SUPPORTING EVIDENCE USE IN COMMUNITY-BASED ORGANIZATIONS

SUPPORTING THE USE OF RESEARCH EVIDENCE BY COMMUNITY-BASED ORGANIZATIONS IN THE HEALTH SECTOR

By

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Abstract

Community-based organizations are important stakeholders in health systems and research evidence can inform many aspects of their work, including their delivery of programs and services and their advocacy for broader system level supports. Unfortunately, there have been few visible efforts, such as those developed for other stakeholders (e.g., health system professionals and policymakers) to support the use of research evidence in community-based organizations. I have begun to address this need in this thesis through four manuscripts that collectively use a mix of approaches and methods to contribute to better supporting the use of research evidence by community-based organizations as well as to evaluating these efforts. Specifically, in the chapters I present: 1) a framework for supporting the use of research evidence by community-based organizations; 2) a scoping review of the key characteristics of community-based organizations; 3) a qualitative study of executive directors and program managers of community-based organizations in three sectors in Ontario, Canada (HIV/AIDS, diabetes, and mental health and addictions) to develop approaches to user-friendly summaries and peer-relevance assessments of systematic reviews; and 4) a protocol for a randomized controlled trial evaluating the effects of an evidence service on community-based AIDS service organizations' use of research evidence. Each of the chapters contributes to the development of a novel area of research in knowledge transfer and exchange and the thesis as a whole provides a framework, resources, and practical tools for those interested in supporting the use of research evidence by community-based organizations. A number of important areas for future research have emerged from this thesis including conducting long-term evaluations of efforts to support the use of research by community-based organizations, developing and refining theories related to whether, how and why they use research evidence, and developing additional strategies to support their use of research evidence, including deliberative dialogues and capacity building.

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Preface

This thesis presents four original scientific contributions (chapters 2-5) as well separate introduction and conclusion sections (chapters 1 and 6). The first chapter, which is entitled Community-Based Knowledge Transfer and Exchange: Helping Community-Based Organizations Link Research to Action, is published in Implementation Science, which is an open access journal. As such, copyright is held by each of the co-authors (myself, Dr. John N Lavis, Dr. Robb Travers and Dr. Sean B. Rourke) and each have provided written permission to McMaster University to reprint the article as part of this thesis.

Chapters 2-5 are co-authored and I am the lead author for each. I conceived of each chapter in collaboration with my supervisor (Dr. John N. Lavis) and my supervisory committee (Dr. R. Brian Haynes, Dr. Parminder Raina, Dr. Greg Stoddart and Dr. Jeremy Grimshaw). Additionally, I completed all data collection and analysis for each chapter. For the chapter entitled Community-Based Organizations in the Health Sector: A Scoping Review, Adrian Guta (a PhD candidate in the Dalla Lana School of Public Health, University of Toronto) completed the duplicate title and abstract reviewing. I drafted all chapters and each co-author read and provided comments and suggested revisions, which I incorporated.

Introduction

Supporting the use of research evidence by stakeholders in the health sector is important for strengthening the health systems within which they work and the programs and services that they provide. Efforts to support the use of research evidence by clinicians (1-6) and policymakers (7-10) have garnered particular attention. Such efforts are important as research evidence can be used to inform many types of decisions about health systems. This could include decisions *about* health systems (i.e., about the governance, financial and delivery arrangements within which health-related programs and services are provided) and *within* health systems (i.e., the programs, services, drugs and devices to fund, cover or deliver) (11). Research evidence can be used to inform the key stages of decision-making processes. In the context of policymaking, decision-making processes often include three important stages: 1) clarifying the problem or issue at hand (12); 2) identifying and selecting options to address the problem (13); and 3) developing a strategy to address how a policy option, program or service will be implemented (14). Unfortunately, despite their importance as stakeholders in health systems, there have been few visible efforts to support the use of research evidence in community-based organizations (i.e., not-for-profit organizations such as non-governmental, civil society organizations, or other grassroots organizations, overseen by an elected board of directors and guided by a strategic plan developed in consultation with community stakeholders) such as those that have been developed for health system professionals (5;15-17) and for managers, and policymakers (10;18;19).

The lack of focus on supporting the use of research evidence by community-based organizations is an important gap to fill as they provide numerous, often highly valued programs and services to the members of their community, frequently to the most marginalized, disadvantaged and stigmatized sections of society (20-28). Similarly, in response to limited access to health services, community-based organizations often provide essential primary healthcare, especially for the very poor, women and children in low- and middle-income countries (24;29).

In addition to providing important health services and programs, community-based organizations often play important advocacy roles with the aim of strengthening the health systems in which they work (21;22;29-31). They are often called upon to collaborate with health system decision-makers and stakeholders in the development of policy, programs and services (32-36), and are increasingly involved in the production of research (37;38). Such activities help to facilitate the involvement of communities and the public in the planning and implementation of their healthcare, which was a key principle of The Declaration of Alma Ata (39). Furthermore, the involvement of community-based organizations (and the public) in decision-making has been shown to increase the likelihood that policies will be appropriate, acceptable and effective (21;40).

I have begun to address this gap through a series of four original scientific contributions that collectively use a mix of approaches and methods to contribute to better supporting the use of research evidence by community-based organizations as well as to evaluating these efforts. Specifically, in chapter 2 I outline a framework for supporting the use of research evidence by community-based organizations by: describing the concepts and methods for community-based research (an approach to research that community-based organizations increasingly turn to given its participatory focus and emphasis on linking research to action) and for knowledge transfer and exchange; comparing the efforts of community-based research to link research evidence to action to those discussed in the knowledge transfer and exchange literature; and using the comparison to develop a framework for 'community-based knowledge transfer and exchange'.

In chapter 3, I present a scoping review of the literature about the key characteristics of community-based organizations. Community-based organizations are often described using diverse terminology and concepts from across a range of disciplines. To help develop a better understanding of the sector, the scoping review identified the existing research literature, conceptually mapped it, and identified gaps and areas for future inquiry.

Chapter 4 consists of a qualitative study that I conducted to further investigate the characteristics of community-based organizations and to develop approaches to preparing user-friendly summaries and peer-relevance assessments of systematic reviews. In this study, I conducted focus groups and follow-up interviews with executive directors and program managers of community-based organizations from the HIV/AIDS, diabetes, and mental health and addictions sectors in Ontario, Canada. In addition, I built on previous research related to developing user-friendly summaries for systematic reviews (11;41) and for peer-relevance assessments (5;11).

In chapter 5, I present a protocol for randomized controlled trial (RCT) designed to evaluate the effects of an evidence service on community-based AIDS organizations' use of research evidence. For the trial I developed '**S**ynthesized **H**IV/**A**IDS **R**esearch **E**vidence' (SHARE), which is an evidence service for those working in the HIV sector. SHARE consists of several components: 1) an online searchable database of HIV-relevant systematic reviews (retrievable based on a taxonomy of topics related to HIV/AIDS and open text search), 2) periodic email updates, 3) access to user-friendly summaries, and 4) peer relevance assessments. The objective of the RCT is to evaluate whether this "full serve" evidence service increases the use of research evidence by key decision-makers in community-based organizations as compared to a "self-serve" evidence service. To further understand the results of the RCT, the study will include a follow-up qualitative study to assess participants' views about and their experiences with the evidence service they received, how helpful it was in their work, why it was helpful (or not helpful), what aspects were most and least helpful and why, and recommendations for next steps.

Combined, these four scientific contributions provide a framework and practical tools to help those involved with supporting the use of research evidence by community-based organizations, offers insight into the key characteristics of community-based organizations and their important roles in health systems, and provides an approach to evaluating knowledge transfer and exchange interventions. As a result, this thesis provides an initial important step towards sustained efforts to support the use of research evidence for community-based organizations.

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Community-based knowledge transfer and exchange: Helping community-based organizations link research to action*

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Abstract

Background

Community-based organizations (CBOs) are important stakeholders in health systems and are increasingly called upon to use research evidence to inform their advocacy, program planning, and service delivery efforts. CBOs increasingly turn to community-based research (CBR) given its participatory focus and emphasis on linking research to action. In order to further facilitate the use of research evidence by CBOs, we have developed a strategy for community-based knowledge transfer and exchange (KTE) that helps CBOs more effectively link research evidence to action. We developed the strategy by: outlining the primary characteristics of CBOs and why they are important stakeholders in health systems; describing the concepts and methods for CBR and for KTE; comparing the efforts of CBR to link research evidence to action to those discussed in the KTE literature; and using the comparison to develop a framework for community-based KTE that builds on both the strengths of CBR and existing KTE frameworks.

Discussion

We find that CBR is particularly effective at fostering a climate for using research evidence and producing research evidence relevant to CBOs through community participation. However, CBOs are not always as engaged in activities to link research evidence to action on a larger scale or to evaluate these efforts. Therefore, our strategy for community-based KTE focuses on: an expanded

model of ‘linkage and exchange’ (*i.e.*, producers and users of researchers engaging in a process of asking and answering questions together); a greater emphasis on both producing and disseminating systematic reviews that address topics of interest to CBOs; developing a large-scale evidence service consisting of both ‘push’ efforts and efforts to facilitate ‘pull’ that highlight actionable messages from community relevant systematic reviews in a user-friendly way; and rigorous evaluations of efforts for linking research evidence to action.

Summary

Through this type of strategy, use of research evidence for CBO advocacy, program planning, and service delivery efforts can be better facilitated and continually refined through ongoing evaluations of its impact.

Background

Strategies for promoting evidence-based medicine have been well established in the literature (1-6), and efforts for facilitating the use of research evidence among health system managers and policymakers have been increasingly articulated in recent years (7-13). Unfortunately, there have been few visible efforts, such as those developed for health system professionals, managers, and policymakers, to support the use of research evidence in community-based organizations (CBOs). By CBOs we mean not-for-profit organizations such as non-governmental, civil society organizations, or other grassroots organizations, overseen by an elected board of directors and guided by a strategic plan developed in consultation with community stakeholders. This is disappointing because CBOs constitute important health system stakeholders as they provide numerous, often highly valued programs and services to the members of their community, who are often marginalized and/or stigmatized members of society (*e.g.*, people living with HIV/AIDS, and/or with mental health and addictions issues). Therefore, in order for CBOs to more effectively link research evidence to action in health systems and to strengthen the health systems in which they work, there is a need to better support their efforts to find and use research evidence. While we recognize that research evidence is only one input into the varied and complex decision-making processes of CBOs, it can play an important role in strengthening the effectiveness of their work.

In order to support the use of research evidence by CBOs, our primary objective is to develop a strategy for community-based knowledge transfer and exchange (KTE) that helps CBOs more effectively link research evidence to action. To address this goal, our specific objectives are: to outline the primary characteristics of CBOs, and why they are important stakeholders in health systems; to outline the concepts and methods of community-based research (CBR) and KTE; to compare the potential of CBR to link research evidence to action to those efforts more commonly discussed in the KTE literature; and to develop a strategy for community-based KTE that builds on both the strengths of CBR and existing KTE frameworks.

Discussion

What are CBOs?

The terminology used to describe CBOs can be quite diverse. The terms civil society organizations, grassroots organizations, and non-governmental organizations are commonly used to refer to the same or similar type of organization. In addition, these descriptors may vary based on the sector or ‘community’ that CBOs serve (*e.g.*, ‘AIDS service organizations’ are often used in the HIV/AIDS sector in Canada). Furthermore, the notion of community and the organization of communities may be operationalized differently depending on the circumstances in which it is used (14). For instance, Jewkes and Murcott (1998) analyzed how ‘community’ is operationalized in the context of identifying ‘community representatives’ for the purposes of achieving community participation. They found that ‘community representatives’ were often drawn from one small part of the voluntary sector (14). In a context where community is limited to what Jewkes and Murcott (1998) call a voluntary sector ‘elite’, the notion of inclusive and democratized health systems decision-making may be compromised (14).

Despite the variability in the language used to describe community and CBOs, there are several descriptions in the literature relating to the core characteristics of ‘community’. The most common and far reaching conceptions of ‘community’ relate to physical location or geographical areas (*e.g.*, neighbourhoods) (15-19), common interests (*e.g.*, values, norms, goals, or more specific attributes of a group such as gender or sexuality) (15-19), and joint action, activities, and patterned social interaction (*e.g.*, volunteer activities and social networks) (16-19). In addition, communities have also been described using a fourth characteristic that involves people organizing and interacting politically for the purpose of producing change (20). Using many of these core characteristics, MacQueen *et al.* (2001) define community as ‘a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings.’

Using the above characteristics and definition of community as a guide, several basic characteristics of CBOs become evident. First, the roles of CBOs are often guided by a specific mission (*i.e.*, an overall goal) that is shaped by commonly held values within the community that the CBO serves. Second, CBOs often have a governance structure consisting of board members that are elected from the members in the community. Third, they are typically not-for-profit organizations that are financed/funded through a combination of government and/or philanthropy (often from the communities they serve). Fourth, CBOs often deliver a specific set of programs or services that are shaped by the mission and values of the organization. Furthermore, many CBOs now have a growing interest in both using and conducting research (often in the form of CBR), with some CBOs explicitly incorporating a mandate to use and produce research evidence as part of their primary functions (21-23).

Why are CBOs important stakeholders in health systems?

Calls for community involvement in health system activities can be found in a number of World Health Organization (WHO) strategies, including the Alma Ata Declaration, *Health for All by 2000*, *Health 21: Health for all in the 21st Century* (24), and the healthy cities initiative (25). The Declaration of Alma Ata was unanimously adopted by all WHO member countries in 1978 with the WHO recently re-affirming its commitment to it in 2008 (26). The Declaration states that:

> ‘primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost the community and country can afford to maintain

> at every stage of their development in the spirit of self-reliance and self-determination' (27).

Further, the Declaration states that the people have a right and duty to participate individually and collectively in the planning and implementation of their healthcare (27). Similarly, the strategies and agreements that have been based on the Alma-Ata Declaration — *Health for All by 2000,* the *Ottawa Charter for Health Promotion* and *Health for All in the 21st Century* — state in their key strategic principles that in order to 'close the gaps' in health (*i.e.*, reduce health inequalities) community action needs to be strengthened, inter-sectoral collaboration among stakeholders is needed and communities and CBOs need be included as key policy stakeholders (24;28).

In addition to these international and national health strategies, WHO's healthy cities initiative also promotes inter-sectoral participation of communities and CBOs for achieving the *Health for All* strategies at the local level (25). By including CBOs, it has been argued that delivery of basic health services (specifically in low-income countries) and accountability for public systems of providers can be improved (29). In sum, CBOs are increasingly being asked to play important roles in health systems throughout the world, and there is a need to help them in this work by supporting their use of research evidence.

CBR — A brief overview of concepts and methods

Community-driven research initiatives are emerging as a useful source of research evidence for CBOs. Specifically, CBR (the terms action research, participatory research, and community-based participatory research are also commonly used in the literature) is rapidly emerging as an approach for addressing the complex health, social, and environmental problems that CBOs often address in their advocacy, program planning, and service delivery efforts (21;30-34).

Perhaps as a corollary to the growing interest in CBR from CBOs and academics in an increasing number of countries, there are a number of definitions available in the published literature (30;32;35-37). One very popular definition, frequently cited in health-related literature, comes from Minkler and Wallerstein (2003) who define community-based participatory research as a:

> '...collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. [Community-based participatory research] begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities' (30).

It is evident from this definition (and others in the literature) that three interrelated core principles or tenets characterize CBR as a unique approach to research: full participation in research processes by community members; producing relevant research evidence; and ensuring action is spurred by study findings (38). In addition to these three principles, Minkler (2005) notes that ‘individual, organizational, and community empowerment also is a hallmark of this approach to research’ (38).

As can be seen, CBR is a ‘user driven’ and action-oriented approach to research (*i.e.*, focused on influencing policy, and practice) that was originally developed to ‘emphasize the participation, influence, and control by non-academic researchers in the process of creating knowledge and change’ (32). The primary argument in support of these efforts to foster collaborative and equitable partnerships with members of the community is that their inclusion helps increase the relevance of the research evidence produced, which has been demonstrated in a number of CBR studies involving marginalized populations (39-42). With more relevant research evidence produced by incorporating local priorities from the outset, the effectiveness of health system planning and reform efforts can potentially be increased and time and money ultimately saved (34).

A good example of the importance of promoting collaboration and partnerships with community comes from the HIV/AIDS sector under the Greater Involvement of People Living with HIV/AIDS (GIPA) principle (43;44), which ‘has evolved into a broad philosophy meant to underpin all forms of intervention (prevention, treatment, support, policy, and research) with persons living with HIV/AIDS’ (22). In the context of CBR, greater involvement of people living with HIV/AIDS can be operationalized in various ways, such as shared decision-making power with researchers or incorporating research skill building for people living with HIV/AIDS as a goal in CBR projects (22). Implementing the GIPA principle through mechanisms such as these has been shown to result in enhanced credibility of community-based AIDS service organizations as policy actors (45), as well as reduced stigma and isolation (46) and increased feelings of personal empowerment and self-worth for people living with HIV/AIDS (47;48).

The CBR approach is also starting to gain recognition on a larger scale with major research funders such as the National Institutes of Health, the Agency for Healthcare Quality and Research, and the Centers for Disease Control in the United States, as well as the Canadian Institutes of Health Research and the Social Sciences and Humanities Research Council of Canada, now providing funds for general operating grants as well as capacity-building in support of community-academic partnership development (49-53). In addition, Science Shops, which were originally developed in the Netherlands in the 1970s, have emerged as important community driven entities throughout the world (*e.g.,* in central and eastern Europe and in China) that ‘provide independent, participatory research support in response to concerns experienced by civil society’(54;55).

KTE — A brief overview of concepts and methods

There are many terms available for what we call KTE or more generally, putting knowledge into action (56;57). For instance, Straus *et al.* (2009) indicate that the terms implementation science and utilization are often used in the UK and

Europe, and dissemination or diffusion are commonly used in the US (57). In Canada, the Canadian Institutes of Health Research, which is the country's largest funding body for health related research, uses the term knowledge translation and defines it 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 through improved health, more effective services and products, and a strengthened health care system'(58). However, as Straus *et al.* note, despite the differing terminology, the core theme or goals that ties them together is moving beyond simple and passive dissemination of research evidence to more effectively facilitate its actual use (57).

While this is an important goal, efforts to link research evidence to action face many challenges. Specifically, Lavis *et al.* (2006) identify four primary challenges related to linking research evidence to action: research evidence competes with many other factors in decision-making processes; decision-makers may not value research evidence as an information input into decision-making processes; available research evidence may not be relevant for certain audiences; and research evidence is not always easy to use (59). However, through a multi-faceted and interactive KTE strategy, the latter three challenges can be addressed in order to allow research evidence to play a stronger and more prominent role in decision-making processes (*i.e.*, to help address the first challenge).

Lavis *et al.* (2006) provide a helpful framework for developing such a KTE strategy that addresses the challenges outlined above. The framework consists of four primary methods for linking research evidence to action: fostering a culture that supports the use of research evidence (*i.e.*, within the target audience); producing research evidence that is relevant to the target audience; undertaking a range of activities for linking research evidence to action (‘producer push,’ facilitating ‘user pull,’ ‘user pull’ and ‘exchange’); and evaluating efforts to link research evidence to action.

The first element of the framework — fostering a culture for research evidence — helps to ensure that target audiences are not only receptive to the idea of using research evidence in their decision-making but also place value on using it in their decision-making. If target audiences are receptive to using research evidence and place value on it as an input into decision-making, it is more likely that efforts to produce relevant research evidence and to disseminate it through integrated strategies (*e.g.*, ‘producer push’ efforts or efforts to facilitate ‘pull’) will be successful in linking it to action.

In the second element of their framework, Lavis *et al.* (2006) highlight the notion that there needs to be research evidence available that is relevant to the topics and issues that decision-makers are addressing in their work (*e.g.*, CBOs in the HIV/AIDS sector may require research evidence about how to organize an HIV prevention program in their community). The production of relevant research evidence can be supported through activities such as priority setting processes that involve target audiences and developing research funding calls based on the priorities identified. Examples of priority setting for research include the Listening for Direction consultation process for health services and policy issues that is conducted with national healthcare organizations in Canada every three years (60), or involving patients or patient representatives in the planning or development of healthcare (61-64) and in setting health system research agendas (65-67)

In addition to producing relevant research evidence, there is a need to ensure that it is likely to yield reliable actionable messages wherever possible (7). A viable option for achieving this is conducting systematic reviews because they analyze the global pool of knowledge in a particular topic area. As a result, reviews constitute a more efficient use of time for research users because all information on a specific topic has already been identified, selected, appraised, and synthesized in one document (59). Systematic reviews also offer a lower likelihood of providing misleading findings than other forms of research (*e.g.*, a single observational study) and provide increased confidence in the findings due to the gains in precision that are obtained through synthesis of multiple studies (59). In addition to these benefits, methods for systematic reviews are rapidly expanding (*e.g.*, realist synthesis, meta-ethnography, or, more generally, syntheses of qualitative evidence), which allows for the incorporation of a broader spectrum of research evidence (68-75). While the methods for syntheses of qualitative evidence are still developing, their production has increased in recent years with the Cochrane Qualitative Research Methods Group's reference database of qualitative reviews now providing references to over 360 syntheses (76). Consequently, reviews are now better able to answer a broader spectrum of questions that may be asked in health systems (*i.e.*, beyond questions of effectiveness) such as cost-effectiveness, and relationships and meanings, which increases their relevance to a broader range of target audiences (*e.g.*, CBOs and health system managers and policymakers) (59;77).

The third element of the framework focuses on activities for linking research evidence to action, which includes four primary strategies that can be employed to produce a multi-faceted approach: 'producer push' efforts (*i.e.*, producers of research disseminating findings to target audiences); efforts to facilitate 'user pull' (*i.e.*, making research evidence available for target audiences when they identify the need for it); 'user pull' mechanisms (*i.e.*, target audiences incorporating prompts for research evidence in their decision-making processes and developing their capacity to find and use research evidence); and 'exchange' efforts whereby the producers and users of researchers engage in a process of asking and answering questions together (*i.e.*, building partnerships and working collaboratively in all stages of the research process, from the setting of research priorities, to conducting research, and linking findings to action). As can be seen, the fourth strategy of 'exchange' is also relevant to fostering a culture for research (*e.g.*, engaging research users in the origination of an idea, proposal development, research conduct, and dissemination may increase the value they place on research) and in the production of relevant research evidence (*e.g.*, through priority setting activities) (11;78;79).

Further building on ‘push’ efforts for linking research evidence to action, there are several steps to work through in order to effectively employ these efforts, which include identifying: the types of messages to be transferred and where they should be drawn from (*i.e.*, systematic reviews, single studies or a combination); the target audience (to ensure the messages from research are presented in a way that is meaningful to them); credible messengers (a trusted messenger may have greater access to or influence among target audiences); and optimal processes and communications structures for delivery of key messages (*e.g.*, providing a database that is searchable based on terms that are meaningful and relevant to the target) (7).

The last aspect of the framework is evaluating our efforts to link research evidence to action in order to determine which aspects of the strategy work (or don’t), how and under what conditions. Without rigorous evaluations of efforts to link research evidence to action, we are left with anecdotal or indirect evidence about what works in KTE, which limits future efforts to modify, refine, and increase the effectiveness of our strategies.

Similarities between CBR and KTE

While KTE is largely about harnessing existing research evidence and CBR is mostly concerned with generating new evidence, the approaches have many similarities with respect to their methods for linking research evidence to action, especially the importance placed on partnerships before, during, and after research initiatives. In order to further illuminate these similarities, we compare the four methods from the KTE literature (with examples) for linking research evidence to action, to examples of common approaches used by CBR. In doing so, we draw on examples from Canada's HIV sector and, to a lesser extent, from other jurisdictions.

As can be seen from Table 1, CBR and those involved in it (*i.e.*, CBOs, researchers, research funders) may employ a number of strategies for linking research evidence to action within the four methods outlined from the KTE literature. Given that CBR encourages partnerships between researchers and community, it is not surprising that this helps to foster a culture that supports the use of research evidence, especially if it is relevant to the needs and priorities of a community. In contrast, we can see that CBR, with the exception of 'exchange' efforts, lacks coordinated large scale efforts that attempt to provide actionable messages from a large pool of knowledge or that attempt to reach beyond the specific community (or individual study) on which a study was focused.

Strengths and limitations of CBR for linking research evidence to action

Based on this comparison, it appears as though CBR is more effective in some of the areas for linking research evidence to action than others. In Table 2, we present, based on the common approaches outlined in Table 1, areas where CBR is particularly strong at linking research evidence to action and areas where it appears to be limited in its reach, in order to help identify domains for strategic expansion.

