Taking the measure of knowledge translation capacity within NeuroDevNet: A baseline environmental scan
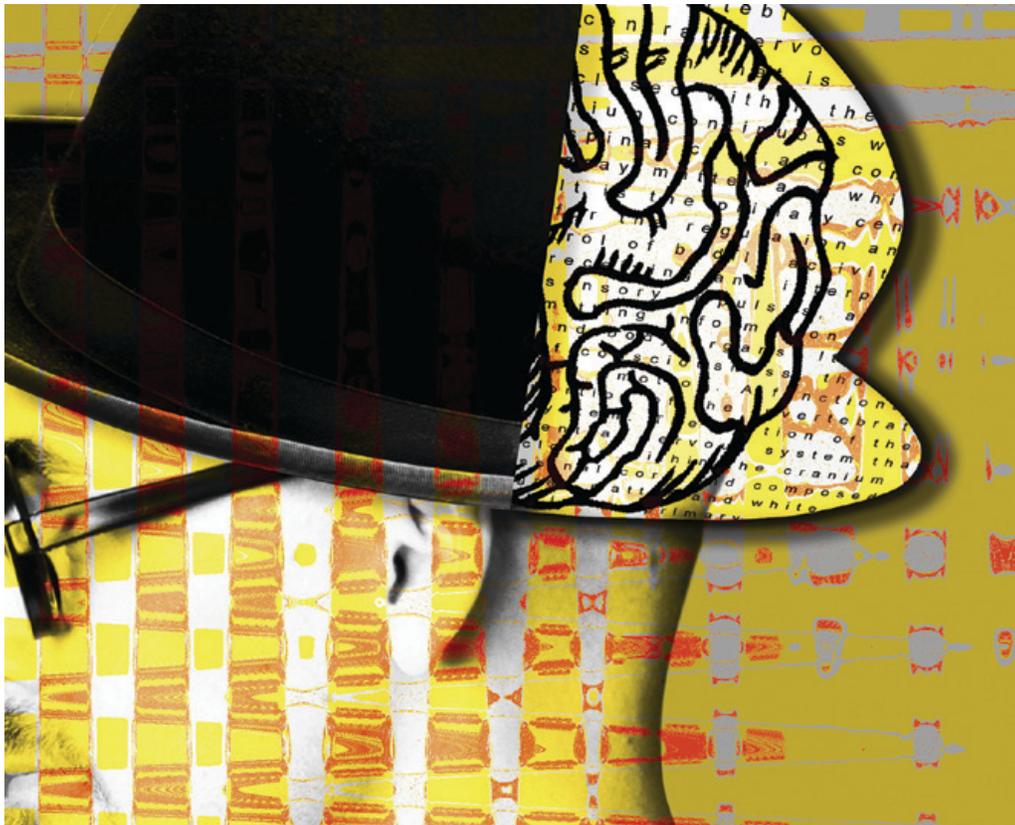
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NeuroDevNet Knowledge Translation Core

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"Between the health care we have and the care we could have lies not just a gap, but a chasm"

Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century

Acknowledgments

We would like to express our gratitude to the NeuroDevNet members for the time they spent responding to the surveys and interviews which are an integral part of this report. They provided significant information that will be of great value to the Knowledge Translation Core moving forward.

Thank you to Marianne Chomiak for her editing skills, and to Tim Gottschick of Basic Elements Design for the design and production of the final document.

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Report Highlights

- Report combines the results of an online survey and in-depth interviews.

- Members are engaged in a variety of KT activities with the most common being knowledge dissemination via conferences and peer-reviewed publications.

- Members' KT challenges cover a spectrum of KT gaps from getting basic science research into clinical trials, clinical research into clinical practice, and informing families of the results of research.

- The audience for members' KT activities are primarily other researchers, however all groups—clinicians, families, public and private corporations—are considered potential audiences.

- Members want opportunities to come together as a network including creating partnerships across projects and cores and identifying common goals and fostering linkages.

- Members ranked highly the activities of fostering of partnerships to advance research and fostering intellectual discourse and knowledge dissemination.

- The creation of a web-based interface for interactions with patients, families, and the public was seen as a mandate for NeuroDevNet.

- Members are interested in the development of best practices and dissemination strategies to improve uptake of evidence.

- Integrated KT is controversial but some members are already engaged in some facets of integrated KT.

- There is an expressed need to have venues that include family perspectives and encourage respectful listening.

- Funded research projects should include a KT component.

- Understanding barriers to knowledge translation was seen as an important skill to develop.

- Some members do not necessarily want to be trained in KT or do plain-language writing, but would rather focus on their research.

- There is interest in knowledge syntheses but some resistance to Cochrane reviews.

- Members have a low level of engagement in social media.

- There is interest in web-based delivery of workshops and seminars.

- The KT Core has developed a list of strategies and activities arising out of the interviews.

Executive Summary

This report combines both the results of an online survey completed by 38 NeuroDevNet members and 14 in-depth interviews (with a subset of these being members who completed the online survey). Respondents represent a cross-section of members, and include clinicians, principal investigators, research scientists, and KT leaders in the various NeuroDevNet projects.

The interviews extend the results of the online survey, which provided baseline data on KT activities of our members and areas for skill development and capacity building. Results of the online survey were also reported in the journal *Seminars in Pediatric Neurology,* Special Issue on NeuroDevNet.[1]

The KT environmental scan provides a rich source of information to assist the KT Core in determining members' desired KT skills, prioritizing strategies for future activities, and identifying services and capacity building needs. The results were analyzed thematically and four themes were identified: 1) experiences and challenges in KT; 2) linkages and partnerships; 3) strategic priorities; and 4) building capacity.

The most frequent means of dissemination that members reported using were publications in peer-reviewed journals and presentations at conferences. Members reported that they are interested in expanding their skills beyond traditional KT methods to include forming partnerships with families through public forums, learning about some integrated research activities, respectful listening, interactive web-based interfaces, and fact sheets. As well, members want other scientists and particularly clinicians included in their KT activities by understanding the barriers to implementing basic science into clinical trials and clinical research into clinical practice.

Further, they recognize the importance of the NeuroDevNet network as a vehicle for expanding their reach, contacts, and initiating new research activities, collaborations, and commercialization. Ongoing communications, dialogue, webinars, and in-person meetings were all seen as means to increase the network-ness of the network, creating the NeuroDevNet community, and as a means for skill development.

A few reservations and controversies were expressed around integrated KT, public engagement, and compiling knowledge syntheses and systematic reviews. The importance of creativity, scientific integrity, and serendipity with regard to research activities suggest that our members do not want to be guided solely by users of research when conducting their research. Also the importance of inclusivity and hearing all voices around issues and not just those of dominant groups and organizations is an important concern in community engagement. Finally, some members were keen on the ability of the KT core to assist with systematic reviews, whereas others were more inclined towards syntheses in the form of best practices, guidelines, and other review methodologies such as scoping reviews.

