Practices and Plans for Knowledge Translation at NeuroDevNet

Nazeem Muhajarine, PhD,* Patricia Fortin, MLS, MSc,† Fleur Macqueen Smith, MA,‡ and Annette Majnemer, PhD§

Knowledge translation at NeuroDevNet, a new Canadian Network of Centres of Excellence focused on brain development, is a core service that spans its 3 demonstration projects: research programs in cerebral palsy, autism spectrum disorder and fetal alcohol spectrum disorder, and integrated as a network-wide activity. This article describes the results of an environmental scan of NeuroDevNet members using a survey of their existing practices and needs completed by 30% of NeuroDevNet’s members (n = 36/120) and key informant interviews with 14 members. Results suggest that most members are somewhat engaged in a number of knowledge translation activities although they tend to be traditional ones, such as attending conferences and giving presentations to other researchers. There is very little in the way of public engagement or consumer-focused activities. It also describes activities underway at the Cerebral Palsy Demonstration Project. This scan is helping members of NeuroDevNet’s knowledge translation core plan and prioritize services and activities within NeuroDevNet.

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There is little doubt that we are in the midst of profound changes in health research, ones characterized by the convergence of ideas and blurring of boundaries of all types, between disciplines, institutions, or scientists and the public and the unprecedented speed in which these transformations are occurring. Examples of transformative changes abound; in health research, these include the Human Genome Project, proteomics, synchrotron technology, nanotechnology, and biopharmaceuticals and in a different scale, prediction, control, and treatment of emerging pandemics, among others.

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, in the case of our Network’s research.

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”1; currently, both interest levels and efforts to improve knowledge implementation are widespread in the health research community.2

KT at NeuroDevNet, a new Canadian Network of Centres of Excellence focused on brain development, is a core service and activity that spans our 3 demonstration projects (ie, research programs in cerebral palsy, autism spectrum disorder, and fetal alcohol spectrum disorder described in detail elsewhere in this issue) and 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 decision makers 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 honored with a KT 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 (Fortin); a Communications and KT Coordinator; KT Coordinators from the 3 demonstration projects; and, eventually, graduate students supported by KT training funds. Muhajarine’s KT Manager from his own research program (Macqueen Smith) has also been involved with NeuroDevNet since the grant writing phase, earlier acting as KT Manager and currently providing ongoing guidance.

There are 3 guiding principles that govern KT at NeuroDevNet:

1. KT needs to be conducted on a network-wide level as well as on a project level.
2. KT is more than the responsibility of any 1 group or set of people; it needs to be integrated with the research taking place across NeuroDevNet and considered as “part of the ‘real’ work of research, not a superfluous add-on.”
3. Successful KT is all about relationships. 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 with established relationships with key stakeholders.

Establishing the KT Core

KT at NeuroDevNet is focused on providing services to NeuroDevNet members. In the initial core platform proposal, we identified 3 priorities: (1) to conduct an environmental scan to identify KT needs and build on KT capacity within the 3 demonstration projects, (2) to create and share synthesis documents of current knowledge and best practices in KT, and (3) to identify and share new knowledge from demonstration projects with key stakeholder groups.

The first step we took to establish the KT core was organizing a session on planning for effective KT in research at NeuroDevNet’s inaugural annual general meeting, which was 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 on our web site at: http://www.neurodevnet.ca/research/kt/tools. This presentation helped to highlight the importance of KT to NeuroDevNet and provide 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 reflected both the activities identified in the initial core platform proposal and an interactive web site for consumers, a key priority identified at our annual meeting.

Setting KT

Priorities for the First 2 Years

Priorities that were identified in the initial work plan, which covers the first half of NeuroDevNet’s 5-year funding period include: (1) creating a web-based consumer information web site 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); and (5) developing a NeuroDevNet newsletter (to be published 5 times a year).

Although it is listed as the second priority, the environmental scan is a key component for informing the activities of the KT core and identifying needed services for NeuroDevNet members and as such was addressed first. The environmental scan consisted of 2 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 principle 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. About 30% of our members have responded to the online survey, and we have conducted 14 in-depth interviews; some preliminary findings from both are discussed later.

Results of the Environmental Scan (Online Survey and Key Informant Interviews)

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 out to NeuroDevNet members. All responses collected through the survey were anonymous; however, respondents were able to provide us with their name and e-mail addresses if they agreed to be interviewed.