As can be seen in Table 2, CBR has a number of strengths for linking research evidence to action at the local level, especially for fostering a culture that supports the use of research evidence, production of relevant research evidence, and ‘exchange’ activities. We can see that the emphasis placed upon partnerships between researchers and community helps to foster a culture that supports the use of research evidence within those CBOs involved in CBR. It also supports the production of relevant research evidence by ensuring that CBR projects address issues that are important to the community while remaining sensitive to their needs. Furthermore, the community networks and partnerships developed through CBR help with ‘push’ efforts targeting the local level. CBO and community participation in CBR also provides important opportunities for capacity building, which helps to facilitate user ‘pull’ because they are better equipped to acquire, assess, adapt, and apply research evidence in their settings.

Although CBR does exhibit several strengths, there are also several limitations that are apparent. For example, in Table 2 we point out that the scope of partnerships with CBOs and community may be limited to those that already have a culture that supports the use of research evidence. As such, the research priorities developed through these partnerships may not accurately reflect the needs of the target audience. An additional limitation that emerges from Table 2 is the mix of research evidence being produced and its impact on the actionable messages that can be derived. CBR is often focused on the production of single, locally-based studies and does not typically synthesize global pools of knowledge on community issues in order to provide actionable messages to a broader audience. This does not mean that single CBR studies are unimportant, because they offer high utility by providing locally applicable information to CBOs, community, and researchers. Our contention is that these studies could be complemented by syntheses of research evidence on community relevant issues because they would help determine whether questions have already been answered in similar communities, allow participants to learn about the strengths and weaknesses of approaches that have previously been used, and would put results in the context of the global pool of knowledge (resulting in actionable messages that have broader applicability). Therefore, while CBR does offer very promising prospects for linking research evidence to action, there is a need to consider expanding these efforts to a larger scale, complementing single CBR studies with syntheses and by expanding KTE activities (*i.e.*, ‘push’, efforts to facilitate ‘pull,’ and ‘pull’).

A framework for community-based KTE

In Table 3, we provide an outline for additional activities that are intended to build upon and complement current CBR efforts for linking research evidence to action. Our proposed framework focuses on four primary areas: developing and maintaining partnerships; increasing the production of community relevant systematic reviews; creating an integrated and large-scale evidence service; and evaluating efforts to undertake CBR and to link research evidence to action. First, across the spectrum of the framework, we maintain CBR principles by placing emphasis on partnerships between researchers, CBOs, community members, and other stakeholders through a model of 'linkage and exchange.' Maintaining these principles is important because it not only helps to ensure the production of 'user driven' relevant and action-oriented research evidence but also helps to position CBOs as policy actors in health system decision-making forums where they may not normally be included.

Second, we outline throughout the framework a greater emphasis on both producing and disseminating systematic reviews that address topics of interest to CBOs because they are more likely to provide reliable actionable messages than single research studies. Furthermore, systematic reviews can represent a more efficient use of time for busy CBOs because they provide a reliable assessment of an entire pool of knowledge on a given topic. Therefore, in Table 3, we outline various activities related to systematic reviews for fostering a culture of research (*e.g.*, engaging CBOs in the conception, production and updating of reviews), generating community relevant reviews (*e.g.*, priority setting processes for areas where reviews can be completed), activities to link research evidence to action (*e.g.*, 'one stop shopping' websites/databases for community relevant systematic reviews and capacity building workshops designed to help CBOs find and use research evidence), and evaluation of efforts to link research evidence to action (*e.g.*, evaluating the impact of 'one stop shopping' websites on the use of research evidence in CBOs).

The third area of focus for our framework is on developing a large-scale evidence service consisting of both 'push' (*e.g.*, email updates to new and relevant systematic reviews) and efforts to facilitate 'pull' (*e.g.*, a 'one stop shopping' database) that highlight the take-home messages (actionable messages where possible) from community relevant systematic reviews in a user-friendly way for CBOs (*e.g.*, short, structured summaries that outline take-home messages, benefits, harms, and costs of the interventions, programs, or services addressed in a review). This type of evidence service will help ensure that CBOs have timely access to relevant and user-friendly systematic reviews either when they face decisions that could be informed by research evidence or when they are asked to participate in forums for health system strategizing and decision-making.

Finally, we propose that there is a need to develop collaborative and rigorous evaluation strategies that assess the impact of activities for linking research evidence to action to allow for ongoing refinement, modification, and expansion of KTE activities. This requires the implementation of a community-based KTE strategy, identification of relevant outcomes to be measured, availability of instruments to measure the desired outcomes, and rigorous study designs (*e.g.*, randomized controlled trials with an accompanying qualitative process evaluation) for the evaluation process.

Implications

Implementing a strategy such as this would build on important KTE structures and processes that have been previously implemented or are in the process of being implemented internationally for other stakeholders. For example, promising KTE services that integrate a number of the activities for linking research evidence to action that we present here are in development through two regional initiatives in low- and middle-income countries — the Regional East African Community Health (REACH) Policy Initiative and the WHO-sponsored Evidence Informed Policy Networks emerging in the Western Pacific, Africa, the Americas, and the Eastern Mediterranean (59;80). Similarly, from the clinical sector, Evidence Updates (81) and McMaster PLUS (5) are good examples of evidence services that disseminate high-quality and high-relevance studies at both the global and regional levels. In addition, results from a cluster randomized controlled trial of McMaster PLUS lends support to the idea of creating an integrated evidence service (*i.e.,* one that combines ‘push,’ efforts to facilitate ‘pull’ and ‘exchange’) because increases in clinicians’ utilization of evidence-based information from a digital library have been found (6).

By building upon existing KTE frameworks and developing this strategy for community-based KTE, we have taken an important step towards recognizing the important roles that CBOs' advocacy, program planning, and service delivery can play in health systems at the international, national, and local levels. In addition, it provides a practical outline for how to expand upon the existing efforts of those engaged in CBR in order to better support the research needs of CBOs. Such a strategy will help CBOs draw upon research evidence when engaging in international, national, and local healthcare system strategies, delivery, and decision-making.

Despite this, there are some potential criticisms and limitations that could be levied against the development of our framework and the framework itself. First, the derivation of our framework by comparing CBR to KTE and then drawing lessons from KTE is often based heavily on the Canadian context (although not exclusively). However, based on the fact that CBR is recognized by many funders and organizations outside of Canada (*e.g.*, the National Institutes of Health, Centres for Disease Control and Prevention, Agency for Healthcare Research and Quality, and 'science shops' that are located in numerous countries around the world), we feel that our descriptions and conclusions are relevant to other communities that are similarly engaged in CBR.

With respect to the framework itself, there are two potential limitations that are apparent. First, eventual implementation of our framework rests on the idea that there are (or will be) community-relevant systematic reviews available to build an evidence service. We believe that this limitation can be addressed through effective priority setting processes with CBOs, such as those in place for health system managers and policymakers (8;79), and through targeted funding streams and/or commissioning of research that address these priorities. Second, our proposal to place increased emphasis on systematic reviews could be argued to diminish the value of CBR and its grass roots approach. While recognizing this concern, we are not proposing that systematic reviews are the only source of research evidence. For instance, the actionable messages that may be derived from systematic reviews could be used in conjunction with locally applicable CBR studies and/or local data. In addition, CBR studies will continue to provide relevant and locally applicable research evidence where no reviews exist.

Future Research

Our framework provides multiple opportunities for future research initiatives. First, in order to allow for timely evaluation, there is a need to develop methods for evaluating the impact of the activities outlined in our framework. Second, there is a need for ongoing priority setting processes for systematic reviews that address the research needs of CBOs. Third, those involved in systematic review production can begin to partner with CBOs and produce reviews based on the priorities identified in order to continually build a stream of reviews to use in a future community targeted evidence service. Fourth, there is a need for in-depth consultation with CBOs in various sectors to determine the types of information that should be highlighted in user-friendly summaries of systematic reviews and optimal formats for the summaries (*e.g.*, 1:3:25 format — one page of take-home messages, three-page executive summary, and 25 page report) (82). Lastly, in-depth consultation about how to categorize and assess the relevance of reviews is needed before our framework can be operationalized.

Summary

With a growing need to make relevant and user-friendly research evidence available to CBOs in order to support their advocacy, program planning, and service delivery functions in international, national, and local health systems, we have developed a strategy for community-based KTE that will help CBOs more effectively link research to action at the community level.

CBR provides a useful source of research evidence as well as tools for linking research to action for CBOs, and the KTE literature provides helpful existing frameworks that can be used to determine strategic areas to help expand upon CBR to develop a strategy for community-based KTE.

CBR provides several useful tools and strategies for linking research evidence to action (*e.g.*, fostering a culture that supports the use of research evidence, promoting the production of relevant research evidence, and disseminating it through processes of ‘exchange’), but it is limited in the scale of its scope and activities and the activities employed for linking research evidence to action (‘push,’ efforts to facilitate ‘pull,’ ‘pull,’and ‘exchange’) are similarly limited in the scope of the target audience reached and the type of research and actionable messages transferred (*i.e.*, focused on single studies, as opposed to syntheses that may have greater applicability across communities).

Our strategy for community-based KTE focuses on: an expanded model of ‘linkage and exchange’; a greater emphasis on both producing and disseminating systematic reviews that address topics of interest to CBOs; developing a large-scale evidence service consisting of both ‘push’ efforts and efforts to facilitate ‘pull’ that highlights actionable messages from community relevant systematic reviews in a user-friendly way; and rigorous evaluations of efforts for linking research evidence to action.

Future research and initiatives in this area should focus on: developing methods for evaluating the impact of the activities outlined in our framework; ongoing priority setting processes for systematic reviews that address the research needs of CBOs; continually build a stream of research evidence to use in a future community-targeted evidence service by having those involved in systematic review production partner with CBOs to produce reviews based on their priorities; and conduct in-depth consultation with CBOs in various sectors for determining the types of information that should be highlighted in user-friendly summaries of systematic reviews, optimal formats for the summaries, and how to categorize and assess the relevance of reviews.

Competing interests

The authors declare that they have no competing interests

Authors' contributions

MGW contributed to the conception, design, wrote the original draft manuscript, and incorporated revisions from each of the co-authors. JNL contributed to the conception and design of the manuscript and provided revisions. RT contributed to the conception and design of the manuscript and provided revisions. SBR contributed to the conception and design of the manuscript and provided revisions. All authors read and approved the final manuscript.

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Table 1. Comparison of knowledge transfer and exchange (KTE) activities and community-based research (CBR) methods/community-based organization (CBO) initiatives for linking research evidence to action

Types of KTE Activities	Examples of KTE Activities	Examples of CBR methods and CBO initiatives
Fostering a culture that supports research use	▪ Some funders require ongoing ‘linkage and exchange’ (*i.e.*, producers and users of research evidence work collaboratively on proposal development and research conduct) (*e.g.*, the Canadian Health Services Research Foundation). ▪ Trusted researchers or knowledge brokers periodically highlight the value of research evidence (*e.g.*, highlighting positive examples of research use in practice or decision-making). ▪ Some funders provide grants for linking research evidence to action.	▪ CBR projects may use community advisory committees to engage community members in guiding the research process and the dissemination of the results. ▪ Some conferences that address issues of community interest develop strategies to include community members (*e.g.*, Community-Campus Partnerships for Health (CCPH) in the U.S.). ▪ Community members often play the role of co-principal investigator in CBR, which helps to foster a sense of leadership, responsibility, and ownership of the research.
Production of research to key target audiences	▪ Some funders engage in priority setting with key target audiences to ensure that systematic reviews and primary research address relevant questions (*e.g.*, the Listening for Direction priority setting process for health services and policy research from the Canadian Health Services Research	▪ Some CBR funders and intermediary organizations periodically organize multi-stakeholder ‘think tanks’ to develop a research agenda through consensus. ▪ CBOs, researchers, research funders, and government periodically form task forces related to specific areas of interest for the purpose of coordinating action on community generated research agendas.

	Foundation) (60). ▪ Some funders commission scoping reviews or rapid assessments of the literature to identify important gaps for targeted research funding. ▪ Some researchers involve members of the target audiences in the research process. ▪ Some networks of systematic review producers commit to updating them regularly (*e.g.*, the Cochrane Collaboration).	▪ CBR requires partnerships between researchers and community during all phases in the research process in order to ensure relevance and sensitivity to community concerns. ▪ Some CBR funders offer ‘enabling’ or ‘seed’ grants to assist in question identification, partnership development and protocol development.
Activities to link research to action		
‘Push’	▪ Some organizations provide email updates that highlight actionable messages from relevant and high quality systematic reviews (*e.g.*, SUPPORT summaries) (83). ▪ Researchers, funders or knowledge brokers will periodically engage in capacity building and consultations with research users to enhance their ability to undertake evidence-informed push efforts that meet the needs of their target audiences.	▪ Some organizations or associations develop websites/databases and listservs dedicated to highlighting research originating in and undertaken through community-university partnerships (*e.g.*, CCPH). ▪ Researchers, funders or knowledge brokers sometimes disseminate fact sheets or newsletters to highlight results from specific studies or about a specific topic of interest (*e.g.*, The Ontario HIV Treatment Network in Canada and CCPH in the U.S.). ▪ CBR partners often initiate community forums to

		present research results. ▪ Academic (and increasingly community) partners involved with CBR often present at conferences and publish in journals.
Facilitating ‘pull’	▪ Some groups provide ‘one stop shopping’ websites that provide user-friendly and high quality systematic reviews relevant to specific target audiences (*e.g.*, Health Systems Evidence)(84). ▪ Researchers, funders or knowledge brokers sometimes undertake capacity building with key target audiences to help better acquire, assess, adapt, and apply research evidence (*e.g.*, WHO sponsored workshops to help policymakers find and use research evidence).	▪ Some CBR projects develop websites to profile their research evidence and provide resources that they have produced as part of their research (*e.g.* the Positive Spaces Healthy Spaces housing project in Canada) (85). ▪ Some organizations or associations develop websites/databases and listservs dedicated to highlighting research originating in and undertaken through community-university partnerships (*e.g.*, CCPH). ▪ Some funders of CBR offer capacity-building resources to bring together community stakeholders for skill-building activities.
‘Pull’	▪ Some research users will design prompts in the decision-making to support research use ▪ Some research users will conduct self-assessments of their capacity to acquire, assess, adapt, and apply research and engage in capacity building activities in these areas.	▪ Some CBOs incorporate prompts to research evidence into their strategic goals or values (*i.e.*, incorporating organizational structures/processes for using evidence).
‘Exchange’	▪ Researchers and research users build partnerships and work	▪ CBR methods and CBR funders require partnerships between researchers and

	collaboratively in setting research priorities, conducting research and linking research to action.	community during all phases in research in order to ensure its relevance (*i.e.*, topics and outcomes measured) and sensitivity to community concerns and to facilitate eventual use of the results (*e.g.*, specific funding calls from the National Institutes of Health in the U.S., the Canadian Institutes of Health Research and the Social Sciences and Humanities Research Council in Canada).
Evaluation	▪ Some researchers and research funders evaluate the effectiveness of their efforts (*i.e.*, one or more of the activities outlined above) for linking research evidence to action.	▪ CBR projects sometimes engage target audiences in reflection processes about the specific impacts the project had (*e.g.*, was quality of life enhanced? If so, how?)

Acronyms used: CBO = community-based organizations, CBR = community-based research, KTE = knowledge transfer and exchange, CCPH = Community-Campus Partnerships for Health,

Table 2. Strengths and limitations of community-based research (CBR) for linking research to action

Types of KTE Activities	CBR strengths	CBR limitations
Fostering a culture that supports research use	▪ Funding typically requires partnerships between researchers and community members and/or CBOs (*e.g.*, funding calls from the National Institutes of Health in the U.S., the Canadian Institutes of Health Research and the Social Sciences and Humanities Research Council in Canada). ▪ Emphasis on capacity building and actionable outcomes resonates well with the grass roots orientation of many CBOs.	▪ Scope of partnerships often limited as community partners are often those that already have a culture that supports the use of research evidence. ▪ Often no dedicated funding for linking CBR to action (as opposed to funding to conduct the research). ▪ The process-oriented nature of CBR can push a project beyond initial timelines, limiting the ability of some partners to remain engaged long-term. ▪ Those who have the most influence on CBO culture (*e.g.*, Executive Directors) are not always included as the community partner from a CBO.
Production of research to key target audiences	▪ CBR projects are often developed through consultation with local communities in order to ensure they are addressing community relevant issues and needs.	▪ CBR projects typically take the form of single locally-based studies and not systematic reviews of studies conducted across a range of communities. ▪ CBR projects are not typically written up in a way that puts the findings in the context of the global pool of knowledge.

Activities to link research to action		
‘**Push**’	▪ Dissemination of actionable messages is often strong at the local level through the use existing networks and partnerships.	▪ Actionable messages derived from CBR projects often not shared on a larger scale (*i.e.*, outside the communities in which the CBR projects were conducted) despite their potential broader applicability. ▪ ‘Push’ efforts in communities limited to projects conducted locally (*i.e.*, potentially informative projects from other communities are not actively ‘pushed’ to relevant target audiences). ▪ Minimal capacity building designed specifically for enhancing ‘push’ efforts.
Facilitating ‘pull’	▪ Capacity-building for research within communities and CBOs through participation in CBR projects is a central goal of the CBR approach.	▪ No capacity building in acquiring, assessing, adapting, and applying research evidence. ▪ Few ‘one-stop shopping’ websites or resources exist that provide user-friendly, high-quality, and community--relevant research evidence (*e.g.*, CBR and/or community-relevant systematic reviews) with the actionable messages clearly identified.

‘**Pull**’	▪ Some CBOs and communities are effective at identifying research needs and partnering in CBR projects or seeking out research evidence.	▪ CBOs typically don’t have in place mechanisms to prompt them to review their programming in light of the available research evidence (either on a rotating basis for select programs or all at once during strategic planning). ▪ Smaller CBOs do not always have the capacity, resources or time to acquire, assess, adapt and apply research evidence in their settings.
‘**Exchange**’	▪ Equitable partnerships between community, researchers and other stakeholders are a core requirement of the CBR approach.	▪ Scope of partnerships often limited to the same researchers and community partners in many projects. Many not representative of the breadth of perspectives in the community. ▪ Other stakeholders (*e.g.*, healthcare managers and policymakers not always sought (or available) for partnerships.
Evaluation	▪ Some projects have systematically evaluated the types of topics previously addressed by CBR and the quality of those projects in order to inform future research and funding initiatives (31).	▪ Minimal efforts in the community sector to evaluate the impact of CBR and other community-based KTE strategies on action beyond those communities most directly involved in the CBR. ▪ If evaluations of the

		impact of research are completed, they may be done by the researchers of the study, thereby introducing a source of bias.

Acronyms used: CBO = community-based organizations, CBR = community-based research, KTE = knowledge transfer and exchange

Table 3: Framework for additional activities for community-based research (CBR) to link research to action

Types of KTE Activities	Proposed Additional Activities for CBR
Fostering a culture that supports research use	▪ Through an ongoing model of 'linkage and exchange', engage CBOs in the development, production and updating of community relevant systematic reviews in order to help increase their perceived value as an input to CBO decision-making. ▪ Widen the scope of CBR partnerships by seeking out new key stakeholders in the community (*e.g.*, knowledge brokers facilitating partnerships with stakeholders that are interested in addressing similar issues). ▪ Provide dedicated funds for projects that attempt to link CBR to action on a large-scale (*i.e.*, not only within local communities but also across jurisdictions at the provincial/state, national and international level). ▪ Within an evidence service that identifies actionable messages from research evidence (see activities for 'push' and facilitating 'pull' below), periodically highlight case studies where research was successfully used in a community setting to inform CBO advocacy, program planning or service provision.
Production of research to key target audiences	▪ Researchers and funders engage CBOs in priority setting processes for CBR studies in areas where there is minimal research, for systematic reviews in areas where there is pool of research evidence already accumulated, and for developing systems to link research evidence to action at the community level. ▪ Produce targeted funding streams based on priority setting with CBOs for CBR, community-relevant systematic reviews and initiatives to develop systems to link research evidence to action at the community level. ▪ Engage CBOs in the development, production and updating of systematic reviews in order to ensure they produce evidence that is relevant.
Activities to link research to action	
'**Push**'	▪ Develop an evidence service that identifies actionable messages for communities from relevant systematic reviews and involve credible messengers in providing them to CBOs in user-friendly formats (*e.g.*, short,

	structured summaries with graded entry to the full details of the review). ▪ Engage CBOs to develop a ‘push’ evidence service with a stream of community relevant systematic reviews (or CBR projects where reviews are not available).
‘Pull’	▪ Conduct periodic capacity-building initiatives with CBOs to help them identify areas where research can be used as an input into their decision-making. ▪ Periodically highlight instances where the use of research evidence made the difference between success and failure of a CBO initiative.
Facilitating ‘pull’	▪ Create an evidence service, in combination with ‘push’ efforts, that provides ‘one stop shopping’ websites/databases of relevant and user-friendly systematic reviews with actionable messages that can be located through search terms that are relevant to CBOs. ▪ Provide capacity-building to CBOs to help build their skills related to acquiring, assess, adapting and applying research evidence in their organization.
‘Exchange’	▪ Engage CBOs in deliberative dialogues where health system stakeholders gather to discuss a pre-circulated evidence brief and have ‘off-the-record’ deliberations (*e.g.*, the McMaster Health Forum). ▪ Engage CBOs in the development, production, and updating of systematic reviews in order to build and maintain partnerships between relevant stakeholders. ▪ Use knowledge brokers and/or other credible messengers to promote additional partnerships with CBOs previously not engaged in CBR and other interested stakeholders.
Evaluation	▪ Researchers, CBOs, and funders work collaboratively to rigorously evaluate the impact of strategies to link research evidence to action such as those outlined above (*e.g.*, evaluating the effectiveness of an evidence service for relevant and user-friendly systematic reviews that combines ‘push’ and efforts to facilitate ‘pull’).

Acronyms used: CBO = community-based organizations, CBR = community-based research, KTE = knowledge transfer and exchange

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Community-based organizations in the health sector: A scoping review

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Abstract

Background

Community-based organizations are important health system stakeholders as they provide numerous, often highly valued programs and services to the members of their community. However, community-based organizations are described using diverse terminology and concepts from across a range of disciplines. To better understand the literature related to community-based organizations in the health sector, we conducted a scoping review to identify existing literature, conceptually map it, and identify gaps and areas for future inquiry.

Methods

We searched 18 databases and conducted citation searches using 15 articles to identify relevant literature. All search results were reviewed in duplicate and were included if they addressed the key characteristics of community-based organizations or networks of community-based organizations. We then coded all included articles based on the country focus, type of literature, source of literature, academic discipline, disease sector, terminology used to describe organizations and topics discussed.

Results

We identified 190 articles addressing topics related to the key characteristics of community-based organizations and/or networks of community-based organizations. The literature is largely focused on high-income countries and on mental health and addictions, HIV/AIDS or general/unspecified populations. A

large number of different terms have been used in the literature to describe community-based organizations and the literature addresses a range of topics about them (mandate, structure, revenue sources and type and skills or skill mix of staff), the involvement of community members in organizations, how organizations contribute to community organizing and development and how they function in networks with each other and with government (e.g., in policy networks).

Discussion

Given the range of terms used to describe community-based organizations, this scoping review can be used to further map their meanings/definitions to develop a more comprehensive typology and understanding of community-based organizations. This information can be used in further investigations about the ways in which community-based organizations can be engaged in health system decision-making and the mechanisms available for facilitating or supporting their engagement.

Background

Community-based organizations are important health system stakeholders as they provide numerous, often highly valued programs and services to the members of their community. Specifically, community-based organizations often provide services and support to the most marginalized, disadvantaged and stigmatized sections of society (1-9). For example, community-based organizations in the HIV/AIDS sector often directly provide services, care and resources to many marginalized and/or stigmatized populations including sex workers, drug users, gay men and the homeless (1;4;8). As Chillag et al. (2002) point out, community-based organizations are well positioned to deliver such services "because they understand their local communities and are connected to the groups they serve" (4). Similarly, in response to limited access to health services, community-based organizations also often provide essential primary healthcare (especially for the very poor, women and children) in low- and middle-income countries (5;10).

In addition to providing important health services and programs, community-based organizations often play important advocacy roles with the aim of strengthening the health systems in which they work (2;3;10-12). They are often called upon to collaborate with health system decision-makers and stakeholders in the development of policy, programs and services (13-17), and are increasingly involved in the development and production of research to inform the development of policy, programs and services (18;19). Such activities help to facilitate the involvement of communities and the public in the planning and implementation of their healthcare, which was a key principle of The Declaration of Alma Ata (20). Furthermore, successful involvement of community-based organizations (and the public) in decision-making has been shown to increase the likelihood that policies will be appropriate, acceptable and effective (2;21).