Results of the environmental scan are now enabling the KT core to develop a catalogue of services, to plan workshops, webinars, and targeted skill development activities for its members, as well as to develop strategic plans for KT over the life of the network. A summary of services, strategies, and activities identified from the interviews is provided at the end of the report.

Background and Introduction

There is little doubt that we are in the midst of profound changes in health research, characterized by the convergence of ideas and blurring of boundaries of all types whether between disciplines and institutions, or between scientists and the public; additionally, these transformations are occurring at unprecedented speeds. Examples of transformative changes abound; in health research these include the Human Genome Project, Proteomics, Synchrotron technology, Nanotechnology, and Biopharmaceuticals, and on a different scale, prediction, control, and treatment of emerging pandemics.

In this new world, the manner in which knowledge is produced, transferred, and taken up by users, and the application of knowledge for immediate benefit is a fundamentally important responsibility placed on the shoulders of scientists and knowledge users alike. This focus on knowledge translation (KT) highlights an important feature of new health research: the interface between knowledge creation/technology application and public and private use of these innovations for the common good of the child.

> The Canadian Institutes of Health Research, Canada's major health funder, defines knowledge translation as "the exchange, synthesis and ethically-sound application of knowledge—within a complex system of interactions among researchers and users—to accelerate the capture of the benefits of research for Canadians".

The Canadian Institutes of Health Research, Canada's major health funder, defines knowledge translation as "the exchange, synthesis and ethically-sound application of knowledge—within a complex system of interactions among researchers and users—to accelerate the capture of the benefits of research for Canadians"[2]; currently, both interest levels as well as efforts to improve knowledge implementation are widespread in the health research community.[3]

Knowledge Translation at NeuroDevNet, a new Canadian Network of Centres of Excellence focused on brain development, is a core service that spans the three demonstration projects, which are research programs in cerebral palsy, autism spectrum disorder, and fetal alcohol spectrum disorder (described in detail elsewhere in this issue). KT is also integrated as a network-wide activity.

NeuroDevNet's KT Core is led by Dr. Nazeem Muhajarine, a social epidemiologist at the University of Saskatchewan who leads a population health research program that conducts collaborative research with decisionmakers on early childhood health and development. His team has been widely acknowledged for their KT work and development of policy- and practice-relevant research, and he has been honoured with a knowledge translation award from the Canadian Institutes of Health Research in 2006, and the Saskatchewan Health Research Foundation's Achievement Award in 2009.

NeuroDevNet's KT team consists of a KT Manager, a Communications and KT Co-ordinator, KT Coordinators from the three demonstration projects, and eventually, graduate students supported by KT training funds. Muhajarine's KT Manager from his own research program has also been involved with NeuroDevNet since the grant writing phase, earlier acting as KT Manager and currently providing ongoing guidance.

There are three guiding principles that govern KT at NeuroDevNet:

• KT needs to be conducted on a Network-wide level, as well as on a project level.

• KT is more than the responsibility of any one group or set of people; it needs to be integrated with the research taking place across NeuroDevNet, and considered to be "part of the 'real' work of research, not a superfluous add-on". [4]

• Successful KT is all about relationships. (p. 146).[3] It is the intent of the KT Core to support demonstration projects in their KT activities to strengthen capacity at the local level, and to support projects who have established relationships with key stakeholders.

Establishing the Knowledge Translation Core

KT at NeuroDevNet is focused on providing services to NeuroDevNet members. In the initial core platform proposal, we identified three priorities:

1. Conduct an environmental scan to identify KT needs and build on KT capacity within the three demonstration projects.

2. Create and share synthesis documents of current knowledge and best practices in KT.

3. Identify and share new knowledge from demonstration projects with key stakeholder groups.

The first step in establishing the KT Core was organizing a session on planning for effective knowledge translation in research at NeuroDevNet's inaugural annual general meeting, held in Montreal in June 2010. This presentation was given by Dr. Melanie Barwick, an Associate Scientist and Scientific Director of Knowledge Translation at SickKids Learning Institute in Toronto; it is available at: **http://www.neurodevnet.ca/research/kt/tools.** This presentation helped to highlight the importance of KT to NeuroDevNet, and provided some practical tools for conducting it.

The next step was to develop a work plan and logic model as a way to move forward within this specialized and geographically widespread network. The intent of the work plan was to assist in developing the survey for the environmental scan, as well as to determine some "quick wins"—KT activities that would add immediate value for our members. Most of the KT Team met in Saskatoon for several days shortly after the inaugural annual meeting to develop this work plan, which included the activities identified in the initial core platform proposal as well as development of an interactive website for consumers, a key priority identified at our annual meeting.

Setting Knowledge Translation Priorities for the first two years

Priorities that were identified in the initial work plan, which covers the first half of NeuroDevNet's five-year funding period, include:

1. Creating a web-based consumer information website and discussion forum

2. Conducting an environmental scan of KT activities already taking place
   (through an online survey and key informant interviews)

3. Creating a tracking system for communication/KT activities

4. Implementing knowledge syntheses (based on topics to be identified through consensus)

5. Developing a NeuroDevNet newsletter (to be published five times per year)

> ...the environmental scan is a key component for informing
> the activities of the KT Core and for identifying needed services for
> NeuroDevNet members...

Although it is listed as the second priority, the environmental scan is a key component for informing the activities of the KT Core and for identifying needed services for NeuroDevNet members, and as such was addressed first. The environmental scan consisted of two parts: an online survey geared toward identifying baseline KT activities that are already being done by our members, as well as their training and capacity building needs, and key informant interviews with NeuroDevNet members including the principal investigators and other scientists working on the demonstration projects. These interviews were intended to build and expand on the responses provided in the online survey.

This report summarizes the results of the KT Core environmental scan which consisted of an online survey (N=38 responses) and in-depth interviews (N=14). About 30% of NeuroDevNet members responded to the online survey, and 14 in-depth interviews were conducted; some preliminary findings from both are discussed below. The focus of this report will be to highlight the results of the interviews. Interviewees represented a cross-section of NeuroDevNet's members and included clinicians, principal investigators, research scientists, and KT leaders in the projects. The total response rate between the survey and the interview represents 31% of NeuroDevNet members.

Online Survey

> The online survey provided baseline data on the KT activities of our members as well as areas for skill development, capacity building, and direction for the interview questions.

Results of the survey are also reported in the journal *Seminars in Pediatric Neurology,* Special Issue on NeuroDevNet.[1]

The online survey was created in-house. Questions were culled from samples of other environmental KT scans in the public domain, and also developed from information needs identified by the KT core. The survey was created and hosted on the University of Saskatchewan's customized Web Survey tool, and a link to it was sent to NeuroDevNet members. The survey was initially piloted with the Principal Investigators and their feedback was reflected in a revised version. All responses collected through the survey were anonymous; however, respondents were able to provide us with their name and email addresses if they agreed to be interviewed.