Demographics

We received a 30% response rate, with 36 of 120 members responding to the survey; of these, 51% were female. Half of the respondents (50%) were in the 50- to 64-year old age range group, 36% were in the 35- to 49-year-old age range group, 8% in the 20- to 34-year-old age group, and 6% identified themselves as 65+ years of age. A range of affiliations was identified, with respondents categorizing themselves into one or more areas within NeuroDevNet. Overall representation was broad, covering the 3 demonstration projects and various research methodologies (Figure 1).

Knowledge translation at NeuroDevNet
Baseline KT Activities

Members were asked to rate the frequency of engagement in a variety of KT activities with 5 possible responses ranging from “never” to “more than 12 times a year.” These responses provided us with some baseline data on KT activities which our members are already engaged in, some of which are highlighted below.

Not surprisingly, “attending talks given at conferences/seminars or lectures” received the highest rating, with 81% doing this from 6 to 12 or more than 12 times per year, and the rest (19%) reported engaging in this activity a minimum of 2 to 5 times per year. Other activities with a high frequency of engagement included the following: (1) conducting research development activities, such as grant applications, with 91% ranging from 2 to 5, 6 to 12, or more than 12 times per year; (2) maintaining own web site, with 89% ranging from 2 to 5, 6 to 12, or more than 12 times per year; (3) providing copies of articles and/or reports, with 89% ranging from 2 to 5, 6 to 12, or more than 12 times per year; (4) improving professional practice through professional associations, with 81% ranging from 2 to 5, 6 to 12, or more than 12 times per year; and (5) providing brief summaries (such as an abstract) of articles, reports, or systematic reviews, with 81% ranging from 2 to 5, 6 to 12, or more than 12 times per year.

We found that NeuroDevNet members have a low level of engagement in social media, such as Facebook and Twitter. With regard to “participating on blogs through writing,” 83% indicated that they write blog posts once a year or less, with 69% indicating they never write blogs; 42% indicated they never read blogs. However, 19% did indicate that they read blogs more than 12 times a year. Also, 53% indicated they never “use Facebook, MySpace, or other social networking software”; however, 33% indicated they use social media 6 to 12 or more than 12 times a year. These 3 activities were all significantly negatively correlated with age (the older the respondent, the less likely he/she was to use social media), and most of our respondents were in the 35 to 65+ years 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 (69% never engaged in either activity). There was a slightly higher rate of participation in online communities, such as wikis, with 53% ranging from 2 to 5 times, 6 to 12 times, or more than 12 times a year, although 28% said they never participate in online communities.

One member spoke to the need to get members engaged in technology for knowledge exchange:

...we have the traditional models where...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...[W]e need to bring people up to a higher comfort level with using web-based technologies, so that you can see people and they can talk to each other...and you can share documents. Right now we're doing too many things just over the telephone, [and] you can't see people's reactions and you can't share documents very well.

This interviewee suggested that the KT core host regular webinars, focusing on a researcher or topic of the month, so people could get together virtually. Finally, NeuroDevNet members indicated that they generally are not engaged in commercializing innovations, with 81% indicating they never “broker a capital investment for innovations;” 64% never “contract commercial partners in product development,” and 64% never “provide disclosures of commercializable discoveries.” One interviewee noted that “trying to pull together the people that actually want to try and do this...would be quite helpful. I think it needs to occur at the macro level, and I think it needs to occur at the micro level.” The respondent then discussed how a business model and funds for commercialization would help focus efforts in this area.

Audiences Identified for KT Activities

Regarding the audience for members’ KT activities, most indicated that other researchers were their primary audience (89%), 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 public (47%). Only 19% of members listed managers in pharmaceutical and other biotechnology companies as an audience for their KT activities.

Priorities Identified for the Network and KT Training

In the survey, we listed 16 KT activities and 5 training 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 priority that ranked the highest was to “foster partnerships to advance research” (81% high and an additional 18% medium priority). Related to this item and ranking second in priority was to “foster intellectual dis-