While the importance of community-based organizations in health systems has been relatively well articulated, their characteristics are described using diverse terminology and concepts from across a range of disciplines. There appears to be little or no consensus about their nomenclature, core functions, and structure. For instance, a number of terms are commonly used to refer to the same, or similar, type of organization, such as those outlined by Bhan et al. (civil society organizations, non-governmental organizations, community-based organizations, faith-based organizations and voluntary organizations) (18). The descriptors used for community-based organizations may also vary based on the sector or 'community' they serve (*e.g.*, AIDS service organizations or community mental health centres). In addition, community-based organizations have also been described as a 'third sector' or the 'third way'. This refers to the gap filled by these voluntary organizations between the decreasing roles of the state and growing market pressures on healthcare delivery (7;22).

In addition to the varied terms used to describe community-based organizations, there are also several conceptions of what constitute essential organizational features. For instance, Milligan & Conradson (2006) state that "the voluntary sector can be viewed as comprising organizations that are formal, non-profit distributing, constitutionally independent of the state and self-governing". They further indicate that "While such organizations may employ paid staff and receive funding from the state their remit is to act for public rather than shareholder benefit" (22). Similarly, Chavis & Florin (1990) assert that voluntary community organizations are geographically based, represent residents of a particular area, volunteer driven, locally initiated and are multi-purpose and flexible allowing them to address a broad array of issues (23). Others have identified five key characteristics of community-based organizations, indicating they must be : 1) organized (i.e., institutionalized to some degree); 2) private (i.e., separate from government); 3) non-profit distributing; 4) self-governing; and 5) voluntary (i.e., some meaningful degree of voluntary participation in the organization's affairs) (7;24;25).

Given the diverse terminology and concepts related to community-based organizations, there is a clear need to assess the extent of the literature related to their key characteristics before undertaking more in-depth analyses of the sector. However, to our knowledge no systematic efforts to identify and outline the existing literature about the characteristics of community-based organizations have been undertaken.

Objectives

Building on this gap in the literature, our objectives for this scoping review were to:

1. identify existing literature related to the characteristics of community-based organizations and networks of community-based organizations;
2. conceptually map the literature according to country focus, sector, discipline, type of literature and topics addressed;
3. identify gaps in the literature and areas for future inquiry that would contribute to a better understanding of the role of community-based organizations in health systems

Methods

We used a scoping review to identify, conceptually map and identify gaps in the literature related to the characteristics of community-based organizations and networks of community-based organizations in the health sector. In general, the aims of scoping reviews are to "map *rapidly* the key concepts underpinning a research area and the main sources and types of evidence available, and [they] can be undertaken as stand-alone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before" (26, emphasis in original). Scoping reviews are often conducted to examine previous research activity, disseminate findings, identify gaps in the research and/or determine the value of conducting a full systematic review (27). Given the lack of existing comprehensive reviews of this topic and that the literature is likely spread across multiple disciplines and sectors, scoping review methods were ideal for taking the first step towards developing a better understanding of the nature and scope of the literature.

We conducted the scoping review using an iterative process that allowed for flexibility in the search, reviewing and conceptual mapping phases. A flexible approach was important to follow as this area of inquiry is not well-defined and, as a result, important literature may have been omitted if a rigid a priori design was followed. As a result, we developed search terms and inclusion/coding criteria at the initial stages of the review but revised them as the study progressed.

Literature searches

We conducted the literature searches through a multi-stage process. First, we conducted a search of 16 databases in Scholars Portal in March 2009 using a combination of search terms that we identified as likely to be used as descriptors of relevant literature (see Appendix 1 for an outline of the databases searched and the search terms used). In addition, we conducted a citation search through the Citation Index provided by ISI Web of Knowledge using 22 key articles that we identified both from our own records and from experts and colleagues. Next, two of us (MGW and AG) initially reviewed a random sample of 200 references from the search results to refine our inclusion criteria and the coding framework (see below for more detailed descriptions of inclusion and coding criteria). Based on our review of the 200 references, we realized that the search was too broad and needed to be refined to community organizations, their mobilization and their key characteristics. We observed that most relevant articles used truncated terms of organi* or mobili* and we therefore included these terms in our revised search strategy (see Appendix 3 for an outline of the search terms used). For the citation searches, we eliminated 15 references from the original list, which we deemed to be outside the scope of the review and then supplemented the list with 7 citations that we located from the initial review of 200 references (see Appendix 4 for the results of the revised citation search). These revised searches were conducted in April 2009 with no limits for publication date or language.

We developed a search strategy for Medline and Embase after reviewing the results from the Scholars Portal and citation search. The terms from our search of Scholars Portal provided an unmanageable set of results in Medline and Embase (n=46,457) and we therefore developed a revised strategy based on our increased familiarity with the literature. Specifically, we searched Medline and Embase in April 2010 using the following search strategy: community-based organi* OR community organi* OR civil society (again no limits were placed on publication date or language).

Study selection

Two of us (MGW and AG) independently reviewed and applied the selection criteria to all titles and abstracts. Our initial selection criteria were very broad and included any literature related to how communities organize. After reviewing the random sample of 200 titles and abstracts from the original search strategy, we narrowed the criteria to only include literature related to the key characteristics of community-based organizations or networks of community-based organizations which we applied to all search results. During the reviewing process, we marked references as either 'include', 'unclear' or 'exclude' and retrieved the full-text (where possible) for any classified as the former two categories.

Full-text coding

We iteratively developed a coding framework to conceptually map the included references. One of us (MGW) developed an initial coding framework, which we collectively revised through discussion and after pilot testing it with ten articles. The coding framework included domains related to the country focus, type of literature, source of literature, academic discipline, disease, terminology used to describe organizations and topics discussed (see Appendix 5 for the full coding framework). For the domain related to the terminology used to describe organizations, we used an outline of five common terms used to describe civil society organizations provided by Bhan et al. (2007) (18) and supplemented this list with 'community mental health centre/organization' given the large number of articles related to mental health that we noted during title and abstract reviewing. One of us applied the coding framework to the full-text of all included articles and calculated the number of articles in each category. If no full-text article was available through our respective libraries (McMaster University and the University of Toronto), we coded the article using the title and abstract if they provided sufficient information and documented the articles for which we could not apply the coding framework.

Results

Our searched yielded a total of 5213 references, which was reduced to 3904 after removal of duplicates (see Figure 1 for a summary of the reviewing process). After reviewing the titles and abstracts from the search results, we included 170 and marked 121 as unclear. Our level of agreement was relatively low with a Kappa of 0.319 ($p<0.001$), 95% CI (0.264, 0.374). However, all assessments were compared with discrepancies resolved by discussion to ensure consistent application of the inclusion criteria.

Upon reviewing the full-text articles we excluded 75 and included *and* coded 190. We were unable to retrieve the full-text versions for 32 articles, from which we were able to reliably assess inclusion and complete coding for six. As a result, we were unable to conduct a final inclusion assessment for 26 articles. Lists of included articles, excluded articles (after full-text review) and articles that we were unable to code are provided in Appendices 7-9 respectively.

We found that just under half of the 190 articles were related to mental health and addictions (n=51, 26.8%) *and/or* HIV/AIDS (n=38, 20.0%) and we present the coding results in Table 1 separately for each of these disease sectors in addition to the overall results. Almost all of the remaining articles addressed a general or unspecified disease sector (e.g. articles discussing organizational structure or the development of networks but not in the context of any specific disease) (n=77, 40.5%) with only three (1.6%) addressing cancer, five (2.6%) cardiovascular disease and two (1.1%) diabetes.

Almost all articles focused on high-income countries (n=166, 87.4%) and were published in journals (n=175, 92.1%). However, 24% of articles related to HIV/AIDS (n=9) discuss organizations in low- and middle-income countries as compared to 15% of all the included articles (n=28). The approach/methods of the articles were varied with most presenting discussion or theory-based content (n=57, 63.3%) and with the majority of the remaining articles providing empirical findings based on case studies (n=48, 25.3%), qualitative methods (n=47, 24.7%) and quantitative surveys (n=44, 23.2%). Similarly, included articles were from a mix of disciplines with most based in health systems, services and policy literature (n=59, 31.1%), population and public health (n=58, 30.5%), organization and administration (n=36, 18.9%), clinical or epidemiology (n=21, 11.1%).

The included articles presented a wide spectrum of terms to describe community-based organizations. The most common term used from the outline provided by Bhan et al. (2007) was community-based organization (n=67, 35.3%), which was the term used in 74% (n=28) of the HIV/AIDS literature. The terms voluntary organization (n=19, 10.0%), non-governmental organization (n=18, 9.5%), civil society organization (n=15, 7.9%) and faith-based organization (n=3, 1.6%) were used less frequently. Community mental health centre/organization was used by 16% (n=31) of the articles, which is driven mostly by the fact that a large proportion of the literature was based in mental health and addictions.

More than a third (n=71, 37.4%) of the articles used a term other than one in our coding framework. We documented each additional term (or terms where more than one was presented) used in the included articles and grouped them thematically (see Box 1 for the groupings of terms and Appendix 6 for a list of all the terms contributing to each grouping). Specifically, we identified eight terms (or very slight variations of terms) that were used in more than one article and an additional eight terms that were used only once. The most popular terms we extracted were related to community coalitions, networks or partnerships (n=20, 10.5%), community health agencies, organizations or centres (n=16, 8.4%), neighborhood associations, congregations, health centers or organizations (n=9, 4.7%), non-profit organizations, agencies, consortium or sector (n=10, 5.3%) or community agencies (n=5, 2.6%).

The topics discussed in the included articles were varied with six of the 11 different topic areas being discussed by at least a quarter of the included articles. Approximately half of the included articles addressed topics related to the mandate or activities of community-based organizations (n=95, 50.0%) or networks/coalitions of organizations (n=88, 46.3%). The other most popular topics addressed were the structure of organizations (n=68, 35.8%), the type or skills of organizational staff (n=58, 30.5%), involvement of community members in the organization (n=53, 27.9%) and sources of revenue (n=53, 27.9%). The topics addressed appear consistent across the HIV/AIDS and mental health and addictions articles except that the former appears to have comparatively more emphasis on revenue sources and the latter tend to focus more on organizational structure and less on networks and coalitions.

Discussion

Principal findings

We identified a relatively large number of articles (n=190) addressing topics related to the key characteristics of community-based organizations and/or networks of community-based organizations. The literature is largely focused on high-income countries and on mental health and addictions, HIV/AIDS or general/unspecified populations of interest. The articles are spread across multiple disciplines with most in health systems, services and policy, population and public health and psychology. A large number of different terms have been used in the literature to describe community-based organizations, which makes it difficult to develop a well defined outline of organizations and their roles in health systems. Lastly, we found literature related to a range of topics about community-based organizations (mandate, structure, revenue sources and type and skill of staff), the involvement of community members in organizations, how organizations contribute to community organizing and development and how they function in networks with each other and with government (e.g., in policy networks).

Study meaning

To our knowledge, this is the first attempt to provide a comprehensive and systematic scoping of the literature related to community-based organizations in the health sector. The results of the review can be used to develop our understandings of the key characteristics of community-based organizations, how they function (individually and in networks), and what roles they are and/or could be playing in health systems. Given the numerous calls over several decades to better engage them in decision-making about health systems (20;28-30), developing a shared understanding of their characteristics and functions is an important and long overlooked step.

This review also complements the existing literature in several ways. First, many of the articles identified in our review discuss topics related to networks, coalitions and/or organizational relationships with government (e.g., policy networks), which provide an important overlap with political theory. The mandate of many community-based organizations often includes advocacy, which frequently takes shape through networks or coalitions of organizations. Depending on how organized a network is, the resources available and the relationship with government (or with other advocacy groups), networks and coalitions of community-based organizations can be important policy actors and influence policy decision-making in a number of ways (e.g., bringing issues onto a government's agenda and helping to determine whether and how a decision is made). Second, involving patients, their families or representatives of patients and their families in the planning or development of healthcare is often highlighted as important activity within health systems (31-34) and community-based organizations can provide opportunities for public engagement in the planning and delivery of programs and services (e.g., through formal governance mechanisms or informal consultative mechanisms and through volunteerism). Lastly, this review complements the broader healthcare management literature that assesses the structure and role of healthcare organizations in health systems (35).

The review also revealed two particularly important findings to consider. First, much of the literature is focused on HIV/AIDS and/or mental health and addictions. This is important to note as most people living with or at risk of HIV/AIDS are from marginalized, stigmatized and/or hard-to-reach communities (36-38), from low- and middle-income countries with high rates of HIV incidence and prevalence (39), require complex care and social supports (40) and are underserved with respect to prevention and treatment (especially in low-middle income countries) (39) . Similarly, people with mental health and addictions issues are often stigmatized within society (37), require complex care and social supports (41) and are often hard-to-reach and underserved (38). As a result, the finding that much of the literature about community-based organizations is focused on HIV/AIDS and mental health and addictions is not entirely surprising as many of these organizations (especially in the HIV/AIDS sector) developed as a grass roots response to gaps in programs and services that governments were not filling and as an advocacy mechanism for broader system level supports. The second notable finding is the lack of literature addressing organizations in the cancer, cardiovascular disease and diabetes sectors as each typically have large networks of charitable and community-based organizations. The minimal amount of literature could be due to a lack of scholarly activity examining the characteristics of community-based organizations or because our search strategy did not include the appropriate terms to identify this literature (see the limitations section below). The third interesting finding to note is the relative lack of literature that is focused on low- and middle-income countries. Given the importance of community-based organizations in the delivery of programs and services and for advocacy in health systems in low- and middle-income countries, the lack of literature is an important gap to fill.

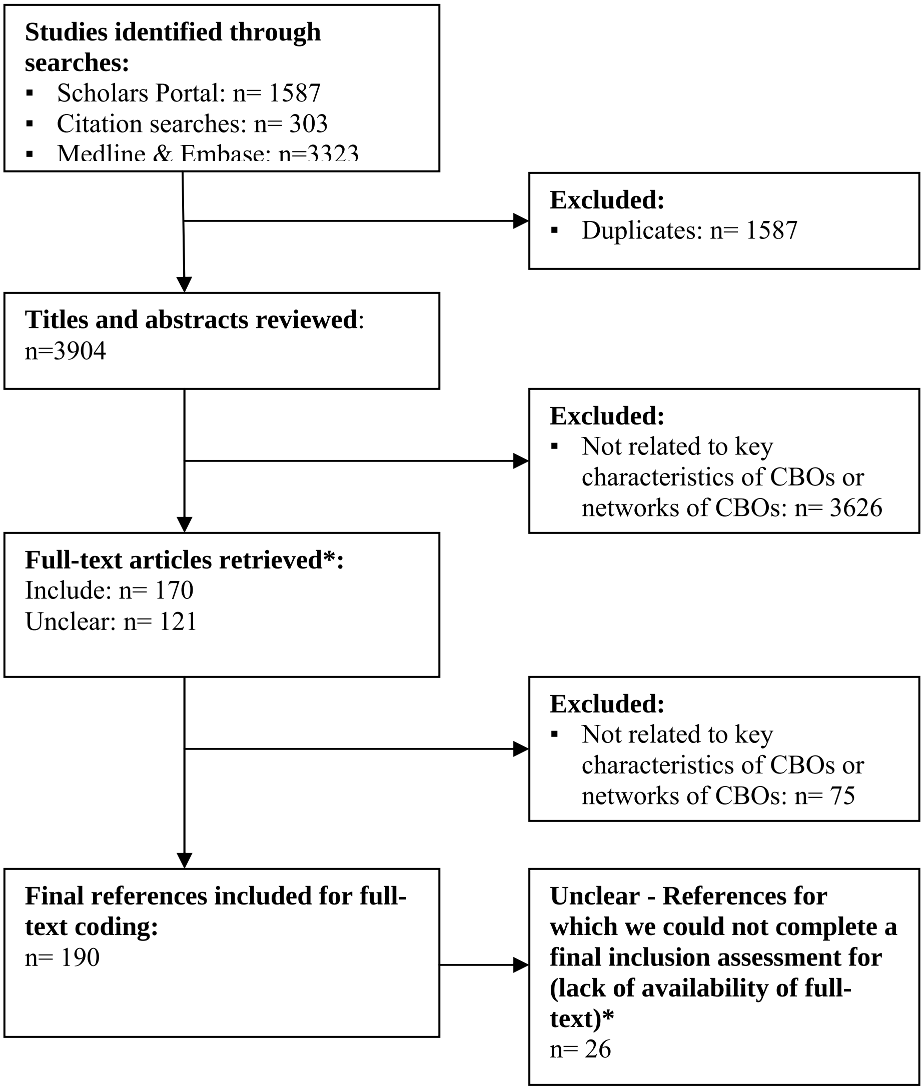
Strengths and limitations

In addition to the novel contribution of this review, the primary strength is the breadth of the search (18 databases and citation searches using 15 articles) and the rigorous and transparent methods we used to review and code the search results. There are two limitations of our review that should also be considered. First, as our results demonstrate, the terminology used to describe community-based organizations is broad and difficult to define. As a result, our search terms may have not captured all relevant literature on this topic. A potential reflection of this is the lack of literature we found related cancer, cardiovascular disease and diabetes despite each having large networks of charitable and community-based organizations. Similarly, we found a lack of literature related to community-based organizations involved in social movements, which further indicates that our search strategy may not have identified all relevant areas of the literature.

Future research

Given the range of terms used to describe community-based organizations, a key area for future research is to use the findings of this scoping review to further map the meanings/definitions of each in order to develop a more comprehensive typology and understanding of the 'third sector'. Doing so will help to further inform the unique role(s) that community-based organizations are and/or could be playing in health systems. Building on this, another key area for future research is to identify the ways in which community-based organizations should be included in health system decision-making and the mechanisms available for facilitating their engagement. Lastly, future research could focus on examining the impact of different organizational characteristics on the type of activities community-based organizations become involved in. For instance, what impact does the type or skills of organizational staff, the skill-mix and/or the number of staff and volunteers in the organization have on the types of services and programs provided and whether the organization engages in advocacy activities.

Figure 1: Flow of study selection



*We were unable to obtain access to 32 articles due to lack of availability at McMaster or University of Toronto Libraries. For six of these articles, the title and abstract provided sufficient information to determine whether it should be included and to apply the coding framework. As a result, we were unable to complete the coding for 26 articles.

Table 1: Results of conceptual mapping of included references

Coding categories	All (n=190)	Articles addressing mental health and addictions (n=51)	Articles addressing HIV/AIDS (n=38)
Country focus			
i. High-income countries	166 (87.4%)	50 (98.0%)	31 (81.6%)
ii. Low- and middle-income countries	28 (14.7%)	0 (0.0%)	9 (23.7%)
iii. Not clearly stated	3 (1.6%)	1 (2.0%)	0 (0.0%)
Source of literature			
i. Journal	175 (92.1%)	40 (78.4%)	37 (97.4%)
ii. Book (whole or chapter)	4 (2.1%)	2 (3.9%)	1 (2.6%)
iii. Report/grey literature	0 (0.0%)	0 (0.0%)	0 (0.0%)
iv. Dissertation	11 (5.8%)	9 (17.6%)	0 (0.0%)
Type of literature			
i. Systematic review	0 (0%)	0 (0.0%)	0 (0.0%)
ii. Review (not systematic)	4 (2.1%)	1 (2.0%)	1 (2.6%)
iii. Quantitative survey	44 (23.2%)	18 (35.3%)	5 (13.2%)
iv. Qualitative study	47 (24.7%)	16 (31.4%)	9 (23.7%)
v. Case study	48 (25.3%)	10 (19.6%)	13 (34.2%)
vi. Theory/discussion paper	57 (30.0%)	16 (31.4%)	11 (28.9%)
vii. Commentary/ editorial	13 (6.8%)	2 (3.9%)	2 (5.3%)
viii. Document analysis	4 (2.1%)	3 (5.9%)	2 (5.3%)
Academic discipline			
i. Health systems, services and policy	59 (31.1%)	15 (29.4%)	14 (36.8%)
ii. Population and public health	58 (30.5%)	8 (15.7%)	19 (50.0%)
iii. Clinical and epidemiology	21 (11.1%)	6 (11.8%)	5 (13.2%)
iv. Social work	9 (4.7%)	1 (2.0%)	2 (5.3%)
v. Sociology	13 (6.8%)	2 (3.9%)	4 (10.5%)
vi. Political science	11 (5.8%)	2 (3.9%)	3 (7.9%)
vii. Anthropology	3 (1.6%)	2 (3.9%)	0 (0.0%)
viii. Psychology	8 (4.2%)	5 (9.8%)	0 (0.0%)
ix. Organizational/administration	36 (18.9%)	19 (37.3%)	2 (5.3%)
Terminology used to describe organizations			
i. Community-based organization	67 (35.3%)	5 (9.8%)	28 (73.7%)
ii. Non-governmental organization	18 (9.5%)	0 (0.0%)	6 (15.8%)
iii. Civil society organization	15 (7.9%)	0 (0.0%)	4 (10.5%)
iv. Voluntary organization	19 (10.0%)	0 (0.0%)	1 (2.6%)
v. Faith-based organization	3 (1.6%)	0 (0.0%)	0 (0.0%)
vi. Community mental health centre/organization	31 (16.3%)	31 (60.8%)	1 (2.6%)
vii. Other†	71 (37.4%)	16 (31.4%)	6 (15.8%)
Topics discussed			
i. Organization structure	68 (35.8%)	26 (51.0%)	10 (26.3%)
ii. Organization mandate	95 (50.0%)	22 (43.1%)	22 (57.9%)
iii. Organization type	15 (7.9%)	6 (11.8%)	4 (10.5%)
iv. Community development	10 (5.3%)	3 (5.9%)	2 (5.3%)
v. Community organizing	32 (16.8%)	4 (7.8%)	5 (13.2%)

vi. Community involvement	53 (27.9%)	14 (27.5%)	12 (31.6%)
vii. Community infrastructure	6 (3.2%)	2 (3.9%)	1 (2.6%)
viii. Social movements	2 (1.1%)	1 (2.0%)	2 (5.3%)
ix. Revenue	53 (27.9%)	13 (25.5%)	15 (39.5%)
x. Type/skill of staff	58 (30.5%)	19 (37.3%)	14 (36.8%)
xi. Networks/coalitions	88 (46.3%)	17 (33.3%)	18 (47.4%)
xii. Relationship with government (policy networks)	30 (15.8%)	6 (11.8%)	8 (21.1%)

†See Box 2 for an outline of the terms used to describe organizations in each of the included articles

Box 1: Terms used to describe organizations*

Community coalition(s)/networks/partnerships (n=20)
Community health agencies/organizations/centres (n=16)
Non-profit organization/agencies/consortium/sector (n=10)
Neighborhood associations/congregations/health centers/organizations (n=9)
Community agencies (n=5)
Health/social service organization (n=4)
Community development corporation/organization (n=2)
Cooperatives (n=2)
Advocacy organization (n=1)
AIDS service organizations (n=1)
Community care access centers (n=1)
Consumer/survivor initiatives (n=1)
Community boards (n=1)
Third sector organizations (n=1)
Mental health organization (n=1)
Rape crisis center (n=1)

*See Appendix 5 for a detailed outline of each of the terms included in the groupings of terms outlined

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Appendix 1: Original Scholars Portal Search

Search Terms	Databases	Results and description
Communit* OR "civil society" (searched using the DE field) AND Organiz* OR service OR develop* (searched using the DE field) AND Health (searched using the DE field)	1. ASSIA: Applied Social Sciences Index and Abstracts 2. Health Sciences: A SAGE Full-Text Collection 3. IBSS: International Bibliography of the Social Sciences 4. PAIS Archive 5. PAIS International 6. Political Science: A SAGE Full-Text Collection 7. PsycINFO 8. Science Citation Index Expanded ™ (1976-current) 9. Social Sciences Abstracts 10. Social Sciences Citation Index 11. Social Services Abstracts 12. Sociological Abstracts 13. Sociology: A SAGE Full-Text Collection 14. Urban Studies & Planning: A SAGE Full-Text Collection 15. Urban Studies Abstracts 16. Worldwide Political Science Abstracts	• This search resulted in 4540 hits, which included peer-reviewed journals, non-peer reviewed journals, conferences and books. • Deemed the search to be too broad and it needed to be focused more on just community organizations, their mobilization and their key characteristics. • Based on a review of 200 randomly selected references from the original cited reference search, most relevant articles used terms that contained the truncated terms of organiz* or mobiliz*

Appendix 2: Original citation search (rank ordered by number of hits)

