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Seizing the moment: communicating ethics, decisions, and neurotechnological approaches to pediatric drug-resistant epilepsy

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It is a fundamental duty of neuroscientists to discuss the results of research and related ethical implications. Engagement with neuroscience is especially critical for families with children affected by disorders such as drug resistant epilepsy (DRE) as they navigate complex decisions about innovations in treatment that increasingly include invasive neurotechnologies. Through an evidence-based, iterative, and value-guided approach, we created the short-form documentary film, *Seizing Hope: High Tech Journeys in Pediatric Epilepsy*, to delve into the relationship between experts with first-hand, lived experience – youth with DRE and caregivers – and physician experts as they weigh medical and ethical trade-offs on this landscape. We describe the co-creation and evolution of this film, screenings, and feedback. Survey responses from 385 viewers highlight new developments in technologies for the treatment of DRE, how families navigate choices for treatment with brain technology, and a sense of hope for the future for children with epilepsy as key attributes of this science communication piece.

KEYWORDS

science communication, neurotechnology, drug resistant epilepsy, neuroethics, decision-making

1 Introduction

Everyone has a stake in understanding how the brain works, and basic and clinical neuroscientists at the frontline of research have a duty to communicate the full spectrum of their work – from study design to results – using effective communication tools that engender understanding and public trust (Illes et al., 2010; National Academies of Sciences, 2017; Humm and Schrögel, 2020). Moreover, the results of neuroscience research extend far beyond the laboratory given their complex interactions with ethical, social, cultural, and regulatory issues. While a scientifically informed public possesses an enhanced capacity to assess risks and benefits in their lives (Racine et al., 2010; Das et al., 2022), the technicalities and sheer abundance of neuroscience output pose a challenge for science communication. People who are engaged with science may be advantaged by access to up-to-date results in this context (Illes et al., 2005; Brownell et al., 2013; Bevan et al., 2020; Canfield et al., 2020).

The ability to engage with advances in neuroscience can be especially challenging for any vulnerable population, including children – with their families – who continue to have seizures despite taking anti-seizure medications (a condition referred to as drug-resistant epilepsy; DRE), and who may benefit from advanced technological approaches to care (McDonald et al., 2021). Indeed, families with children with DRE – about 30% of the 500,000 affected children annually in North America – face complex decisions when weighing the ethical magnitude of failed drug interventions, risks and benefits of emerging neurotechnologies, and effects on the continuous development of the body and brain.

Over a 4-year period, we used conventional quantitative and qualitative methods to investigate the priorities and concerns that drive decision-making and communication regarding neurotechnological treatments for DRE to respond to this challenge. Relevant neurotechnologies involve, for example, neuromodulatory invasive approaches such as deep brain stimulation and vagus nerve stimulation, and less invasive strategies such as transcranial magnetic stimulation. We found that physicians and families alike seek freedom from seizures as the highest priority for all types of interventions (Hrinco et al., 2021; McDonald et al., 2021; Apantaku et al., 2022a,b; Illes et al., 2022). Physician decision-making about the best fit for the treatment of DRE in young patients involves consideration for the type of approach, risks, and availability of evidence; the latter is especially challenging when an innovation is still in early phases of testing and clinical application. Parents are concerned about stigma (Hrinco et al., 2021; Alam et al., 2022) and affected youth value autonomy (Udwadia et al., 2021). Results related to these findings were translated into eight publicly available infographics (<https://neuroethics.med.ubc.ca/res/nih-epilepsy-resources>). For rural and remote communities, the most significant social justice issue is access to education about treatments for epilepsy in the face of highly limited resources (Harding and Illes, 2021; Illes et al., 2022; Harding et al., 2023).

Given this prior empirical work, we applied an iterative, value-guided approach to the creation of a short-form documentary film, *Seizing Hope: High Tech Journeys in Pediatric Epilepsy* (<https://www.youtube.com/watch?v=KmkKbt3TA6s>), featuring both children with DRE and caregivers as community experts and physicians with expert medical knowledge (Nuechterlein et al., in press). The film documents the journeys of four Canadian families as they learn, understand, and explore ethical trade-offs – such as the availability of evidence and risk of complications from an intervention, access barriers, financial burden, stigma, invasiveness, cosmesis – around emerging neurotechnologies for the brain. In its exploration of critical decision-making factors surrounding neurotechnologies, *Seizing Hope* as a non-academic communication tool, aims to bring hope to and empower the children afflicted with DRE and their families.

