

Knowledge Exchange for Attention Deficit Hyperactivity Disorder Research: An Integrated Evidence and Knowledge Exchange Framework Leading to More Effective Research Dissemination Practices

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Abstract

Introduction: Knowledge Exchange refers to activities that help to create and support the conditions and culture that lead to the most effective access, implementation, utilization, and evaluation of the most credible evidence for improved mental health outcomes for children and youth in Ontario. Although knowledge exchange and associated concepts such as knowledge transfer and translation are increasingly well developed in other aspects of health and healthcare, it is underdeveloped in mental health generally. This paper introduces some of the basic concepts of knowledge exchange and calls for more development of knowledge exchange in the area of Attention Deficit Hyperactivity Disorder Research. **Methods:** This is a discussion paper that presents a general overview of the Centre's approach to knowledge exchange. It links the discussion to related concepts and to the need to overcome the research to practice gap. The Integrated Evidence and Knowledge Exchange Framework of the Provincial Centre of Excellence for Child and Youth Mental Health is introduced. Areas of active development in knowledge exchange are categorized into three objectives: context, content, and capacity. **Results:** The use of an Integrated Evidence and Knowledge Exchange Framework for the Centre's Grants and Awards program activities and evaluation has begun to explicitly and transparently link the evidence on effective knowledge exchange with the evidence on effective treatment for children and youth with mental health difficulties including ADHD. This framework is expected to produce greater transparency as well as improved attainment of outputs, outcomes, and impacts of these grants and awards in child and youth mental health. **Conclusions:** Knowledge exchange activities may reduce the confusion for parents & caregivers, practitioners, researchers, and administrators, seeking the most credible data, information and knowledge about the most effective treatments for ADHD. An active process that seeks to improve knowledge exchange for ADHD is needed. **Key words:** knowledge exchange, practice improvement, research support, communication

Résumé

Introduction: L'échange des connaissances porte sur les activités qui aident à créer et à appuyer les conditions et la culture qui permettent d'accéder aux données les plus crédibles sur les améliorations en santé mentale constatées chez les enfants et les adolescents en Ontario, d'appliquer ces données, de les utiliser et de les évaluer aussi efficacement que possible. Bien que l'échange des connaissances et les concepts connexes comme le transfert et la traduction des connaissances sont de plus en plus développés dans d'autres secteurs de la santé et des soins, ce concept est généralement sous-utilisé en santé mentale. Cet article présente quelques concepts de base sur l'échange des connaissances et propose de les développer dans le domaine du TDAH. **Méthodologie:** Ce document de travail présente une vue d'ensemble des principes sur lesquels se base l'échange des connaissances. Il fait le lien avec certains concepts connexes et la nécessité de réduire l'écart entre la recherche et la pratique. Le Cadre d'échange des preuves et des connaissances mis en place par le Centre provincial d'excellence en santé mentale de l'enfant et de l'adolescent est présenté en parallèle avec les domaines—comme le contexte et la capacité— qui doivent être développés. **Résultats:** Le Centre provincial d'excellence en santé mentale de l'enfant et de l'adolescent a utilisé le Cadre d'échange des preuves et des connaissances pour fournir des informations détaillées qui ont aidé le programme de subvention et de récompense à évaluer les demandes. Cette procédure devrait améliorer la transparence, aider à atteindre les objectifs, définir les résultats et évaluer l'incidence de ces subventions et récompenses dans le secteur de la santé mentale des enfants et des adolescents. **Conclusions:** L'échange des connaissances peut aider à diminuer la confusion qui règne chez les parents et les dispensateurs de soins, les intervenants, les chercheurs et les administrateurs en les aidant à rechercher les données, les informations et les connaissances les plus crédibles sur les traitements les plus efficaces du TDAH. Il est nécessaire de mettre en place un processus de délibération actif destiné à améliorer l'échange de connaissances sur le TDAH.

Mots clés: échange des connaissances; amélioration de la pratique; appui de la recherche; communication

Introduction

Knowledge Exchange is the term adopted by the Provincial Centre of Excellence for Child and Youth Mental Health (the Centre) to refer to activities that help to create and support the conditions and culture that lead to the most effective (and when possible, the most efficient) access, implementation, utilization, and evaluation of the most credible evidence for improved mental health outcomes for children and youth in Ontario.