	Reference	**Number of hits**
1	Etzioni, A. (1993) *The Spirit of Community: the Reinvention of American Society*. New York: Simon & Schuster. Pp.247-267	467
2	Duncan, J. and Ley, D. (1993) “Introduction: representing the place of culture” in Duncan, J. and Ley, D. (eds) *Place/ Culture/ Representation*. Routledge: London. pp.1-21.	224
3	Eng, E. and E. Parker. 1994. Measuring community competence in the Mississippi Delta: The interface between program evaluation and empowerment. *Health Education Quarterly* 21, no. 2:199-220.	102
4	Gittell, R. and A. Vidal (1998). *Community Organizing: Building Social Capital as a Development Strategy*. Thousand Oaks, CA, Sage.	101
5	Minkler, M. and N. Wallerstein. 1997. Improving health through community organization and community building. In *Community Organizing and Community Building for Health*, ed. Minkler, M., 26-50. (New Brunswick: Rutgers University Press).	94
6	Jewkes, R., & Murcott, A. (1998). Community representativeness: representing the "community"? *Social Science and Medicine*, 46(7), 843-858.	44
7	Hasson, S. & D. Ley (1994) Neighbourhood Organizations and the Welfare State. University of Toronto Press. (Chapter 1: "Neighbourhood organizations, the city, and the state")	39
8	Piven, F. F. and R. A. Cloward (1979). *Poor People's Movements: Why They Succeed, How They Fail*. New York, NY, Vintage Books (Random House).	35
9	Jewkes, R. and A. Murcott (1996) *Meanings of Community*. Social Science and Medicine, 43(4), pp.555-563.	34
10	Popple, K. (1995) *Analysing Community Work: Its Theory and Practice*. Philadelphia, PA: Open University Press. (Chapter 3 & 4)	17
11	Bullock, A. (1990) Community Care: Ideology and Lived Experience, in Ng, R., G, Walker and J. Miller, *Community Organizing and the Canadian State*. Toronto: Garamond Press.	16
12	Campfens, Hubert, ed. (1997). *Community development around the world: Practice, theory, research, training.* Toronto: University of Toronto Press, p.13-46; p.439-469.	15
13	Boutilier, M., S. Cleverly, R Labonte. (2000). “Community as a setting for health promotion”. In B. Poland, L. W. Green and I. Rootman (eds), *Settings For Health Promotion: Linking Theory and Practice*. Thousand Oaks, CA, Sage.	12

14	Lyon, L. (1989) *The Community In Urban Society.* Toronto: Lexington Books. (Chapter 8: "Community development")	10
15	Dixon, J. (1989). "The limits and potential of community development for personal and social change". Community Health Studies, 13(1), 82-92.	10
16	Rabrenovic, Gordana (1996) "Introduction: Economic restructuring, urban change and neighborhoods in crisis" in *Community Builders: A tale of neighborhood mobilization in two cities.* Temple University Press: Philadelphia.	9
17	Mondros, J. and W. Wilson (1994). *Organizing for Power and Empowerment.* New York, NY, Columbia University Press.	6
18	Lotz, Jim (1998). "The origins of community development." Pp. 113-126 in *The Lichen Factor: The Quest for Community Development in Canada* University College of Cape Breton Press, Sydney NS.	5
19	Rubin, H. J. and I. S. Rubin (1992). *Community Organizing and Development (2nd ed).* New York, NY, Macmillan.	4
20	Lotz, J. (1987). Community development: a short history. Journal of Community Development, May/June, 41-46.	3
21	Stall, S. & Stoecker, R. (1997). Community Organizing or Organizing Community? Gender and the Crafts of Empowerment. Toledo, OH: COMM-ORG Working Paper.	1
22	Murphy, P & J Cunningham. (2003). *Organizing for community controlled development: Renewing civil society.* Thousand Oaks, Calif.: Sage Publications. 339 pp.	0

Appendix 3: Revised Scholars Portal Search

Search Terms	Databases and hits	Results and description
communit* OR "civil society" (searched using the DE field) AND organi* OR mobili* (searched using the DE field) AND health (searched using the DE field)	1. ASSIA: Applied Social Sciences Index and Abstracts 2. Health Sciences: A SAGE Full-Text Collection 3. IBSS: International Bibliography of the Social Sciences 4. PAIS Archive 5. PAIS International 6. Political Science: A SAGE Full-Text Collection 7. PsycINFO 8. Science Citation Index Expanded ™ (1976-current) 9. Social Sciences Abstracts 10. Social Sciences Citation Index 11. Social Services Abstracts 12. Sociological Abstracts 13. Sociology: A SAGE Full-Text Collection 14. Urban Studies & Planning: A SAGE Full-Text Collection 15. Urban Studies Abstracts 16. Worldwide Political Science Abstracts	• This search resulted in 1587 hits, which included peer-reviewed journals, non-peer reviewed journals, conferences and books. • The only revision to this search was the elimination of the terms 'service' and develop* in the second line of the search strategy, which were replaced with mobliz* and mobilis*. • Search was run in April 2009

Appendix 4: Revised citations searched (rank ordered by number of hits for original citations and supplementary citations)

	Citations kept from original search	**Number of hits**
1	Gittell, R. and A. Vidal (1998). *Community Organizing: Building Social Capital as a Development Strategy*. Thousand Oaks, CA, Sage.	101
2	Minkler, M. and N. Wallerstein. 1997. Improving health through community organization and community building. In *Community Organizing and Community Building for Health*, ed. Minkler, M., 26-50. (New Brunswick: Rutgers University Press).	94
3	Hasson, S. & D. Ley (1994) Neighbourhood Organizations and the Welfare State. University of Toronto Press. (Chapter 1: "Neighbourhood organizations, the city, and the state")	39
4	Popple, K. (1995) *Analysing Community Work: Its Theory and Practice*. Philadelphia, PA: Open University Press. (Chapter 3 & 4)	17
5	Bullock, A. (1990) Community Care: Ideology and Lived Experience, in Ng, R., G, Walker and J. Miller, Community Organizing and the Canadian State. Toronto: Garamond Press.	16
6	Rabrenovic, Gordana (1996) "Introduction: Economic restructuring, urban change and neighborhoods in crisis" in *Community Builders: A tale of neighborhood mobilization in two cities.* Temple University Press: Philadelphia.	9
7	Rubin, H. J. and I. S. Rubin (1992). *Community Organizing and Development (2nd ed).* New York, NY, Macmillan.	4
8	Stall, S. & Stoecker, R. (1997). Community Organizing or Organizing Community? Gender and the Crafts of Empowerment. Toledo, OH: COMM-ORG Working Paper.	1
	Supplementary citations	**Number of hits**
9	Gittell M, Ortega-Bustamante I, Steffy T. Social capital and social change - Women's community activism. Urban Affairs Review 2000;36(2):123-47.	11
10	Stoecker R, Vakil A. States, cultures, and community organizing: Two tales of two neighborhoods. Journal of Urban Affairs 2000;22(4):439-58.	6
11	Saegert S. Building civic capacity in urban neighborhoods: An empirically grounded anatomy. Journal of Urban Affairs 2006;28(3):275-94.	3
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Appendix 5: Coding framework for included references

Eligible?

Eligible for inclusion if it addresses the ways in which community-based organizations function as a single organization or as a network of organizations

☐ Yes ☐ No

If yes, then assess reference based on coding categories i-viii below

i. Information used to code

☐ Full-text article
☐ Title and abstract
☐ Title only

ii. Country focus

☐ High-income countries
☐ Low- and middle-income countries

iii. Type of literature

☐ Systematic review (needs to have explicit search and selection criteria)
☐ Review (not systematic)
☐ Theory/discussion paper
☐ Other (specify)
☐ Qualitative study
☐ Commentary/editorial
☐ Quantitative survey
☐ Case study

iv. Source of literature

☐ Journal
☐ Grey literature
☐ Book (whole or chapter)
☐ Other (specify)

v. Academic discipline

☐ Health services, systems and policy
☐ Population and public health
☐ Social work
☐ Organization/management/administration
☐ Psychology
☐ Sociology
☐ Other (specify)
☐ Clinical and Epi
☐ Political science
☐ Anthropology

vi. Disease sector

☐ HIV/AIDS
☐ Cancer
☐ General/not specified
☐ Mental health and addictions
☐ Cardiovascular disease
☐ Other (specify)
☐ Diabetes

vii. Terminology used to describe organizations

☐ Non-governmental organization
☐ Community-based organization
☐ Community mental health centre/organization
☐ CMHC/CMHO
☐ Voluntary organization
☐ Faith-based organization
☐ Civil society organization

viii. Topics discussed

☐ Organization type/models
☐ Geographical focus
☐ Community infrastructure
☐ Networks/coalitions
☐ Community involvement
☐ Other (specify)
☐ Mandate of CBOs
☐ Type/skill of staff
☐ Social movements
☐ Organizational structure
☐ Relationship with government (policy networks)
☐ Revenue sources
☐ Community development
☐ Community organizing

Appendix 6: Outline of terms extracted from included studies that describe community-based organizations

Community coalition	Community coalition(s)/networks/partnerships (n=20)
Community coalition	
Community coalition	
Community coalition	
Community coalitions	
Community coalitions	
Community coalitions	
Community coalitions	
Community coalitions	
Community coalitions	
Community coalitions	
Community coalitions	
Rural health coalitions	
Inter-organizational networks	
Consumer networks	
Community-based coalitions	
Community-based networks	
Community health partnerships	
Community health promotion coalitions	
Coalitions	
Community service networks	
Community agencies	Community agencies (n=5)
Community agencies	
Community agencies	
Community agencies	
Community agency	
Community health and welfare agencies	Community health agencies/organizations/centres (n=16) -Add ‘Community center’ - Add ‘Local community service center’
Community health care organization	
Community health center	
Community health centers	
Community health centers	
Community-based behavioral health providers	
Community health organization	
Community health promotion coalitions	

Community organization	
Community organization	
Community organizations	
Community organizations	
Community planning organizations	
Community centre	
Local community service centers	
Local community service centers	
Advocacy organization	Advocacy organization (n=1)
AIDS service organizations	AIDS service organizations (n=1)
Community care access centers	Community care access centers (n=1)
Community development corporation	Community development corporation/organization (n=2)
Community development organization	
Neighborhood committees	Neighborhood associations/congregations/health centers/organizations (n=9)
Neighborhood association	
Neighborhood associations	
Neighborhood congregations	
Neighborhood health centers	
Neighborhood health centers	
Neighborhood organization	
Neighborhood organizations	
Cooperative neighborhood organizations*	
Community governed non-profit primary care organizations	Non-profit organization/agencies/consortium/sector (n=10)
Non-profit agencies	
Non-profit organization	
Non-profit organizations	
Non-profit organization	
Non-profit organizations	
Non-profit sector	
Non-profit sector	
Non-profit service consortium	
Not-for-profit organizations	
Cooperatives	Cooperatives (n=2)

Cooperative neighborhood organizations	
Health service organization	Health/social service organization (n=4)
Human service agencies	
Service organizations	
Social service agencies	
Consumer/survivor initiatives	Consumer/survivor initiatives (n=1)
Community boards	Community boards (n=1)
Third sector organizations	Third sector organizations (n=1)
Mental health organization	Mental health organization (n=1)
Rape crisis center	Rape crisis center (n=1)

*Included in two categories: 1) Neighborhood associations/congregations/health centers/organizations; and 2) Cooperatives

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Helping community-based organizations use systematic reviews

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Abstract

Background

Supporting the use of research evidence by policymakers has garnered significant attention. Unfortunately, there have been few visible efforts to support the use of research evidence in community-based organizations. To begin to address this gap, we examined community-based organizations' role in health systems, their views about and experiences with research evidence (specifically systematic reviews), and their preferences for making systematic reviews easier to use.

Methods

We conducted a qualitative study involving executive directors and/or program managers of community-based organizations in the HIV/AIDS, diabetes and mental health and addictions sectors in Ontario, Canada. We conducted a series of focus groups, developed approaches for producing user-friendly summaries and peer-relevance assessments for systematic reviews and then pilot tested and revised the approaches through follow-up one-on-one semi-structured interviews with focus group participants.

Results

We conducted five focus groups with 31 executive directors and program managers of community-based organizations (two each with HIV/AIDS organizations and mental health and addictions organizations and one with diabetes organizations) and 16 one-on-one semi-structured interviews. Key characteristics of community-based organizations that were highlighted include

the importance of involving community members in the formation, governance and functioning of the organization, as well as being guided by a mission, vision and set of values and having mandates that are typically shaped by the populations and geographic regions they serve. The focus groups identified strong support for a structured user-friendly summary that includes a plain-language summary, a succinct outline of the 'take-home messages,' and a summary of the benefits, harms and costs of the intervention/topic being addressed. We also found support for assessing the relevance of systematic reviews by categorizing them by topic and population addressed and for providing scores from peer-relevance assessments of the review.

Discussion

This study provides a unique and novel contribution to the literature by highlighting the important roles and characteristics of community-based organizations in health systems and practical tools for supporting their use of research evidence (approaches for user-friendly summaries and peer-relevance assessments of systematic reviews). These tools can be used by those interested in supporting community-based organizations and by anyone interested in providing the results of reviews in a more accessible format. The limited response rates and the fact that all interviews and focus groups were conducted in one province of Canada should be considered when assessing the applicability and transferability to organizations in other countries.

Background

Supporting the use of research evidence by policymakers has garnered significant attention (1-4). Such efforts are important as research evidence can be used to inform decisions both *about* health systems (i.e., about the governance, financial and delivery arrangements within which health-related programs and services are provided) and *within* health systems (i.e., the programs, services, drugs and devices to fund, cover or deliver) (5). Specifically, research evidence can be used to inform the key stages of decision-making processes – clarifying the problem or issue at hand (6); identifying and selecting options to address the problem (7); and developing a strategy to address how a policy option, program or service will be implemented (8). Unfortunately, there have been few visible efforts, such as those developed for health system professionals (9;10) and for managers, and policymakers (4;11;12), to support the use of research evidence in community-based organizations.

The lack of focus on supporting the use of research evidence by community-based organizations is an important gap to fill as they are important health system stakeholders. Community-based organizations provide numerous, often highly valued programs and services to the members of their community, often to the most marginalized, disadvantaged and stigmatized sections of society (13-21). In addition to direct service provision, community-based organizations also play important advocacy roles with the aim of strengthening the health systems in which they work (14;15;22-24), collaborate with health system decision-makers and stakeholders in the development of policy, programs and services (25-29), and conduct or partner in the conduct of research (30;31).

Given the important roles of community-based organizations in health systems and that research evidence can inform many aspects of their work (delivery of programs and services, advocacy for broader system level supports and collaboration with policymakers) there is a need to support their efforts to find and use research evidence. Potentially important to this is providing them with research evidence that is synthesized, has been assessed for relevance and written in ways that highlights what they need to know.

Systematic reviews are a key source of research evidence for many reasons. First, using systematic reviews constitutes a more efficient use of time for research users than using single studies because all information on a specific topic has already been identified, selected, appraised, and synthesized in one document (32). Systematic reviews also typically offer a lower likelihood of providing misleading findings than other forms of research (*e.g.*, a single experimental study) and can provide increased confidence in the findings due to the gains in precision that are obtained through synthesis of multiple studies (32). Furthermore, systematic reviews are increasingly incorporating a broader spectrum of research evidence (e.g., syntheses of qualitative evidence) (33-40). Consequently, reviews are now better able to answer many types of questions that may be asked in health systems (*i.e.*, beyond questions of effectiveness) such as cost-effectiveness, and how and why interventions work, which increases their relevance to a broader range of target audiences (32;41).

Approaches to producing user-friendly summaries of systematic reviews have been developed by several groups,(11) and methods for assessing their relevance to practice or decision-making have been developed for clinicians (10;42) and for health system managers and policymakers (5). These approaches provide useful starting points for developing similar products for community-based organizations to support their use of research evidence. However, we first need to better understand community-based organizations, their views about and experiences with research evidence, their preferred approaches for summarizing systematic reviews and assessing their relevance, and the specific types of information they would like to see highlighted in user-friendly summaries. We sought to address these issues through a qualitative study. While our ultimate goal is to develop an evidence service designed specifically for community-based organizations, our findings are designed to have broader implications for those trying to support the use of research evidence by community-based organizations.

Methods

We conducted a qualitative study involving executive directors and/or program managers of community-based organizations in the HIV/AIDS, diabetes and mental health and addictions sectors in Ontario, Canada. We conducted a series of focus groups, developed approaches for producing user-friendly summaries and peer-relevance assessments for systematic reviews based on the findings from the focus groups and then pilot tested and revised the approaches through follow-up one-on-one semi-structured interviews with focus group participants.

Focus groups

Sample frame

We developed a sample frame of community-based organizations in the HIV/AIDS, diabetes and mental health and addictions sectors using publicly available lists provided by provincial networks and government service directories in each sector. Specifically, we drew on the Ontario AIDS Network (specifically their membership list) in the HIV/AIDS sector, the Canadian Diabetes Association[1] and Association of Ontario Health Centres[2] for the diabetes sector and the Canadian Mental Health Association (CMHA) and ConnexOntario[3] (specifically the organizations listed under the Drug and Alcohol and Mental Health directories) for the mental health and addictions sector.

Our goal was to conduct two focus groups with representatives (either the executive director or a program manager) from organizations in each sector with 8-10 participants in each group and we required participants to be present in-person. This necessitated either conducting the focus groups at a meeting where the participants were already gathered or only considering organizations from our

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[1] http://www.diabetes.ca/

[2] http://www.aohc.org/aohc/index.aspx?CategoryID=11&lang=en-CA

[3] http://www.connexontario.ca/

local area (Greater Toronto Area in Ontario, Canada). In the HIV/AIDS sector executive directors and/or program managers from most organizations attend the annual Ontario HIV Treatment Network annual research conference and we therefore narrowed our sample frame to those attending (n=34). In the diabetes sector, we were unable to identify a meeting where organizations gathered and we therefore narrowed our sample frame to the Greater Toronto Area, which provided a sample frame that was sufficient for only one focus group (n=15). Lastly, in the mental health and addictions sector we decided to split the sample frame into those organizations from the Ontario branch of the CMHA (they hold periodic meetings with the executive directors of member organizations) (n=26) and those we identified that are based in the Greater Toronto Area on ConnexOntario (n=62). While this limited one of the focus groups to CMHA organizations, it allowed us to capture more breadth in terms of geographic focus.

Sampling and participants

We purposively sampled organizations from the HIV/AIDS and mental health and addictions sectors to obtain a sample with a mix of organizational characteristics that we identified as being important distinguishing features across community-based organizations. The five organizational characteristics included: 1) organization type ("grassroots" vs. less ties to the communities they serve), 2) organizational mandate (advocacy, program/service delivery and/or research), 3) source of funding (government and/or philanthropic donations), 4) geographical focus (rural or urban and regional, provincial or national), and 5) number and type of staff (lay vs. professional staff). The information that allowed us to categorize organizations was drawn from their websites. We included all organizations from the diabetes sector given that we only had 15 in the sample frame

From each organization that we selected for the sample, we invited the executive director to participate in a focus group. We indicated that if they were interested in participating they could either participate themselves or delegate the task to the most appropriate manager in the organization (someone with a decision-making role about programs, services and/or advocacy). We approached the executive director first, as for many CBOs they would be the key decision-maker that would have the most impact on whether research evidence is used to inform decision-making about programs, services and advocacy and if not, they would be best poised to identify the most appropriate manager.

Data collection

One of us (MGW) conducted each focus group by facilitating discussion and soliciting specific feedback about four areas of interest. First, we asked participants to describe the key characteristics or features of community-based organizations. We provided prompts about what the defining features of community-based organizations are, including whether they thought there are distinctive types of organizations (e.g., grassroots organizations vs. those not as connected to communities), what kinds of mandates organizations have (e.g., advocacy, service and program delivery and/or research) and how the revenue sources, geographical focus and the skill-base of the organization contribute to understanding community-based organizations. Next we asked about participants' views about and experiences with systematic reviews (e.g., had they heard of them before and would they find them useful and why). Third, we solicited feedback about how to develop user-friendly summaries of systematic reviews for community-based organizations. Based on previous research with health system managers and policymakers (5;43), we presented and asked for feedback on a general approach for developing user-friendly summaries, which includes providing a plain language summary, a succinct outline of the 'take-home messages' and a summary of the benefits, harms and costs of the intervention/topic being addressed. Lastly, we asked about methods for assessing the relevance of systematic reviews. We provided examples of potential approaches including categorizing reviews according to topic, type of question asked (e.g., clinical, economic or socio-political) and/or peer-relevance assessments similar to the approach used successfully for Evidence Updates (a physician targeted evidence service) (9) and to a similar approach we developed for health system managers and policymakers, which asks users to use a five-point scale to rate a review's immediate and future relevance and how useful it is (5).

Interviews

Using the findings from the focus groups we developed a prototype for a user-friendly summary and for a peer-relevance assessment tool and pilot tested them through follow-up one-on-one semi-structured interviews. We invited all those who attended one of the focus groups (n=31) to participate in a brief (approximately 30 minutes) telephone or in-person interview with one of us (MGW). Prior to the interview, participants were sent a template for a user-friendly summary, three summaries that had been completed for reviews related to their sector and a prototype for a peer-relevance assessment tool (see the results section for a detailed outline of each).

Analysis

During the focus groups we took notes and both within and across focus groups we revised the prompts to inquire about emerging themes in greater depth. Similarly, during the interviews, we kept detailed notes and iteratively revised the interview questions as well as the user-friendly summary prototype, example summaries and the peer-relevance assessment tool based on the feedback we received. All focus groups were taped and transcribed verbatim. We analyzed the transcripts by developing structured summaries of each, reviewing our notes, selectively revisiting the original recordings, and noting key findings, themes and illustrative quotes.

Results

Focus groups

Of the 63 executive directors and program managers of community-based organizations we invited to participate in focus groups, 24 (38%) were from the HIV/AIDS sector, 15 (24%) from the diabetes sector, and 24 (38%) were from the mental health addictions sectors. From this pool of willing participants, 31 agreed to participate (49% response rate) in one of the five scheduled focus groups. We held two focus groups with participants from each of the HIV/AIDS sector (n=12, with 5 in one group and 7 in the second) and the mental health and addictions sector (n=15, with 9 in one group and 6 in the second), and one focus group in the diabetes sector (n=4). Those who agreed to participate in the focus groups in the HIV/AIDS and mental health and addictions sectors did not noticeably differ in terms of the sample characteristics. However, those who agreed to participate in the diabetes focus group were predominately from diabetes-specific organizations and most of the non-responders were from community health centres that have a mandate beyond diabetes.

Several consistent themes emerged from the focus groups about the key characteristics or features of community-based organizations. First, participants in all focus groups highlighted that a core feature of community-based organizations is community involvement. Community involvement was discussed in several contexts including the formation of organizations (e.g., “grassroots” responses to issues), organizational governance (e.g., most organizations require a minimum level of community representation on their board of directors) and the functioning of the organization (e.g., working as volunteers or as staff). For instance one participant from the mental health and addictions sector highlighted that they “…use people who have experience with mental health issues. And they’re essential to all of our organizations and in many of our organizations to our staff, too.” (R8M1). Another participant highlighted that community-based organizations emerge out of local communities coming together to address specific areas of need or gaps in programs and services. Specifically, the participant indicated that:

> “each of the branches started with a similar kind of history where people who knew the local community came together because they were concerned about mental health services and formed the organization. So in the early days of each branch they were doing very little service provision. They were involved in addressing issues of need. In my community they were addressing the lack of hospital services, they became instrumental in developing other types of services like the addictions program and so on. And we all have a similar kind of history. And that’s what we carry as what a community agency is, that our roots are within the community. So it’s not just who we serve but who supports us as an organization.” (R2M1)

Another participant in the same group noted that “…when we refer to what ‘community-based’ is, it is that citizens coming together and saying, ‘We need support in this community so that when people leave for specialized care and they come back and are supported or wouldn’t have to leave in the first place.’” (R2M1). Similarly, in response to being asked what the distinguishing features of community-based organizations are, a participant from the diabetes sector indicated that “…as a CHC [community health centre], or the CHC sector, we’re small, we’re accessible, we are rooted in the heart of the community…” (R2D1).

Another related theme was the mandate of community-based organizations and how at the most fundamental level they are guided by a mission, vision and set of values that shape their core functions of providing programs, services and advocacy. As one participant noted, “[t]he most important piece is the vision and values” (R2M1). Beyond the guiding principles and core functions, a common theme was that organizational mandates are either geographically or population-based. A participant from the HIV/AIDS sector indicated that they "…think a lot of organizations that do HIV work in the province are either geographically-mandated or mandated by community of interest. And that could be very broad in terms of ethno-racial communities, in terms of Aboriginal, in terms of gay men." (R3H2).

Overall, the discussions in the focus groups highlighted the complexity of community-based organizations, not only in terms of their structure and mandates but also in the coordination and cooperation between organizations through networks and associations and in attaining sufficient funding for their activities. For instance, the broad mandates of many organizations requires varied skill sets, which often includes volunteers, people with lived experience and professionals of whom all need to be coordinated and function together. At the network level, many participants noted the need for both intra- and inter-sectoral collaboration as well as coordination of members or branches of larger umbrella organizations. A participant in the diabetes focus group highlighted this complexity by discussing a national umbrella organization and indicating "you've got this hierarchy where the national level certainly serves the community through their mission and their mandate, but they don't have any direct contact. They send it to the chapter or the branch or the region." (R1D1). Lastly, community-based organizations often need to secure both public funding and philanthropic donations in order to sustain their work. This funding can also be uncertain, inconsistent, temporary and/or come with 'strings' attached (e.g., government funding requiring specific programs to be delivered).