2 Methods

2.1 Pre-testing

We benefitted from the opportunity to reach out to families and physicians in the research phases of this large program of work

who provided consent for recontact. We queried for the desired types of communication products that would be meaningful to them and would extend the reach of infographics we had already developed directly from the research findings. Based on their feedback and receptivity to a film product, we then further queried families about where they seek informational resources (e.g., online at home, at clinics) and with whom to fully characterize the target audience; amount of time devoted to learning about DRE and their child's condition; desired documentary length and format; whose voices they would like to hear; preferences for sound, production quality, and visuals; biases toward one or more interventions; and importance of story-telling and entertainment. The questionnaire for physicians focused on different ways to describe the latest advances in neurotechnology, features of other successful educational resources, and a key message they would like to share with families and patients. Overall, responses emphasized that the topic must be explained in lay terms, the documentary shorter than 30 minutes, and the voices of both families and their children as well as medical experts featured. Special effects and entertainment were not considered to be of high value.

2.2 Creation of *Seizing Hope*

The answers to the pre-test questionnaire combined with principles of science communication and design thinking provided the path to the creation of *Seizing Hope* for healthcare professionals, stakeholder networks, and social circles of those with pediatric DRE. Design thinking is a step-by-step process and proven methodology that helps create products in response to user needs (<https://dschool.stanford.edu/>; Kalmár and Stenfert, 2020).

Empathize: Through the use of interviews and empathy maps, we identified how the users think, feel about, and engage with our topic of DRE and the ethics that surrounds neurotechnology.

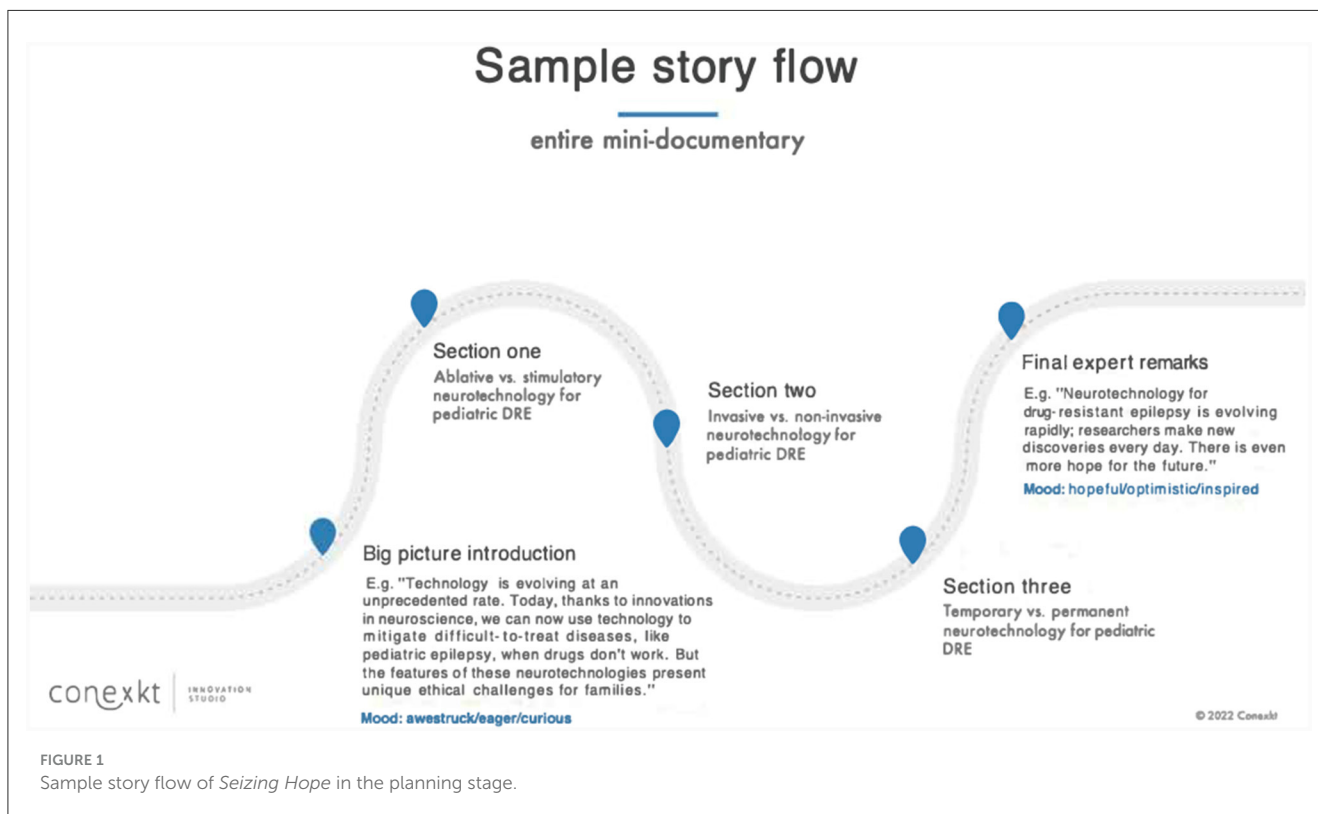
Define: We established the problem that our findings will help our audience resolve. The problem was identified through user personas, user stories, user journeys, and problem statements.

