The Retinoblastoma Research Booklet: A Catalyst for Patient Involvement in Retinoblastoma Research

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Abstract

Peer-to-peer recruitment efforts are important in generating interest and participation of patients as partners in research but difficult to sustain when face-to-face interactions are limited. The *Retinoblastoma Research and You!* booklet, co-developed by patients, researchers and health professionals, serves as a guide for patient engagement in research while retaining an element of personalization. The *Retinoblastoma Research and You!* booklet was developed through two virtual workshops to iterate and finalize the booklet design and content. The booklet outlines how individual patients' lived experiences and skills can influence retinoblastoma research and highlights real-world examples of patient-partnered research activities at different stages of the research process.

Key Points

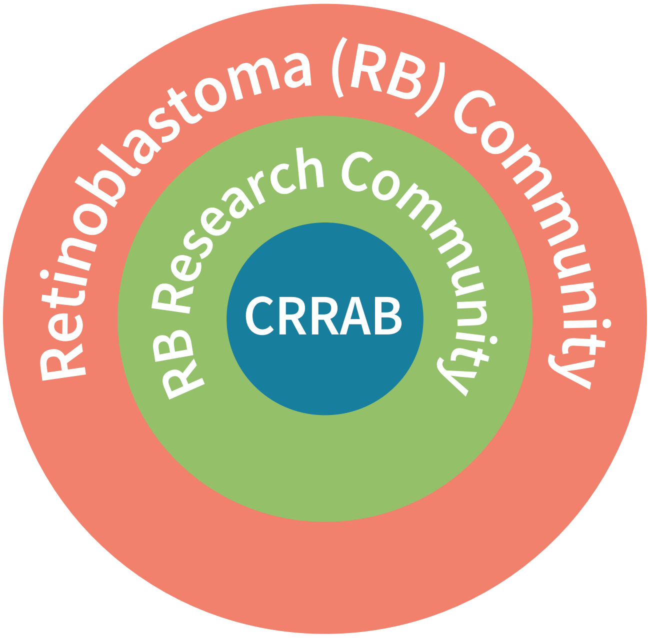
- The Canadian Retinoblastoma Research Advisory Board aims to identify and include a large and diverse group of patients in retinoblastoma research to create research that is meaningful and relevant to patients and improves outcomes.
- To facilitate recruitment, we developed a booklet with patient partners that outlines how individual patients' lived experiences and skills can influence retinoblastoma research. The booklet highlights real-world examples of patient-partnered research activities at different stages of the research process that is further illustrated through patient testimonials.
- The booklet was distributed through the retinoblastoma clinics and relevant cancer advocacy organizations across Canada in order to reach new patients and encourage them to get involved.

Introduction

Retinoblastoma is a childhood eye cancer with lifelong implications for survivors and their families. As such, patients (i.e., those with lived experience of the disease, including family and friends [CIHR 2014]) have expressed a desire to become involved in research as a means to improve care and impact on current and future patients. As described in our accompanying manuscript in this special issue (Ristevski et al. 2022), the Canadian Retinoblastoma Research Advisory Board (CRRAB) was developed with the ultimate goal to have patients work *alongside* researchers and health professionals to create meaningful retinoblastoma research that is relevant to patients and improves outcomes. Much of this work is led by a "parent in research" – an individual with lived experience of retinoblastoma who is employed as part of a research team. The CRRAB membership is drawn from those enrolled in the retinoblastoma research community (i.e., people in the retinoblastoma community who are interested in research and formally join by signing up online), which is situated within the broader retinoblastoma community (i.e., anyone who is

P = Patient with lived experience of retinoblastoma. R = Researcher with expertise in retinoblastoma. H = Health professional with expertise in retinoblastoma.