Use of research evidence as well as the production of research was mentioned by several focus group participants as an important feature of their work. In the mental health sector, especially those from CMHA organizations, it was cited as a core mandate of what they do. Highlighting this function of community-based organizations, one participated stated "I think that having to acquire, assess, adapt and apply research evidence is something that is an important thing to inform all that we do. And many of us actually participate in developing that evidence. Also running the research as well as being informed by the research." (R8M1). Similarly, many participants in the HIV/AIDS sector highlighted their involvement in community-based research and how they see it as being important to their work yet hard to do consistently given that it's often not part of their core mandate. Further, organizations in the HIV sector noted the difference between acquiring and assessing research vs. adapting and applying as the latter is harder and much more dependent on the resources available to modify existing programs or implement new ones.

Despite many being aware of the importance of using research evidence and some being involved in the production of research, most had not previously heard of systematic reviews. The exceptions to this were some participants in one of the HIV/AIDS and the mental health and addictions (specifically the one with participants from CMHA branch organizations) focus groups where a number of participants indicated knowing what systematic reviews were (some noted knowing what they were not the correct name for them). However, while some of the participants knew what systematic reviews are, few had actually tried to search for one. As one participant that knew of systematic reviews indicated, "…doing the literature review and looking for evidence and information, we've probably all been involved in that, but looking for a systematic review it's, in and of itself, I've never tried to do that." (R1H1).

However, once provided with details about what systematic reviews are, all participants indicated that they would be potentially useful in their work. One participant highlighted that "[i]t will also stop us from reinventing the wheel" indicating that "oh somebody's done that and that's pretty good and pretty conclusive and here's what those results were" (R2H1). In addition, another participant noted that systematic reviews would be useful for engaging in constructive debate with other stakeholders saying that they "expect that it [using systematic reviews] would level the playing field, that everyone would be, there would be a central and more systematic way of identifying what might useful…" (R4H1). A participant from the mental health and addictions sector highlighted that "…when just looking for things, when you're looking for research often like maybe you might end up with something that's more piecemeal where if you have a systematic review then there's some assurance that you've captured what's out there." (R2M2) Another highlighted the different ways in which systematic reviews could be useful to their work:

> "So it seems like a very useful approach at two points. The application point but there's also the question of kind of the program development and program

> management point in the agency. Kind of not framing it only within a kind of 'seeking money' framework. It's also about seeking improvement in organizations, right? So I think, yeah, it's much clearer if it's kind of framed in that way for me."…"We do prevention, but are we doing prevention well enough. And do we have all the data we need to be doing good prevention. Right? So it's, yeah, potentially a very valuable tool." (R3H2)

While reviews were widely accepted as being a useful source of research evidence to inform the work of community-based organizations, some noted some potential limitations in their application. One participant highlight that reviews may lack important detail in descriptions of the interventions or programs that were studied:

> "They wouldn't describe in any detail what the programs look like. They would just sort of say, 'Case management for homeless people.' Like they would just describe it in two sentences, which doesn't actually tell you what it looked like on the ground…and they wouldn't really unpack like some of the reasons why things might've worked or not worked and what contexts and factors were at play that might've--because they kind of do it at this high level that basically, it really abstracts it to a level that I think makes them not very useful to people who are trying to apply them on the ground." (R2M2)

Similarly, another participant in the same focus group indicated that:

> "it depends on what you're using it [a systematic review] for. So if it's something where you need to understand how something, how something happened or what the content of it is, then it might not be as useful. But if you're looking more at outcomes and effectiveness, that's, I think maybe a different situation where a systematic review that says, "This worked," or "This didn't work," might be more effective. So I guess it depends on the depth of the content that you need to understand for what you're doing." (R1M2)

However, after highlighting that reviews are increasingly drawing many types of research evidence, including qualitative evidence that may help better explain how and why interventions or programs work, both participants were more intrigued at the idea of using systematic reviews.

When asked about the proposed format for developing user-friendly summaries, all participants were very supportive of the approach of providing a plain language summary, a succinct outline of the 'take-home messages' and a summary of the benefits, harms and costs of the intervention/topic being addressed. In response to whether a plain language summary would be helpful, one participated responded with "Absolutely. It's a pre-screening tool so you don't have to through all the stuff you don't want to read" (R2H1) and another participant indicated that "…certainly the simpler the better and then if you want more you can dig for more, but that's what's going to be the hook." (R2M1). Similarly, participants liked the idea of pulling out the take-home messages and providing them at the start of the summary with one participant saying "I like the take-home messages. You know, three key points that you can walk away with" (R5H2) and another indicating that "if you've got the take-home message, if you've got the succinct message up front saying, "Here's what it is," people who want to delve into it more will do that." (R9M1).

We also asked if user-friendly summaries such as the ones we outlined would help them use information from systematic reviews in their work. The response was similarly positive with participants providing sentiments such as that they "shouldn't have to either sort through a lot of technical language or read a 30-page paper. Which I wouldn't get to. I wouldn't." (R8M1) and another saying that:

> "the truth is a lot of the research that comes out is completely inaccessible for people who aren't researchers and that's most people who do the kind of work in the community, for example. So any way of having this material translated in a way that people can understand, it's easily accessible, it's summarized, is I think really fantastic." (R3D1)

In the last section of discussion in the focus groups about assessing the relevance of systematic reviews, we received mixed feedback. All of the groups were supportive of the idea of categorizing systematic reviews according to topic and population. Specific ideas were categorizing reviews according to the social determinants of health, topics related to treatment, care and support and about specific populations. Such an approach would allow for flexibility of searching and for them to have a better chance pulling up reviews that are relevant to their needs. In contrast, the reactions in all of the focus groups toward completing peer-relevance assessments and using the results of these assessments as a filter for reviews they would receive in updates through an evidence service (i.e., only receiving reviews that have received a minimum level of relevance rating) was largely not supported or viewed as being useful. Some participants noted concerns about whether those completing the peer-relevance assessments were reflective of them with one participant saying "I would immediately question who's doing that" (R2H1), and others indicating "I would say don't bother" (R6M1), "…there's no way you can get consensus out [of] anybody" (R3M1) and "I can say how relevant it is to my work. I don't know how comfortable I would feel determining if it's relevant to your work." (R4M2). Some participants were somewhat open to the idea noting that they would at least like to see what the process would look like.

Development of user-friendly summaries and peer-relevance assessments

Based on the feedback received through the focus groups, we developed a template for a user-friendly summary and an approach for peer-relevance assessments. We also developed three summaries of recent systematic reviews for each sector. The template we developed for pilot testing in the interviews is provided in Appendix 1 and on the first page it provides sections for the full citation for the review, a brief outline of the topic of the review, a plain language summary and 3-4 key messages provided by the review. The longer version of the summary provides the findings of the review but presented in three sections related to the benefits, harms and costs of the intervention or program investigated in the review. Specifically, the section related to benefits highlights whether the review found evidence for benefits, no benefits or insufficient evidence for benefits related to the intervention or program investigated. Similarly, the section related to costs further breaks down the findings into health system costs (i.e., cost estimates for a healthcare system or a jurisdiction within a healthcare system) and cost-effectiveness estimates. In addition, each section provides space to highlight equity consideration and local applicability considerations.

Based on the mixed feedback we received about the approach for peer-relevance assessments, we decided to solicit feedback about the same approach we outlined for them in the focus groups. The peer-relevance assessment tool consists of three questions with 5-point scales that ask about their views on a reviews immediate relevance (How relevant is this summary to decision-making in your organization or jurisdiction right now?), future relevance (How relevant would this summary be to decision-making in your organization or jurisdiction in the future?) and usefulness (How useful is the information presented in this summary to decision-making in your organization or jurisdiction?). The full peer-relevance tool is provided in Appendix 2.

Interviews

Of the 31 focus group participants that we invited for a follow-up one-on-one semi-structured interview, 16 agreed (52%). The majority of those who agreed to participate were from the HIV/AIDS sector (n=10, 62.5%) with four (25%) from the mental health and addictions sector and two (12.5%) from the diabetes sector.

Overall, the user-friendly summaries were well received by the executive directors and program managers of community-based organizations that we interviewed. The format of the summaries was consistently mentioned as being helpful. Specifically, all participants thought that providing the plain language summary and the take-home messages on the one-page summary was helpful. The positive reactions to the structure of approach of the summary are highlighted in Box 1 with illustrative quotes from many of the participants. In addition to the format, most participants found that providing the results in the format of benefits, harms and costs was unique yet helpful way of presenting information. As one participant from the diabetes sector highlighted, “I also like what you said, that you’re bringing into consideration harm, equity, because these are sometimes those aspects that are not captured in reports." (R8D). Another participant from the diabetes sector similarly noted that "you really made it easy for me as someone on the applied side of health care to see what was insufficient evidence and what was of no benefit or, and clearly what was of benefit. So I really liked the benefits section. And the same goes for the 'harms' so it's very clear, nice, well done." (R9D).

While the approach was helpful, several participants noted that a users-guide to the structure and the type of content that is included under each heading would be helpful because the terminology is slightly different than what they are accustomed to. Similarly, one participant from the mental health and addictions sector did not find the user-friendly summaries as helpful as others indicating that "I found it almost a little bit too detailed…. so I actually found the first page to be really useful and that the second and third page to be more detailed than--like I think if you need that kind of detail then you can just read the actual review." (R3M). Other suggested revisions were very minor and included: 1) ensuring that it was made clear that the information was directly cited from the review, 2) ensuring those accessing the summaries know that the original review should be cited as the source of the information and providing the citation, and 3) streamlining the format by providing the equity and local applicability sections at the end rather than repeating them after each of the benefits, harms and costs sections. Based on this feedback, we produced a slightly revised user-friendly template and modified each of the example summaries to reflect the formatting changes in the template. The revised template and each of the summaries are provided in Appendix 3.

In contrast to the user-friendly summaries, the feedback we received about the peer-relevance assessments clearly rejected the notion of using scores as a way of filtering the systematic reviews that users of an evidence service would receive. Reasons provided were similar to those from the focus group, including not knowing who was completing the assessments, questioning whether they were representative of their specific interests and concerns about missing important information. While all participants rejected the idea of using the peer-relevance assessment scores as a filter, most supported the idea of providing scores alongside systematic reviews records in a future evidence service. Related to this was that participants highlighted that they would like to rate the relevance of reviews while using/engaging with them as opposed to being sent reviews to assess. One participant highlighted the overall sentiment of the interviewees by stating:

> "I would prefer to have the scores provided for me versus using as a filter. Because I think sometimes scoring can be arbitrary. We all use different lenses to rate something. So I would love to see a score that others had provided, perhaps comments as well, but I would still not want to run the possibility of not seeing something that had possibly been scored low by another set of users." (R13H)

This quote also highlights the theme of providing a user-forum that emerged from the interviews. Several participants noted that having a space to share comments would helpful in order to gain insight into reviews that others found useful and why. As one participant highlighted, "[a]llowing people to make comments, general comments as well, about, you know, that they've used it, that they found it very, very useful and stuff like that, those kinds of things, more general comments, would be helpful, too." (R12H). As this theme emerged in the interviews, we incorporated a prompt in the interview guide and all participants were supportive of including this type of forum.

While the general idea of peer-relevance assessment was supported provided that scores were not used a filtering mechanism, views about the questions to include in the peer-relevance assessment tool were more varied. Many pointed out that the question about future relevance was difficult to answer and was not helpful. Others noted that while asking about both relevance and usefulness made sense, that the process should as simple as possible. Highlighting this idea, one participant from the mental health and addictions section indicated that "My overall response to it is as simple as possible and not make it complex. The more complex it is, the less likely too many people are to take the time to give it to you." (R2M). The consensus emerging from the interviews was to only use one question and the most intuitive question appeared to the one asking how useful the information from the systematic review is.

Discussion

Principal findings

Through five focus groups in three sectors (HIV/AIDS, diabetes and mental health and addictions) with 31 executive directors and program managers and follow-up interviews with 16 focus group participants we have developed a better understanding of the key characteristics of community-based organizations, their views about and experiences with systematic reviews and approaches to user-friendly summaries and peer-relevance assessments of systematic reviews. We found that community-based organizations are complex as they are involved in multiple activities (program and delivery and advocacy), function through intra and inter-sectoral networks and often balance multiple and inconsistent revenue sources that may come with requirements or 'strings' attached. Key characteristics that were highlighted include the importance of involving community members in the formation, governance and functioning of the organization, being guided by a mission, vision and set of values and having mandates that are typically shaped by the populations and geographic regions they serve.

Most executive directors and program managers had not previously heard of systematic reviews prior to the focus groups. However, after learning of what systematic reviews are, most thought that they were a helpful source of research evidence that could inform their programs, services and advocacy. In addition, the approach to developing user-friendly summaries of systematic reviews that provide a plain language summary, a succinct outline of the 'take-home messages' and a summary of the benefits, harms and costs of the intervention/topic being addressed was widely supported and was viewed as being helpful to supporting their use of systematic reviews. Lastly, with respect to assessing the relevance of systematic reviews, we found that community-based organizations support the idea of categorizing reviews according to topic and populations but not the idea of using scores from peer-relevance assessments to filter the reviews that users would receive. Our findings indicate that the preferred approach to incorporating peer-relevance assessments is to: 1) only ask one targeted question (how useful the information from the review is) in order to keep the process as simple as possible, 2) only ask for relevance assessments when users are accessing a review through the evidence service (i.e., not actively soliciting assessments through regular updates), 3) provide scores of the peer-relevance assessments in the record of a systematic review, and 4) supplement the peer-relevance assessment with a “user forum” for each systematic review record.

Study meaning

The approaches we have developed for producing user-friendly summaries and peer-relevance assessments of systematic reviews fill an important gap in supporting the use of research evidence by community-based organizations that we have highlighted in previous work (44). These tools can be used by those interested in supporting community-based organizations and by anyone interested in providing the results of reviews in a more accessible format. One way that we plan to use the findings is in the development of a large-scale evidence service for community-based organizations consisting of both 'push' efforts (i.e., periodically highlighting new and relevant systematic reviews) and efforts to facilitate 'pull' (i.e., categorizing reviews so that they are easily retrievable and providing user-friendly summaries to facilitate their use).

It is interesting to note that the feedback we received in this study about the user-friendly summaries and the peer-relevance assessments for systematic reviews largely mirror what we found in a similar qualitative study with health system managers and policymakers in Canada (5). The health system managers and policymakers and the executive directors and program managers from community-based organizations prefer the same format and information provided in the user-friendly summaries. Perhaps the more interesting finding is that both groups had similar reactions to the use of peer-relevance assessments by indicating concerns about using the scores as a filter for what they receive (5). In contrast, clinicians seem to not share the same concerns given their sustained involvement in conducting peer-relevance ratings for services such as EvidenceUpdates.

There are two possible explanations for the congruent findings related to peer-relevance assessments. First, as compared to clinicians, health system managers and policymakers and executive directors and senior managers of community-based organizations are much less homogenous as a group. For instance, clinicians may be able to place more trust in the ratings of peers in the same specialty given that they have very similar needs for research evidence. The second likely explanation is the 99.96% noise reduction for clinicians that is achieved through the relevance ratings provided through EvidenceUpdates (45).

By reducing approximately 50,000 potentially relevant articles per year to 3,000 that meet essential critical appraisal and content criteria (94% noise reduction), and further reducing this to approximately 20 articles per year for clinicians after the clinical relevance review (if set at the highest cut-off) (99.96% noise reduction), EvidenceUpdates provides a much more manageable volume of literature to draw from. Therefore, given that community-based organizations and health system managers and policymakers likely face substantially smaller volumes of relevant literature (e.g., there are a total of 1278 policy relevant systematic reviews in health systems evidence for policymakers to draw from) (46), filtering evidence based on relevance is likely less important.

Strengths and limitations

Our study has three main strengths. First, we have built on previous research in the knowledge translation literature related to developing approaches for user-friendly summaries and peer-relevance assessments for systematic reviews and adapted them specifically for community-based organizations working in the health sector. Given that there have been few visible efforts to support the use of research evidence by community-based organizations, this study provides a unique and important contribution. Now those working to support the use of research evidence by community-based organizations can begin to mobilize findings from systematic reviews using our approach for user-friendly summaries and develop approaches to categorizing reviews in their sector to facilitate their retrieval. In addition, we are now well poised to develop a large-scale evidence service that supports the use of systematic reviews by community-based organizations. Second, we conducted this study with executive directors and program managers of community-based organizations from three different sectors, which enhances the applicability and transferability of our findings. Lastly, we provide in-depth information about the key characteristics of community-based organizations, which contributes to better understanding their important roles in health systems. Potential limitations that should be considered include limiting the sample to participants from community-based organizations in one Canadian province (Ontario) and to some extent from one of the major urban areas in the province (the Greater Toronto Area), having the majority of the interviews come from the HIV/AIDS sector and the low response rate for the focus groups and interviews. It is also possible that many of the participants were already supportive of this work, and we therefore may not have obtained feedback from those with less favourable views of using research evidence to inform their programs, services and advocacy. Lastly, the findings are related to community-based organizations in one high-income country and could therefore not be representative of organizations in low- and middle-income countries or other high-income countries.

Future research and initiatives

There are several areas for future research and initiatives to continue efforts to support the use of research evidence by community-based organizations. First, it is important for both those developing systematic review methods and those producing systematic reviews to continue with efforts to conduct them in way that provide the types of evidence that community-based organizations need to inform their programs, services and advocacy. This could involve including multiple types of evidence in systematic reviews (e.g., including both quantitative and qualitative methods) and ensuring that the interventions or programs under evaluation are described in sufficient detail in order to allow CBOs to better assess whether and how they can applied in their local settings. Another important area of future work is to develop and implement capacity building initiatives that help community-based organizations acquire, assess, adapt and apply research evidence to inform their programs, services and advocacy. This could involve conducting assessments of specific areas where community-based organizations in different settings require capacity building and then partnering with organizations (or networks of organizations) to develop materials (e.g., online interactive tutorials) and provide interactive workshops.

In addition to the above areas for future research, we are currently pursuing two specific initiatives using the findings of this study. The first is to develop an evidence service that incorporates the products developed in this study (user-friendly summaries and peer-relevance assessments). Developing an evidence service involves identifying relevant systematic reviews, categorizing them in order facilitate easy retrieval, producing user-friendly summaries, providing relevance assessments and user-forums as part of each systematic review record. This information would then be provided to community-based organizations through an easy to use interface. The second research initiative is to evaluate the effects of an evidence service and its different components on the use of research evidence by community-based organizations. Quantitative (e.g., through a randomized controlled trial), qualitative and short and long-term evaluations are important in order to not only assess whether such interventions have effects on the use of research evidence but also to provide insight into whether and how knowledge translation interventions support the use of research evidence by community-based organizations. Evaluation is a critical component for helping to further refine and enhance future interventions.

Box 1: Quotations highlighting views on the structure of the user-friendly summaries

"I really like the key messages right up front. I actually like sort of the way it's broken down, so there's just a one-page summary right off the top, almost like a sub-summary type of thing" (R4H)

"It's short and I like the key messages. It's the way I learn from things. So if I was going through something I would, this is exactly what I do is pull out key messages. And it gives me a good idea of what's there. If there's something there that I need more on then I would go to the next part." (R5H)

"For me it's the different layers of identification. So first it's the topic and then it's the plain language summary and then it's the key messages. So it's not just you're presenting the information as a plain language summary. I see the different levels would be helpful to help people navigate and understand the initiative or the program you are reviewing." (R8D)

"I also like what you said, that you're bringing into consideration harm, equity, because these are sometimes those aspects that are not captured in reports." (R8D)

"…for someone who is not into research and that I have an interest and it's something I want to get more into, I can read this, I can manage it and I understand it." (R10H)

"One of the things I like is it's a one-pager. Like that's important to me for a lot of things because there's so many things coming across the desks, that I look at the--I like that and I look at the three of them, I like that it's one page, I can pick it up and go, 'Yup' or 'No.'" (R10H)

"…it's organized both visually, easy-to-flow, it makes sense, and it's also organized logically. I can understand it as I look through each of the sections. And thirdly it's in plain language itself" (R11H)

"I like this template because it does analyze the stuff that I like to know." (R12H)

"I was actually really surprised how interesting I found them. I found it a little strange that I was actually surprised that once I actually got into them they were quite engaging and actually I think a very useful tool to have on-hand." (R13H)

"I liked the progression of the information throughout the document. I loved the fact that you're starting with, almost starting with a plain language summary, which for me really creates a point of access for people who are maybe a little research-averse or evaluation-averse. And there are key messages up front as well so you don't have to wade through necessarily the entire document. What I really liked as well is, of course, an examination of the benefits in language that is easily understood. But I actually found a lot of the information in the brief summary to be the most digestible pieces of the whole document. I also like that there’s kind of an area for equity considerations. I think that’s incredibly valuable for organizations that are committed to equity and anti-oppression.” (R13H)

“I think it is an accessible format. I do like the fact that your summary, that I can tell right from page one if I want to continue onwards or not.” (R14H)

“…what I did like were the key messages and basically what in a plain language manner what is it about. It’s a quick reference so I could just see that and say, “Okay, this is what I’m looking for,” or “This might be relevant to what I’m researching or help with a funding proposal” or something like that.” (R15H)

“…for somebody in my position, a one-pager like this is exactly what I want to see.” (R16M)

“I like the key messages section. Because again it’s like three points that you look at and then you’re able to quickly determine if this is something that would be useful.” (R17H)

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Appendix 1 – Original user-friendly summary template

Program in Policy Decision-Making
www.researchtopolicy.org

Brief summary of: [insert review title]

Full citation
[insert full citation]

Topic of the review
[brief summary of PICO or relevant aspects of the objectives]

Plain language summary
[Paraphrased summary from the review. In the case of Cochrane reviews, use the plain language summary provided]

Key messages from the review (weighing of benefits, harms and costs)

- Key message 1
- Key message 2
- Key message 3
- Key message 4

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Detailed summary of: [insert review title]

Review findings:

- **Benefits**
    - **The review found evidence for benefits related to:**
        - [insert findings or N/A]
    - **The review found evidence that indicated there are no benefits related to:**
        - [insert findings or N/A]
    - **The review found a insufficient evidence for benefits related to:**
        - [insert findings or N/A]
    - **Equity considerations**
        - [insert relevant equity considerations or 'No equity considerations were provided as part of the findings in the review']
            - Were there any important differences in need (prevalence, baseline risk or health status) reported between advantaged and disadvantaged populations that might lead to health inequities being increased, reduced or unaffected?
            - Were there any plausible reasons reported for anticipating important differences in benefits between advantaged and disadvantaged populations that might lead to health inequities being increased, reduced or unaffected?
    - **Local applicability considerations** (Health care setting characteristics, jurisdiction studied, populations assessed, resources needed)
        - [insert findings or 'No local applicability considerations were provided as part of the findings in the review']
- **Harms**

  - **The review found the following harms/adverse events:**
    - [insert findings or 'No harms or adverse events were reported']

  - **Equity considerations related to harms:**
    - [insert findings or 'No equity considerations related to harms or adverse events were reported']

  - **Local applicability considerations related to harms:**
    - [insert findings or 'No local applicability considerations related to harms or adverse events were reported']

- **Costs**
  - **Health system costs** (i.e., cost estimates for a healthcare system or a jurisdiction within a healthcare system)
    - [insert findings or 'No information related to health system costs was reported']

  - **Cost-effectiveness estimates**
    - [insert findings or 'No cost-effectiveness estimates were reported']

  - **Equity considerations related to costs:**
    - [insert findings or 'No equity considerations related to costs were reported']

  - **Local applicability considerations related to costs:**
    - [insert findings or 'No local applicability considerations related to costs were reported']

Appendix 2 – Peer-relevance assessment tool for community-based organizations

1. Please read the following summary for a systematic review and then rate its immediate relevance, future relevance, and usefulness.

[Insert summary #1]

1a. Immediate relevance: How relevant is this summary to decision-making in your organization or jurisdiction right now?

Score	Criterion
☐	Beyond my area of decision-making but may be of interest to my organization or jurisdiction
☐ 5	Definitely relevant
☐ 4	Probably relevant
☐ 3	Somewhat relevant
☐ 2	Probably not relevant
☐ 1	Not relevant

1b. Future relevance: How relevant would this summary be to decision-making in your organization or jurisdiction in the future?

Score	Criterion
☐	Beyond my area of decision-making but may be of interest to my organization or jurisdiction
☐ 5	Definitely relevant
☐ 4	Probably relevant
☐ 3	Somewhat relevant
☐ 2	Probably not relevant
☐ 1	Not relevant

1c. Usefulness: How useful is the information presented in this summary to decision-making in your organization or jurisdiction?

