Results

Part A: knowledge mobilization tool evaluation – results

All primary study participants who indicated that they would like to receive a summary of the research findings were invited to complete the KM tool evaluation; six (40%) completed the KM Tool Evaluation Survey. This served as member checking and allowed for more in-depth participant feedback on how useful the various tools may help to achieve KM goals, and for which audiences they may be best suited.

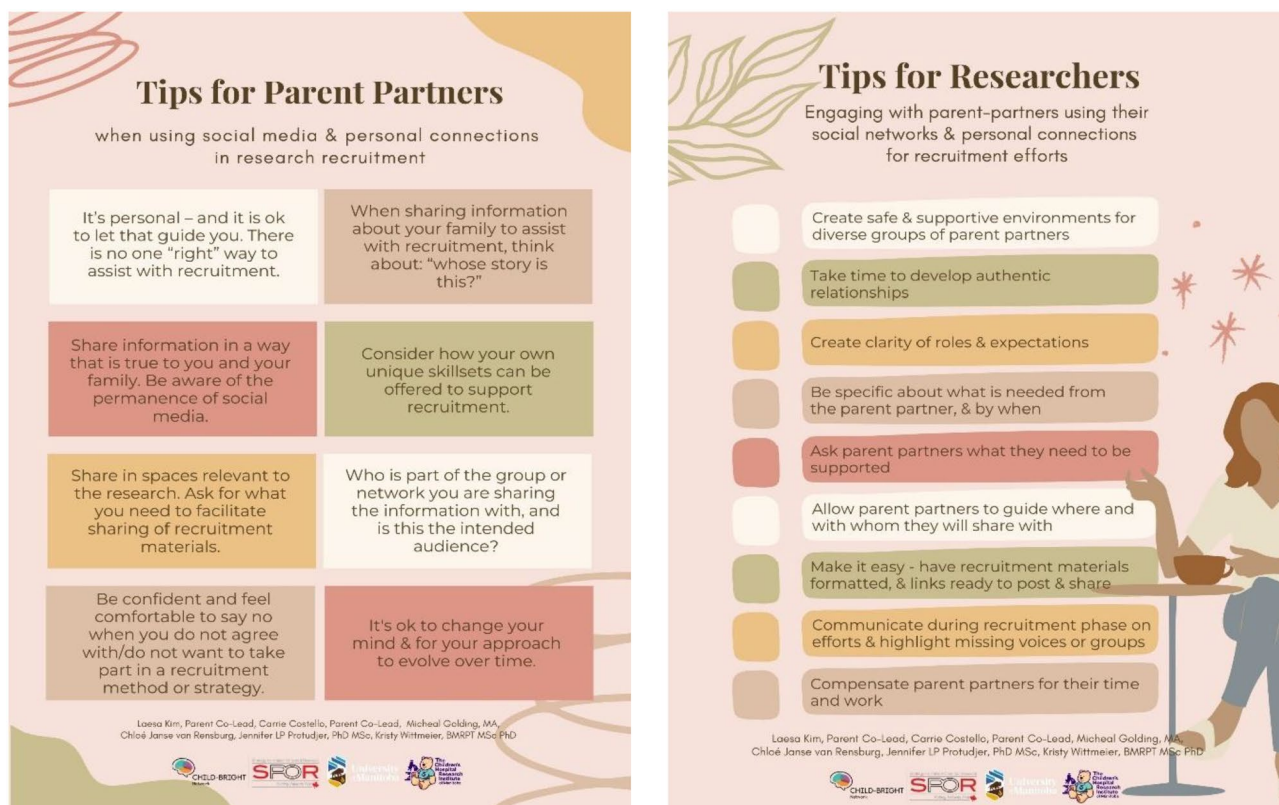


Fig. 1 (continued)

Participants' overall satisfaction: A summary of the knowledge mobilization tools' positive aspects and areas for improvement is provided in Table 2. All KM evaluation participants (100%, 6/6) reported that parent/caregiver views were adequately reflected in the lay summary, tip sheets, and painting series. Participants were also likely or very likely to recommend the lay summary, tip sheets, and painting series to other parent partners who are being asked to help with recruitment in research projects, once any recommended edits were made. The lay summary and tips sheets were described as concise, easy to read, but still full of information. Plain language was mentioned as a positive feature of each of the tools (for the paintings, this refers to the accompanying write-up). The paintings elicited unique feedback that focused on their beauty, and their ability to evoke emotions and prompt reflection.

Beautiful painting(s) and write ups! I felt like they represented hope, partnerships, and a journey.
(P-KM-01)

Participants commented on the layers of meaning within the paintings, and that there was "more there than meets the eye" (P-KM-06). The accompanying write-ups were

perceived as helpful to draw out additional meaning and detail.