Ideate: We combined our findings to determine the type of product that will best fulfill our audience's needs.

Prototype: We created early drafts of the different types of products and the results they can bring to our target audience. We chose the path that would yield the highest impact based on responses from the interviews and surveys.

Refine: We tested the film by screening early versions with internal users among the research team, returned to participants from the initial pre-test phase for feedback, and integrated their feedback into the evolving product.

The five fundamental steps of design thinking that culminates in a story flow (Figure 1).



2.3 Participant recruitment

Prospective families to be featured in *Seizing Hope* were identified through prior engagement in the research arms of the project and the clinical collaborators of the team (PJM, MBC, and GMI). To protect patient and family privacy and confidentiality, clinicians reached out by telephone and email, or at the time of a clinic visit, to relevant families with children in their practices to ascertain their interest in participating. Families who expressed interest were screened by JR. This screening process considered a variety of factors such as the patient's age, gender, ethnicity, location, living conditions, duration of epilepsy, ability to answer questions on camera, caregivers' or siblings' willingness to participate in the film, neurotechnologies used or considered, any other surgical interventions for epilepsy, the success of these interventions, the distance traveled for care, and any other relevant notes. The goal was to ensure that the film would represent a diverse range of neurotechnologies and ethical challenges faced by different families from various socioeconomic backgrounds. In essence, we sought to feature families with different experiences and stories.

After the screening process, the four selected families received detailed information about the study and provided informed consent (UBC # H18-02783). We then scheduled a comprehensive online interview with the caregivers, during which they shared both their story and the story of the patient or child.

3 Filming

3.1 Process

Filming was scheduled, with four possible scenarios considered:

1. The best-case scenario involved a full day of filming with, for example, a meeting at the family's favorite park, filming a meeting with a specialist, lunch, an interview, and recording background videos of the family around the home (referred to as B-roll footage).
2. The next best scenario involved a half-day of filming, focusing on the interview and B-roll footage at home.
3. The third scenario involved a two-hour filming session at home, primarily focused on the interview.
4. The fourth scenario was used when the family preferred not to have filming at their home and involved an interview at another location.

In all cases, we aimed to start with the top preference and work our way down as necessary, with the goal of creating a documentary that portrayed the experiences and challenges faced by families dealing with pediatric DRE.

The filming process was a collaborative effort, involving a film director on set, one or two sound engineers, the producer, and in most instances, one or both of the Executive Producers (JI, PJM) who were also co-principal investigators of the larger study. We elected to film at the families' homes whenever possible. This choice was made to provide a personal touch and offer a glimpse into the daily lives and routines of the families. In the event a family's home was not suitable for filming, we used a rented house. We aimed to capture the interactions between caregivers, patients, and their siblings or other family members to portray the reality of their lives.

Before initiating the formal interviews, we took the time to familiarize ourselves with each family, ensuring everyone felt comfortable with the process. After this, we set up the necessary equipment (cameras, microphones, and lighting) and conducted tests to ensure optimal recording conditions. We then conducted

seated interviews with the caregivers and, when possible, the affected youth.

When filming the experts, we chose to film at their place of work, whether that was a university or a university hospital, to establish their expertise and contextualize their comments within their professional environment.

This approach to filming allowed us to create an engaging, personal, and authentic depiction of the experiences and challenges faced by families dealing with pediatric DRE, as well as the professionals dedicated to helping them.

3.2 Supporting materials

We developed branding, press, screening, and educational kits (Press Kit: <https://med-fom-neuroethics.sites.olt.ubc.ca/files/2023/05/Seizing-Hope-Press-Kit.pdf>; Screening Kit: <https://med-fom-neuroethics.sites.olt.ubc.ca/files/2023/05/Seizing-Hope-Screening-Kit.pdf>; Educational Kit: <https://med-fom-neuroethics.sites.olt.ubc.ca/files/2023/05/Seizing-Hope-Educational-Kit.pdf>) and partnered with university and institutional communications departments for product dissemination. We used calendar listings (partner and provincial epilepsy society websites/blogs, university and inter-department event calendars and communication channels, local newspaper ads, Eventbrite listings, and social media event pages) to disseminate event details.