FIGURE 1.
CRRAB schematic



Navigating the Canadian retinoblastoma research landscape starts with the retinoblastoma community, including but not limited to patients, researchers and health professionals. The retinoblastoma research community is a subset of the broader community and includes those who express an interest in retinoblastoma research. CRRAB is a further subset of the retinoblastoma research community and includes those who actively participate in and contribute to patient-partnered research and related activities.

personally or professionally connected to retinoblastoma in Canada, including but not limited to patients, researchers and health professionals) (Figure 1).

A major CRRAB goal is to identify and include a large and diverse group of patients in research and have them join the retinoblastoma research community, an online database that endeavours to enroll a diverse and inclusive group of people who have already been affected by retinoblastoma, as well as newly affected individuals. Members are invited to specify their desired level of involvement, which may include (1) receiving information about retinoblastoma, including research results and updates, and (2) being contacted by The Hospital for Sick Children (SickKids) – where the majority of Canadian retinoblastoma patients are managed – retinoblastoma research team and/or external researchers for information about retinoblastoma and research opportunities (Gelkopf et al. 2020; White et al. 2019). To optimize benefit, involved patients should extend beyond those who most regularly participate, and incorporate a diversity of individuals representing different demographics (i.e., sex, geography, language, age, etc.) and lived experiences (i.e., relationship to retinoblastoma, treatment course, diagnosis, etc.).

To attract diverse participation, CRRAB generates awareness of, and interest in, patient engagement in research using a variety of methods, often relying on the strength of peer-to-peer networks, social media and the power of personal stories. Volunteer-led social media efforts share personal stories and create thematic content to inform followers about research results, upcoming events, research opportunities and the importance of participating in retinoblastoma research. Face-to-face discussions about retinoblastoma research during retinoblastoma clinic days at SickKids have proven successful, as have patient-led conferences and research symposia. However, since the onset of the COVID-19 pandemic, restrictions to in-person interactions temporarily halted recruitment and engagement efforts, requiring a new mode of recruitment that still maintains a semblance to peer-to-peer networking.

The purpose of this project was to improve patient recruitment and involvement in CRRAB through the development of (1) a novel recruitment and educational tool, the *Retinoblastoma Research and You!* booklet (https://www.rbcanadaresearch.com/introducing-the-retinoblastoma-research-and-you-booklet/) and (2) a distribution plan to reach retinoblastoma patients to introduce or re-engage them with CRRAB.

Patient Engagement Methods and Outputs

Co-creation of the *Retinoblastoma Research and You!* booklet

Prior to the start of this project, attendees at monthly CRRAB working group meetings (including patients, researchers and health professionals) had begun to brainstorm content for the proposed booklet, creating rough designs using Microsoft PowerPoint. The funding from the Ontario Strategy for

Patient-Oriented Research SUPPORT Unit (OSSU) Engaging Multi-stakeholders for Patient Oriented-research Wider Effects and Reach (EMPOWER) Award facilitated further work to (i) design and implement two virtual workshops to iterate and finalize the booklet design and content and (ii) produce and distribute physical and electronic booklets to the patient community.

Design and leadership of workshops

The parent in research (IV) collaborated with the scientist (HD) to design the structure and content of the workshops, each contributing their lived or scientific expertise, respectively. In collaborative brainstorming meetings, they formulated goals for each workshop (e.g., desired feedback, tangible outputs) and considered effective methods to stimulate discussion and consensus among participants (e.g., Zoom polls, pre-readings, etc.). Equipped with information from these meetings, the parent in research developed workshop materials and used the structure of regular lab meetings to present and refine the materials with input from the scientist and the broader research team. The parent in research took overall responsibility for project implementation, drawing on her personal lived experience of retinoblastoma and work experience as a member of a health research team to lead the development of the booklet; this facilitated action as a liaison, or bridge, between scientific, health professional and patient contributors to the project.