Improvement suggestions for the written tools largely focused on grammatical features. An exception was that one participant noted that compensation (a major topic discussed in the interviews and focus groups) was inadvertently missed from the tip sheets and needed to be included. Another suggested stronger wording to support parent/caregivers in saying no to research/recruitment tasks that they were not comfortable with, directly relating back to the topic of ethical recruitment practices within the primary study. For improvements to the painting series, a recommendation was provided to have a more balanced write-up about the theme *Learned Decision Making*. This was perceived to focus too much on when parents/caregivers might not want to share personal experiences, which did not accurately reflect the primary study's focus group discussions. The *Motivations* painting and write-up was also mentioned by a participant, who connected with the negative weight of expectations on caregivers while juggling multiple roles, as depicted by the painting and corresponding write-up. We subsequently included an introductory statement, indicating that this painting was inspired by a conversation with one of the parent co-leads, which allows

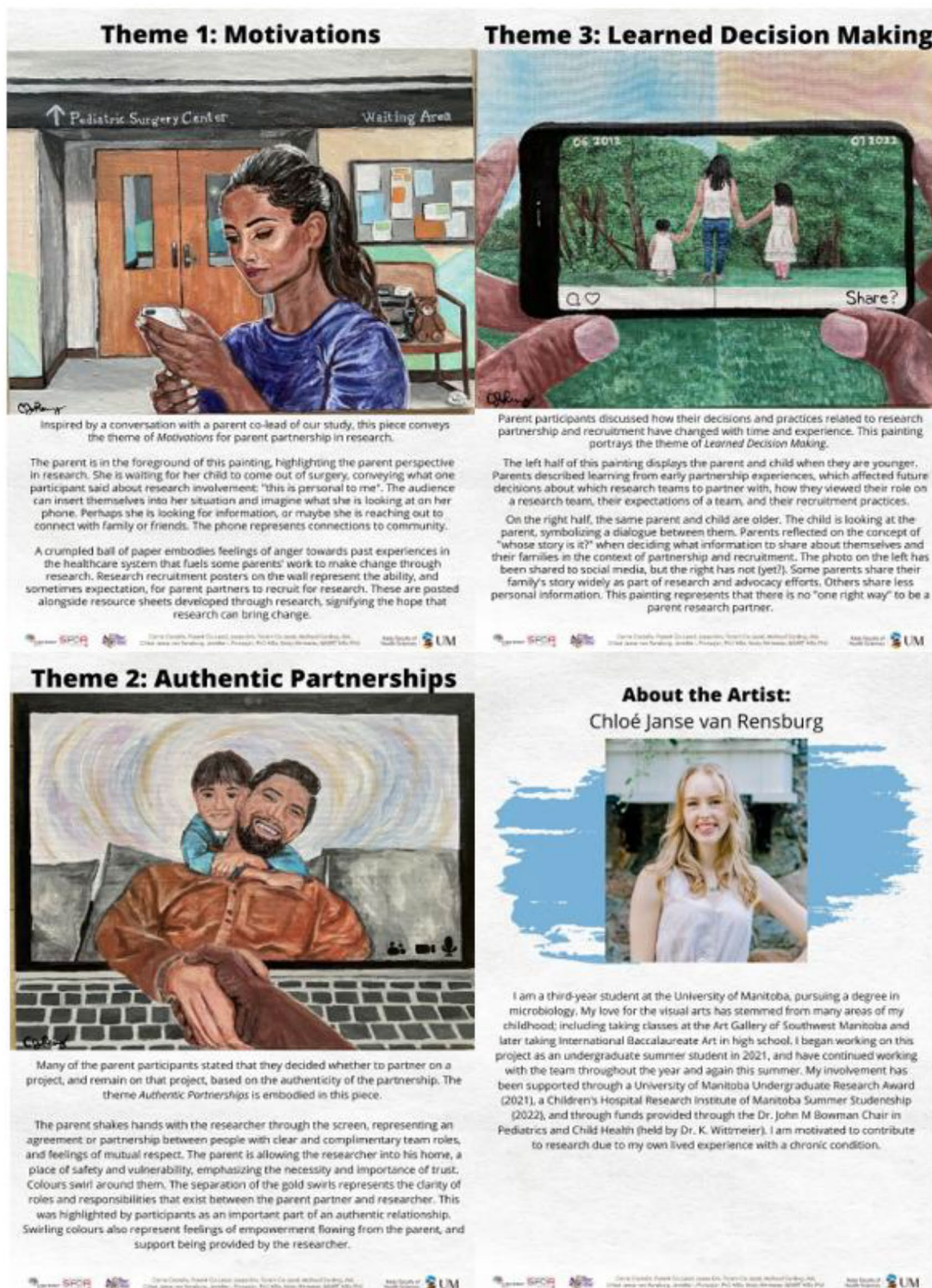


Fig. 1 (continued)

the research data to be (re)interpreted through real life experience.