3.3 Post-screening feedback survey

We designed a twelve-question survey that was tested iteratively with feedback integrated from the research team and study participants who agreed to be recontacted. The survey was motivated by our desire to learn the strengths and weaknesses of the film as a communication tool about pediatric DRE, neurotechnology, and decision-making; explore whether we met the goal of empowering families with information in a new format through this medium; inform future communication products; and, the desire to share our experience with others in the research community who seek to engage with and reach public and patient audiences.

Viewers were probed for their feedback in five categories: background and experience with DRE, overall reaction to the film, potential for recommending the film to others, willingness to learn more about using technological treatment for epilepsy, and key messages of the film. Surveys were distributed at the screening event for immediate responses, and made available to audiences thereafter. We illustrate findings for variables of interest based on the actual number of responders to a given question, and use direct quotations to broaden the context of the quantitative data.

4 Results

4.1 Characteristics of the film

The key specifications and details of the documentary are shown in Table 1.

TABLE 1 Film specifications.

Film specification	Details
Project type	Documentary
Genres	Science, Documentary
Runtime	30 min 24 s
Completion date	June 6, 2022
Country of origin	Canada
Country of filming	Canada
Language	English
Shooting format	1920x1080
Aspect ratio	16:9

4.2 Public and academic screenings

The final version of *Seizing Hope* was screened in-person, virtually, and as a hybrid event at 20 public events and 10 academic events across 16 cities in 5 countries (Australia, Canada, France, Netherlands, United States, including Puerto Rico) after its world premiere in Vancouver, British Columbia, Canada. In-person screenings were held at venues accessible to people with all types of abilities and transit-friendly, such as community theaters, public libraries, and auditoriums. Three were held in conjunction with major conferences reaching both academic and clinical professionals: Institut Neurosciences Cognition Day (October 2022, Paris, France), International Neuroethics Society Annual Meeting (November 2022, Montréal, Québec, Canada), and American Epilepsy Society Annual Meeting (December 2022, Nashville, Tennessee, USA).

We collaborated with local partners to lead screenings by providing guidance on promotions and logistics. Partners were encouraged to connect with their own venue and catering suppliers (for in-person events) and host their own platform (for virtual and hybrid events). Partners were supplied with the press kits and customizable branding collaterals for promotion. Depending on the event format, ~1–3 months of planning were needed for each screening. This allowed for sufficient time to book the venue and catering, secure and brief panelists, and event promotion. Every screening was immediately followed by a moderated 30-min panel discussion with medical experts and ethicists, and a question-and-answer (Q&A) forum. Ten screenings also included one or more family members featured in the film.

For virtual events, a week prior to the event date, partners were provided a password-protected link from which they could play and stream the film via screenshare. At this time, we reminded them to run the film in full-length to check their bandwidth and troubleshoot, as needed. The Q&A forum was managed by a moderator, usually the partner, by checking the chat and question windows of the virtual platform.

For in-person events, we coordinated with the audio-visual team of the venue in advance and played the film directly from

our equipment (i.e., laptop or USB). The Q&A forum portion was managed similarly as a virtual event.

Some partners recorded the moderated Q&A discussion of the virtual event for their archiving. It is important to note we did not allow any recording while the film was being played at both virtual and in-person events, as the film was still being adjudicated for film festivals at the time.

For conferences, we worked with partners to secure screening times at the conference programs and to lead the events. Partners were either part of the programming committees or had access to host an outreach event as part of the conference program. We provided guidance on the logistics (i.e., venue selection and management, catering), customizing branding and strategizing promotions, and staffing. Event details and branding were shared through partner and conference social media channels, and newsletters.

All told, the screenings welcomed nearly 1,000 viewers. Screenings were held either at noon local time, late afternoon, or early evening to accommodate viewers with different needs. Registration using the platform Eventbrite allowed for a convenient registration process and organizer-attendee communication experience, as well as for viewer tracking for survey reporting purposes.

4.3 Film festival screenings

Seizing Hope was submitted to 12 film festivals that were chosen either for their focus on scientific topics, or local to the research and film team and serving the regional community: Chilliwack Independent Film Festival (Selected), #LabMeCrazy! Science Film Festival, Abbotsford Film Festival, Calgary International Film Festival, DOXA Documentary Film Festival, Imagine Science Film Festival, International Public Health Film Competition 2022, Prague Science Film Fest, Sundance Film Festival, Vancouver International Film Festival, Vienna Science Film Festival, and Whistler Film Festival + Summit.

4.4 Viewers and respondent feedback

4.4.1 Characteristics

We received a total of 385 fully or partially completed responses to the post-screening survey that was available to film viewers, representing an estimated 39% response rate (Table 2). Thirty percent (103/347) were healthcare providers, 14% (49/347) were caregivers or parents of children with DRE, and the remaining 56% (195/347) identified other self-reported reasons for attending a screening (Table 2). Forty percent (140/347) of all respondents identified interest in the ethics of technologies for the brain as a reason for attending a screening.