Recruitment of workshop participants

An open invitation was sent to CRRAB members to attend the virtual workshops, which opened the possibility for participation across Canada, removing the barrier of travel. Thus, the travel restrictions of the pandemic did not affect recruitment, especially because CRRAB activities have routinely used virtual platforms for monthly and quarterly meetings since its start. Workshop dates and times were chosen to coincide with monthly working groups to facilitate availability of members. To ensure a broad representation of retinoblastoma experiences in the workshop, the parent in research additionally reached out to CRRAB members with unique lived experiences and professional expertise to round out the group.

The workshops were attended by one research student and 13 CRRAB members representing patients (three parents, six survivors, one survivor/parent), one researcher and two health professionals. The team included a variety of professional specialties, including an ophthalmologist, a retired genetic counsellor, an elementary school teacher and children's book author, a leader in digital health solutions and others with general business experience. Some participants also served as retinoblastoma advocates working with collaborating organizations, the Canadian Retinoblastoma Society (https://www.rbsociety.ca/) and Know the Glow Foundation (https://knowtheglow.org/). In terms of geography, attendees represented British Columbia, Ontario, Alberta and Newfoundland.

Implementation of workshops

In advance of the workshop, the parent in research prepared and sent the participants the draft content created using Microsoft PowerPoint, as well as draft designs and page layouts created by a hired graphic designer. Workshop One began with a brief icebreaker of introductions and sharing of their relationship to retinoblastoma and motivation for being involved in research.

Each workshop followed human-centred design methodology consisting of three phases: ideation, rapid prototyping and refinement. Workshop One focused on the look and feel of the booklet, including font, colour scheme and general page design as well as the front cover design. Workshop Two focused on finalizing specific graphics within the booklet and the design of the back page. Focused on these goals, all stakeholders discussed the merits of each design, suggested changes and voted to reach consensus. The graphic designer made modifications in real time and offline to produce new prototype designs. Online surveys were used between workshops to gather additional inputs, and revised designs were reviewed in the final workshop. Final suggestions for refinement were incorporated by the graphic designer after the workshops, in consultation with the parent in research.

Patients in particular were encouraged to draw on their personal experiences to contribute to booklet development. CRRAB member JK created a custom quick response (QR) code that opens to a list of various retinoblastoma-related links to inform the reader of the different ways they can be involved. He described his experience as follows:

> As restaurants reopened, I noticed that a large proportion of menus had disappeared; many establishments had gone paperless – making their menus accessible via scanning a QR code sticker on the tabletop. I thought to myself, "What if we could do the same thing for the retinoblastoma research booklet, so that every time an ophthalmologist was treating a patient or advising a parent, they would be able to scan something quickly to take with them?"

In this creative experience, Jay was able to use his professional skills as a leader in digital health solutions and create a simple but impactful contribution to the booklet.