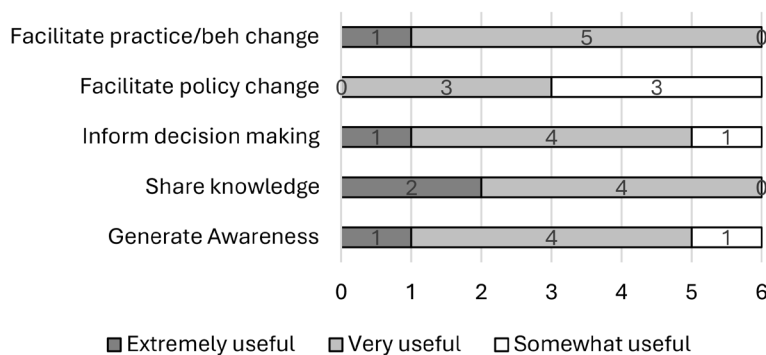
Usefulness for KM goals: Quantitative responses to questions about KM tool usefulness are presented in

Figs. 2 and 3, along with representative participant quotes. Overall, participant responses to "How useful do you think this tool would be for [each of the stated KM goals]" clustered in the higher usefulness response

Table 2 KM tool evaluation survey response summary

What was done well?		
Lay Summary	Tip sheets	Paintings and Write-ups
Parent views were represented Easy to read, good use of plain language, well written Appropriate length Useful for researchers interested in partnering	Parent views were represented Easy to read, good use of plain language Concise, point form Helpful for new and experienced partners Visually pleasing • Pleasing to the eye • Colourful • Interesting to look at	Parent views were represented Clear depiction of themes Unique and engaging • Allows for reflection on personal experiences • Can be a conversation starter • Validates a range of emotions • Considerate of a variety of audiences Visually pleasing • Appropriate level of detail • Thoughtful • Pleasing to the eye Write-ups help convey the symbolism contained in the paintings
What could be improved?		
Lay Summary	Tip sheets	Paintings and Write-ups
Improve formatting: • Break up paragraphs • Bolded words or headings More emphasis on specific ideas: • Parents having the power to choose to engage in research/ recruitment or not	Improve formatting: • Use the same font for all tips • Inconsistent use of capitalization Remove numbers to decrease confusion, the tips shouldn't be followed in a particular order • Minor grammatical mistakes Additional tip suggestions • Tip about parent compensation Use stronger wording about ability to say no	Improve clarity for the age difference of the mother in the <i>Learned Decision Making</i> painting Minor grammatical mistakes in written section Shorten the written sections <i>Motivations</i> painting may convey too many expectations

Lay Summary



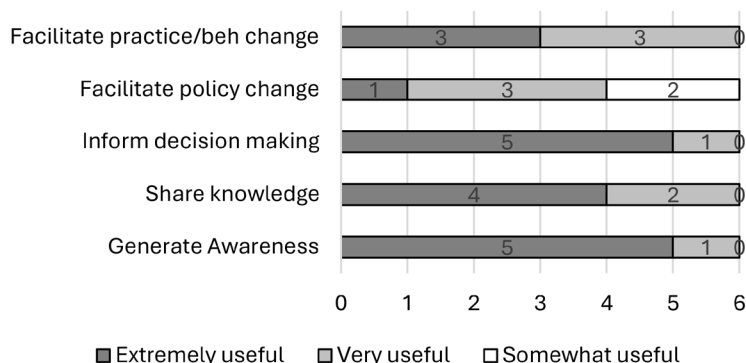
"...it is straightforward and easy to read. I like the take home message focusing on "the strong research team working together for a common outcome." This feels like an action-oriented way to end the summary, which is great!" P-KM-01

Fig. 2 a. How useful would this tool be to achieve KM goals? Lay summary. Legend: Participant quote featured in text box. *Response options "not at all useful" and "unsure" received zero responses and are therefore not included. Beh = behaviour; P-KM-0X = participant ##. **b.** How useful would this tool be to achieve KM goals? Tip sheets. Legend: Participant quote featured in text box. *Response options "not at all useful" and "unsure" received zero responses and are therefore not included. Beh = behaviour; P-KM-0X = participant ##. **c.** How useful would this tool be to achieve KM goals? Paintings and write-ups. Legend: Participant quote featured in text box. *Response options "not at all useful" and "unsure" received zero responses and are therefore not included. Beh = behaviour; P-KM-0X = participant ##

categories. Eighty-three to 100% (5 to 6/6) of participants responded that each of the KM tools would be Very useful or Extremely useful for achieving stated KM goals, with the exception of "facilitating policy change", to which 50–67% (3/6 to 4/6) of participants responded that the tool(s) would be either Very useful or Extremely useful. No responses of Not at all useful or Unsure were received for any stated KT goal across tools. Open-ended responses highlighted the clarity of messaging across the tools and the action-oriented nature of the tools as

contributing to high usefulness scores. One participant raised challenges with sharing KM tools, providing a suggestion to work actively with research institutes to distribute the tip sheets (Fig. 2b, participant quote). The uniqueness of the paintings was noted, along with their ability to validate partnership experiences. As one participant noted, as they allow for a range of emotional responses, they could function well as a conversation starter.