The majority of respondents (238/328, 73%) self-identified as white; 27% (90/328) as of another or mixed ethnic background.

TABLE 2 Self-identified characteristics of respondents.

Description	N	% of respondents to the question (N = 347)
Person interested in the ethics of technologies for the brain	140	40
Healthcare provider	103	30
Caregiver or parent of a child with drug resistant epilepsy	49	14
Advocate for people living with epilepsy	34	10
Researcher involved in epilepsy research	29	8
Advocate for people living with brain disorders	29	8
Advocate for people living with disabilities	28	8
Person with epilepsy	8	2
Sister or brother of a child with drug resistant epilepsy	6	2
Other (self-identified)	76	22

Of the respondents who indicated gender, 68% (236/346) identified as a woman and 31% (106/346) identified as a man; 1% (4/328) identified as other, trans, or non-binary. Most (359/385, 93%) respondents were English speaking; 7% (26/385) provided responses in French. Thirty-three percent (114/345) were under 30 years of age, 42% (146/345) were 31–50 years old, and 25% (85/345) were over 51 years old.

Thirty-three percent (120/369) of respondents viewed the film at a clinic or hospital, 28% (104/369) from their home location, 23% (85/369) at school, 13% (48/369) at a movie theater, and 3% (12/369) at a film festival.