Of those who responded to the survey, 51% were female, 50% were in the 50-64-year age range, 36% in the 35-49-year age range, 8% in the 20-34-year age range, and 6% identified themselves as 65+ years.

A range of affiliations were identified, with respondents categorizing themselves into one or more areas within NeuroDevNet. Overall representation was broad, covering the three demonstration projects and some research specialties (Figure 1).
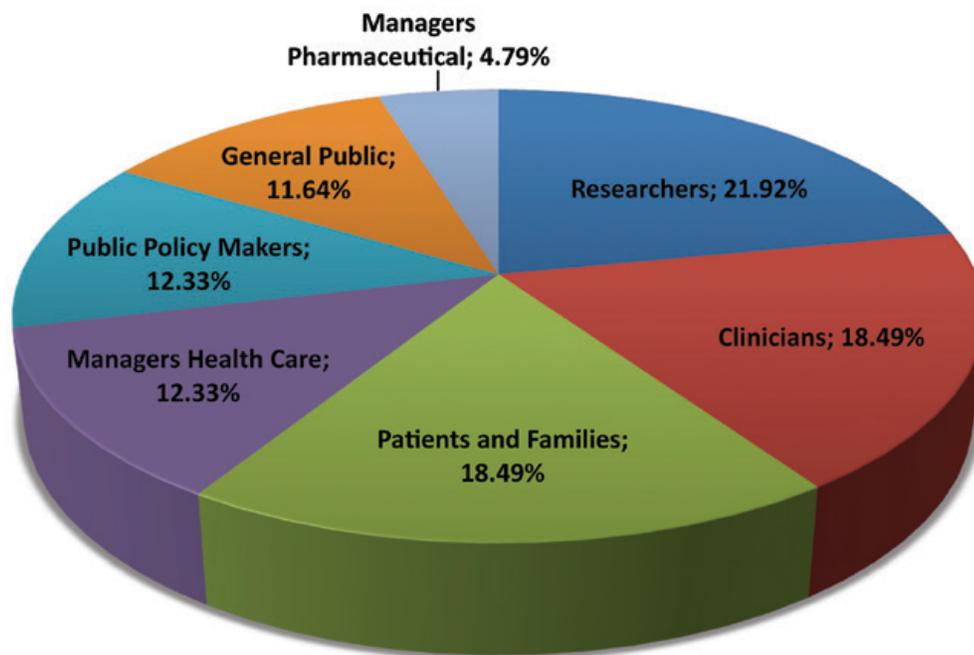
Figure 1: Affiliations of those who responded to the online survey

Interviews

Fourteen interviews were conducted and include responses to 8 questions (in Appendix 1) that were developed from the results of the online survey. These questions were intended to add depth to the survey and to address some issues that were not in the survey. Interview times ranged from 22 min. to 72 min. with the average interview lasting 45 min. Interviews were conducted from September 2010 to November 2010, in-person or by telephone. Interviews were recorded, transcribed, and analyzed in NVivo. All respondents provided consent and agreed to let the KT core use the information they provided to assist in developing services and strategic directions. This report provides a thematic analysis of the responses to the survey and interview questions.

Results

The results of the survey and interview questions are described in detail in this section, and categorized into four themes: Experiences and Challenges in KT, Linkages and Partnerships, Strategic Priorities for KT, and Building Capacity. A fifth topic, Technology Use for KT, is also discussed.

Theme 1: Experiences and Challenges in KT

Our members are involved in delivering a variety of KT activities to families, clinicians, media, and other researchers. Some KT activities that members are active in include: practice guideline development, evidence-based summaries of research trials, lay summaries of clinical research projects, and conducting meetings and workshops for the public.

From survey results, activities with a high frequency of engagement included: conducting research development activities such as grant applications with 91% engaging in this activity from 2-12 times per year; similar frequencies per year and high percentages of engagement were seen for the following activities: maintaining own website (89% of respondents); providing copies of articles and/or reports (89%); improving professional practice through professional associations (81%); providing brief summaries (such as an abstract) of articles, reports or systematic reviews (77%).

Not surprisingly, the activity from the survey with the highest rating was "attending talks given at conferences/seminars or lectures" with 81% of respondents indicating that they engage in this activity at least once every two months or more frequently.

> "…as far as I'm concerned, publishing a paper or going to a conference and presenting it is knowledge transfer. So what I've been doing for the last 15 years or however long I've been on staff here [is] now what's become the special thing."

This comment highlights the fact that these routine methods of knowledge dissemination, primarily to other researchers, are now considered KT activities.

There is nevertheless an awareness of the shortcomings of these methods of disseminating research findings in that they may not lead to implementation or result in practice change. In KT there are two known gaps in research: one gap is between research in basic science and clinical research, and the second gap exists in the translation of clinical research to changes in practice and policy and ultimately resulting in healthier populations.

The know-do gap between publication of research findings and their implementation into practice is echoed in this respondent's personal experience with knowledge dissemination, revealing a keen awareness of the need to include another level that targets and tailors messages for different audiences:

> "…I remember 20 years ago doing studies that I thought were brilliant… then being irritated with doing excellent randomised trials and then being invited around the world to talk about these trials and then coming back home and seeing that indeed the knowledge that we had created was not being applied… it took me considerable time to understand that… you may pursue something just for its own interest but if you want to change things you'd better think about receptors as well… the receptor organizations, receptor knowledge base, the receptor anything."

Respondents mentioned a variety of challenges in doing KT. For instance, one respondent mentioned engaging in knowledge dissemination activities to both families and the media and commented that "speaking directly to groups is more positive than communication with media". Some spoke to the difficulty of communicating the results of clinical research in a timely and relevant manner to families due to the time it takes to do clinical trials: "By the time you get the piece of paper ready to send out to families it sometimes has been a few years since they participated in the study". Nevertheless, it was seen as an opportunity to conduct some "end-of-project KT" where the researcher develops and implements a plan to make users aware of research results.

> "Almost all of our studies are health services with kids and families, and we will send it to every family that is involved and we will send it to every kid that's involved. 'Remember that study that you and your family were involved in three years ago... here is what we found, here's what we think it means for kids and families... here's what it means for front-line service providers, here's what it means for program managers, here is what it means for policy...'"

> "And what we're planning to do when we finish the study and we have our results is to do focus groups with different stakeholders who might be interested in the results and ask them, well how do you think we should be using these results?"

Another challenge that one person mentioned was the difficulty in engaging families due to the challenge of determining whether or not they are providing the information the family wants to hear. This person thought it was easier to do KT with clinicians. An ongoing challenge lies in getting clinicians to implement new interventions into practice versus simply disseminating information to them.