Tip Sheets



The trick will be how to disseminate this tip sheet so that it results in impact. Maybe you could persuade all the network [research institutes] to distribute to their in-house stakeholders. P-KM-05

Fig. 2 (continued)

Useful for various audiences: Similarly, when asked “How useful do you think [this KM tool] would be for the following people/groups?”, responses clustered in the higher usefulness categories, with zero responses in the Not at all useful and Unsure categories. Each of the three KM tools (summary, tip sheets, paintings) was rated by the participants as Very or Extremely useful for parents new to partnering in research, and research trainees (Fig. 3a-c). Though with slightly more variability, the three tools also were rated in the high usefulness categories for parents with partnership experience, researchers with and without partnership experience, and research networks (83–100%, 5/6 to 6/6 participants). Lastly, the summary and tip sheets received the lowest usefulness rating for research funders, with 67% or 4/6 participants rating as Very or Extremely useful, while all participants (100%, 6/6) rated the painting series as Very or Extremely useful for this audience. Open-ended responses again highlighted the importance of clear messaging that allows multiple audiences to interact with the tools. One participant shared that the visual nature of the paintings would make them more accessible/inclusive across languages and literacy levels.

Part B: partnership evaluation - results

All six research team members completed the partnership evaluation survey. During team discussion of PPEET survey findings, members confirmed that the results from the Likert scale questions, including the categorization of “What went well” and “What could be improved”, accurately reflected their experiences on the team. Of the 17 Likert items, 12 reached 100% consensus as “What went well” (i.e., 100% rating of Agree or Strongly Agree) while five items showed divergent perspectives and were categorized as “What could be improved.” Results from Likert scale questions, categorized by the above two headings as well as PPEET domain, are presented in Tables 3 and 4.

What went well: Knowledge gained; personal and team level qualities.

Team members were satisfied with their partnership experience, the time they invested in the study, and the knowledge that was gained related to research partnership and the primary study topic (domain: Overall experience). Team members were pleased with what the study had achieved (domain: Impacts and influence of the engagement initiative), and that team members could express their views freely and have their views heard (domain: Sharing your views and perspectives about being a member of this research team).

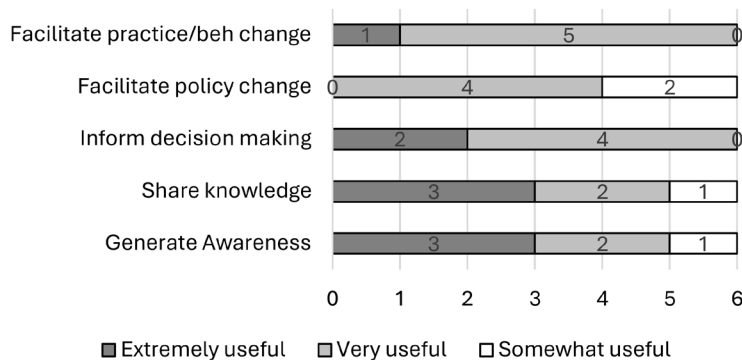
When inductively analysed independent of PPEET domains, open text responses within the “What went well” category were grouped into four sub-categories focused on personal and team level qualities. These included humility, balance, honesty, and positivity. Comments about humility pertained to members of the research team being willing to learn from one another. Team members highlighted that everyone had their own skillsets, strengths, and experiences, and that each of these brought value to the project.

I think everyone came from a humble place to learn from each other, from each other's individual experiences and skillsets. (P-PE-06)

Members also agreed that the team felt balanced. Comments were made regarding the ratio of parent-partners to researchers to students being well-distributed, and how this resulted in a smoother decision-making process. The balance of roles amongst the team additionally enhanced the discussions providing each team member with increased opportunities to share their ideas and ask questions regardless of their role on the team.

Everyone was respectful and participated where and as much as they could. (P-PE-02)

Paintings and Write ups

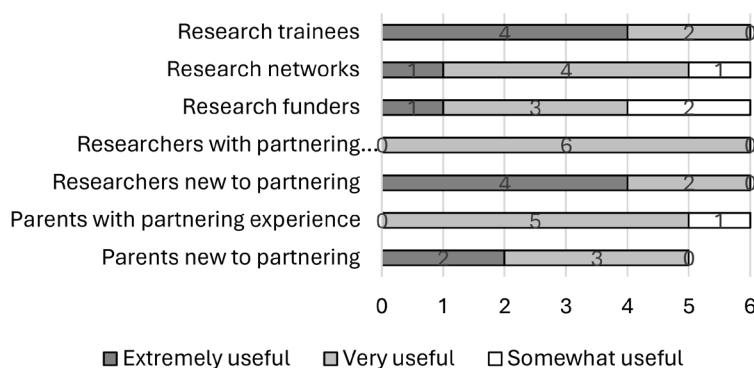


"The descriptions [write ups] below [the paintings] identifies key messages. Could be validating. There are a range of emotions not just "feel good". Conversation starter." P-KM-02

"Hope they get used widely. Academics don't use visuals enough generally, so great idea." P-KM-06

Fig. 2 (continued)

Lay Summary



"Clear and well written summary that is easy to follow and accessible to a wide variety of audiences." P-KM-01