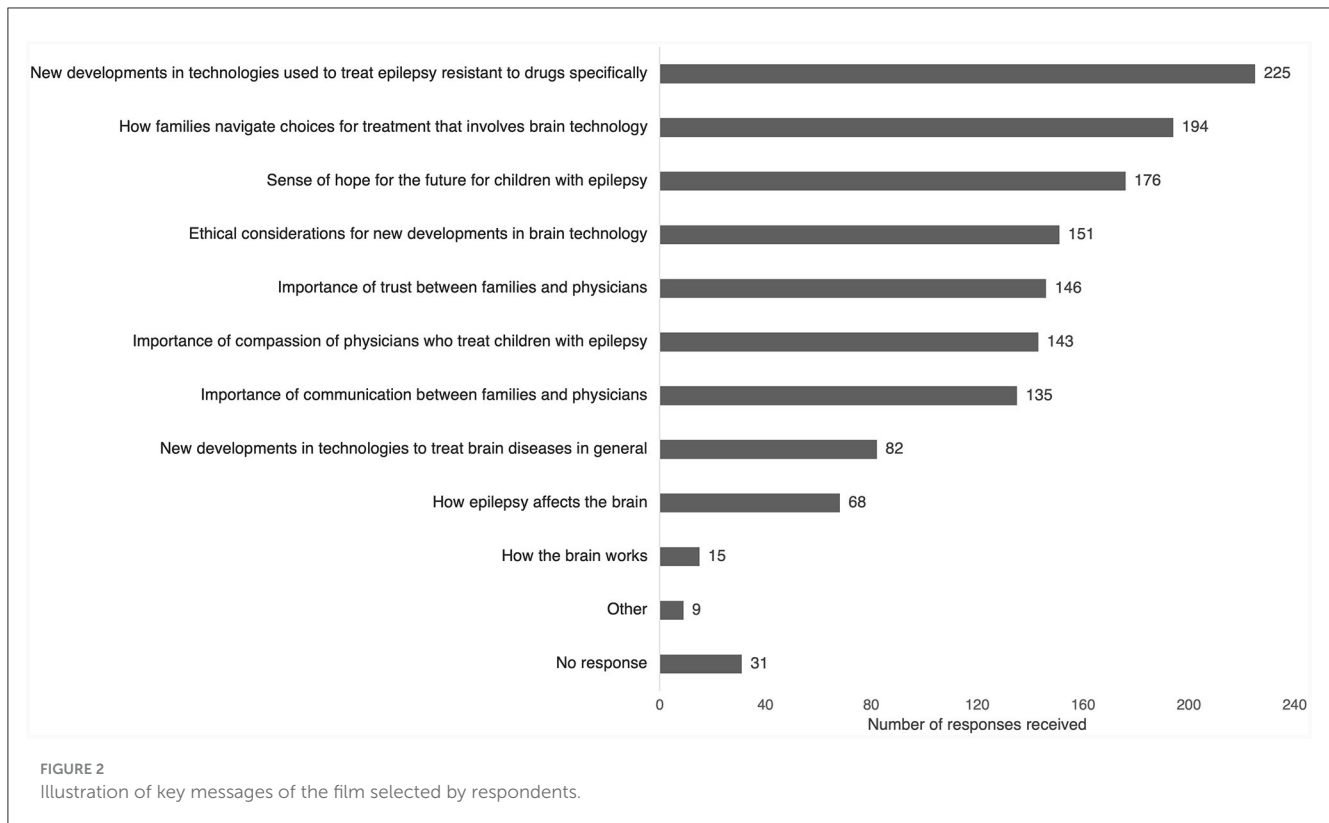
4.4.2 Receptivity

Eighty-seven percent (309/356) of respondents rated the film as either excellent ($n = 190$) or very good ($n = 119$). Ninety-four percent (333/356) of respondents indicated they would likely or definitely recommend the film to a family with a child affected by epilepsy, and 83% (294/356) to the general public (someone unaffected by epilepsy). After viewing the film, 88% (312/353) were motivated to learn more about technological treatments for epilepsy.

4.4.3 Key messages

The key messages of the film were generated from all survey respondents who responded to the question as determined by prevalence in the data (Figure 2).

Sixty-four percent (225/354) highlighted the ethics of new developments in technologies used to treat epilepsy that is resistant to drugs as a key message of the film:



“We need more awareness of treatment options for epilepsy. Many ethical concerns were brought up in the comments about performing surgery on children, but there are ethical concerns about not doing surgery, pumping a child full of drugs, and letting them seize uncontrollably. ...”

(Advocate for people living with epilepsy, woman, over 51 years old, USA)

More than half of respondents (194/354, 55%) identified how families navigate choices for treatment that involves brain technology as a key message:

“I really appreciated...what had happened in the lives of the family dealing with DRE. Trust is paramount. Understanding what we’ve all been through and continue to go through in pursuit of healing can only help practitioners move toward solutions.”

(Caregiver or parent of a child with DRE, woman, 31–50 years old, USA)

“... importance of involving the child in their own health care decisions”.

(Person interested in the ethics of technologies for the brain and other self-identified role, woman, under 30 years old, Canada)

“... very important to hear the perspective of patients and families, in order to fill the evident gaps in their needs, particularly in their medical care and access to resources.”

(Researcher involved in epilepsy research, woman, over 51 years old, USA)

A sense of hope for the future for children with epilepsy was the third most important take-away message (176/354, 50%):

“As a parent of a son with DRE, I can relate with the other parents and children featured in this video. This video would have been good to watch before our journey in preparation for our son’s resection. None of the content was new for us but would have given us HOPE [sic] when we really needed it 5 years ago. ... There is so much involved so this might give someone a better idea to what the journey might look like.”

(Caregiver or parent of a child with DRE, man, 31–50 years old, USA)

“The film ... truly brought hope where it had been lost.”

(Advocate for people living with epilepsy, woman, 31–50 years old, Canada)

“The film is very empowering, especially the comments from all 4 families and [sic] how physician-family/patient communication is so important.”

(Other self-identified role, woman, over 51 years old, Canada)

The most selected take-aways for respondents from screenings in Canada ($n = 218$) and the USA ($n = 106$) were undifferentiated from those selected by all survey respondents: new developments in technologies used to treat epilepsy resistant to drugs specifically; how families navigate choices for treatment involving brain technology; and, a sense of hope for the future for children with epilepsy. Similarly, there was no difference in the most selected take-aways by age. Respondents self-identifying as women (154/236, 65%) and men (63/106, 59%) selected the same key take-aways as respondents overall: 53% (124/236) of female respondents indicated a sense of hope for the future for children with epilepsy as the key third take-away from the film; 48% (51/106) of male respondents placed the importance of trust between families and physicians among the top three. We find similar feedback from caregivers. Healthcare providers additionally selected the importance of trust between families and physicians (51/103, 50%) among the top message list. A small number of respondents ($n = 8$) self-identified as being a person living with epilepsy. Their selected key take-aways were the same as healthcare providers, with the addition of how families navigate choices for treatment that involves brain technology, a sense of hope for the future, the importance of compassion from treating physicians, new developments in technologies, and how epilepsy affects the brain as equally important.

Respondents provided further open comments on themes in *Seizing Hope* that were beyond the scope of the survey questions. For example:

“... touches on multiple public health concepts and determinants of population health, such as access to care, geographic and economic disparities, cultural and other determinants of health. It could be a tremendous learning resources [sic] for public health programs ... [as] ... a great resource to facilitate larger discussions about public health ethics and health care development ...”

(Person interested in the ethics of technologies for the brain and other self-identified role, woman, 31–50 years old, Canada)

Fewer than 10% (29/356, 8%) of responses and comments were negative. Two percent (6/356) of respondents rated the film as fair or poor or would not recommend the film to a family with a child affected by epilepsy; seven percent (24/356) would probably or definitely not recommend the film to the general public. Representative comments were:

“... This seems like it was made by the device company rather than a team including experts in ethics.”