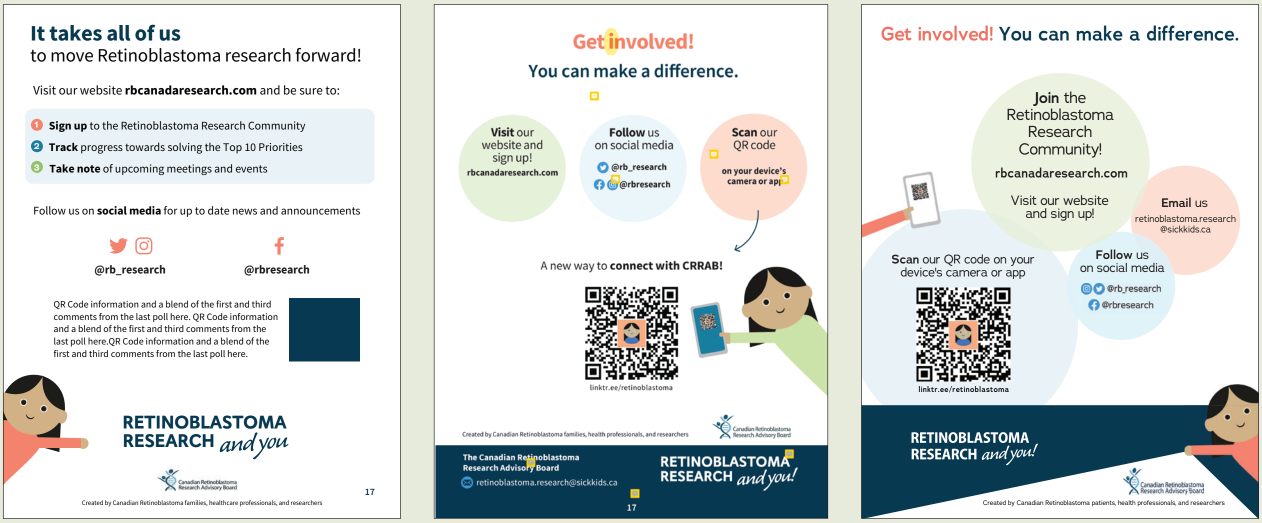
Figure 2 illustrates how the human-centred design process was used to co-design the back cover of the booklet. The content in the back cover was initially agreed upon, with the main goal being to drive readers to visit the CRRAB website (Figure 2a). The ideation phase facilitated generation of the idea of including a QR code, which was subsequently rapidly prototyped and included in the design (Figure 2b). Through the process of refinement, the content and layout were finalized (Figure 2c). The iterative, discussion-based process facilitated crosstalk and opportunity for workshop participants to debate on the understandability and relevance of the booklet's content for the target patient audience. For example, because some workshop participants indicated that they were unfamiliar with how to use a QR code, instructions on "how to use" were incorporated into the final booklet.

Final booklet

The resultant *Retinoblastoma Research and You!* booklet (Figure 3) provided in a hard copy and digital version was created to be accessible to those with low and impaired vision by incorporating accessible design standards. The booklet outlines how individual patients' lived experiences and skills can influence retinoblastoma research with their participation in CRRAB activities. The booklet highlighted accessible routes for patients to get involved in research and showcased real-world examples of patient-partnered research activities at different stages of the research process. These real-world examples were further illustrated through testimonials written by Retinoblastoma Research Champions (https://www.rbcanadaresearch.com/join-crrab/champion-program/about_champion_program/), patients who actively promote patient engagement in research.

FIGURE 2.
Iteration of the booklet back cover

The human-centred design process was used to co-design the back cover of the booklet:



(a) The content of the back cover was initially agreed upon, with the main goal being to drive readers to visit the CRRAB website;

It takes all of us
to move Retinoblastoma research forward!

Visit our website **rbcanadaresearch.com** and be sure to:

1. **Sign up** to the Retinoblastoma Research Community
2. **Track** progress towards solving the Top 10 Priorities
3. **Take note** of upcoming meetings and events

Follow us on **social media** for up to date news and announcements

@rb_research **@rbresearch**

QR Code information and a blend of the first and third comments from the last poll here. QR Code information and a blend of the first and third comments from the last poll here.QR Code information and a blend of the first and third comments from the last poll here.

RETINOBLASTOMA RESEARCH *and you*

Canadian Retinoblastoma Research Advisory Board

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Created by Canadian Retinoblastoma families, healthcare professionals, and researchers

(b) the ideation phase facilitated the idea of including a QR code, which was subsequently rapidly prototyped and included in the design; and

Get involved!
You can make a difference.

Visit our website and sign up!
rbcanadaresearch.com

Follow us on social media
@rb_research
@rbresearch

Scan our QR code
on your device's camera or app

A new way to **connect with CRRAB!**

linktr.ee/retinoblastoma

Created by Canadian Retinoblastoma families, health professionals, and researchers

Canadian Retinoblastoma Research Advisory Board

The Canadian Retinoblastoma Research Advisory Board
retinoblastoma.research@sickkids.ca

RETINOBLASTOMA RESEARCH *and you!*

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(c) through the process of refinement, the content and layout were finalized.