"It is a helpful tool for partners that are new to research." P-KM-04

Fig. 3 a. How useful would this tool be for various audiences? Lay summary. Legend: *Response options "not at all useful" and "unsure" received zero responses and are therefore not included. **1 missing response (5/6) for the audience "Parents new to partnering". Abbreviations: Researchers with partnering... = Researchers with partnering experience; "P-KM-0X" = participant ##. **b.** How useful would this tool be for various audiences? Tip sheets. Legend: *Response options "not at all useful" and "unsure" received zero responses and are therefore not included. Abbreviations: Researchers with partnering... = Researchers with partnering experience; "P-KM-0X" = participant ##. **c.** How useful would this tool be for various audiences? Paintings and write-ups. Legend: *Response options "not at all useful" and "unsure" received zero responses and are therefore not included. Abbreviations: Researchers with partnering... = Researchers with partnering experience; "P-KM-0X" = participant ##

Honesty was also a fundamental team dynamic. Members discussed how they were able to be honest if they felt that they could not take on a given task, and that they could then share the workload with other members. Finally, team members agreed that a positive environment was facilitated. Members were respectful with one another and provided support whenever needed. Opinions were respected, acknowledged, and considered. It is also important to note that all team members felt that they made an impact on the project overall.

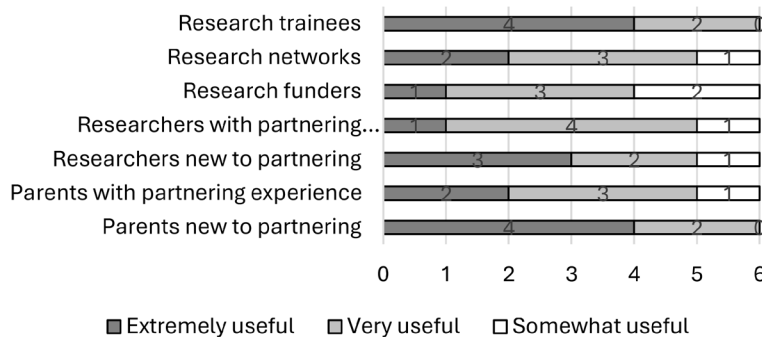
There was always a kind camaraderie between team members (P-PE-06).

What could be improved: Systemic barriers to sustained partnerships.

Areas for improvement were also presented back to the group for discussion. This category included open text responses commenting on concerns or suggestions for future partnerships. Time, finances, and logistics (domain: Communication and supports for participation) were identified as subcategories within "What could be improved". Lack of an engagement model/decision making hierarchy, and a lack of diversity on the team were also areas for improvement (domain: Sharing your views and perspectives about being a member of this research team).

Regarding time, most team members felt that they spent more or much more time on the study than initially expected (n=5), while also reflecting that many projects, research or otherwise, take longer than expected. The overall duration of the project was also longer than initially expected, however members agreed that more time

Tip Sheets



“Good tips with important messaging for parent partners both new and already engaged in research.”
P-KM-01

Fig. 3 (continued)

was necessary to provide flexibility and build relationships within the team. This also had budgetary or financial implications.

I do feel like many of us ended up spending more time, and the researchers more money than expected. (P-PE-03)

Though the team had been successful with their funding application to a national network to support this project, alternate sources of funding and in-kind support were leveraged (e.g., for research coordinator costs, student researcher funding, and KM tool development) as the scope of the work grew beyond the budget. Team members also acknowledged that different roles on research teams were paid in different ways (e.g., academic salary versus parent co-lead stipend versus studentship grants).

Discussions around the responses also revealed logistical concerns. First, team coordination and organization could have been improved. Examples that were provided included setting clear deadlines and more regular meetings to support accountability. Most team members were engaged in other projects and commitments, and it was acknowledged that it was difficult to enforce hard deadlines for every part of the project. Busy schedules also presented challenges for organizing meetings that worked for all team members. Another logistical item was the opportunity for improved role clarity early in the project. Team members discussed how their role changed from how it was initially defined.

[I] took on more of the coordination than I expected, (and) was not able to take on the data analysis as expected due to my own lack of time and family responsibilities. (P-PE-03)

A lack of role clarity impacted decision-making. While balance (in roles and decision-making) was noted as a positive aspect of the team, members also reflected on

how decision-making sometimes felt “awkward”, as decisions were generally made using “around the table” consensus rather than delegating final decision-making to a specific individual(s), thus necessitating negotiation of decision-making power in real-time. Some members shared that they were sometimes torn between wanting to please other team members versus being confident in the research space to share challenging opinions and views, demonstrating that social desirability can remain a factor even when partnerships are perceived as balanced.

There was an internal dialogue of deciding to speak freely versus say what I think others on the team may want to hear (P-PE-06)

The team discussed the dynamics of having parent partners as co-leads of a study, noting structural precarity. Specifically, there was a lack of organizational support and structure for parents leading research projects, including coordination and funding challenges (e.g., leveraging academic salaries versus stipends). Team members indicated that they provided a lower rating on questions related to allowing for a range of viewpoints and perspectives to be shared as it was acknowledged that our team was of limited racial and ethnic diversity. The team discussed that limited diversity affects every step of the research process, from forming the question to interpreting and sharing findings. There was agreement that further research and meaningful engagement on this topic with a more diverse team will be necessary to provide a more robust response to the research question. For this to occur, systemic barriers to partnership must be identified and addressed.