> An ongoing challenge lies in getting clinicians to implement new interventions into practice versus simply disseminating information to them.

One respondent spoke to a situation where community clinicians refused to implement a test due to lack of services and long waiting times for referrals. Identifying barriers to uptake is a well-recognized KT challenge in trying to implement research findings into clinical practice or to effect practice change, as one person stated about their efforts to pilot a project:

> "...I agree completely with money but I almost feel like there is a resistance, it's like there is something about the value added that we have not convinced people about... So there is something about telling people what to do that we have to handle differently, it was not that the data wasn't there, it wasn't that we were asking for an enormous task, it's a 6 months commitment thing, but they had their own strong views and they didn't agree and that was it."

It is an ongoing challenge that KT needs to address by using tools, identifying strategies, and inviting experts to help our members understand barriers to change.

One respondent commented on the challenge in terms of the level or lack of public interest in translating basic science research. However, it was suggested that any research that engages patients and families should have the results published on the website. This echoes the above comments around end-of-project KT and getting the message out to patient, family, and clinician stakeholders:

> "I don't know whether anybody besides other researchers cares about the level of monoamine inhibitors in a rat brain, it's not that that's not important but that's not something that's likely to be on a website... but I think that there should be and this could be a policy issue within NeuroDevNet that any project that NeuroDevNet is involved with that involves children and/or families or at least involves human subjects that there is an expectation that there be a 2- or 3-page plain language annual report that is sent to everybody on a study and it's... posted on the website."

However, some mentioned that an important knowledge translation effort would include helping families and clinicians to understand the importance of basic science research that eventually informs the conduct of clinical trials and new discoveries.

> ...an important knowledge translation effort would include helping families and clinicians to understand the importance of basic science research that eventually informs the conduct of clinical trials and new discoveries.

Finally, some respondents spoke in general to the challenge of doing KT and that it is not a role that they wish to engage in and that it should be the role of specialists in KT:

> "Okay, so my experience with knowledge translation has started with the recognition that I'm not the best person to initiate it, so I try to work with people who are good at knowledge translation."

Theme 2: Linkages and Partnerships

Respondents to the survey indicated their audience for KT activities; although categories were not mutually exclusive, most still indicated that 'other researchers' were their primary audience (89%). This category was followed by clinicians and patient groups and families (each 75%). Other audiences identified were public policy makers (53%), managers in health care institutions (50%), and the general public (47%). Only 19% of members listed managers in pharmaceutical and other biotechnology companies as an audience for their KT activities.
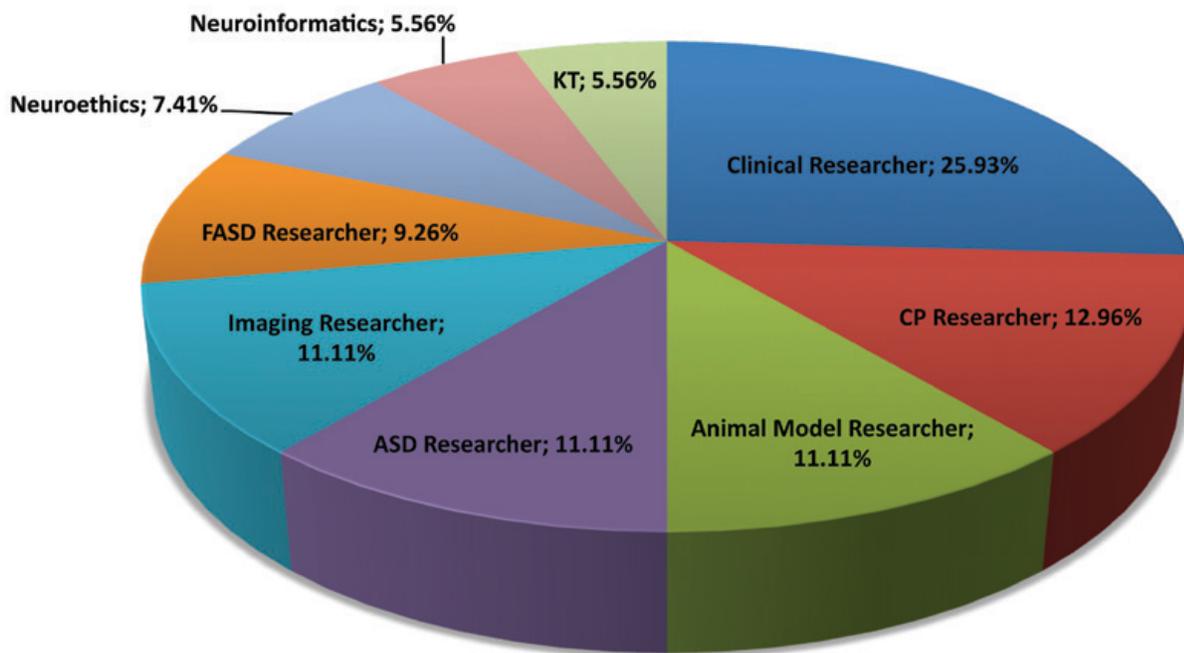
Figure 2: Audience for KT Activities

> Respondents described the need to establish a variety of linkages and partnerships both within and external to NeuroDevNet.

Respondents described the need to establish a variety of linkages and partnerships both within and external to NeuroDevNet. Some of these included the need to sustain and improve the internal connections within the network, as well as external linkages with other researchers outside of NeuroDevNet. Partnership development with families, advocacy groups, clinicians, and decision makers was also recognized as important. A couple of members also spoke to the need for commercialization partnerships.

Respondents commented on the importance of communications and opportunities to meet within NeuroDevNet to foster linkages and connections in order to establish and maintain the network; and the importance of the annual meeting as a venue for knowledge exchange and interaction between the presenters and the audience.

> "I do think having a common set of goals and making sure that there is some link that can be articulated between what the cores are doing and what the projects are doing,... otherwise we become colleagues that are each doing our own thing."

> "I think it's a process... I think that there needs to be ongoing dialogue between the projects and the cores in general."

Also, the importance of the network in establishing connections amongst researchers across Canada is highlighted by this comment:

> "I don't have good connections in British Columbia actually. So I think that's one of the strengths of NeuroDevNet... there may be opportunities... we've done very well in Ontario and the East coast in our project, we've got major nodes in every city..."

Finally, because NeuroDevNet is newly launched, comments were made around identifying roles and relations within the Network, including identifying expertise and common interests that may already exist but are unknown to members:

> "The projects are still trying to figure out what our roles are and how we kind of fit into the network so I think we just need to keep talking about it."

> "There may be Bob over here who is really interested in this kind of issue but Bob doesn't have those links, but Mary does... and if Bob knew that Mary had those links then maybe Bob and Mary could work together to make use of those links... I think it's so challenging to communicate this to each other."