It is recognized that there are other similar terms in current usage that include (but are not

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limited to): knowledge transfer (Broner et. al. 2001), knowledge translation (Pablos-Mendez & Shademani 2006), knowledge management (Jadad et. al. 2000), dissemination (Berwick 2003), and diffusion (Steckler et. al. 1992). While the existence of many similar terms has led to some confusion, this is not uncommon in a growing field that is both complex and emergent.

The exchange of knowledge infers a multi-directional movement of data, information, practice, experience, and knowledge among many actors. The Centre includes at least the following stakeholders among their knowledge exchange actors: children, youth, parents, caregivers, teachers, service providers, researchers, advocates, policy makers and the public at large (Provincial Centre 2006). The exchange process also infers a creation of added value or determination of exchangeable value of the raw material – as in any market exchange – in this case, the marketplace that interacts with ADHD research.

Knowledge exchange has arisen from a complex knowledge production process that has often failed to consistently move the most credible evidence from practice and research into improvements in health outcomes. This is referred to as the knowledge to practice gap (Carnine 1997). It is also a result of the information revolution in which the expert is no longer the dominant source of knowledge (Jadad & Gagliardi 1998). The increased competition between sources of information has led to heightened confusion among all stakeholders as to what is the “best” method of ensuring positive outcomes for those in need.

Examples of confusion about what is the most credible knowledge or the most effective treatment for ADHD are common. Parents receive mixed messages from multiple sources – television (ADHDNews 2007), magazines (Gordon 2004), and school boards (Parker 1992). Researchers and practitioners debate discrepancies in the literature. Policy makers decide on payment for treatment, often with incomplete or conflicting knowledge (Swensen et. al. 2004).

This confusion benefits no one and may be the cause of greater morbidity and possibly, greater mortality. Studies from the United States and the Netherlands suggest that

globally 30-40% of patients do not receive care complying with current scientific evidence and 20-25% of the care provided is not needed or potentially harmful (Eccles & Grimshaw 2004). The Clinical Research Roundtable at the US Institute of Medicine suggested that failure to translate new knowledge into clinical practice and healthcare decision-making was a major barrier preventing human benefit from advances in biomedical sciences (Eccles & Grimshaw 2004).

It is clear that this level of confusion, uncertainty, and potential harm to children and youth is unacceptable. The extent to which it applies to ADHD research and practice must be carefully examined. But the question that must be asked by all involved, whether parents and caregivers or service providers and researchers, is what can be done to improve the situation.

Precedents

There are precedents in other jurisdictions that bring together the evidence on mental health difficulties and the evidence on knowledge exchange. Two examples include initiatives found in the United States and the United Kingdom.

The National Institute of Mental Health in the United States provides health information on a range of mental difficulties in formats that are adapted to a variety of audiences including individuals, parents, practitioners, clinical researchers, and the media. NIMH publications are free and available in HTML or PDF formats from the Internet. Some are “easy-to-read” introductions, while other publications are more detailed booklets and fact sheets. Hard copies are available by dialing a toll-free telephone number. Spanish translations are available. Education programs and videocasts support the content of these publications. The NIMH recognizes that knowledge from research must be made accessible, both physically and conceptually, for multiple sets of recipients and that it should be easy to share and engage with.

In the United Kingdom, the Royal College of Psychiatrists provides mental health information not only for its members, but also for parents, teachers, and young people. The RCPsych also engages with the Press and Parliamentary policy and decision makers to

influence the environment that supports the conditions that lead to good mental health. It is also producing podcasts as an alternative to text-based documents.

These two examples show that it is possible to provide concise, audience specific knowledge to multiple audiences. In both examples, resources and an infrastructure are dedicated to the process of “popularizing” research knowledge. Without these resources, it is unlikely that such a system would emerge. It is unclear however, whether the mental health of either population has been directly improved by these initiatives. While both examples both “pull” audiences to their sites and “push” information out to them, it is unclear whether the behaviors and practices of these multiple audience groups are more evidence-based or not. This may perhaps, only be determined by measuring their behaviors and practices over time – through a process of linkage and exchange – as suggested by the Canadian Health Services Research Foundation.

Moving from knowing to doing

The Centre and its partners and volunteers, recognize that systematic, transparent, and explicit methods, based on the best available and most credible evidence, is the place to start reducing the confusion found in conflicting policies, practices and programs aimed at improving the lives of children, youth and their parents and caregivers dealing with mental health difficulties.