### Table: Affiliations of those who responded to the online survey

<table>
<thead>
<tr>
<th>Affiliation</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism Spectrum Disorder Researcher</td>
<td>6 (17)</td>
</tr>
<tr>
<td>Cerebral Palsy Researcher</td>
<td>7 (19)</td>
</tr>
<tr>
<td>Fetal Alcohol Spectrum Disorder Researcher</td>
<td>5 (14)</td>
</tr>
<tr>
<td>Clinical Researcher</td>
<td>14 (39)</td>
</tr>
<tr>
<td>Animal Model Researcher</td>
<td>6 (17)</td>
</tr>
<tr>
<td>Imaging Researcher</td>
<td>6 (17)</td>
</tr>
<tr>
<td>Knowledge Translation Researcher/Specialist</td>
<td>3 (8)</td>
</tr>
<tr>
<td>Neuroethics Researcher/Specialist</td>
<td>4 (11)</td>
</tr>
<tr>
<td>Neuroinformatics Researcher/Specialist</td>
<td>3 (8)</td>
</tr>
</tbody>
</table>

Figure 1 Affiliations of those who responded to the online survey.
course and knowledge dissemination” (78% high and 19% medium). As one member 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.

This idea was further extended in the interviews in which several members commented on the importance of the annual meeting as a venue for knowledge exchange and interaction between the presenters and the audience.

Other KT priorities that ranked highly included core KT practices and challenges as follows: (1) transfer research findings into clinical practice (72% high and 22% medium), (2) develop best practices (64% high and 17% medium), and (3) develop knowledge transfer skills (how to get evidence into practice) (56% high and 33% medium). One member spoke about the challenges of getting evidence into frontline clinical practice:

it’s not about plain language, it’s about understanding the dynamics of [knowledge] translation, what is important in translation, why is just communicating data failing, and what is it about uptake that is not necessarily directly linked to data? I would attend a workshop where somebody who has spent time looking at [knowledge] 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.

Of the 5 training activities listed, none received a high priority. Nonetheless, comments made in the interviews indicated that members could be engaged in a variety of KT workshops on topics, such as choosing and using KT frameworks, skills needed for successful KT, and guidelines on how to write a KT plan in a grant proposal. One interviewee suggested that KT mentoring with research findings would be useful: “even in terms of reviewing [KT] materials before they go out, and reviewing manuscripts, and . . . helping me . . . think about what is the knowledge translation strategy that [could arise] from [these research findings].”

Although we believe that knowledge synthesis is a core KT activity, training in “Cochrane methodology for systematic reviews” received a low priority rating by 53% of members. We are exploring additional reasons for this in our interviews. One respondent noted that the Cochrane model makes sense for therapeutics, but that many questions do not fit this model:

what’s the best clinical practice beyond the drug, what’s the best way to . . . deliver a nurse practitioner model of care—that’s not going to ever meet the Cochrane standards. [there are] other kinds of models, [and] I think it would be useful for people to engage in a conversation about that. . . . The challenge with the Cochrane methodology [is that it] relies on randomized controlled trial evidence, and so as a result, when the Cochrane Consortium does a review, almost nothing meets the standard . . . the groups that I’ve been involved with [are now using] the Grade methodology, which was developed by Gordon Guyatt, and colleagues at McMaster University; the power of that methodology is that it examines all of the literature.

Implications of These Findings for NeuroDevNet’s KT Services

The responses to the survey indicate that members already conduct a number of research-related KT activities, with other researchers as their primary target audience. This method of KT is identified as “end-of-grant knowledge translation” by the Canadian Institutes of Health Research, in which researchers disseminate findings at the end of a study, as opposed to integrated knowledge translation, in which research users are involved throughout the research cycle.1 Ongoing efforts to foster research partnerships, intellectual discourse, and sharing of research are all collectively seen as high-priority KT activities. These results are not surprising, given that we are first and foremost a research organization with an emphasis on translational research. Furthermore, these types of KT activities have traditionally been pursued by researchers across academic centers.

There is recognition that there is a gap between research discoveries and their application in clinical practice. To this end, support and training in KT methodologies are needed. The KT core is focusing on providing workshops and education around KT core practices and challenges, such as knowledge dissemination skills, evidence-based KT practices, barriers to implementing research in the clinical or public arena, and other training needs. The intent is to build members’ capacity for being more effective in their KT activities, particularly targeted at clinicians and families. As one interviewee said:

I think we are really good at asking research questions and developing research projects that answer those questions, but [it’s time to] take it to the next step. I’m a little bit more aware of that because of being a clinician, so I think I’m pretty good at taking it to the clinical people, but not . . . at taking it to the children and families. So I think that there is a lot of capacity building that can be done.