Discussion

By evaluating the KM tool package produced through the primary study, as well as the research team member partnership, we have been able to identify strengths and opportunities for improvement in both areas specific to

Paintings and Write ups

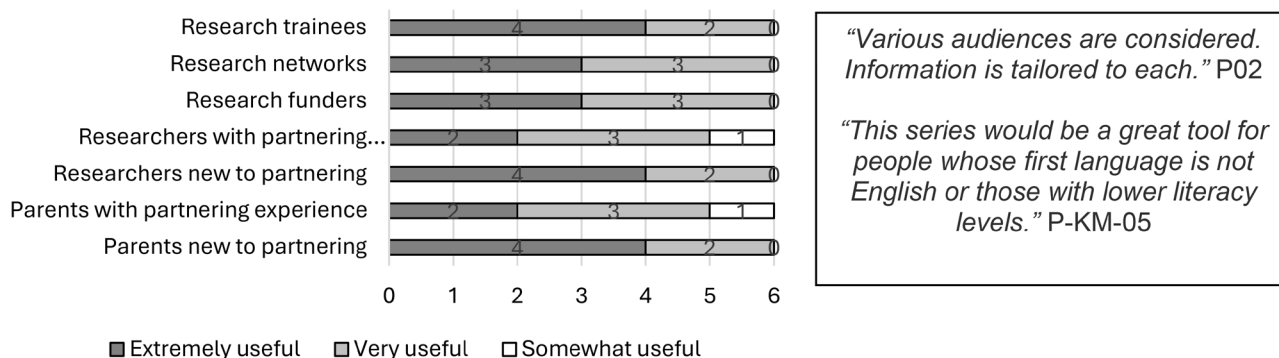


Fig. 3 (continued)

this team's work, with broader implications for others working in knowledge tool development and partnership-based research. It was valuable to receive feedback from a portion of the participants of the primary study on the KM tool package. While published tool development guides and expert KM opinions informed the KM planning for the primary study, it is still a challenge to know how the tools might be perceived by others once shared. Message clarity was identified as an important feature of all tools, which contributed to overall high satisfaction and usefulness scores. The feedback we received provided the opportunity to further improve message clarity by addressing grammatical and formatting issues. Participants also caught an important omission related to discussions about compensation for research partners. Our team also gained a deeper understanding of the emotional impact of arts-based KM tools, with participants commenting both on the uniqueness and beauty of this form of knowledge sharing. Participants also pointed out the layered messaging that can be taken from the work; both intended and unintended. Some minor changes were made to the actual paintings to address nuance (e.g., making an age difference more observable in a then/now portrait of parent and child), however much of the feedback about unintended messaging was addressed through altering the writing that accompanied the painting.

At the onset of our primary study, our team did not set out to create an arts-based knowledge mobilization tool, however by using a KT planning template and leveraging the artistic talents of the student researcher team member, we were able to delve into a newer-to-us but growing area. Arts-based knowledge translation (ABKT), broadly defined as the use of artistic approaches to share research findings, has been described both as a method, or a field unto itself [21, 22]. Reiger and colleagues provide the following as tenets of ABKT: "(a) facilitates iterative approach with audience members; (b) incorporates meaningful aesthetic qualities; (c) engages audience

members through the contextual representation of research findings; and (d) enables a diverse range of people to access and reflect on research outputs" [23]. ABKT approaches have been praised for their ability stimulate dialogue and change through emotional responses [24]. Participant responses to the paintings in the KM evaluation survey align with several of these points, including the aesthetic qualities, engaging nature, accessibility of the format, and the ability to function as a conversation starter.

Two camps have been described within ABKT: one aligning with the evidence-based medicine movement, with a focus on producing 'visually appealing' products to mobilize research findings; the other focusing on the development of evocative artistic pieces that move research findings beyond typical academic spaces [22]. According to this delineation, one could argue that the evidence-based approach to ABKT was used with our tip sheets, in that they were not developed as artistic works however attention was paid to their visual appeal so that they would be ready-to-share/ready-to-use products rather than a list of tips embedded in the text of an academic manuscript. In contrast, the painting series allowed our team to move into the evocative space. The feedback from participants demonstrated the different effects of the tip sheets (and lay summary) versus the paintings. Feedback on the former tended to highlight message clarity, and usefulness for meeting KM goals. Feedback on the paintings revealed some of the highest ratings on usefulness across various audiences, and in response to open-ended questions participants spoke to their personal emotional responses to the work. This feedback was highly encouraging for our team, and we encourage others who have not worked in the space of ABKT to consider if/how these methods and practices may help improve engagement with KM tools [21–23].

Regarding the partnership evaluation, we were interested to find that the topics that arose through our

Table 3 Results of PPEET survey, category of “What went well?”