Get involved! You can make a difference.

Join the Retinoblastoma Research Community!
rbcanadaresearch.com
Visit our website and sign up!

Email us
retinoblastoma.research@sickkids.ca

Scan our QR code on your device's camera or app

linktr.ee/retinoblastoma

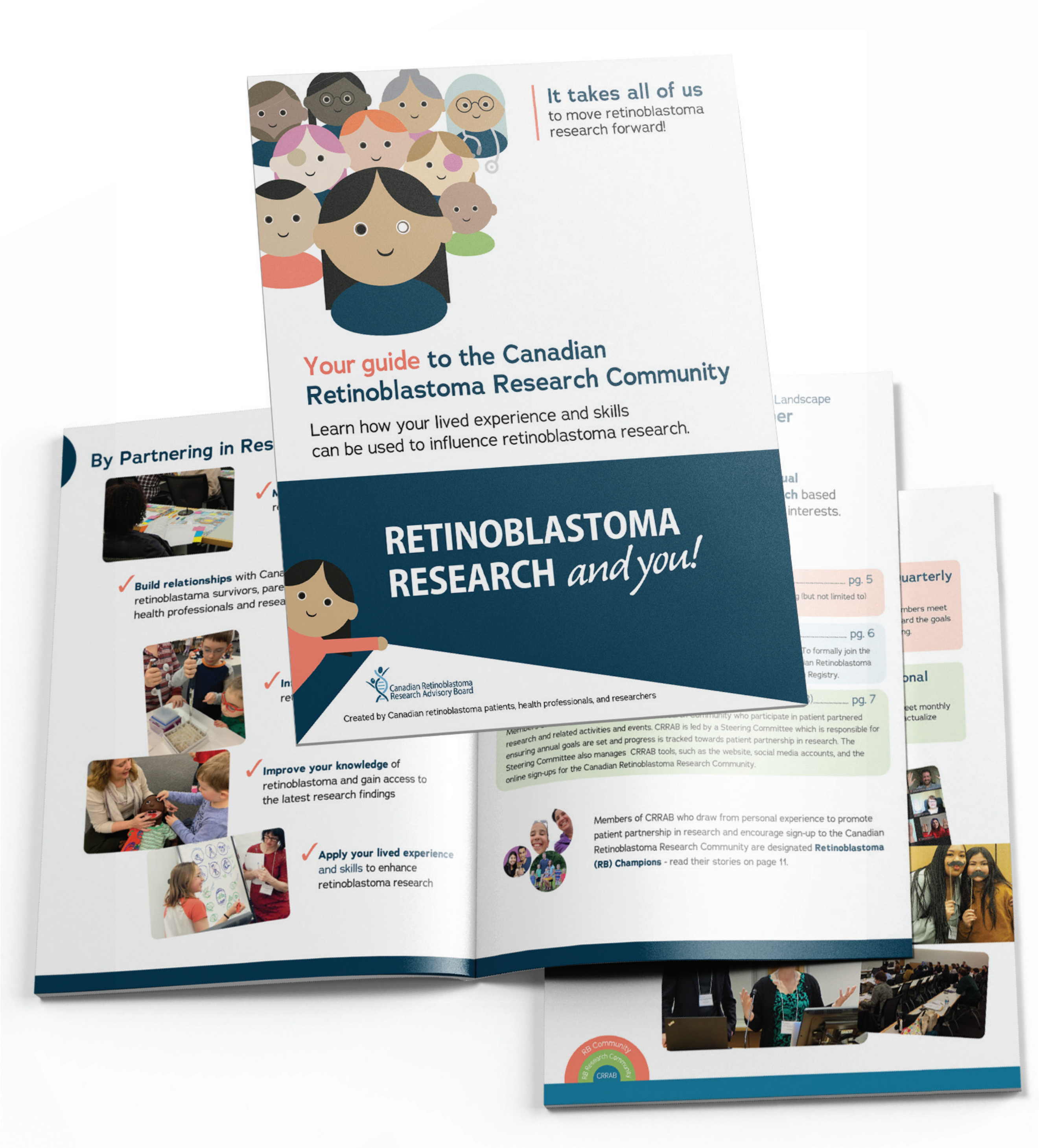
Follow us on social media
@rb_research
@rbresearch