Establishing community relations is seen as an essential role for NeuroDevNet.

Establishing community relations is seen as an essential role for NeuroDevNet. There were several comments about the need to engage families and non-profit stakeholders. As well, clinicians were also considered an important group to reach, and included in greater numbers than we currently have in the NeuroDevNet community:

> "I think community engagement includes the parents' advocacy community, I also think community engagement includes clinicians, and you probably appreciate they are a huge missing piece here."

Some comments were made around activities for community engagement including holding public forums, developing factsheets, participation on the Board, as well as public podcasts or webinars and CIHR café scientifique types of activities:

> "…annual meetings, holding public forums can sensitize the scientific community to the knowledge user's needs and priorities."

> "…is actually getting family representatives into our boards, into our research boards and whether that's something we can think about for NeuroDevNet."

One of our members spoke to being very active in community engagement in order to showcase their research or research findings, but indicated that requests to present and speak at smaller public venues were becoming too demanding. The thought was that doing higher profile events that reach a broader audience are a better return on the time investment and identifying these opportunities could be a role for KT:

> "…it was an 18-minute show but it reached I don't know how many million viewers. So getting the message to the most people… we were in the media, we were on the cover, we were in the CBC National… the impact is broad so getting the right person on the right shows… where we can have broader impact as opposed to going to talk to 20 high school students where only 10 of them show up… So if you can work to identify those types of venues that would really be wonderful."

At the same time, respondents were cautious around public engagement and reminded us to be conscious of whose interests we are serving:

> "I think that it would be important to continue to try to reach out to stakeholders in the community around the types of projects that are being examined. That's sometimes a little bit tricky to do, there are some risks to doing that as well… because sometimes interest groups may try to push one agenda…"

There was also concern expressed about the difficulty of trying to bring families in at the national level, so the family forums where families could express their needs, opinions, and issues are important venues for including the family perspective. While inviting families to participate in webinars was suggested, there was also concern that their participation would inhibit conversations.

> While inviting families to participate in webinars was suggested, there was also concern that their participation would inhibit conversations.

A few comments were made around including decisionmakers (that is, policymakers and administrators in provincial and federal governments) as part of community engagement and to take advantage of internal connections that members of NeuroDevNet may have with decisionmakers. The importance of engaging families in order to get the attention of decisionmakers was not lost on one respondent and closes the circle of public engagement by recognizing that families also influence decisionmakers, and in fact may be more credible in the eyes of decisionmakers than scientists.

> "…it would be interesting to know what existing relationships people have with decision-makers of various sorts because I think building on those platforms…"

> "If you want the politicians to listen to you then the public is a much better way to the politicians' heart than are scientists… Scientists are seen very much as a special interest group. They are interested in more money for their project…"

Theme 3: Strategic Priorities for KT

Our online survey listed 16 KT activities that we asked our members to prioritize as "high", "medium", or "low", in relation to their relevance to their work with NeuroDevNet.

The KT priorities that ranked the highest were to "foster partnerships to advance research" (81% high and 18% medium priority). Related to this item, and ranking second in priority was to "foster intellectual discourse and knowledge dissemination" (78% high and 19% medium). As one thoughtful respondent commented:

> "Much of the KT language is [unclear] on how we would do this, so I guess that's why I'm attracted to the intellectual discourse… [as it] emphasizes some effort to engage with a public interest standard about who the user is or should be, and in whose interests we transfer what knowledge, to what ends."

Related to this was having a discourse on useful KT, where early findings may not yet be amenable to knowledge translation, or the relevance of the findings still needs to be determined, and that poorly conducted research should not be translated. This speaks to the need to translate research that has met a test for validity, reliability, and relevance.

> …need to translate research that has met a test for validity, reliability, and relevance.

As is widely acknowledged, relationship-building is integral to working effectively with decisionmakers. That said, researchers cannot compromise the strength and relevance of the research they conduct to appease decisionmakers; research needs to be both highly valid and highly policy-relevant to have the best chance of improving policy and practice (Martens & Roos, 2005). In their 2005 article on interactions between health services researchers and decisionmakers, Martens and Roos created a very useful grid of researcher/user involvement and its relationship to influences on policy and practice, which we have reproduced below with permission.
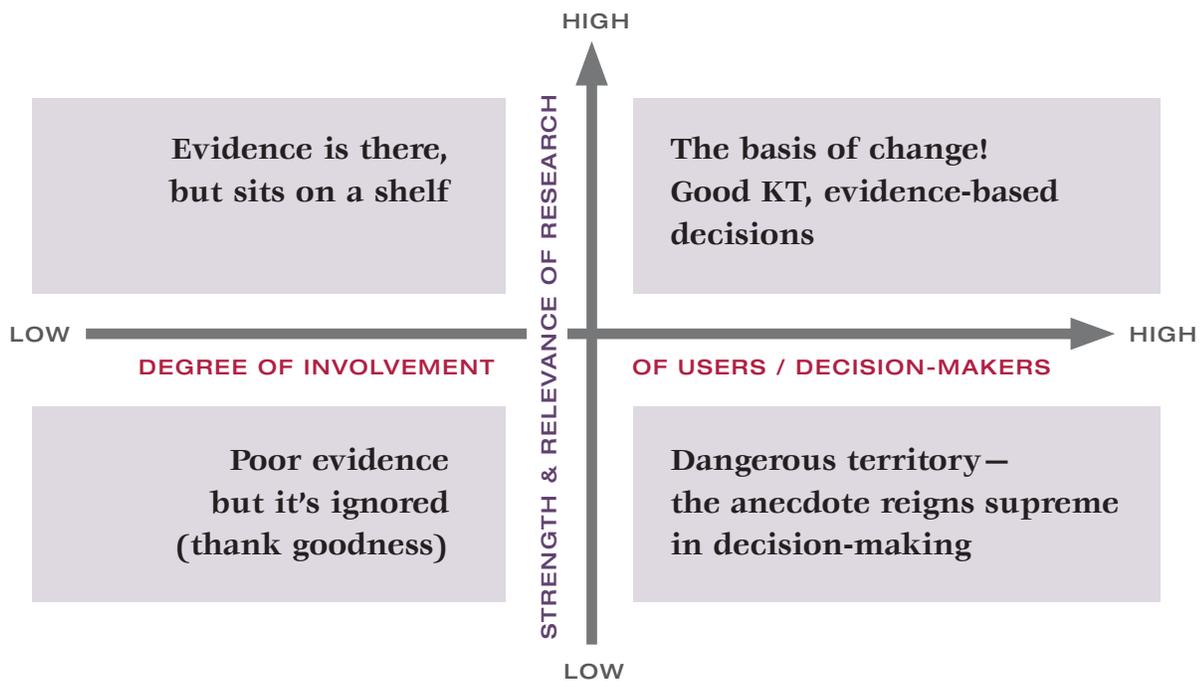
Figure 3: Martens and Roos' Hypothesized Grid