What went well?						
PPEET Domain	Question	SA % (n)	A % (n)	N % (n)	D % (n)	SD % (n)
Overall experience	As a result of my experience being a member of this research team, I am better informed about how parent partners feel about using personal and social networks for recruitment in research projects	83% (5)	17% (1)	0% (0)	0% (0)	0% (0)
Overall experience	Overall, I am satisfied with my experience being a member of the research team for the BRIGHTER study	83% (5)	17% (1)	0% (0)	0% (0)	0% (0)
Overall experience	Being a member of the BRIGHTER research team is a good use of my time*	80% (4)	20% (1)	0% (0)	0% (0)	0% (0)
Overall experience	As a result of my experience being a member of this research team, I am better informed about parent partnership on a research team	67% (4)	33% (2)	0% (0)	0% (0)	0% (0)
Impacts	I think that the BRIGHTER study is achieving its stated objective of determining the benefits and drawbacks of parents using their personal and social connections for recruitment in research projects	67% (4)	33% (2)	0% (0)	0% (0)	0% (0)
Impacts	I am confident that the input provided by each member of the research team is taken into consideration	17% (1)	83% (5)	0% (0)	0% (0)	0% (0)

Table 3 (continued)

Sharing views and perspectives	I can express my views freely	67% (4)	33% (2)	0% (0)	0% (0)	0% (0)
Sharing views and perspectives	I feel that my views are heard	67% (4)	33% (2)	0% (0)	0% (0)	0% (0)
Sharing views and perspectives	The individuals participating as members of the research team represent a broad range of perspectives and skills (e.g., in terms of life experience)	17% (1)	83% (5)	0% (0)	0% (0)	0% (0)
Communication and supports	I have a clear understanding of the purpose of the BRIGHTER study	67% (4)	33% (2)	0% (0)	0% (0)	0% (0)
Communication and supports	I have had access to the information I need to be able to carry out my role as a member of this research team	50% (0)	50% (0)	0% (0)	0% (0)	0% (0)
Communication and supports	My role was clearly defined/understood from the start of the project	33% (2)	67% (4)	0% (0)	0% (0)	0% (0)

SA=Strongly Agree, A=Agree, N=Neither Agree nor Disagree, D=Disagree, SD=Strongly Disagree

*Of the 37 questions in the survey, 36 were completed by all team members and one question was answered by 5 team members

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Adaptations have been made to the Evaluation Tool for the purposes of the study reported within this manuscript ("BRIGHTER")

evaluation using the PPEET aligned with the main themes of the primary study that this work is embedded within. This thematic convergence is not completely surprising, as the primary study described what caregiver research partners needed to feel supported in research

involvement in general, as well as related to the task of sharing recruitment material through personal networks. The resulting themes from the primary study: *Authentic partnerships, Motivations, and Learned Decision Making*, equally apply to our internal partnership evaluation,

Table 4 Results of PPEET survey, category of “What could be improved?”

What could be improved?						
Domain	Question	SA	A	N	D	SD
Sharing views and perspectives	I am comfortable with the way decisions are made in the research team	50% (0)	33% (2)	17% (1)	0% (0)	0% (0)
Sharing views and perspectives	A wide range of views on discussion topics is shared	33% (2)	50% (0)	17% (1)	0% (0)	0% (0)
Sharing views and perspectives	Our team represents diverse perspectives (e.g. considering race, ethnicity, gender diversity)	0% (0)	33% (2)	0% (0)	67% (4)	0% (0)
Communication and supports	The goals for the parent and researcher partnership model were discussed between team members	33% (2)	50% (3)	17% (1)	0% (0)	0% (0)
Communication and supports	The financial/logistical supports I need to be a team member of the BRIGHTER study have been available (e.g., support for childcare, meetings at times that work for my schedule)	50% (3)	33% (2)	0% (0)	17% (1)	0% (0)

SA=Strongly Agree, A=Agree, N=Neither Agree nor Disagree, D=Disagree, SD=Strongly Disagree

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where the team valued the respect, authenticity, and equal opportunity for decision making provided to all members. Having a parent co-led research team facilitated the alignment of values between the primary study participants (caregivers) and the research team.

Team members each had their own unique motivations that facilitated their involvement in this work, which helped justify some of the barriers encountered, for example, related to higher time demands of the work. The evaluation allowed our team to consider the pros and cons of how we worked, which will undoubtedly feed into decision making for future partnership work. Ensuring more clearly defined role descriptions, pursuing higher levels of funding to support actual time on the project, and establishing decision making flow are key learnings from this work.

In the broader literature there has been a lag between initiatives that called for increased patient/public engagement in research and the practice of evaluating engagement work [11]. However, there is an increasing awareness of the tools available to conduct evaluations, and a corresponding increase in our understandings of the range of impacts of engagement work [3, 7]. A scoping review published in 2020 compiled data on 14 health research partnership evaluations [3]. All included studies used qualitative methods to evaluate partnerships, and a range of engagement techniques and durations of involvement were observed. The review described impacts such as personal growth and development, new relationships, and empowerment. Practical considerations, including barriers and facilitators experienced within partnerships, were also summarized. In alignment with our findings, time (needing/taking more time, time pressures), busy/changing life circumstances, and adequate funding/resources were highlighted as barriers that were experienced. Contrasting with our results, the review reported barriers related to power imbalances and use of jargon. Our team did not experience power imbalances, rather our team members discussed the tension between consensus versus efficiency. While around-the-table consensus supported trust building, it created friction in terms of slower timelines and role ambiguity. Our findings support a hybrid governance model for future work, for example, democratic for conceptual goals but delegated for administrative tasks. Task delegation can be divided among team members, in alignment with their time allotted to the project and their areas of expertise. Our team also avoided issues related to the use of jargon. One reason for this is that the parent-partners proposed the study idea and therefore had a strong grasp of the concepts leading into the work. This can be conceptualized as (one of many) parent-led advantages, where in this case jargon is filtered from the project, as parent

co-leads set the linguistic tone from the protocol stage forward.