RETINOBLASTOMA RESEARCH *and you!*

Canadian Retinoblastoma Research Advisory Board

Created by Canadian Retinoblastoma patients, health professionals, and researchers

FIGURE 3.
The *Retinoblastoma Research and You!* booklet



The *Retinoblastoma Research and You!* booklet is a guide to patient engagement in retinoblastoma research in Canada developed by CRRAB members to encourage patients to join the Canadian retinoblastoma research community and participate in CRRAB by outlining how individual patients' lived experiences and skills can influence retinoblastoma research.

Development of a distribution plan for the booklet

For effective distribution of the booklet, it was critical to obtain buy-in from health professionals and patient stakeholders. At workshops and CRRAB regional working groups, CRRAB members discussed how patients access the latest information and research and how researchers and health professionals typically share research results. Patients revealed that a key mode for accessing information was through trusted stakeholders, such as health professionals and advocacy organizations. In turn, an exhaustive list of stakeholders and organizations was created by the research team and then prioritized by consensus at the workshops. Workshop participants reflected on potential organizations they themselves were members of, or had heard of in the past, which could help identify retinoblastoma patients beyond those who most regularly participate.

Distribution via health professionals

The parent in research presented the overview of the booklet and its purpose to the Canadian Retinoblastoma Tumor Board (attended by health professionals who manage retinoblastoma throughout Canada). The board members helped develop a distribution plan to target their clinics' patients, providing insights on logistics and requesting a standard operating procedure (SOP) to guide their involvement.

The final distribution plan included dissemination of the hard copy booklets in clinics and digital booklets via e-mail directly to patients. The SOP, developed by the parent in research in collaboration with the scientist (who reviewed the draft SOP for clarity, format and content), included suggested talking points to use with patients, an e-mail template and guidance on answering patient questions about the booklet. In addition, the QR code that was included on the booklet's back cover was printed in a sticker format to be adhered to professional ID badges to serve as a readily accessible method to connect patients with electronic resources – particularly important if print booklets ran out.

Distribution via media toolkit

It was decided that the booklet could be shared with identified professional and advocacy organizations using a media toolkit composed of a press release, social media posts and a poster along with instructions on how to use each media toolkit component.

CRRAB members drafted the media toolkit components at CRRAB monthly working groups, and an undergraduate research student helped refine them working alongside the parent in research and a scientist. The first iteration of the media toolkit was shared via e-mail with Jill Robert, a patient partner, who provided feedback from a patient perspective as well as a health network perspective due to her work. The patient partner was asked to assess language, style, visuals and the overall function and flow of the media toolkit.

Patient partners also played a key role in providing feedback to improve the distribution and uptake of the media toolkit and offered to also share it with their networks. For example, Mary Connolly-Wilson, a retired genetic counsellor, contributed to developing a plan on reaching genetic counsellors and also championed the booklet within her personal and professional network.

Key Messages

The *Retinoblastoma Research and You!* booklet, co-developed by patients, researchers and health professionals, serves as a guide for patient engagement in research while retaining an element of personalization that will help increase recruitment and participation in CRRAB. Patients co-created the booklet with researchers, health professionals and a graphic designer, incorporating their views and experiences on what is helpful to know about partnering in research and its benefits, which go beyond shaping research and include forming connections with other patients and professionals in the retinoblastoma community.