The collaborative construction of Ontario’s child and youth mental health system is the basis for the Centre’s “Integrated Evidence and Knowledge Exchange Framework”. This framework emphasizes that both: *what* the child and youth mental health practice evidence is and; *how* it is exchanged among the diverse stakeholders, must be founded on equally credible scientific methods. While it is recognized that the complexity of mental health difficulties does not always fit easily into a simple formula, we must be clear about what we know with great certainty and what is still subject to ongoing scrutiny. Both the practice and the method of exchange must be based on most credible evidence. Where there is uncertainty, explicit and transparent discussion must lead stakeholders towards continual improvements

to build greater certainty.

The knowledge exchange process and the evidence evaluation process must work in partnership. In order to determine the most credible evidence, the same methods are applied to both the mental health and the knowledge exchange practices.

Communicating what we know to be credible evidence must be done using equally credible practices. While the tasks of each “stream” of activity are by nature different, they must work together. The objectives of knowledge exchange can be grouped into three categories: *context*, *content*, and *capacity*.

Context

Context refers to the circumstances and conditions surrounding a situation, event, or group. In the context of ADHD research, knowledge exchange includes the effort required to determine the credibility of the evidence for effective knowledge exchange for ADHD. If there is no evidence to support a particular knowledge exchange initiative, provide evidence that it does not work. Make the criteria for effectiveness explicit. Engage in an iterative and transparent process that seeks continued efforts to improve efficiency. Make links to other initiatives in child and youth mental health, whether specifically focused on ADHD or related difficulties, in other jurisdictions and seek potential innovations. Given that the context for ADHD research includes many stakeholders, focusing on the credibility of evidence and transparency of process ensures that the contributions of all parties are based on evidence rather than their ability to influence political processes, emotional and spiritual beliefs, or funding of practice and programs that are in the best interest of shareholders rather than the best interest of children, youth and the their parents and caregivers.

It is important to identify known barriers to knowledge exchange in the following areas: *access* – both physical and conceptual understanding; *implementation and utilization* – what are the incentives to facilitate the introduction and use of evidence and the infrastructure to support maintenance, when they do not exist how may they be constructed, and; *evaluation* – to support continual improvement of practice, policy, programs, and perspectives.

It is equally important to identify and connect with stakeholders to determine: the diversity of stakeholders – always ask who else needs to know about this; preferences and biases – how can results best be received by those who need them; formats – think beyond the text bias, can the results be presented in audio, video, arts-based, or other formats; timing or frequency – how often should a message be repeated to be accepted and incorporated into personal and professional practices, and; source – is the right person or organization delivering the evidence for the audiences you are trying to influence. It cannot be stressed strongly enough that while bias is an inherent part of the human condition, the influence of bias that does not privilege the well-being of those in care can be minimized with a focus on credibility of evidence and transparency of process.

Finally, carefully consider existing resources and capacity for knowledge exchange. There may be people, institutional structures, relationships that are under or poorly utilized and may be modified or adapted to enhance knowledge exchange.

Content

The content of any research on ADHD should be linked to other credible evidence in child and youth mental health to increase the possibility of positive outcomes. The Centre engages in systematic searches and systematic reviews to ensure that new research priorities are addressing a clearly identified previously uninvestigated need. The systematic review process ensures that the content being submitted to a knowledge exchange process is high credibility and potential for leading to positive outcomes in the target audiences.

The content of knowledge exchange research should be linked to credible strategies that favor population-based mental health outcomes. This must be supported by exchanges across a range of subject matter areas (disciplines, professions, stakeholder cultures) to identify opportunities for innovations to produce solutions or adaptive improvements to complex problems. As such, it is important to measure levels of dissemination of research content into practice, policy, and programs. We need to establish the process by which, in the

case of ADHD research, credible evidence is reaching the education system, parents, popular media outlets, and the growing unregulated media outlets

While the global diffusion and the prevalence of ADHD means that it could become one of the leading childhood mental health difficulties treated with medication, it is crucial that recommendations of treatment with medication be linked to independent systematic reviews that assess the effectiveness of such treatment. Equally, knowledge exchange methods used by pharmaceutical companies, parents associations, and religious groups, such as social networking (McPherson et. al. 2001), social marketing (Martin et. al 1998), and direct to consumer techniques (Hollon 1999) should not be ignored. Rather, they should be considered, evaluated, and implemented where suitable.