The facilitators noted in the scoping review align with the positive evaluative components that we found, as well as with existing best practice recommendations for research partnerships [25]. Respectful relationships, time, funding, and flexibility were among the most frequently reported engagement facilitators in the scoping review. These findings are also congruent with those of Karlsson and colleagues who conducted a rapid review to describe roles that research partners hold, factors that support involvement, and how partner involvement or knowledge is used [12]. Partnership enablers were categorized into five main groups, including training, personality and communication skills, remuneration, time, and trust. Improved quality of research, as well as improved knowledge exchange were among the notable benefits of partnership described by included studies [12]. Within our study, the parent co-leads held an important role in every phase of the work, including the development of the KM tools. In this way, lived experience informed the suite of tools prior to receiving feedback from the primary study participants, and the feedback from participants served to further improve the tools.

As with any study, there are limitations to our work. A limitation of the KM tool evaluation is that only a portion of participants from the primary study provided feedback on the KM tool package. This feedback, however, was still highly valuable in identifying opportunities to improve the clarity and impact of the tools, while enhancing our understanding of how the tools affected participants on a personal level.

A limitation of our partnership evaluation was that it was conducted internally and our group was small ($n = 6$). As such, research team members may have exercised some caution in how they chose to respond to open text questions in case they could be identified. An external evaluation of a larger team would overcome these limitations; however, due to resource constraints and the reality of our team composition this was not feasible. The potential benefits of an internal evaluation should also be considered, including the ability to tailor the evaluation to the project based on familiarity with the context of the work, strong relationships within the team that enhance participation, and the ability for team members to deeply engage with the evaluation process and findings such that capacity for future evaluation work, and understanding of evaluation findings are enhanced [26].

In conclusion, in terms of the KM tools, feedback from participants was imperative to ensure that their perspectives and views were accurately represented. Participant feedback also allowed our team to observe the differing impact of more traditional KM tools when compared with arts-based tools. We encourage others in health

research to explore and learn from the ABKT literature, to continually broaden our collective perspectives and practices related to sharing knowledge. We direct readers to Kukkonen and Cooper's arts-based knowledge translation (ABKT) planning framework, Archibald's classification schema of arts-based knowledge translation strategies, and Archibald's description of the continuum of arts-based research and knowledge translation for further guidance [21, 22, 27]. Through our teams' study and reflection on our engagement practices we determined that there is no one-size-fits-all approach to engaged/partnered research. However, our findings and the work of others continue to highlight the need for authentic and trusting relationships, for early and clear discussions about roles, time commitments, compensation, and decision making. Finally, we recommend building evaluations into research from the beginning, to support confidence in knowing that research team members are supported and feel respected, and to maximize the impact of the work.

Abbreviations

ABKT	Arts-based knowledge translation
KM	Knowledge mobilization
PPEET	Public and Patient Engagement Evaluation Tool
P-KM-XX	Participant number for KM Tool Evaluation
P-PE-XX	Participant number for Partnership Evaluation

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

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Author contributions

CJvR – data curation (equal); investigation (equal); formal analysis (equal); visualization (lead); writing – original draft preparation (equal); writing – review and editing (equal). LK – conceptualization (equal); funding acquisition (equal); investigation (equal); formal analysis (equal); writing – review and editing (equal). CC – conceptualization (equal); funding acquisition (equal); investigation (equal); data curation (equal); writing – review and editing (equal). MG – formal analysis (equal); writing – review and editing (equal). JLP – methodology (equal); project administration (equal); supervision; writing – review and editing (equal). KW – funding acquisition (equal); methodology (equal); project administration (equal); supervision (lead); writing – review and editing (equal).

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Data availability

Data are being retained at the primary research site (University of Manitoba); however, due to the small sample size and potential for identification, it will not be made available for sharing at this time.

Declarations

Ethical approval

Ethical approval for this study was received by the University of Manitoba Health Research Ethics Board (HS24672 [H2021:077])

Consent for publication

Not applicable.

Competing interests

CJvR, LK, CC, MG, and KW have no competing interests to declare. JLP is section head of Allied Health and co-lead of the research pillar for the Canadian Society of Allergy and Clinical Immunology and is on the steering committee for Canada's National Food Allergy Action Plan. She reports consulting for Ajinomoto Cambrooke, Novartis, Nutricia, and ALK-Abelló.

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