While we have yet to formally evaluate the impacts of patient involvement in this project, some patient partners explained the value of patient involvement in this project in their own words:

[Patient involvement in this project] helped to shape the content in a relevant way based on what we wished we had available to us. As a patient, it took me 30 years to obtain an awareness about any sort of retinoblastoma community. Moving forward, I hope that future patients will be connected to our community and obtain support much, much faster.

– Jay Kiew

At my daughter's diagnosis, I felt overwhelmed, but I didn't feel I was provided with many things that gave me hope. I believe this booklet not only provides valuable information; it also provides hope to those affected by retinoblastoma.

– Alena Vincent

My parents really struggled to come to grips with my diagnosis 20 years ago – what it meant for me, what it meant for our family, what I would and wouldn't be able to do – and had a lot of difficulty finding others to connect with who had been through it before. Knowing that I'm making it easier for another family is a great feeling!

– Mitch Hendry

The discussion-based human-centred design structure of the workshops helped bring to the forefront ideas from patients that are typically not discussed by researchers alone. For example, prior study has shown that motivations and expectations of patient involvement in research differs among patients and researchers (Schilling et al. 2019). In our project, during a discussion about the benefits of patient partnership in research, a parent shared that a personal benefit that they experienced by partnering in research was in connecting with other families affected by retinoblastoma. In addition, the feeling of making a difference for future affected families was important to them. These ideas helped enrich the discussion beyond just the potential patient impact on the research itself to include the impact of research partnership on patients themselves. Consequently, the discussion was incorporated into the content of the booklet.

Another important impact on the project was in exposing stakeholders at the periphery of the CRRAB network to patient engagement in research. For example, the recruitment of an undergraduate research student to this project resulted in them building research expertise in patient engagement and benefiting from mentorship from the parent in research. Similarly, the participation of the parent in research in the Canadian Retinoblastoma Tumor Board allowed the participation of health research stakeholders in this project, who – while members of CRRAB – would not be able to regularly attend meetings and workshops. This way, the health professional perspective was incorporated into the project and relayed to workshop participants via the parent in research.

The completion of the project was not without its challenges. Commonly with larger groups, ensuring all ideas are considered appropriately makes the process more complex and time consuming. The use of videoconferencing software came with its usual drawbacks: microphone/camera issues, inability to speak simultaneously, accessibility concerns regarding the chat function and scheduling across different Canadian time zones. We worked around this as best we could by scheduling meetings during weekends and lunch hours, with duplicate meetings to accommodate for different time zones and frequent e-mail reminders to avoid missed meetings. E-mails and one-on-one meetings were the most requested methods for participants who wanted to connect outside the group meetings. However, we believe that the early and routine engagement of patient partners through CRRAB helped ensure adequate recruitment of patient partners to this particular project, as shown for other projects (Vat et al. 2017). Still, it is possible that the virtual mode excluded participation by individuals who lacked a reliable Internet connection or suitable electronic device. Furthermore, we noticed that the virtual experience removed most of the casual conversations and networking common during past in-person research workshops, a feature that many CRRAB members value. We attempted to stimulate this by spending a little more time at the beginning of videoconferences with icebreaker activities. Another challenge we noticed during the pandemic was a decrease in participation by researchers and health professionals in the meetings; while we normally have a patient to non-patient ratio of 1:1 at our meetings, for this project it was 3:1. The decline in non-patient participation might be the result of the added strains and stressors induced by the pandemic and experienced by those working in the health field (Unadkat and Farquhar 2020).

The reach and uptake of the booklet, as well as the effect of the media toolkit, are currently being evaluated by standard knowledge translation metrics; results will be reported in a future publication. Booklets continue to be distributed virtually through a variety of means. CRRAB members are actively working on developing a French version to serve the francophone population in Canada.

In summary, peer-to-peer recruitment efforts are an important part of generating interest and participation of patients as partners in research. In the absence of in-person recruitment efforts, the *Retinoblastoma Research and You!* booklet – by nature of being co-created by patients and containing patient stories and impact on research – serves as a stopgap to fill this need.

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