To assist NeuroDevNet researchers to connect more easily with children and families, the KT core is investigating the feasibility of creating a consumer web site focused on neuroscience and the 3 research priority areas as a means to inform patient groups, families, nonprofits, and general public on our research activities. We are also pursuing knowledge synthesis activities with members, including organizing teams for systematic reviews and planning a webinar to provide an overview of knowledge synthesis methodologies to facilitate this important KT work.
Conclusions
Our environmental scan of NeuroDevNet members’ KT activities suggests that most of our members are somewhat engaged in a number of KT activities and strategies for both uptake and dissemination of knowledge. These tend to be traditional KT activities, such as attending conferences and giving presentations to other researchers, often known as end of grant KT. There is very little in the way of public engagement or consumer-focused activities. The one-on-one interviews that are being conducted with key stakeholders enabled us to explore members’ engagement in KT activities in more depth as well as priorities for capacity building. These interviews will further inform KT needs and the range of services that the KT core should strive to provide at NeuroDevNet. Ultimately, the goal is to develop innovative and effective strategies for the dissemination of best practices and the results of NeuroDevNet research to improve the health and well-being of children with neurodevelopmental disorders.

KT Activities in the Cerebral Palsy Demonstration Project

NeuroDevNet offers the opportunity for the 3 demonstration projects to develop and synthesize new research evidence on the causal pathways that underlie common brain disorders of childhood. Each demonstration project (autism spectrum disorder, fetal alcohol spectrum disorder, and cerebral palsy) is planning a number of KT strategies to optimize dissemination, uptake, and use of new research discoveries by key stakeholders. These KT efforts will not only focus on the research being generated by each of the demonstration project teams but will also focus on KT activities that promote the uptake of existing evidence in the literature on a variety of rehabilitation and medical treatments that have not been adequately translated into practice. Furthermore, we will be able to share objective research on currently popular expensive therapies that may lack adequate evidence to recommend their use with appropriate target groups.

The Cerebral Palsy Demonstration Project (CPDP) will synthesize research evidence on “hot topics” in a user-friendly format by preparing several newsletters each year, each one focused on a topic of timely importance to clinicians and to families. A researcher or group of researchers will provide an overview of what is known on a particular topic, written for a lay audience, avoiding the use of technical jargon, statistics, or data and emphasizing key take-home messages. In particular, the ways in which current knowledge can be applied to clinical practice or can be used by families will be explicitly described. Newsletters may contain additional perspectives of other researchers, clinicians, and family members. Helpful resources, such as important publications and websites, will be provided.

Currently, the CPDP is working on 3 topics: (1) the state of knowledge on stem cells as a treatment for cerebral palsy, (2) virtual reality as a rehabilitation intervention for cerebral palsy, and (3) parents’ perspectives on needs for effective parenting of a child with cerebral palsy. These bilingual (French and English) newsletters will be disseminated through various national and international networks and will be posted on the NeuroDevNet and Childhood Disability LINK web sites (www.neurodevnet.ca, www.childhooddisability.ca).

Each year, the CPDP will also host a public forum that will include key stakeholders, such as clinicians, families, policymakers, managers, researchers, and individuals with cerebral palsy to facilitate knowledge translation and exchange. At the first NeuroDevNet annual meeting in Montreal (June 2010), a panel with representatives from several stakeholder groups discussed their perspectives on what should be prioritized for research related to cerebral palsy. Next year, we hope to hold a public forum in Toronto focusing on stem cell research.

The CPDP will capitalize on the availability of the KT core services in a number of ways. The KT core will assist the CPDP in expanding their network of stakeholders and partners, thus facilitating more widespread knowledge translation and exchange. Members of the KT core will provide expertise in the enhancement of public awareness through media initiatives, policy briefs, and reports. We expect that the KT core will provide critical guidance in the use of effective KT strategies at our public forums. For example, staff will be able to help analyze our focus group activities and strategies for both uptake and dissemination of knowledge. These tend to be traditional KT activities, such as attending conferences and giving presentations to other researchers, often known as end of grant KT. There is very little in the way of public engagement or consumer-focused activities. The one-on-one interviews that are being conducted with key stakeholders enabled us to explore members’ engagement in KT activities in more depth as well as priorities for capacity building. These interviews will further inform KT needs and the range of services that the KT core should strive to provide at NeuroDevNet. Ultimately, the goal is to develop innovative and effective strategies for the dissemination of best practices and the results of NeuroDevNet research to improve the health and well-being of children with neurodevelopmental disorders.

References