(Healthcare provider and other self-identified roles, woman, 31–50 years old, USA)

“[T]his video appears to be an infomercial selling investigative neuromodulation procedures. I suspect the families interviewed in the documentary may have had a positive experience doing it, but the choice of exclusively positive outcomes and positive views of neuromodulation presents a biased view at best.”

(Healthcare provider and other self-identified roles, man, 31–50 years old, USA)

“... what happens when the intervention addressed in the film is not successful ... [?]”

(Person interested in the ethics of technologies for the brain, woman, under 30 years old, USA)

“... what would happen if the technology fails?”

(Person interested in the ethics of technologies for the brain, woman, under 30 years old, Canada)

5 Discussion

We co-created a short-form health documentary film with families and physicians focused on the ethics of neurotechnology of DRE and priorities and values for decision-making in the care of affected youth. Findings from post-screening surveys emphasized the importance of communication about new developments in technologies for the treatment of DRE, how families navigate choices for treatment with brain technology, and a sense of hope for the future. In further response to the feedback received, we created a second communication product – *Advancements in Neurotech for Kids with Epilepsy* (<https://www.youtube.com/watch?v=BBMMDacHuegandt=1s>). Unlike *Seizing Hope* that is intended for viewing in private, schools, or clinic waiting rooms, *Advancements in Neurotech*, at <5 min in duration, is intended for shared real-time viewing with physicians and families during clinical encounters. To date, there have been over 1,000 private viewings of *Seizing Hope* since its public release in May 2023. *Advancements in Neurotech*, released in September 2023, has received 237 views as of February 2, 2024.

We endeavored to deliver a product that was free of bias, conflict, or commercial interests. Nonetheless, some viewers responded that the film appeared to be a marketing tool or was too emotional to be truthful. We accept these concerns at face value. We also acknowledge that only girls with DRE were featured in the film and that their stories were at least somewhat positive. The incidence of DRE across genders is approximately 50%–50% (Medel-Matus et al., 2022). No families whose experience with neurotechnology was unsuccessful agreed to be filmed. We report findings descriptively only so as not to overstate or over interpret them. No statistics were applied as no hypotheses were tested. Comparisons for countries beyond North America were not possible given the limited number of responses from them.

The findings suggest that *Seizing Hope* met the scientific and educational communication goals about ethical choices for

neuromodulation and DRE. Supported by infographics, and screening and press kits, *Seizing Hope* was responsive to and featured the full range of expert voices in the DRE journey. It can be shown in an academic health context with panel discussions, in the clinic, or stand-alone for private viewing. We honor the families who shared their experiences and stories for the benefit of others on a similar medical, technological, and ethical navigation path for DRE.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by the University of British Columbia # H18-02783. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

JJ: Conceptualization, Data curation, Funding acquisition, Investigation, Methodology, Resources, Supervision, Visualization, Writing – original draft, Writing – review & editing, Formal analysis, Project administration, Validation. PJM: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing – review & editing. GM: Writing – review & editing, Conceptualization, Methodology. MBC: Conceptualization, Methodology, Writing – review & editing. RN: Conceptualization, Methodology, Writing – review & editing. MB: Methodology, Project administration, Writing – review & editing. AN: Formal analysis, Visualization, Writing – review & editing. SPG: Formal analysis, Writing – original draft, Writing – review & editing, Visualization. JR:

Conceptualization, Software, Writing – original draft, Writing – review & editing.

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Conflict of interest

JR is employed by the Conexkt Innovation Studio.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

- Alam, A., Parfyonov, M., Huang, C. Y., Gill, I., Connolly, M. B., Illes, J., et al. (2022). Targeted whole exome sequencing in children with early-onset epilepsy: parent experiences. *J. Child Neurol.* 37, 840–850. doi: 10.1177/08830738221113901
- Apantaku, G., Aguiar, M., Kaal, K. J., McDonald, P. J., Connolly, M. B., Hrinco, V., et al. (2022a). Understanding attributes that influence physician and caregiver decisions about neurotechnology for pediatric drug-resistant epilepsy: a formative qualitative study to support the development of a discrete choice experiment. *Patient* 15, 219–232. doi: 10.1007/s40271-021-00544-w
- Apantaku, G., McDonald, P. J., Aguiar, M., Cabrera, L. Y., Chiong, W., Connolly, M. B., et al. (2022b). Clinician preferences for neurotechnologies in pediatric drug-resistant epilepsy: a discrete choice experiment. *Epilepsia* 63, 2338–2349. doi: 10.1111/epi.17328
- Bevan, B., Calabrese Barton, A., and Garibay, C. (2020). Broadening perspectives on broadening participation: professional learning tools for more expansive and equitable science communication. *Front. Commun.* 5, 52. doi: 10.3389/fcomm.2020.00052
- Brownell, S. E., Price, J. V., and Steinman, L. (2013). Science communication to the general public: why we need to teach undergraduate and graduate students this skill as part of their formal scientific training. *J. Undergrad. Neurosci. Educ.* 12, E6–E10.
- Canfield, K. N., Menezes, S., Matsuda, S. B., Moore, A., Mosley Austin, A. N., Dewsbury, B. M., et al. (2020). Science communication demands a critical approach that centers inclusion, equity, and intersectionality. *Front. Commun.* 5, 2. doi: 10.3389/fcomm.2020.00002
- Das, J., Forlini, C., Porcello, D. M., Rommelfanger, K. S., and Salles, A. (2022). Neuroscience is ready for neuroethics engagement. *Front. Commun.* 7, 909964. doi: 10.3389/fcomm.2022.909964