They describe the grid thus:

"In the south-west quadrant, low user involvement and poor research design results in research that will probably be ignored. The most dangerous quadrant is likely the south-east, where the anecdote reigns supreme. There may be a high degree of user involvement but a low degree of research validity. An example of this situation is anecdotal 'evidence' (usually based on only one case) brought to a board or planning group. In the north-west quadrant, researchers create highly valid research but do not engage their users in any way, either before, during or after, and the evidence may simply sit on the shelf. The north-east quadrant is hypothesized as effective in producing evidence-based change, where a high degree of both user and researcher involvement from start to finish ensures highly valid research and highly policy-relevant research. These factors yield the highest probability that the evidence will be translated into action. However, researchers need to be aware of the time and resource implications of establishing a sense of trust to enable this type of collaboration (Bowen et al. in press; Denis and Lomas 2003)." [5]

One respondent echoed the sentiment described in the grid:

> "I think there is way too much knee-jerk KT happening. I chair a peer review committee where reviewers ask 'well, are you translating knowledge?' And they're doing the research, God knows if it's going to be right, it's research, don't make them translate it, for God's sake don't translate it, please don't translate it. Can we not translate this?"

> ...there was overwhelming support for the creation of a web-based interface for interactions with patients, families, and public...

In the interviews, there was overwhelming support for the creation of a web-based interface for interactions with patients, families, and public: "I think that it's probably something NeuroDevNet needs to do as part of its mandate". At the same time there was recognition that there are a number of websites providing patient/family information and the concern was not to duplicate existing sites and also acknowledgement of the time and effort it takes to develop a website:

> "...I think the last thing the world needs is another journal and the second to last thing the world needs is another website. I think it's feasible and I think it's a great idea. It's still going to cost you money and to think that anybody can do it off the side of their desk, it's crazy..."

However, it was also recognized that NeuroDevNet's focus on brain development in children has potential to fill information gaps in this area: "Understand the neuroscience; understand imaging and the brain, yes I agree. I think that would be great". As well, our research focus on ASD, FASD, and CP is seen as an opportunity to provide links to credible information thus providing a vetted source for patients and families:

> "...by identifying good resource links, this website will give you this type of information and will provide a place to go to find good, credible websites versus the junk out there that's not very good, and parents don't really know how to differentiate that."

Respondents also thought communicating NeuroDevNet's basic science research to the general public and helping them to understand the value and importance of academic research was an important KT strategy.

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Transferring research findings into clinical practice is another recurring theme amongst our respondents: 72% rated it as high priority and 22% ranked it as medium priority. Respondents were also hopeful that NeuroDevNet research would eventually influence health services policy and practice:

> "…again I'm far removed from that in my research but I think as a multi-disciplinary group bringing the basic science and the human research together… that I think has the potential to have a powerful impact on policy because you not only have findings in the kids but you back it up with the basic science findings and so I think that's an important KT goal as well."

Other areas that received notable support as KT activities include the development of best practices, and dissemination strategies to improve uptake of evidence. Although developing best practices was ranked a KT priority there were some opposing views due to the time and work involved in their compilation:

> "I find guidelines are a ton of work because they usually [have] very rigid methodology… it ends up being really hundreds of hours of work and the problem then is that they are out there and nobody reads them or they don't necessarily result in practice change, so I don't know that I would put my eggs in that basket so much."

Integrated KT, (where knowledge users are involved in the research process by identifying research questions, defining methodologies, as well as interpreting and disseminating findings), was a controversial topic amongst some of our respondents…

Integrated KT, (where knowledge users are involved in the research process by identifying research questions, defining methodologies, as well as interpreting and disseminating findings), was a controversial topic amongst some of our respondents, who had salient comments around issues related to politics, scientific integrity, autonomy, and creativity. They thought that involving families was important to gain additional insight, but families should not set the scientific research agenda because it's not their expertise. On the other hand, we need to engage in respectful listening, as quotes from several respondents demonstrated:

> "…[to] undertake research identified by a target user community could be fabulous if I think that the right interests are being served by that, and could be deeply problematic in other contexts."

"...undertake research identified by a target audience, I don't know, I always have a little bit of trouble with that... then all we'll be looking at is every Tom, Dick, and Harry alternative therapy that comes out."

"Undertaking research identified by target user communities, I worry about that aspect. What we do is targeted already to these specific disorders but I think there has to be curiosity-driven research and investigator-driven research and not prescribed research because you never know where an important finding is going to emerge that has tremendous relevance for practice, for translation directly into the clinical setting. So I would hate to not have the freedom to do investigative or initiated curiosity-driven research."

Integrated KT was not identified as a priority activity by any of our interview respondents and those who spoke to it were on the side of caution and tended towards a prescribed view of integrated KT as that of letting patients and families direct the research, as opposed to other aspects which could include a forum convened to prioritize and fund what research directions or questions a field should pursue.

"...end users don't direct the research, the end users influence the research questions, and if you are doing basic science then your end users might be other scientists, and if you are doing clinical research that you want to transfer into the clinic then your end users may be clinicians or they may be families..."

"I think they have a misunderstanding, the end users don't direct the research, the end users influence the research questions, and if you are doing basic science then your end users might be other scientists, and if you are doing clinical research that you want to transfer into the clinic then your end users may be clinicians or they may be families. I mean what's the use of developing a wonderful intervention that families won't use."

One respondent spoke to efforts to develop, in the workplace, an interdisciplinary collaborative around a group of people interested in research. The group wants clinician investigators and research scientists, but also representatives from individuals and family members with the idea that "research can guide practice but practice can guide research". It was thought that in this way research projects and questions that would get generated would not only be important to the scientists and clinicians, but also important for the day-to-day questions for those living with the disease. Indeed, this respondent was definitely talking about integrated KT and went on to state:

> "But on a practical level bringing clinicians and researchers together is challenging because they think in different mindsets, and so throwing into the mix the families it is challenging to get output that is meaningful to the different partners in this."

Finally, another researcher spoke to being pro-active throughout a research project and using aspects of integrated KT:

> "…so for example we are going to each of the recruitment sites and we're just planning a pizza lunch type thing where we meet with clinicians who may or may not be involved in recruitment but just to make them more aware of the study as we're collecting data, why we're doing the study, why it might be important for them, some of the early findings…"

> It seems that although there is not a lot of support for integrated KT within NeuroDevNet, some of our members are actively engaged in trying to integrate knowledge users into their research projects.