Score	Criterion
☐ 5	Highly useful: I would definitely use this
☐ 4	Probably useful: I would likely use this
☐ 3	Somewhat useful
☐ 2	Probably not useful: I would likely not use this
☐ 1	No useful: I would definitely not use this

Appendix 3 - Final user-friendly summary template and worked examples

Program in Policy Decision-Making
www.researchtopolicy.org

Brief summary of: [insert review title]

Topic of the review
[brief summary of PICO or relevant aspects of the objectives]

Plain language summary
[Paraphrased summary from the review. In the case of Cochrane reviews, use the plain language summary provided]

Key messages from the review (weighing of benefits, harms and costs)

- Key message 1
- Key message 2
- Key message 3
- Key message 4

Full citation
All material presented in this summary is taken directly from the full systematic review publication and should be cited as follows:

[insert full citation]

Program in Policy Decision-Making
www.researchtopolicy.org

Detailed summary of: [insert review title]

Review findings:

- **Benefits**
  - **The review found evidence for benefits related to:**
    - [insert findings or N/A]
  - **The review found evidence that indicated there are no benefits related to:**
    - [insert findings or N/A]
  - **The review found insufficient evidence for benefits related to:**
    - [insert findings or N/A]
- **Harms**
  - **The review found the following harms/adverse events:**
    - [insert findings or 'No harms or adverse events were reported']
- **Costs**
  - **Health system costs** (i.e., cost estimates for a healthcare system or a jurisdiction within a healthcare system)
    - [insert findings or 'No information related to health system costs was reported']
  - **Cost-effectiveness estimates**
    - [insert findings or 'No cost-effectiveness estimates were reported']
- **Additional information that could influence the applicability of the findings**

- **Equity considerations**
  - [insert relevant equity considerations or 'No equity considerations were provided as part of the findings in the review']
    - Were there any important differences in need (prevalence, baseline risk or health status) reported between advantaged and disadvantaged populations that might lead to health inequities being increased, reduced or unaffected?
    - Were there any plausible reasons reported for anticipating important differences in benefits between advantaged and disadvantaged populations that might lead to health inequities being increased, reduced or unaffected?

- **Local applicability considerations** (Health care setting characteristics, jurisdiction studied, populations assessed, resources needed)
  - [insert findings or 'No local applicability considerations were provided as part of the findings in the review']

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Brief summary of: Culturally appropriate health education for type 2 diabetes mellitus in ethnic minority groups

Topic of the review
This review assessed the effects of culturally appropriate health education interventions for people with type 2 diabetes mellitus in ethnic minority groups.

Plain language summary
The review found eleven randomized controlled trials (RCTs) of culturally appropriate diabetes health education in the world literature that met the selection criteria (participants from a defined ethnic minority group living in a middle income or high income country, over 16 years in age, with type 2 diabetes mellitus, and receiving a culturally tailored health education intervention). Culturally appropriate health education improved blood sugar control in participants, compared with those receiving 'usual' care, at three and six months post-intervention, to be of potential clinical importance if sustained. Knowledge about diabetes, and healthy lifestyles also improved. None of the other clinical outcome measures such as cholesterol, blood pressure or weight showed any improvement, nor were there any improvements in quality of life outcomes for patients.

Key messages from the review (weighing of benefits, harms and costs)

- This review has shown that culturally appropriate health education is better than 'normal' practice for minority communities. This does not only mean delivery of health education in the patients' mother tongue, but also adaptation of teaching and learning methods to suit cultural and community needs as well as the content of the education itself

- Culturally appropriate health education should be the 'gold standard' for health education programmes targeted at ethnic minority communities, because it has the potential to result in clinically significant improvements for HbA1c and cholesterol, and in significant improvements in knowledge about diabetes and its management.

- Culturally appropriate health education programs did not have a significant impact on blood pressure, quality of life measures, other patient based outcomes and body mass index measurements as compared to those not receiving 'usual care'.

- None of the studies were long-term or included economic analysis, so clinically important long-term outcomes and cost outcomes could not be studied.

Full citation

All material presented in this summary is taken directly from the full systematic review publication and should be cited as follows:

Hawthorne K, Robles Y, Cannings-John R, Edwards AGK. Culturally appropriate health education for type 2 diabetes mellitus in ethnic minority groups. *Cochrane Database of Systematic Reviews* 2008, Issue 3. Art. No.: CD006424. DOI: 10.1002/14651858.CD006424.pub2.

Program in Policy Decision-Making
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Detailed summary of: Culturally appropriate health education for type 2 diabetes mellitus in ethnic minority groups

Review findings:

- **Benefits**
  - **The review found evidence for benefits related to:**
    - **Glycaemic control**
      - Culturally appropriate health education programmes improved glycaemic control in participants from ethnic minority communities with type 2 diabetes mellitus, compared with those receiving 'usual care'.
      - This improvement was seen at three and six months post intervention, but was lost at one year post intervention. The level of improvement at both three and six months appears to be of sufficient magnitude to be clinically important
    - **Cholesterol levels**
      - Total cholesterol levels improved in the intervention group at one year post intervention but other measures of lipid levels did not show a significant difference (HDL-cholesterol, LDL-cholesterol or triglycerides)
    - **Knowledge about diabetes and its management**
      - Knowledge scores improved in the intervention group at three, six and twelve months after the delivery of the intervention. There was a tail-off in this improvement with time, as might be expected if there was no further reinforcement of the intervention.
      - None of the studies reported using educational reinforcement techniques to enhance retention of information.
      - The review found four studies in which the effect of altering the intensity and timings of the culturally appropriate health education programme was evaluated. there appeared to be a dose-related

    - effect of health education in that the more intensive arms appeared to show more improvement in some outcome measures.

  - **The review found evidence that indicated there are <u>no benefits</u> related to:**
    - Blood pressure
    - Quality of life measures
    - Patient based outcomes
    - Body mass index measurements

  - **The review found <u>insufficient evidence for benefits</u> related to:**
    - Altering the intensity and timing of education programs
      - The review found four studies in which the effect of altering the intensity and timings of the culturally appropriate health education programme was evaluated. There appeared to be a dose-related effect of health education in that the more intensive arms appeared to show more improvement in some outcome measures.

- **<u>Harms</u>**

  - **The review found the following harms/adverse events:**
    - No studies followed patients up in the longer term, or looked at diabetic complication rates.

- **<u>Costs</u>**

  - **Health system costs** (i.e., cost estimates for a healthcare system or a jurisdiction within a healthcare system)
    - No information related to health system costs was reported

  - **Cost-effectiveness estimates**
    - No cost-effectiveness estimates were reported

- **<u>Additional information that could influence the applicability of the findings</u>**

  - **Equity considerations**
    - Several possible sub-group analyses were planned but the data provided by the studies selected were not sufficient to evaluate them all. As a result the following variables were not investigated in the data: age, gender, educational status of participants, length of time since diagnosis of diabetes, presence or absence of diabetic complications.

- **Local applicability considerations** (Health care setting characteristics, jurisdiction studied, populations assessed, resources needed)
  - **Type of intervention and method of delivery**
    - The effects of combining different approaches appeared to be greater than those of the overall findings
    - One study found that attitudinal scales improved in both groups receiving the health education, with a larger effect in the group receiving both one to one and group education but found there was no difference in HbA1c.
    - Another study found that physical activity improved in both intervention groups (i.e., one to one and group education) and that there was no difference between them in HbA1c, calorie intake or diabetic knowledge.
  - **Type of health educator**
    - It is not clear from the data if including a dietician in the health education team results in better outcomes than link workers or diabetes nurses
    - However, each type of health educator appears to have an effect on improvingHbA1c at six months, and knowledge at either three or six months post intervention.
  - **Duration of intervention**
    - Insufficient data to conduct an analysis on the impact of the duration of the intervention
  - **Health care system delivering the intervention**
    - Comparing results for studies conducted in the USA (n=5) with those in Europe, both appeared to show that HbA1c improved at six months, although the USA studies did not show an improvement in knowledge at six months while the European studies did show an improvement.
    - An improvement in knowledge at 12 months post intervention was shown in the USA studies, making it likely that the effects of intervention in the USA and Europe are similar.
  - **Types of health education supplied to different ethnic minority groups**
    - The review subdivided the studies into those aimed at South Asians, African-Americans and Hispanic individuals. Each of these ethnic groups showed improvements inHbA1c and knowledge in intervention groups compared with control groups during the six month period post intervention. These

    improvements were not sustained beyond six months in any group (only two studies per group were analyzed, limiting the weight that can be put on the results).

- **Location**
    - It was not always possible to identify the venue(s) at which the health education intervention took place. In some studies a mixture of primary and secondary care venues were used for the convenience of participants, so the impact of venue could not be assessed.

Program in Policy Decision-Making
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Brief summary of: Dietary advice for the prevention of type 2 diabetes mellitus in adults

Topic of the review

This review assessed the effects of type and frequency of dietary advice for the prevention of type 2 diabetes mellitus. Studies where the intervention was dietary advice with an aim of reducing weight and risk of developing type 2 diabetes mellitus were included in this review. Studies that compared the effects of dietary advice versus no dietary advice or dietary advice versus different dietary advice were also included. Studies were not included if they included medication that was provided differently in the control and intervention groups.

Plain language summary

Two trials randomized 358 participants to dietary advice and control treatment groups. The longest duration of dietary advice was six years and the only other trial lasted 12 months. Dietary advice appears to be effective in reducing the risk of diabetes by 33% compared to control group over six years. After 12 months, dietary advice appears to have beneficial effects on indicators of metabolic control. Data on mortality, morbidity, health-related quality of life, adverse effects and costs were not reported.

Key messages from the review (weighing of benefits, harms and costs)

- Although more evidence is required, the data which are available do suggest that there are benefits in following an energy-controlled diet with an increase in consumption of fresh fruit and vegetables, and a decrease in simple sugars intake. However, another overriding factor is the frequency of support and guidance provided by the dietary advisors, which occurred at least every 3 to 6 months in both studies, encouraging compliance to the prescribed diets.

- A clinical trial that investigated the effects of diet, exercise and diet plus exercise on the incidence of diabetes in people with impaired found that the dietary intervention group had a 33% reduction in the incidence of diabetes after 6 years

- Due to the lack of studies and available data, additional research needs to be carried out into the best type of diet, and the optimal frequency and type of contact with dietary advisors, to maximize participant compliance to any prescribed dietary treatments.

Full citation
All material presented in this summary is taken directly from the full systematic review publication and should be cited as follows:

Nield L, Summerbell CD, Hooper L, Whittaker V, Moore H. Dietary advice for the prevention of type 2 diabetes mellitus in adults. *Cochrane Database of Systematic Reviews* 2008, Issue 3. Art. No.: CD005102. DOI: 10.1002/14651858.CD005102.pub2.

Program in Policy Decision-Making
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Detailed summary of: Dietary advice for the prevention of type 2 diabetes mellitus in adults

Review findings:

- **Benefits**
  - **The review found evidence for benefits related to:**
    - **Incidence of type 2 diabetes**
      - In a study of impaired glucose tolerance and diabetes (conducted in Da Qing, Hei Long Jiang Province, China) the incidence of type 2 diabetes in the control group was 67.7% which was reduced to 43.8% in the diet group. Overall, the dietary intervention group had a 33% reduction in the incidence of diabetes after 6 years

    - **Glycaemic control measures (insulin resistance, fasting insulin, blood glucose and plasma lipoprotein profiles and**
      - In the Oslo Diet and Exercise Study, the calculated relative insulin resistance varied widely in participants. However, despite the large variation, the diet intervention lowered the mean insulin resistance after 12 months from 4.6 to 4.2.

      - Other significant insulin-related changes in the Oslo study were fasting insulin for diet versus control; fasting C-peptide for diet versus control; fasting proinsulin for diet versus control and overall insulin resistance for diet versus control.

    - **Anthropometric measures (weight and body mass index)**
      - In the Oslo Diet and Exercise Study weight was reduced noticeably in the diet group. Significant differences were also reported for BMI for diet group versus control group

- **The review found evidence that indicated there are <u>no benefits</u> related to:**
  - N/A

- **The review found <u>insufficient evidence for benefits</u> related to:**
  - Time to development or diagnosis of type 2 diabetes mellitus, quality of life, mortality and morbidity and maximal exercise capacity were not measured in either of the included studies.

- **<u>Harms</u>**
  - **The review found the following harms/adverse events:**
    - No harms or adverse events were reported

- **<u>Costs</u>**
  - **Health system costs** (i.e., cost estimates for a healthcare system or a jurisdiction within a healthcare system)
    - No information related to health system costs was reported
  - **Cost-effectiveness estimates**
    - No cost-effectiveness estimates were reported

- **<u>Additional information that could influence the applicability of the findings</u>**
  - **Equity considerations**
    - In the Da Qing study, dietary treatment and advice differed for participants of BMI less than 25kg/m² (lean) and participants with a BMI greater than 25kg/m² (overweight) and some analyses were done to compare the two sub-groups.
      - Analyses indicated that incidence rates of diabetes in the control group of overweight participants were higher than incidence in the lean participants control group.
      - In the lean participants, the incidence of developing diabetes was not significantly changed by the dietary intervention.
  - **Local applicability considerations** (Health care setting characteristics, jurisdiction studied, populations assessed, resources needed)
    - Of the two studies which compared dietary advice to a control group, one was based in Da Qing, Hei Long Jiang Province, China and one in Oslo, Norway.

- In the Da Qing Impaired Glucose Tolerance and Diabetes Study, there were 33 clinics involved compared with only one in the Oslo Diet and Exercise Study

- All of the participants were home-based or free-living but received dietary advice by attending a clinic or at a university hospital

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Brief summary of: Individual patient education for people with type 2 diabetes mellitus

Topic of the review
This review evaluated the effectiveness of individual patient education on metabolic control, diabetes knowledge and psychosocial outcomes. This review only included studies where individual patient education formed the major component of the intervention. If a study used both individual and group education then it was included only if the individual component was a systematic programme designed for individual education.

Plain language summary
Nine studies involving 1359 participants met the inclusion criteria. Six studies compared individual education to usual care and three compared individual education to group education (361 participants). There were no long-term studies and overall the quality of the studies was not high. Individual face-to-face patient education for type 2 diabetes over a six to twelve month period did not significantly improve glycaemic control, body mass index, blood pressure or total cholesterol in the short or medium term compared with usual care. In the studies comparing individual education to group education, there was no significant difference between individual or group education at 12 to 18 months nor a significant difference in the impact of individual education versus group education on BMI, systolic or diastolic blood pressure.

Key messages from the review (weighing of benefits, harms and costs)

- Individual education when compared to usual care did not have a significant impact on glycaemic control as reflected by glycated haemoglobin A1c (HbA1c) at 6 to 9 months or 12 to 18 months.

- In a subgroup of those with a baseline HbA1c greater than 8%, finding suggest suggests a benefit of individual education on glycaemic control when compared with usual care.

- There did not appear to be a significant impact of individual education on body mass index, blood pressure or total cholesterol.
- Group education appeared to have a greater impact on glycaemic control than individual education at 6 to 9-months and there was no significant difference between the impact of individual education and group education on body mass index, systolic or diastolic blood pressure with both groups having an improvement from baseline during the study.

Full citation
All material presented in this summary is taken directly from the full systematic review publication and should be cited as follows:

Duke SAS, Colagiuri S, Colagiuri R. Individual patient education for people with type 2 diabetes mellitus. *Cochrane Database of Systematic Reviews* 2009, Issue 1. Art. No.: CD005268. DOI: 10.1002/14651858.CD005268.pub2.

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Detailed summary of: Individual patient education for people with type 2 diabetes mellitus

Review findings:

- **Benefits**
  - **The review found evidence for benefits related to:**
    - **Diabetes knowledge**
      - One study found individual education significantly improved all knowledge subsets at six months as 78% of the study group could name one complication of diabetes compared with 18%at the start of the study and there was no significant change in the control group.
      - Based on one study that used a 14 point knowledge score to assess knowledge at baseline and six months, both the group and individual intervention groups had significant improvements in knowledge compared to baseline. However there was no significant difference between individual and group education in knowledge scores
      - Using a different knowledge score, another study found a significant difference between the groups at 6-months favouring group education but no significance between group and individual education at 12 months.
  - **The review found evidence that indicated there are no benefits related to:**
    - **Metabolic control, measured by glycated haemoglobin A1c (HbA1c)**
      - In the six studies comparing individual face-to-face education to usual care, individual education did not significantly improve glycaemic control over a 12 to 18 month period

        - In the two studies comparing individual to group education, there was no significant difference in glycaemic control between individual or group education at 12 to 18 months

    - **Psychosocial outcomes**
        - There was no significant difference between the effects of individual and group education on quality of life measures as measured through two different scales (ATT-19 and SF-36)

    - **Physical measures (body mass index or blood pressure)**
        - Based on two studies, there was no significant decrease in BMI at 12 to 18 months in the individual education group as compared to 'usual care'
        - There was no significant difference between individual and group education in reduction in BMI at 6 to 9 months
        - Individual education had no significant effect on systolic blood pressure but there was a trend favouring individual education for reduction in diastolic blood pressure
        - There was no significant difference between individual and group education on reduction in systolic or diastolic blood pressure

    - **Metabolic (lipids)**
        - Individual patient education had no significant effect on total cholesterol compared with usual care
        - Only one study assessed total cholesterol which demonstrated no significant difference between individual education and group education in change in total cholesterol over 3, 6 or 12 months.

    - **Smoking**
        - One study found a significant reduction in the number of participants who quit or reduced the amount of smoking in those receiving individual education versus usual care but the percentages of smokers were significantly different between the two groups at baseline.
        - One study of group education just failed to reach significance in favouring smoking cessation over individual education but there were substantial differences in the number of smokers between the groups at baseline

- **The review found <u>insufficient evidence for benefits</u> related to:**
    - **Self-management**
        - One study found no significant difference in percent of behavioural goals achieved between the group and individual education groups

        and no affect on self reported physical activity after six months within each group
    - Another study with a sample of only women found significantly better diet self-management with a trend towards better exercise self-management among those receiving individual education.

- **Harms**
    - **The review found the following harms/adverse events:**
        - Despite being included as a primary outcome of the review, there was no available data from the included studies on diabetes complications

- **Costs**
    - **Health system costs** (i.e., cost estimates for a healthcare system or a jurisdiction within a healthcare system)
        - Despite being included as a primary outcome of the review, there was no available data from the included studies on healthcare costs

    - **Cost-effectiveness estimates**
        - No cost-effectiveness estimates were reported

- **Additional information that could influence the applicability of the findings**
    - **Equity considerations**
        - There did appear to be a significant benefit of individual education on glycaemic control in a subgroup analysis of three studies involving participants with a higher mean baseline HbA1c greater than 8%

    - **Local applicability considerations** (Health care setting characteristics, jurisdiction studied, populations assessed, resources needed)
        - Three trials were carried out in the United States, one in Australia, one in Spain, one in the Netherlands, one in Japan, one in Hong Kong and one in the United Kingdom.
        - The included studies did not provide any data on health services utilization

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Brief summary of: Mass media interventions for promoting HIV testing

Topic of the review

This review assessed the effect of mass media interventions and the most effective form of mass media intervention at a general population level or in specific target populations, in relation to changes in HIV testing.

Plain language summary

Use of the mass media is one of the important strategies in communicating behavioral change in relation to HIV/AIDS prevention. Mass media are used to promote voluntary HIV counseling and testing and to sustain test-seeking behavior. This review found 35 studies that assessed mass media interventions for promoting HIV testing and all concluded that mass media were effective. While mass media campaigns have shown an immediate and significant overall effect on voluntary counseling and testing, no significant long-term effect was demonstrated. This may have been due to the short duration of the campaigns.

Key messages from the review (weighing of benefits, harms and costs)

- Mass media campaigns designed to raise awareness of HIV/AIDS have shown immediate and significant effects in the promotion of voluntary counseling and testing for HIV

- No long-term effects were seen on mass media interventions for promotion of HIV testing

- There was no significant impact of detecting seropositive status after mass media intervention for promoting HIV testing

- These results were mainly based on multiple media interventions for the general public. Only one study was based on televised interventions and one study targeted blood transfusion recipients.

- The review was unable to compare the type of mass media interventions, sexual orientation of persons, characteristics of messages, or to assess cost effectiveness due to a lack of relevant studies.

Full citation
All material presented in this summary is taken directly from the full systematic review publication and should be cited as follows:

Vidanapathirana J, Abramson MJ, Forbes A, Fairley C. Mass media interventions for promoting HIV testing. *Cochrane Database of Systematic Reviews* 2005, Issue 3. Art. No.: CD004775. DOI: 10.1002/14651858.CD004775.pub2

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Detailed summary of: Mass media interventions for promoting HIV testing

Review findings:

- **Benefits**
  - **The review found evidence for benefits related to:**
    - Promotion of voluntary counseling and testing
      - This review shows mass media can influence the uptake of voluntary counseling and testing. They have a significant immediate and overall effect.
      - However, mass media showed no significant long-term impact on uptake of HIV testing. This may be due to the duration of the intervention being too short.
  - **The review found evidence that indicated there are no benefits related to:**
    - The number of infected persons diagnosed through voluntary counseling and testing
      - No significant effect was detected in general in relation to increasing the number of infected persons diagnosed through voluntary counseling and testing after mass media intervention promoting HIV testing.
      - However, this finding was limited to a small number of studies conducted in one non-epidemic country.
  - **The review found insufficient evidence for benefits related to:**
    - N/A
- **Harms**
  - **The review found the following harms/adverse events:**
    - No harms or adverse events were reported
- **Costs**

  - **Health system costs** (i.e., cost estimates for a healthcare system or a jurisdiction within a healthcare system)
    - No information related to health system costs was reported

  - **Cost-effectiveness estimates**
    - No cost-effectiveness estimates were reported

- **Additional information that could influence the applicability of the findings**

  - **Equity considerations**
    - While the studies assessed in the review targeted different populations include the general public (9 studies with one only assessing outcomes in commercial sex workers), pregnant mothers (2 studies), gay community (1 study), blood transfusion recipients (1 study), and women (2 studies), all individual study results showed positive impacts of mass media on uptake of HIV testing. These findings further supported the use of mass media in promoting HIV testing.

  - **Local applicability considerations**
    - Seven studies were done in United Kingdom, three in the United States of America, two in Australia, and one each in Canada and Israel.

    - Several different categories of interventions were identified. Most studies used multimedia and one each used video, television, and group education (i.e., participatory education and didactic education with skills training). Two studies used leaflets and discussion with participants. Multimedia included television, radio, newspapers, leaflets, and posters.
      - However, the review was unable to compare the effectiveness of different types of mass media interventions
    - Although this review was limited to developed countries, television and radio can be used in both literate and non-literate communities. Therefore, the findings are likely to be applicable to developing countries as well.

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Brief summary of: Patient support and education for promoting adherence to highly active antiretroviral therapy for HIV/AIDS

Topic of the review

This review assesses the effectiveness of patient support strategies and education for improving adherence to highly active antiretroviral therapy (HAART) in people living with HIV/AIDS.

Plain language summary

This review identified 19 studies involving a total of 2,159 participants that evaluated an intervention intended to improve adherence. Ten of these studies demonstrated a beneficial effect of the intervention. Interventions targeting practical medication management skills, those administered to individuals vs. groups, and those interventions delivered over 12 weeks or more were associated with improved adherence to antiretroviral therapy. In addition, interventions targeting marginalized populations such as women, Latinos, or patients with a past history of alcoholism were not successful at improving adherence. No studies were found that evaluated the quality of the patient-provider relationship or the clinical setting.

Key messages from the review (weighing of benefits, harms and costs)

- Interventions targeting practical medication management skills, those interventions administered to individuals vs. groups, and those interventions delivered over 12 weeks or more were associated with improved adherence outcomes.

- Interventions targeting marginalized populations such as women, Latinos, or patients with a past history of alcoholism were not successful at improving adherence.

- The review was unable to determine whether effective adherence interventions were associated with improved virological or immunological outcomes.

Full citation
All material presented in this summary is taken directly from the full systematic review publication and should be cited as follows:

Rueda S, Park-Wyllie LY, Bayoumi A, Tynan AM, Antoniou T, Rourke S, Glazier R. Patient support and education for promoting adherence to highly active antiretroviral therapy for HIV/AIDS. *Cochrane Database of Systematic Reviews* 2006, Issue 3. Art. No.: CD001442. DOI: 10.1002/14651858.CD001442.pub2

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Detailed summary of: Patient support and education for promoting adherence to highly active antiretroviral therapy for HIV/AIDS

Review findings:

- **Benefits**
  - **The review found evidence for benefits related to:**
    - Individual level interventions
      - When interventions were provided at the individual level, 67% (10/15) were successful compared to a 0% (0/4) success rate observed with interventions provided in a group setting.