- Harding, L., and Illes, J. (2021). RE: Canadian assessment of deep brain stimulation access: the Canada study. *Can. J. Neurol. Sci.* 48, 130–131. doi: 10.1017/cjn.2020.151
- Harding, L., McFarlane, J., Honey, C. R., McDonald, P. J., and Illes, J. (2023). Mapping the landscape of equitable access to advanced neurotechnologies in Canada. *Can. J. Neurol. Sci.* 50, s17–s25. doi: 10.1017/cjn.2023.18
- Hrincu, V., McDonald, P. J., Connolly, M. B., Harrison, M. J., Ibrahim, G. M., Naftel, R. P., et al. (2021). Choice and trade-offs: parent decision making for neurotechnologies for pediatric drug-resistant epilepsy. *J. Child Neurol.* 36, 943–949. doi: 10.1177/08830738211015010
- Humm, C., and Schrögel, P. (2020). Science for all? Practical recommendations on reaching underserved audiences. *Front. Commun.* 5, 42. doi: 10.3389/fcomm.2020.00042
- Illes, J., Blakemore, C., Hansson, M., Hensch, T., Leshner, A., Maestre, G., et al. (2005). International perspectives on engaging the public in neuroscience. *Nat. Rev. Neurosci.* 6, 977–982. doi: 10.1038/nrn1808
- Illes, J., Lawson, A., and McDonald, P. J. (2022). Ethical considerations for discrete choice experiments with caregivers. *J. Empir. Res. Hum. Res. Ethics* 17, 426–430. doi: 10.1177/15562646221112339
- Illes, J., Moser, M. A., McCormick, J. B., Racine, E., Blakeslee, S., Caplan, A., et al. (2010). Neurotalk: Improving the communication of neuroscience research. *Nat. Rev. Neurosci.* 11, 61–69. doi: 10.1038/nrn2773
- Kalmár, É., and Stenfert, H. (2020). Science communication as a design challenge in transdisciplinary collaborations. *J. Sci. Commun.* 19, C01. doi: 10.22323/2.19040301
- McDonald, P. J., Hrincu, V., Connolly, M. B., Harrison, M. J., Ibrahim, G. M., Naftel, R. P., et al. (2021). Novel neurotechnological interventions for pediatric drug-resistant epilepsy: Physician perspectives. *J. Child Neurol.* 36, 222–229. doi: 10.1177/0883073820966935
- Medel-Matus, J. S., Orozco-Suárez, S., and Escalante, R. G. (2022). Factors not considered in the study of drug-resistant epilepsy: Psychiatric comorbidities, age, and gender. *Epilepsia Open* 5, S81–S93. doi: 10.1002/epi4.12576
- National Academies of Sciences, Engineering, and Medicine. (2017). *Communicating Science Effectively: A Research Agenda*. Washington, DC: National Academies of Sciences, Engineering, and Medicine.
- Nuechterlein, A., Boyle, Q., and Illes, J. (in press). “Reimagining expertise and neutrality toward epistemic justice in research, clinical translation, and policy: a perspective from neuroethics,” in *Overcoming the Myth of Neutrality: Expertise for a New World*, ed. A. Lavazza (Oxfordshire: Routledge Press).
- Racine, E., Waldman, S., Rosenberg, J., and Illes, J. (2010). Contemporary neuroscience in the media. *Soc. Sci. Med.* 71, 725–733. doi: 10.1016/j.socscimed.2010.05.017
- Udwadia, F. R., McDonald, P. J., Connolly, M. B., Hrincu, V., and Illes, J. (2021). Youth weigh in: views on advanced neurotechnology for drug-resistant epilepsy. *J. Child Neurol.* 36, 128–132. doi: 10.1177/0883073820957810