Another role for KT that was highlighted was reviewing research projects funded by NeuroDevNet, such as the Opportunities Initiative, to evaluate and incorporate a KT piece, as well as setting minimal guidelines for KT so that it is integrated into research projects and reflected in the budget. The KT core could identify elements of KT that should be incorporated into grant writing for NeuroDevNet funded research. This could also be built into trainee awards, so they are thinking about and exposed to a KT component early on in their training.

Finally, although commercialization was a low priority activity identified at this early stage in our survey, with few members engaging in commercialization of their research findings, it was nevertheless recognized as an important strategy within NeuroDevNet by some of the respondents:

> "…to take basic research into clinical trials… there's a tie-in there to the commercialization piece which is an important component of the raison d'etre of NeuroDevNet."

There was some concern expressed on how commercialization would be done, and suggestions included having focused expertise embedded within the projects as well as bringing members together who are truly interested and want to pursue commercialization of their discoveries:

> "So we really need to have it be a KT person or a commercialisation person strategically embedded within the group either full-time or part-time. I recognize it's hard to do if the group is maybe generating one patent a year…so just having people sitting in Vancouver doesn't really help us much unless they're really embedded with us in some way…"

> "…it's a little bit hard to get a handle on, so I think trying to pull together the people that actually want to try to do this would be quite helpful. So I think this is really important, I think it needs to occur at the macro level and I think it needs to occur at the micro level…"

Theme 4: Building Capacity

There were few training activities listed in the survey that seemed to be of interest to members. Some interest was shown in plain language writing workshops (68% ranking medium or high priority), evidence-based KT practices (72% ranking as medium or high priority) and communities of practice (61% ranking as medium or high priority).

> Members requested that NeuroDevNet set up opportunities for projects and cores to network and update at the annual conference, as well as web-based opportunities to meet throughout the year.

Most of the respondents felt that within their projects they had established a "type" of community of practice through regular meetings either via teleconference or in-person. Members requested that NeuroDevNet set up opportunities for projects and cores to network and update at the annual conference, as well as web-based opportunities to meet throughout the year. Some thoughts were expressed on linking "interest groups" around common themes that cross the projects; looking at challenges and issues related to developmental disabilities; and fostering activities that cross project lines:

> "I think the notion of having interest groups that cross the projects that deal with similar themes and think about collaboration like how do you approach knowledge translation of imaging genetics or ethical issues in genetic testing or diagnosis?"

Interest was expressed in skill development workshops, specifically related to evidence-based KT, KT frameworks, and how to approach KT from a practical level, such as what to include in a research proposal and how to facilitate KT that works. Understanding barriers to knowledge translation was once again seen as an important skill to acquire, specifically with regards to translating research into clinical practice.

> "…it's about understanding the dynamics of translation, what is important in translation, why is just communicating data failing, what it is about uptake that is not necessarily directly linked to data. I would attend a workshop like that. I would attend a workshop where somebody who has spent time looking at translation sat down and said we have failed because of this and this and these are the kinds of things we need to be thinking about."

> Identifying and supporting skill development to meet the challenges inherent in translating research to clinical practice or to effect policy change should be a significant capacity-building focus for the KT core.

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At the same time there was some resistance to developing certain KT skills, for instance, there was some interest in plain language workshops, but it was also seen that this type of KT training and maybe KT in general took time from research:

> "Well I don't think it makes sense for me to learn how to write. I've got enough stuff to do. Quite frankly, if there is a need to translate my work into plain language, somebody else who knows how to do this is probably in a better position to do it than me…"

> "In other words, for us to become trained in KT is that what you mean? Well I guess that sort of fits the fact that we want to do our research and not necessarily be trained in KT."

Knowledge syntheses products are integral to KT practice and often provide the content for informing families, clinicians, and policymakers about emerging issues, new developments, state of research, and identifying gaps in knowledge and setting research agendas. However, there was some resistance to this type of activity and primarily with regards to Cochrane methodology for systematic reviews:

> "I mean Cochrane reviews are great and they are very rigorous, most of them are fairly well done, but unfortunately—and this is probably the state of science or clinical research—most of them state at the end that more research is needed, and I think this frustrates people because they want some guidance, they don't want to hear that conclusion…"

"It's not that methodology is flawed it's just that the outcome is always the same that there's not enough research to support the evidence and maybe not enough interpretation of what does this mean at a clinical level."

It was also suggested that Cochrane-style reviews, which are generally clinically focused on interventions and clinical trials, may not be appropriate for basic and translational research:

"I guess if there are 5 different genetic studies all showing different kinds of things [a] Cochrane review is not going to answer the issues."

However, there was interest expressed in doing other types of reviews such as scoping reviews or applying grades to the literature according to levels of evidence, and consensus-building to provide an overview of the state of research in certain areas. Another respondent saw systematic review services as useful since they did not have that capacity where they are working:

"I'm really excited about the systematic reviews, I'm going to think a little bit more about that… I'm getting invited more and more to do things like opinion pieces and editorials and often when I do those I need to have a systematic review done in some way to make sure I'm not saying something that's already out there. That's why I asked to see some of your material because I wouldn't know how deep you go or don't go… because I've never done this before, I don't really know."

Another respondent commented that it was more about thinking about what "knowledge synthesis question could complement what we are doing".

Engaging in a conversation about what systematic reviews are, what is a meta-analysis and different types of reviews, and not necessarily learning how to do it would also be a valuable training activity. Others commented on the time and training required to do a systematic review, and it didn't make sense for them to become systematic reviewers.

It was also mentioned that literature reviews were likely developed for the NeuroDevNet proposal and if this is the case they should be summarized and targeted to different recipients and put on the website. Strategic and targeted knowledge syntheses could be an important activity to support translational research, provide content for families and clinicians on the website, and even support the linking of researchers and clinicians, as well as informing research activities.

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Technology Use for KT

We found from the survey that NeuroDevNet members have a low level of engagement in social media such as Facebook and Twitter (53% indicated they never "use Facebook, MySpace or other social networking software, and 33% indicated they use social media at least 2 or more months a year). With regard to "participating on blogs", 69% of respondents indicated they never write blogs; and 42% indicated they never read blogs. These three activities were all significantly negatively correlated with age (the older the respondent, the less likely he or she was to use social media), and the majority of our respondents were in the 35-65+ age group.

The production of audio and video podcasts also ranked as activities with low levels of participation, with 92% and 94% indicating once a year or less or never, respectively. There was a slightly higher rate of participation in online communities such as wikis, although 28% said they never participate in online communities.

However, a few comments were made around delivering workshops, including conducting webinars, doing podcasts, and using advanced technologies. One respondent commented on the advantages of a webinar in that they could do a "lunch and learn" session and include their research staff. As well, it was noted that we needed to take advantage of technology in order to reduce expenses and save time. In general, and because of time constraints, it was thought that these should be relatively short and in-person workshops no longer than a half day.