    - Longer-term interventions
      - 86% (6/7) of the interventions provided over 12 weeks or more successfully improved adherence compared to those interventions delivered under 12 weeks (0/8 or 0% success rate).

    - Medication management strategies
      - Interventions that targeted the improvement of patient's medication management skills were fairly successful (6/8 or 75% success rate) when compared to interventions designed around cognitive behavioral therapy and motivational interviewing approaches (1/7 or 14% success rate)
      - The interventions that focused on medication management skills consistently used reminders or memory aids, such as beepers, alarms, medication boxes, planning cards, paging systems, text messaging, or visual aids.
      - In general, these interventions were designed to improve the levels of adherence by improving the participant's medication management skills (e.g., medication information, tailored drug schedules, medication dossettes, side-effect management, and reminder devices) and by helping patients identify and address barriers to adherence (e.g., problems patients might face in real-life situations or strategies to manage side-effects).

  - **The review found evidence that indicated there are <u>no benefits</u> related to:**
    - Group-based adherence interventions (see results above)
    - Short-term (less than 12 weeks) adherence interventions (see results above)
    - Cognitive behavioral therapy and motivational interviewing approaches (see results above)

  - **The review found <u>insufficient evidence for benefits</u> related to:**
    - Virological or immunologic outcomes
      - The review was unable to determine whether improved adherence extended to improved viral or immunologic outcomes.
- **Harms**
  - **The review found the following harms/adverse events:**
    - No harms or adverse events were reported

- **Costs**
  - **Health system costs** (i.e., cost estimates for a healthcare system or a jurisdiction within a healthcare system)
    - No information related to health system costs was reported

  - **Cost-effectiveness estimates**
    - No cost-effectiveness estimates were reported

- **<u>Additional information that could influence the applicability of the findings</u>**

  - **Equity considerations**
    - Several of the studies that looked at marginalized populations such as women, Latinos, or patients with a past history of alcoholism were not successful at improving adherence. This may suggest that a different approach needs to be developed in order to design effective interventions for these populations.
    - Six studies specifically targeted patients who reported difficulties with adherence or who presented with poor adherence at study baseline

  - **Local applicability considerations**
    - Twelve studies were conducted in the US, two in Spain, two in France, two in Australia, and one in Switzerland.

    - All interventions were directed at patients, individually or in groups, rather than at providers or health care systems.

- The interventions were delivered by lay individuals, health advocates, social workers, psychologists, nurses, pharmacists, and physicians.

- The review was unable to ascertain whether success was associated with:
  - the type of provider administering the intervention
    - many interventions were delivered by different combinations of providers (e.g., pharmacists/ nurses, physicians/nurses) and it was not feasible to disentangle the effects of a single provider or a particular combination of providers
  - the number of visits over which the intervention was provided
  - the antiretroviral experiences of patients
  - delivery at tertiary or academic centers
  - the targeting of patients reporting poor adherence at baseline.

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Brief summary of: Setting and organization of care for persons living with HIV/AIDS

Topic of the review

This review evaluated the effectiveness of the setting of care (concentration and volume of patients, participation in clinical trials, incorporating trainees, travel time to providers) and the organization of care (case management, multi-disciplinary care, multi-faceted treatment, hours of service, outreach, health information systems) on medical, immunological/virological, psychosocial and/or economic outcomes for persons living with HIV/AIDS.

Plain language summary

This review identified 28 studies involving 39,776 study subjects that examined how and where to provide care for people living with HIV/AIDS. Centres with a lot of HIV/AIDS patients often had lower death rates. The number of patients needed to get these results was very different in each study so it is not clear what the right number is. Settings with case management had fewer deaths and had higher use of antiretroviral medications. There were several other promising interventions to increase antiretroviral use (using several health interventions at the same time and using computerized reminders), to reduce hospital admissions (using multiple health disciplines and increasing hours of operation), and reducing length of hospital stay (telephone notices and advice for providers).

Key messages from the review (weighing of benefits, harms and costs)

- Existing studies suggest that centralizing care in high concentration high volume centres could lead to improved outcomes including mortality. Unfortunately, this evidence is mixed and is limited to developed country settings.

- Case management may also associated with improved outcomes but the limited number of studies and the varying definitions of case management leave considerable doubt about how best to implement such programs.

- Multidisciplinary and multi-faceted treatments, health information systems and extended hours of operation are promising interventions but evidence about their effectiveness is so far lacking.

Full citation
All material presented in this summary is taken directly from the full systematic review publication and should be cited as follows:

Handford C, Tynan AM, Rackal JM, Glazier R. Setting and organization of care for persons living with HIV/AIDS. *Cochrane Database of Systematic Reviews* 2006, Issue 3. Art. No.: CD004348. DOI: 10.1002/14651858.CD004348.pub2

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Promoting excellence and innovation in HIV research and care

Detailed summary of: Setting and organization of care for persons living with HIV/AIDS

Review findings:

- **Benefits**
  - **The review found evidence for benefits related to:**
    - Case management strategies
      - The only study that examined mortality in relation to case management found significantly lower mortality in the case management group.
      - Another study of case management found higher rates of anti-retroviral use and indicated prophylaxis in the case management group but no difference in hospital admission rates.
      - Case management was described somewhat differently in these studies, precluding direct comparisons.
      - Case management was associated with increased entry and continuity of medical care in one study, but there is otherwise little indication in these studies of the pathways through which case management may improve outcomes.

    - High hospital and ward volume
      - Nine studies examined the relationship between hospital, ward or clinic concentration or volume of patients and the majority of these found lower mortality in settings with greater concentration or volume.

    - Settings that conduct clinical trials
      - Four studies examined use of ARVs in relation to settings that conduct clinical trials and three of these found higher proportions of patients on ARVs in settings that conduct trials.
      - One study that examined hospitalization found no difference between settings that did and did not conduct trials.

        - It is difficult to draw conclusions for practice from the results but there are enough promising findings to indicate that multidisciplinary and multi-faceted treatments, health information systems and hours of operation should be considered when designing health services and should be research priorities.
            - <u>Multi-disciplinary teams or multi-faceted treatment</u>
                - Multidisciplinary or multi-faceted treatment was associated with increased ARV use by pregnant women in two studies, but not in a third study, and with decreased hospitalization in one study.
            - <u>Health information systems</u>
                - Health care information systems were not associated with mortality or hospital admission in one study but in the same study computer alerts and reminders for primary care physicians appeared to increase the initiation of ARVs and indicated prophylaxis.
            - <u>Hours of operation</u>
                - Evening and weekend clinic hours were associated with decreased hospitalization rates in one study but another study did not find that relationship with increased hours.
    - **The review found evidence that indicated there are <u>no benefits</u> related to:**
        - <u>Use of trainees in delivery of care</u>
            - Three studies assessed the effect of the incorporation of trainees in the delivery of healthcare. None of these studies demonstrated a statistically significant impact on in-hospital mortality with this feature
    - **The review found <u>insufficient evidence for benefits</u> related to:**
        - <u>Outreach</u>
            - There were no studies included that had outreach or travel time to providers as an intervention.

- **Harms**
    - **The review found the following harms/adverse events:**
        - No harms or adverse events were reported

- **Costs**
    - **Health system costs** (i.e., cost estimates for a healthcare system or a jurisdiction within a healthcare system)
        - No information related to health system costs was reported

  - **Cost-effectiveness estimates**
    - No cost-effectiveness estimates were reported

- **Additional information that could influence the applicability of the findings**

  - **Equity considerations**
    - Multidisciplinary or multi-faceted treatment was associated with increased ARV use by pregnant women in two studies, but not in a third study, and with decreased hospitalization in one study.

  - **Local applicability considerations**
    - None of the studies in this review were conducted in resource-poor settings

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Brief summary of: Effectiveness and cost effectiveness of counselling in primary care

Topic of the review

This review assessed the effectiveness and cost effectiveness of counselling in primary care for patients with psychological and psychosocial problems considered suitable for counselling.

Plain language summary

Eight studies (controlled trials) were identified through searches of the literature up to the end of June 2005. Outcomes from the studies were statistically combined and economic information summarized. Findings indicate that counselling for psychological problems is better than usual general practitioner care in the short-term but is not any better in the long-term. In addition, findings indicate that patients are satisfied with counselling and that people who receive counselling in primary care from a trained counsellor are more likely to feel better immediately after treatment and be more satisfied than those who receive care from their general practitioner. Lastly, although some types of healthcare utilisation may be reduced, counselling does not seem to reduce overall healthcare costs.

Key messages from the review (weighing of benefits, harms and costs)

- Counselling for psychological problems is better than usual general practitioner care.
- People who receive counselling in primary care from a trained counsellor are more likely to feel better immediately after treatment and be more satisfied than those who receive care from their general practitioner.
- Over the long-term, counselling is not any better than care from a general practitioner
- Patients allocated to counselling tended to be satisfied with the help they receive from counsellors, and more satisfied than those who remain under ’usual care’.

- Some types of healthcare utilisation may be reduced but counselling does not seem to reduce overall healthcare costs.

Full citation
All material presented in this summary is taken directly from the full systematic review publication and should be cited as follows:

Bower PJ, Rowland N. Effectiveness and cost effectiveness of counselling in primary care. *Cochrane Database of Systematic Reviews* 2006, Issue 3. Art. No.: CD001025. DOI: 10.1002/14651858.CD001025.pub2.

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Detailed summary of: Effectiveness and cost effectiveness of counselling in primary care

Review findings:

- **Benefits**
  - **The review found evidence for benefits related to:**
    - Short-term outcomes of counselling
      - Counselling is more effective than usual care in terms of mental health outcomes in the short term
    - Patient satisfaction
      - Patients allocated to counselling tended to be satisfied with the help they receive from counsellors, and more satisfied than those who remain under ’usual care’.
  - **The review found evidence that indicated there are no benefits related to:**
    - Long-term outcomes of counselling
      - Four trials reporting long-term outcomes with ’usual care’ as a comparison found that patients receiving counselling did not differ in psychological symptom scores compared to patients receiving ’usual care’.
  - **The review found insufficient evidence for benefits related to:**
    - N/A
- **Harms**
  - **The review found the following harms/adverse events:**
    - No harms or adverse events were reported
- **Costs**
  - **Health system costs** (i.e., cost estimates for a healthcare system or a jurisdiction within a healthcare system)

    - Counselling may be associated with some reductions in health service utilisation, but overall costs did not seem to be reduced, and may be increased
    - It has been suggested that counsellors working in primary care can lead to a reduction in health service utilisation, including fewer referrals to psychiatric services, fewer prescriptions and fewer GP consultations and the evidence from this review indicate that modest reductions in health service utilisation did take place.

  - **Cost-effectiveness estimates**
    - Costs associated with counselling may be higher, however, the interpretation of the cost effectiveness analyses is complex, because changes in outcomes such as Beck Depression Inventory scores are not as interpretable as conventional economic outcomes such as quality adjusted life years (QALYs).

- **Additional information that could influence the applicability of the findings**

  - **Equity considerations**
    - One trial with chronic patients found that counselling was no more effective than usual care
    - The difference in outcomes between cognitive-behavioural therapy and counselling in older patients with anxiety was relatively large.

  - **Local applicability considerations**
    - Only practitioners with a formal counselling qualification equivalent to British Association of Counselling and Psychotherapy accreditation levels were included in the review (see http://www.bacp.co.uk/education/whatiscounselling.html for their definition of counselling. The results can only be generalised to similar patients and counsellors. This means that the evidence is restricted to counselors with BACP accreditation or equivalent.
    - For the purposes of the review, counselling was not an integral component of other mental health care activities (e.g. nursing, medical care) but constitutes a distinct and separate treatment intervention, offered as a series of sessions, following an assessment which generates a therapeutic plan.
    - All studies included in the review described therapeutic interventions with individual clients involving face to face contact between patient and counsellor. Although there were differences in the therapeutic models used (e.g. non-directive counselling, psychodynamic counselling, cognitive-behavioural counselling), the interventions were considered homogenous for the purposes of analysis.

- Counselling may be described using a number of specific terms, including non-directive, person-centred and process-experiential.
- Counselling may be offered by a variety of professionals (e.g. counsellors, community psychiatric nurses (CPNs), practice nurses, social workers, clinical psychologists, GPs and health visitors).

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Brief summary of: Paraprofessionals for anxiety and depressive disorders

Topic of the review

This review assessed the effectiveness of any kind of psychological treatment for anxiety and depressive disorders performed by paraprofessionals (i.e., partial replacements for healthcare professionals) and examined whether the results apply to clinical anxiety and depressive disorders (potentially affecting all aspects of social functioning).

Plain language summary

Mental health care systems often do not have the resources to meet the increasing need for care of those with anxiety and depressive disorders. This review investigated the effectiveness of any kind of psychological treatment conducted by paraprofessionals. The few studies found did not allow conclusions about the effect of paraprofessionals compared to professionals in the treatment of anxiety and depressive disorders. Pooling data from three studies, involving women only, indicated a significant effect for paraprofessionals compared to no treatment. The evidence so far may justify the development and evaluation of programs incorporating paraprofessionals in treatment programs for anxiety and depressive disorders.

Key messages from the review (weighing of benefits, harms and costs)

- The few studies included in the review did not allow conclusions about the effect of paraprofessionals compared to professionals
- Data from three studies, involving women only, indicated a significant effect for paraprofessionals (all volunteers) compared to no treatment.
- The evidence so far may justify the development and evaluation of programs incorporating paraprofessionals in treatment programs for anxiety and depressive disorders.

Full citation
All material presented in this summary is taken directly from the full systematic review publication and should be cited as follows:

Boer PCAM, Wiersma D, Russo S, Bosch RJ. Paraprofessionals for anxiety and depressive disorders. *Cochrane Database of Systematic Reviews* 2005, Issue 2. Art. No.: CD004688. DOI: 10.1002/14651858.CD004688.pub2.

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Detailed summary of: Paraprofessionals for anxiety and depressive disorders

Review findings:

- **Benefits**
  - **The review found evidence for benefits related to:**
    - Paraprofessionals versus control (waiting list or placebo) at post-treatment (n=220 from five comparisons)
      - Pooled results from five comparisons including a total of 220 participants found a significant difference favouring paraprofessionals compared to the control condition
      - Removing one study from statistical pooling because of indistinct definition of post treatment measurement resulted in a strongly significant effect
  - **The review found evidence that indicated there are no benefits related to:**
    - Paraprofessionals versus professionals at post-treatment and follow-up
      - Pooled results from five comparisons including a total of 160 participants indicated no significant difference between paraprofessionals and professionals at post treatment
      - One comparison with 61 participants found no significant difference between conditions at 6, 9 or 12 months.
    - Paraprofessionals versus control (waiting list or placebo) at follow-up
      - One comparison with 61 participants found no significant difference between conditions at 6, 9 or 12 months.
  - **The review found insufficient evidence for benefits related to:**
    - N/A

- **Harms**
  - **The review found the following harms/adverse events:**
    - No harms or adverse events were reported

- **Costs**
  - **Health system costs** (i.e., cost estimates for a healthcare system or a jurisdiction within a healthcare system)
    - No information related to health system costs was reported

  - **Cost-effectiveness estimates**
    - No cost-effectiveness estimates were reported

- **<u>Additional information that could influence the applicability of the findings</u>**

  - **Equity considerations**
    - Pooled data from three studies (n=188), all involving women only, indicated a strongly significant effect for paraprofessionals (all volunteers) compared to no treatment.

  - **Local applicability considerations**
    - ’Paraprofessionals’ were defined as mental health care workers, paid or voluntary, unqualified with respect to the psychological treatment for anxiety and depressive disorders, and replacing professionals in the treatment of patients with anxiety or depressive disorders. Nurses and counsellors are professionals as well, but when performing therapy requiring the skills that were an essential (as opposed to optional) part of the training for a psychiatrist or psychologist, they were defined as paraprofessionals.
    - Paraprofessionals were volunteers without professional background in four studies, and one study used advanced undergraduates in the experimental condition.
    - Significant questions remain about the conditions under which paraprofessionals can be effective. Most studies mention some selection, training and supervision of paraprofessionals. If paraprofessionals, volunteers or patients, can be effective therapists (with no training or minor initial training), or can offer support because of their personal experience with the underlying problem, this will bring psychological treatment within the scope of psycho-education or education alone.

Program in Policy Decision-Making
www.researchtopolicy.org

Brief summary of: Case management for persons with substance use disorders

Topic of the review
This review had three objectives:
1. To assess whether case management reduces substance use and improves quality of life compared with other forms of treatment;
2. To evaluate whether case management links patients with the services they need and whether this linkage is related to the effects of case management;
3. To study whether other potential mediating variables (e.g. model of case management, type of population served, methodological characteristics of studies) affect case management-outcomes.

Plain language summary
One strategy for linking patients with alcohol and drug use disorders with relevant services is case management, where a single case manager is responsible for linking patients with multiple relevant services. A total of 15 controlled studies with 6694 participants were included in the review (all from North America except one from Europe). Findings indicate that case management effectively linked people with substance abuse to community and treatment services as compared to treatment as usual or other viable treatment options, such as psycho-education or brief interventions. However, evidence that case management reduces drug use or produce other beneficial outcome is not conclusive.

Key messages from the review (weighing of benefits, harms and costs)

- Case management is effective as a strategy for linking substance abusers to community and treatment services, as compared to treatment as usual or other viable treatment options, such as psycho-education or brief interventions.

- This review does not provide convincing support that case management is as effective to reduce illicit drug use and to affect other primary outcome measures such as employment, housing, and criminal activities, given the rather small, and mostly non-significant effects found.

- The use of a manual to guide the case management intervention may be an effective strategy to increase the degree of linkage.
- Other factors that are likely to influence linkage are models of case management, availability of training and supervision, and the degree of integration of case management in the local network of services.

Full citation

All material presented in this summary is taken directly from the full systematic review publication and should be cited as follows:

Hesse M, Vanderplasschen W, Rapp R, Broekaert E, Fridell M. Case management for persons with substance use disorders. *Cochrane Database of Systematic Reviews* 2007, Issue 4. Art. No.: CD006265. DOI: 10.1002/14651858.CD006265.pub2.

Program in Policy Decision-Making
www.researchtopolicy.org

Detailed summary of: Case management for persons with substance use disorders

Review findings:

- **Benefits**
  - **The review found evidence for benefits related to:**
    - Linking substance abusers to community and treatment services
      - This review of case management for persons with substance use disorders shows that this intervention is effective as a strategy for linking substance abusers to community and treatment services, as compared to treatment as usual or other viable treatment options, such as psycho-education or brief interventions.
    - Family/social relations
      - One study reported outcomes on family/social relations and the effect was significant
    - Living situation/housing
      - Outcomes on living situation was reported by three studies and the effect was small, but significant

  - **The review found evidence that indicated there are no benefits related to:**
    - Employment outcomes
      - One study mentioned employment outcomes and the effect was small and non-significant
    - Legal outcomes
      - Outcomes concerning legal problems were reported by four studies and the overall effect size was non-significant
    - Psychiatric symptoms
      - Psychiatric symptoms were reported by two studies, showing no difference between case management and the control intervention
    - Physical health

        - One study reported outcomes on physical health and the effect was small
    - Treatment satisfaction
        - One study provided information concerning treatment satisfaction, showing a non-significant effect that favoured the case management condition
    - HIV risk
        - Four studies reported outcomes on HIV risk behaviour and the effect was small and non significant

  - **The review found <u>insufficient evidence for benefits</u> related to:**
    - Rehospitalization
        - None of the studies reported data on rehospitalization rates that could be extracted and therefore no analyses on this outcome measure could be completed
    - Alcohol use
        - Outcomes related to alcohol use were available for two studies and the overall effect was non-significant and the results were conflicting.

- **Harms**
  - **The review found the following harms/adverse events:**
    - No harms or adverse events were reported

- **Costs**
  - **Health system costs** (i.e., cost estimates for a healthcare system or a jurisdiction within a healthcare system)
    - No information related to health system costs was reported

  - **Cost-effectiveness estimates**
    - No cost-effectiveness estimates were reported

- **<u>Additional information that could influence the applicability of the findings</u>**

  - **Equity considerations**
    - Although several studies included patients requiring opioid substitution treatment, most of them concerned patients who were out of treatment when assigned to case management or control.
    - Degree of co-occuring mental illness - Not enough studies reported on this variable to allow for meaningful comparisons

  - **Local applicability considerations**

- Of the 15 studies included in the review, three used the brokerage case management model, eight an intensive case management model, two the strengths-based case management model, and two studies used assertive community treatment.
    - Enough studies were available to compare the effect sizes of intensive, brokerage and strengths-based case management. The highest effect was found for strengths-based case management, followed by brokerage, and intensive case management.
    - Differences between types of case management were not significant
- This review shows that efforts to improve the homogeneity of the intervention delivered (e.g., by manualizing case management) may contribute to its effectiveness - as far as linking is concerned - when compared with non-manualized applications.

Effects of an evidence service on community-based AIDS service organizations' use of research evidence: A protocol for a randomized controlled trial*

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*This protocol has received ethics approval from the McMaster Research Ethics Board (Project Number 10-268) and we plan to submit for publication to Implementation Science.

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Abstract

Background

To support the use of research evidence by community-based organizations we have developed '**S**ynthesized **H**IV/**A**IDS **R**esearch **E**vidence' (SHARE), which is an evidence service for those working in the HIV sector. SHARE consists of several components: 1) an online searchable database of HIV-relevant systematic reviews (retrievable based on a taxonomy of topics related to HIV/AIDS and open text search), 2) periodic email updates, 3) access to user-friendly summaries, and 4) peer relevance assessments. Our objective is to evaluate whether this "full serve" evidence service increases the use of research evidence by key decision-makers in community-based organizations as compared to a "self-serve" evidence service.

Methods/design

We will conduct a two-arm randomized controlled trial (RCT), along with a follow-up qualitative process study to explore the findings in greater depth. One key decision-maker (e.g., the executive directors or program manager) from each community-based organization affiliated with Canadian AIDS Society (n=120) will be invited to participate and will be randomized to receive either the "full-serve" version of SHARE (the searchable database, e-mail updates, user-friendly summaries, and peer relevance assessments, as well as access to worksheets that help community-based organizations find and use research evidence) or the "self-serve" version (a listing of relevant systematic reviews with links to records on

PubMed and worksheets that help community-based organizations find and use research evidence) using a simple randomization design. The trial duration will be 10 months (two-month baseline period, six-month intervention period, and two month cross-over period), the primary outcome measure will be the mean number of logins/month/user between baseline and the end of the intervention period and the secondary outcome will be participants' intention to use research evidence. For the qualitative study, 15 participants from each trial arm (n=30) will be purposively sampled. One-on-one semi-structured interviews will be conducted by telephone on their views about and their experiences with the evidence service they received, how helpful it was in their work, why it was helpful (or not helpful), what aspects were most and least helpful and why, and recommendations for next steps.

Background

Community-based organizations (CBOs) are important stakeholders in health systems (1;2) as they provide a wide spectrum of programs and services to the members of their community, link with other health and social services to help provide care, and advocate for broader system-level supports. CBOs are increasingly being called upon to use research evidence to inform their programs and advocacy and to be more involved in health system decision-making. To do this, they need support in finding and using research evidence to help them plan and deliver more effective and cost-effective programs and strengthen health systems.

However, there are many potential challenges related to research use. Barriers that have been consistently identified across different sectors include the complexity of research evidence, organizational barriers, lack of available time, poor access to current literature, lack of timely research, lack of experience and skills for critical appraisal, unsupportive culture for research, lack of actionable messages in research reports, and limited resources for implementation (3-7). Given these barriers it is not surprising that, generally, a lack of uptake of research evidence has been noted in many different sectors (8-12).

While there are strategies for supporting the use of research evidence by clinicians (13;14), and health system managers and policymakers (15-20), there is still an important gap in the availability of specific strategies for CBOs (21). Many existing strategies for supporting the use of research evidence are based on experience and anecdotal evidence rather than on rigorous evidence of effects (15;22;23). Moreover strategies designed for supporting the use of research evidence by healthcare organizations and governments may not be relevant to the specific contexts and capacity of CBOs. To begin to fill this gap, we have developed an evidence service which for those working in the HIV sector, which is entitled **S**ynthesized **H**IV/**A**IDS **R**esearch **E**vidence' (SHARE) (see below for a detailed description of SHARE).

Efforts to facilitate the use of research evidence often focus on four clusters of knowledge translation activities ("producer push", facilitating "user pull", "user pull" and "exchange" efforts) (24), and the SHARE database primarily fits within two of these strategies. First, SHARE constitutes an effort to facilitate "user pull" by allowing users to easily identify relevant synthesized research evidence and access user-friendly summaries when they identify the need for it. In addition, SHARE also constitutes a "producer push" effort by providing periodic email updates that highlight synthesized research evidence that has been newly added to the database. This type of activity largely promotes awareness of new synthesized research evidence, but it could also have more direct impact on the use of synthesized research evidence by profiling systematic reviews that address issues that CBOs may be grappling with at a particular time. What SHARE does not include are "user pull" mechanisms (i.e., target audiences incorporating prompts for research evidence in their decision-making processes and developing their capacity to find and use research evidence) or "exchange" efforts, which focus on the producers and users of researchers building partnerships and working collaboratively in the production and interpretation of research evidence (24).