Capacity

The capacity for knowledge exchange in ADHD appears to be underdeveloped (York, A. & Lamb, C. 2005), although there is clear consumer demand (Conrad & Leiter 2004) for accessible and utilizable research results. The challenge of building capacity to engage in knowledge exchange in ADHD includes the abilities to: articulate needs; link to partners for improvement of outcomes; identify and engage with (access, implement, utilize, evaluate) credible evidence in the wider domain of child and youth mental health, and; identify and engage with (access, implement, utilize, evaluate) credible evidence in knowledge exchange. It is unclear what is the current capacity to address existing and to identify emerging barriers to utilization of ADHD research however, there appears to be sparse efforts on improving the effectiveness and efficiency of knowledge exchange methods based on the results of evaluation and experimentation. It is also unclear whether there is capacity to measure dissemination and diffusion of credible ADHD evidence into policy, practice, and programs.

Starting Points

The starting point for knowledge exchange activities at the Centre is with a framework that explicitly outlines an overview of the people, processes, and potential return for engaging in

these activities. In the example of the “Grants and Awards Programs” the knowledge exchange framework provides details about the following: the date, version, title, and background information of the framework; the principal contact person for the framework, as well as details for Centre personnel, consultants, and technical experts who will be included in the knowledge exchange activities, and; knowledge exchange tools that will be used such as a checklist, plain language summaries of research reports, multi-stakeholder policymaker meetings, synthesis papers, a conference, travel grants, website use, wiki use, and email.

The framework presents in detail, the time-frame, goals (such as building relationships among diverse stakeholders in child and youth mental health, pushing out research and process results, pulling in stakeholders to discuss results, facilitating implementation in practice, increasing uptake of research, increasing capacity for knowledge exchange in CYMH, increasing public awareness of evidence for support of an integrated CYMH system), output (such as products: papers, reports, syntheses, meetings, conferences, and processes: discussion, critique and development of practice, stakeholder involvement, development of relationships, capacity development, training) outcomes (including that results are understood by multiple stakeholders, development of accessible products, increased knowledge and awareness of CYMH issues in Ontario, stronger networks, increased capacity for knowledge exchange of CYMH research, increased uptake of results into practice, policy, and perspective, increased trust among stakeholders), and expected impact of the proposed knowledge exchange activities.

In this example the impact is expected to be the setting of precedent for knowledge exchange in CYMH grants, a movement towards integrated CYMH system and a movement towards increased infrastructure for evidence-based practice in CYMH. The knowledge exchange activities are directly linked to an evaluation framework of the Grants and Awards Programs.

Action for ADHD

Knowledge exchange activities may reduce the confusion for parents and caregivers, prac-

tioners, researchers, and administrators, seeking the most credible data, information and knowledge about the most effective treatments for ADHD. An active process that seeks to improve knowledge exchange for ADHD is needed in Canada. The examples from the US and the UK demonstrate that with resources and an infrastructure, it is possible to concisely provide evidence to multiple audiences.

The Centre has begun the process of linking a systematic evidence assessment process to a systematic knowledge exchange process however; the efforts required are outside the resources or abilities of any single institution or agency. It is becoming increasingly clear that knowledge exchange that pushes, pulls, links, and engages all partners in the process of how to produce the best outcomes for those in our care, indeed must actively involve all partners.

Given this necessary involvement, as a clinician and/or a scientist are you exchanging knowledge in the most effective ways to the most appropriate and extensive audiences? Doing the best possible research or developing the most important clinical evidence and then not actively engaging in the processes most appropriate to the broadest of audiences significantly minimizes the value of important work. Yet, for many, the path is set – research, publish...research, publish...After all, getting set in one’s ways is a human condition.

This article focuses on knowledge exchange and presents concepts in three associated categories – context, content and capacity. It is hoped that with this framework, clinician scientists can be more mindful and therefore more inclusive about how better to disseminate their new findings. What do we know? To whom should the information be conveyed, in what format and at what educational level should it be translated? Should it be pushed out in various and different formats and via different media? In essence, how can new findings reach extensive and diverse audiences in the most appropriate formats, in a timely and user-friendly manner? Furthermore, how can I best link to other stakeholders? What information do they have that I need?

Taking important new findings to this new level of knowledge exchange may not be comfortable for clinician scientists who are not ini-

tially used to doing this. However, the effort will be reinforced by far enhanced uptake of the new findings. Such change can only enhance the field of child and youth mental health. Similarly, it will also allow for the development of best practices in knowledge exchange. Such a change in dissemination of child and youth mental health information is essential.

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