"...I would appreciate webinars. If you would organise a lecture that we don't have to fly to so I can get my lab together, they can get their lunch, they can sit around and all learn something that would be really nice."

"So it's a real issue. So we need to make the technology work for us. So of course we have the traditional models where you get in a car, you get more usually on an airplane, then you take several days out of your time and you go meet with people. And that's wonderful but you can only do so much of that. So on an ongoing basis, I think we need to link in with the technology platform in NeuroDevNet. So we need to bring people up to a higher comfort level with using web-based technologies..."

Discussion and Conclusions

The KT environmental scan provides a rich source of information to assist the KT Core in determining members' baseline KT activities and skills, prioritizing strategies for future activities, and identifying capacity-building needs.

Knowledge dissemination activities via publication in peer-reviewed journals and presentations at conferences were common activities most frequently engaged in by members. Nevertheless, there are a few respondents who were trying to advance their skills beyond dissemination by doing or attempting different facets of integrated KT with their research. As well, with regards to communicating research, members were using a variety of methods including providing summaries and talks to families, community organizations, clinicians, and some members are active in talking to the media at both a local and national level.

Members are interested in expanding their skills to include forming partnerships with families through public forums, some integrated research activities, respectful listening, interactive web-based interfaces, and factsheets. As well, members want other scientists and particularly clinicians included in their KT activities by understanding the barriers to implementing research into clinical practice. Further, they recognize the importance of the NeuroDevNet network as a vehicle for expanding their reach, contacts, and initiating new research activities, collaborations, and commercialization. Ongoing communications, dialogue, webinars, and in-person meetings were all seen as means to increase the network-ness of the network, creating the NeuroDevNet community and as a means for skill development.

A few reservations and controversies were expressed around integrated KT, public engagement, and compiling knowledge syntheses and systematic reviews. The importance of creativity, scientific integrity, and serendipity with regard to research activities suggest that our members do not want to be guided solely by users of research when conducting their research. Also, inclusivity and hearing all voices around issues and not just those of dominant groups and organizations is an important concern in community engagement. Clinicians, policymakers, and other researchers are important connections and recipients of research products. Finally, some members were keen on the ability of the KT core to assist with systematic reviews, whereas others were more inclined towards syntheses in the form of best practices, guidelines, and other review methodologies such as scoping reviews.

> The results of the environmental scan are now enabling the KT core to develop a catalogue of services, plan workshops, webinars, and targeted skill development activities for its members and to develop strategic plans for KT over the life of the network.

The results of the environmental scan are now enabling the KT core to develop a catalogue of services, plan workshops, webinars, and targeted skill development activities for its members and to develop strategic plans for KT over the life of the network. A list of services, strategies, and activities identified from the interviews is provided on the following pages.

Summary of Services, Strategies, and Activities Identified for the KT Core

General

- Assist members to be pro-active about communicating and interpreting results of research to all involved—families, patients, front-line clinicians by providing assistance and training with plain language writing and dissemination plans.

- Encourage and assist members to communicate intent purpose and challenges of their research projects to potential stakeholders throughout the life-cycle of the project.

- Encourage and assist members to consider integrated KT as a methodology that may be appropriate at the clinical research level.

KT Frameworks and Guidelines

- Incorporate a KT framework in Opportunities Initiative and other initiatives funded by NeuroDevNet.

- Assist members with developing end-of-grant KT through workshops and/or webinars.

- Develop guidelines for end-of-grant KT and outline budgetary needs.

- Provide training on integrated KT and conducting research using variations of integrated KT.

Patient/Family Engagement

- Develop an interactive consumer and clinician web presence.

- Profile our members and their basic science research and its value on the website.

- Develop links to evidence-based and reputable sites related to ASD, CP, and FASD.

- Encourage members to use the KT core to develop, edit, and disseminate factsheets and plain language summaries of their research, as well as literature reviews.

KT Skills Development

- Develop educational materials around principles of change management (to support clinical practice change).

- Offer expert workshops on barriers to KT.

- Offer a variety of KT skills development workshops either internally or using external experts.

Networking and Partnerships

- Provide web-based opportunities among projects to share research progress and challenges via webinars.

- Provide opportunities for members who engage in activities that cross all projects to network, to share, and to communicate their work.

- Ensure that members have networking time at annual meetings and other NeuroDevNet- sponsored events.

- Start a community of practice around commercialization. Include interested members and perhaps secure the services of an outside expert.

- Include NeuroDevNet members' contacts with decisionmakers and other groups in the contact database and/or develop a database of contacts that members have and share.

- Facilitate and create opportunities for members to share and present their research so that there is broad impact through media, contact with decisionmakers, family forums, and any other venues that may be suitable.

Knowledge Syntheses

- Develop a policy/culture around having the KT Core receive all relevant literature reviews past and current to translate into plain language summaries for website.

- Promote knowledge syntheses and encourage members to enlist the KT Core in leading different types of systematic reviews.

- Provide training in the various knowledge synthesis methodologies.

Appendix 1: Interview Questions

1. Can you describe your experience doing KT—what has worked well and what hasn't, in your own work? Please give examples.

2. The following KT Activities received high priority ranking by a majority respondents (as of Aug 25)
    - Create a web-based interface for interactions with patients, families and public
    - Develop best practices
    - Dissemination strategies for improving uptake of evidence
    - Develop knowledge transfer skills (how to get evidence into policy and practice)
    - Evaluate impact of research
    - Foster intellectual discourse and knowledge dissemination
    - Transfer research findings into clinical practice
    - Undertake research identified by target user community
    - Involve knowledge users in guiding the overall direction of your research

    If you have to choose the top three activities amongst these, which would they be?
    Are there any high priority activities that are not on the above list?

    Can you talk about experiences that you or any member of your team have had in any of these KT activities?

3. KT Training —No training and development activity received a high priority by a majority of respondents— the following training activities received a medium priority by the majority of respondents (as of Aug25):
    - communities of practice (see definition)
    - plain language writing workshops
    - evidence based KT practice (systematic reviews of what works)

    What would be your top training activity?
    Are there any high priority training needs that are not on the above list?
    Can you talk about experiences that you or any member of your team have had in terms of KT Training?

4. Etienne Wenger defines Communities of Practice as "groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly."
    In relation to communities of practice, what do you see to be a focus for initiating a CoP, and ultimate purpose of a CoP?
    How do you think a community of practice model should be organized within NeuroDevNet?

5. Do you participate in or conduct any other forums for knowledge exchange and/or networking between researchers? Please give examples.

6. Knowledge synthesis is considered an integral part of KT, but Cochrane systematic review methodology training received a low priority—any thoughts on this?
    Do you have any topics or key issues that you think could benefit from a Systematic Review?

7. How should KT be done at the project level?
    What would it take for KT to be a success at the project level?

8. What do you see as community engagement within the projects?

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