Objectives

Our objective is to evaluate whether (and how and why) this "full serve" evidence service increases the use research evidence by key decision-makers in community-based organizations as compared to a "self-serve" evidence service.

Methods/design

We will conduct this trial using a sequential explanatory mixed methods design (25), beginning with the RCT and then following up with a qualitative process study to explore the RCT findings in greater depth. The trial will run for 10 months, which includes a two-month baseline period where all participants receive the "self-serve" evidence service, a six-month period where the intervention group will receive the "full-serve" evidence service and the control group will continue to receive the "self-serve" evidence service and a final two-month period where both groups will receive the "full-serve" version of SHARE.

RCT methods and design

Study population and recruitment

We will invite the executive director from each CBO affiliated with the Canadian AIDS Society[1]. The study invitation will indicate that if they are interested in participating they can either enroll in the study or delegate enrolment

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[1] http://www.cdnaids.ca/web/casmisc.nsf/pages/welcome

to the most appropriate manager in the organization (i.e., only one respondent from each organization will be included in the study). To ensure clarity in our study recruitment, we will outline to the executive director that we are interested in enrolling one key decision-maker from the organization, which could either be themselves or another manager provided the manager has a decision-making role about programs, services and advocacy and provided the manager does not include the conduct of research among their core responsibilities. Given that SHARE is currently only provided in English, we will exclude organizations that do not have a key decision-maker who is comfortable participating and corresponding in English.

We are contacting executive directors for two primary reasons. First, we are interested in enrolling one key decision-maker from each organization given the intent is to facilitate the use of research evidence in decisions about CBOs' programs, services and advocacy. For many CBOs the key decision-maker that would have the most impact on whether research evidence is used to inform decision-making about programs, services and advocacy will be the executive director. For instance, in many small- and medium-sized organizations, the executive director will manage both the organization and the decision-making for most or all programs, services and advocacy the organization is involved with. Second, while CBOs often differ in their size, focus and structure, the executive director position exists for all CBOs and therefore provides a consistent decision-maker to approach for the entire sample. For some CBOs (especially larger organizations with a multiple managers), the executive director may not be directly involved with the development of and decision-making about programs, services and advocacy, in which case they will still be best poised to help us identify the most appropriate key decision-maker (e.g., a program manager) from the organization for the study.

Based on the membership list provided by the Canadian AIDS Society on their website, there are 120 community-based organizations available to draw the sample from. Drawing on previous experience with this sector, we expect to achieve an approximate response rate of 70%. To increase our response rate, the Canadian AIDS Society will send out an email to all its members, encouraging them to participate by highlighting the importance of the trial. We will provide additional incentive to enroll in the trial by holding a draw where we will select three participants' organizations to receive prizes (gift cards) worth $500, $250 and $100.

Interventions

We will run a two-arm RCT with a "full-serve" evidence service ('**S**ynthesized **H**IV/**A**IDS **R**esearch **E**vidence' **– SHARE**) as the intervention arm and a "self-serve" version as the control arm. The components of each version of SHARE are outlined in Table 1 and described below.

Intervention arm – "full serve" evidence service

Participants allocated to this study arm will receive access to a "full-serve" version of SHARE, which provides:

1) an online searchable database of HIV-relevant systematic reviews (retrievable based on a taxonomy of topics related to HIV/AIDS and open text search – see Appendix 1 for the taxonomy of topics);
2) periodic email updates (at least one per month) highlighting reviews recently added to the database;
3) access to user-friendly summaries produced by us or by others (when available);
4) links to scientific abstracts;
5) peer relevance assessments, which involves periodic requests (contained in the single record for each review) to complete a brief assessment of how useful the information in the newly added review is (one question with a five-point scale – see Appendix 2 for additional details) with the average score posted once an assessment is completed;
6) an interface for participants to leave comments (up to 250 characters in length) in the records of systematic reviews in the database (e.g., if a participant wants to leave a comment indicating the review was useful and why);
7) links to full-text articles (when publicly available); and
8) access to worksheets that help CBOs find and use research evidence

To provide access to user-friendly summaries (see component three above) we will provide links to user-friendly summaries produced by 9 groups (when available) from around the world – 1) Australasian Cochrane Centre (AAC)

Policy Liaison Initiative, 2) Database Review of Effects (DARE), 3) Effective Health Care Research Programme Consortium, 4) Evidence AID, 5) Health Knowledge Network, 6) Health-Evidence.ca, 7) Reproductive Health Library, 8) Rx for Change, and 9) Supporting Policy Relevant Reviews and Trials (SUPPORT).

Control arm

Participants allocated to the control group will only be provided website access to a listing of systematic reviews that are organized by year of publication with links to the record on PubMed (or another publicly available source when not available on PubMed) and access to worksheets that help CBOs find and use research evidence.

Table 1: Components of the "full-serve" and "self-serve" evidence service

Evidence service components	**"Full-serve" – SHARE**	**"Self-serve" - Control**
1. Access to records for HIV-relevant systematic reviews*	X	X
2. Searchable database – Reviews retrievable using taxonomy of topics related to HIV/AIDS and open text search	X	
3. Email updates highlighting newly added reviews	X	
4. Access to user-friendly summaries produced by us or by others	X	
5. Links to scientific abstracts	X	X*
6. Peer-relevance assessments†	X	
7. Links to full-text (when publicly available)	X	
8. Access to worksheets that help CBOs find and use research evidence	X	X

* The "self-serve" version will be provided as a listing of reviews grouped by year of publication with titles hyperlinked to their scientific abstract.

†Based a 5-point scale that asks how useful the reviews is and through a user-forum provided for each review record

Randomization

Participants will be randomized using a simple randomization design. After consenting to participate in the trial, participants will be randomly assigned to either the “full-serve” or the “self-serve” evidence service. We will assign a unique participant ID number to each participant and then provide the list of IDs to a statistician (TB) who will conduct the randomization and keep a log in a secure password protected folder at the Ontario HIV Treatment Network to provide a clear audit trail. The statistician will then communicate directly with the SHARE database administrator at the Ontario HIV Treatment Network (external to the research team) who will send the updates to individuals with access to the “full-serve” version of SHARE (the updates will be written by MGW and checked by the co-investigators). The statistician (TB) is a member of the study team but will only be involved with randomization at the start of the trial and the data analysis upon completion of the trial. Therefore, participants and all investigators except the statistician (TB) will be blinded to group assignment.

Outcomes

Measuring the impact of knowledge transfer and exchange (KTE) interventions, such as the evidence service proposed here, poses significant challenges as there is a long chain of factors between a KTE intervention such as SHARE and the health status of clients of CBOs or of broader populations

(10;26). For instance, it has been demonstrated that assessing the impact of KTE interventions on the practice of physicians poses challenges due to the fact that many factors other than the practice guidelines or recommendations that were disseminated may influence how practices are changed (27-29).

Given these constraints, our primary and secondary outcomes for the trial are proxy measures for research use. The primary outcome will be a measure of utilization that is similar to what Haynes et al. (2006) used in their trial of the McMaster Premium Literature Updating Service (PLUS) (30). Specifically, we will track the mean number of logins/month/user across trial groups during each of the baseline period, intervention period, and cross-over period. We will also provide related descriptive measures such as the proportion of users per month in each of the "full-serve" and "self-serve" groups, the frequency with which systematic review records and related resources are accessed (e.g., URLs to abstracts, user-friendly summaries and/or full-text), and the number of times the email updates to the "full-serve" group are forwarded.

Each version of the evidence service will be hosted on the Ontario HIV Treatment Network server and for the duration of the trial will require a user login that will be used to link each participant's identification with their usage of the evidence service website. SHARE is a new database that is not yet publicly available (it will be upon completion of the trial), which allows us to evaluate it without participants being able to gain access from a publicly available site. In addition, requiring a user login will help protect against contamination of the intervention and control group. However, we cannot protect fully against the possibility of users sharing information given that many may collaborate with each other.

We anticipate that participants from some organizations may want their staff to use the evidence services as a resource in their work. In absence of the availability of additional login IDs and passwords, participants may share their access, which limits our ability to accurately track usage by the key decision-maker in each CBO. However, measuring these "spill-over" effects of the usage of each version of the evidence service is potentially informative and therefore, we will indicate to each participant that additional logins and passwords will be provided to anyone else in their organization upon request. This will allow us to not only accurately measure the use of the evidence service by the key decision-maker enrolled in the trial but also provide descriptive analyses of the spill-over effects observed in the intervention and control groups.

For the secondary outcome, we will use the theory of planned behaviour to measure participants' intention to use research. The theory of planned behaviour proposes a model about how human action is guided (31;32) and consists of three variables – attitudes (i.e., beliefs and judgments), subjective norms (i.e., normative beliefs and judgments about those beliefs) and perceived behavioural control (i.e., the perceived ability to enact the behaviour) – that shape the behaviour intentions of people, which is subsequently a strong predictor of future behaviour (32-34). In Figure 1, we outline the model of the theory of planned behaviour and map how different elements of the evidence service may affect each of the three variables.

The theory of planned behaviour has been extensively used and tested in the fields of psychology and healthcare. Systematic reviews conducted in the psychology field have demonstrated that the theory explains about 39% of the variance in intention and about 27% of the variance in behaviour (33;34). A number of studies have demonstrated the feasibility of producing valid and reliable measures of the key theory of planned behaviour constructs for use with healthcare professionals (35-37). A systematic review suggests that the proportion of the variance in healthcare professionals' behaviour explained by intention was similar in magnitude to that found in the broader literature (38). With the successful transfer of the theory from assessments of individuals to assessments of healthcare professionals involved in an agency relationship with their patients, we are confident in its further transfer to key decision-makers in community-based organizations in agency relationships with other decision-makers and staff in their organization.

Using a manual to support health researchers who want to construct measures based on the theory (32), our colleagues have developed and sought preliminary feedback on a data-collection instrument by first assessing face validity through interviews with key informants and then pilot testing it with 28 policymakers and researchers from 20 low- and middle-income countries who completed it after participating in a KT intervention (39). In addition, Boyko et al. (2010) found moderate test-retest reliability of the instrument using Generalizability Theory (G=0.50) (40) when scores from a sample of 37 health system policymakers, managers, professionals, citizens/consumers and researchers participating in stakeholder dialogues convened by the McMaster Health Forum were generalized across a single administration, and even stronger reliability (G=0.9) when scores were generalized across the average of two administrations of the tool (39). In the reliability assessment by Boyko et al. (2010), the first administration of the tool immediately followed a McMaster Health Forum stakeholder dialogue, which may have promoted enthusiasm for using research evidence among participants. This likely produced higher measures of intention on the first administration of the tool as compared to the second, resulting in the lower G-score. Given that we won’t be administering the tool in a similar atmosphere of enthusiasm for using research evidence it is likely that the level of reliability of the tool will be sufficient without two administrations at both baseline and follow-up.

We have slightly modified the wording in each of the questions of the tool to reflect the different intervention being tested (SHARE) and the target audience (community-based organizations) (see Appendix 3). We will administer the instrument during the baseline period, as well as at the end of the six-month intervention period, through a brief online survey that takes approximately 10 minutes to complete. We will use unique identifiers for each participant to ensure their responses to the previous survey are linked for calculations of before-and-after changes in their intention to use research evidence. We will follow-up with participants who do not complete the survey once per week for three weeks to minimize the number of participants lost to follow-up.

Data management and analysis

Data will be entered into SPSS 16.0 using the unique participant identifier assigned during the randomization process. Analyses will be conducted by two members of the team (MGW & TB) and, during the analysis, all investigators except for one of us that is involved in the both the analysis and randomization (TB) will be blinded to the key linking the participants to their unique identifiers.

We will treat both outcome measures as continuous variables and analyze the change in these measures over time using a two-way mixed effects linear repeated measures analyses of variance (ANOVA), which will assess the effects within groups, between groups and over time with the latter as the main feature of interest. In addition, we will control for five variables - province the organization is located in, size of organization (as measured by number full-time equivalent staff in the organization), number of clients served each year by the organization, whether the participant is full-time or part-time, and whether they have had research training in the past – using analysis of covariance. Each of these variables may at least partially explain research use (e.g., the amount of staff support an executive director or manager has may determine the extent to which they can spend time finding and using research evidence), and therefore adjusting for them will allow for a better assessment of the effects of the intervention.

Moreover, as part of a secondary analysis, we will assess whether there is an interaction between each (entered as a fixed factors) and the outcome measures. Given the likelihood that the distribution of the outcomes will be skewed, we will transform the data where necessary and possible, which may include adjusting the time period for which we calculate the mean number of logins/month/use if the number of logins is low (e.g., calculating the mean over two months) if there are insufficient data for analysis. We will also qualitatively compare the number of participants in the intervention and control groups that do not complete the follow-up survey and attempt to assess if there are reasons for why they dropped out based on their baseline characteristics.

For all analyses, we will use the intention to treat principle, report 95% confidence intervals and consider P-values equal to or less than 0.05 (two-tailed) to be significant. For the primary outcome measure (mean logins/month/user) missing data is irrelevant as it is a naturalistic measure. For the secondary outcome measure (obtained through the survey), missing data can be taken into account through the use of a mixed-effects model.

Statistical precision

Given a fixed sample size of approximately 85 executive directors/program managers (70% of 120 organizations) a sample size calculation is not relevant. Instead, we have calculated the level of statistical precision that we can expect given our fixed sample size of approximately 85 participants. To calculate the expected statistical precision in the trial, an estimation of intra-class correlation coefficient (ICC) of measurements for individuals over time for the primary outcome is required. However, we have no mechanism to estimate the ICC due to the fact that no similar study with this population has been conducted (at least to our knowledge). Therefore, we calculated estimates of statistical precision for ICCs of 0.2, 0.3, 0.5, 0.7 and 0.8 based on a 6-month trial period with 80% power, an estimated standard deviation of 1.0, significance of 0.05 (two-sided test) and 42 participants per study group (total n=85) (41). Assuming the primary outcome data will be collected from all 85 organizations during the intervention period at 6 follow-up points (one per month), the time-averaged detectible differences (in standard deviation units) between the two groups is at best 0.35 (for ICC=0.2), which increases with successively greater ICCs to 0.39 (for ICC=0.3), 0.47 (for ICC=0.5), 0.53 (for ICC=0.7) and 0.56 (for ICC=0.8).

Qualitative methods/design

Given that this is the first RCT evaluating a KTE intervention for community-based organizations (at least to our knowledge) and the inherent limitations associated with measuring research use as an outcome, we will conduct a qualitative process study after the completion of the trial to explore the RCT findings in greater depth. The qualitative study will explore how and why the evidence service worked (or didn’t work), determine how participants used the “full-serve” and “self-serve” evidence services, including the degree of contamination between the intervention and control groups, and other factors that may have influenced their use.

Sample

We will use a mixed method sequential nested sampling procedure whereby a larger sample is analyzed in one study (RCT) and a subset of the larger sample is selected for further inquiry in the second study (42). Specifically, 15 participants from each trial arm (n=30) will be purposively sampled (43;44). First, we will divide the participants according to whether they received the "full-serve" or "self-serve" evidence service. Next, we will purposively sample participants with a breadth of perspective by ensuring there is a mix of participants with different outcomes from the trial (i.e., varying levels of research use and intention to use research) and from different regions of the country. We have assumed a 70% response rate, which means that we should sample approximately 40 key decision-makers to achieve a sample size of 30.

Data collection

One-on-one semi-structured telephone interviews will be conducted with key decision-makers about their experiences with the evidence service, including whether and how they used it (and the degree of 'contamination' between the two arms of the RCT, if any) and why, whether and how it was helpful in their work and why, what aspects were most and least helpful and why, and recommendations for next steps. In addition, we will ask participants about any recommendations for how to improve upon our efforts to support the use of research evidence by community-based organizations. Lastly, for the document analysis, we will collect all comments provided in the user forums for each systematic review record

Data management and analysis

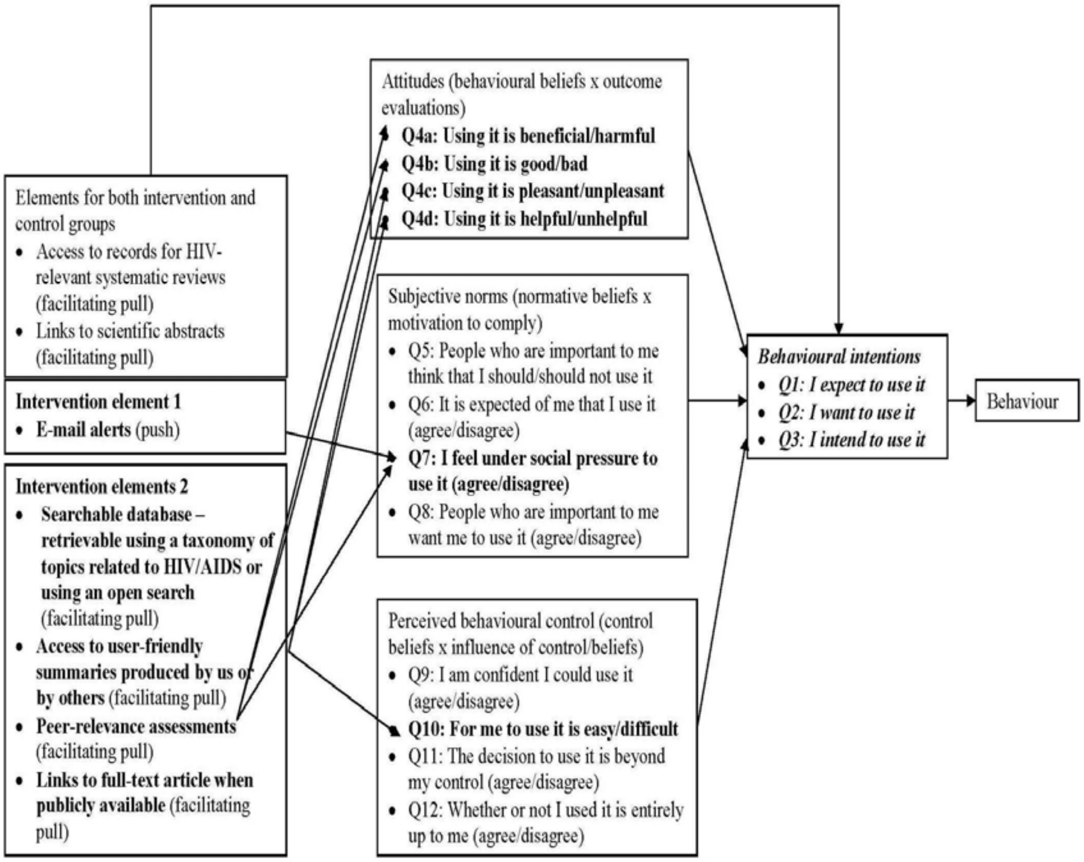
We will tape and transcribe all interviews, use N-Vivo 8 for data management of both the interview transcripts and document analysis, and use a constant comparative method for analysis (45-47). Specifically, two reviewers will identify themes emerging from each successive wave of four to five interviews and iteratively refine the interview guide until we reach data saturation. This strategy will allow the reviewers to develop codes and broader themes in N-Vivo 8 that reflect the emerging and increasing levels of nuance that will inevitably result from the continuous checks that are involved in the constant comparative method (45;47). We will also conduct member checking once analysis is completed (i.e., we will send a brief, structured summary of what we learned from the interviews and invite comment on it). Lastly, we will use the document analysis of the comments left in the user forum to help further our understanding of how participants engaged with the “full-serve” version of SHARE.

Discussion

To our knowledge, this will be the first RCT to evaluate the effects of an evidence service specifically designed to help community-based organizations find and use research evidence. As we have outlined elsewhere (21), efforts to support the use of research evidence by community-based organizations have been limited. In addition, rigorous evaluations of the effects of these strategies remains a critical gap in the KTE literature (21;24;48). This study will begin to address this gap by providing a rigorous evaluation of the effects of a KTE intervention for community-based organizations and by examining how and why the intervention succeeds or fails. In addition, this trial will complement a similar RCT we are planning to conduct with policy analysts and advisors in the Ontario Ministry of Health and Long-Term Care (49) and will contribute to an emerging evidence base about similarities and differences in ‘what works’ in KTE across different target audiences (13;14;50).

The main limitation of this trial is the relatively small sample size that we have available to draw upon. However, while the sample size is relatively small, we are still reaching an entire sector of community-based organizations, which will help provide more generalizable results. In addition, through our partnership with the Canadian AIDS Society and their support with study recruitment, we hope to achieve a high response rate. Another potential limitation is study contamination between the intervention and control groups as some participants may collaborate with each other and share their login and password. To assess contamination we have included a question in the follow-up survey asking if they shared their login and password with anyone else outside their organization. In addition, we are assessing spill-over effects within each organization by providing additional logins and passwords (upon request) to anyone else in the participants’ organization.

Figure 1: Linkages among the intervention, contextual developments, and theory of planned behaviour constructs



List of abbreviations

- SHARE = **S**ynthesized **H**IV/**A**IDS **R**esearch **E**vidence
- CBO = community-based organization
- RCT = randomized controlled trial
- KTE = knowledge transfer and exchange

Competing interests

Three of the authors (MGW, JNL & SBR) were involved in the development of the SHARE database and remain involved in its continuous updating. SHARE is the intervention being tested in the trial.

Authors' contributions

MGW conceived of the study, participated in its design, and drafted the protocol. JNL participated in the design of the study and helped draft the protocol. JG and RBH participated in the design of the study and provided feedback on drafts of the protocol. TB participated in the design of the study, performed the sample-size calculations, and provided feedback on drafts of the protocol. SBR provided feedback on drafts of the protocol. All authors read and approved the final manuscript.

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Appendix 1 - SHARE (Synthesized HIV/AIDS Research Evidence) taxonomy of topics

1. People and context

Jurisdiction(s) studied:
☐ High income country
☐ Low- and middle-income country
☐ Not reported
Specify Country/continent
☐ North America
  ☐ Canada
  ☐ United States
☐ Europe
☐ Africa
☐ Asia
☐ Australasia
☐ Latin America & Caribbean

Population of interest
☐ General adult population
☐ Men who have sex with men
☐ Heterosexual men
☐ Women
☐ Pregnant women
☐ Aged/older adults
☐ Youth (15-24)
☐ Childhood (5-14 years)
☐ Infancy/Early Childhood (birth - 4 years)
☐ Aboriginal people
☐ Injection drug users
☐ Drug users (non-injecting)
☐ Ethnocultural communities
☐ Transgendered communities
☐ Immigrants
☐ Refugees
☐ Prisoners
☐ Sex workers
☐ Homeless/marginally housed communities
☐ Not specified

Co-morbidities and infections
☐ Mental health and addictions
  ☐ Depression
  ☐ Neurocognitive function
  ☐ Severe and persistent mental illness
  ☐ Personality disorders
  ☐ Injection drug use/users
  ☐ Other drug use/users
  ☐ Alcohol
  ☐ AIDS-related mental illness (e.g., dementia)
☐ Co-infections
  ☐ Hepatitis C
  ☐ Hepatitis A or B
  ☐ Sexually transmitted infections

  - ☐ Tuberculosis
  - ☐ Malaria
- ☐ Treatment side effects
  - ☐ AIDS related lymphomas
  - ☐ HIV/HAART associated dyslipidemic lipodystrophy (HADL)
- ☐ Other co-morbidities/co-occurring illnesses

2. Problem/issue definition

- ☐ Testing/Detection/Diagnosis
- ☐ Epidemiology (monitoring the burden and spread of HIV)

3. Options for addressing a problem or issue

Determinants of health

- ☐ Income and Social Status
- ☐ Social Support Networks
- ☐ Education and Literacy
- ☐ Employment/Working Conditions
- ☐ Social Environments
- ☐ Physical Environments
- ☐ Personal Health Practices and Coping Skills
- ☐ Healthy Child Development
- ☐ Biology and Genetic Endowment
- ☐ Health Services
- ☐ Gender
- ☐ Culture

Health system arrangements

- ☐ Governance arrangements
  - ☐ Policy authority
  - ☐ Organizational authority
  - ☐ Commercial authority
  - ☐ Professional authority
  - ☐ Consumer & stakeholder involvement
- ☐ Financial arrangements
  - ☐ Financing
  - ☐ Funding
  - ☐ Remuneration
  - ☐ Financial incentives for patients
  - ☐ Resource allocation
- ☐ Delivery arrangements
  - ☐ To whom care is provided & with what efforts to reach them
  - ☐ By whom care is delivered
  - ☐ Where care is provided
    - ☐ With what information & communication technology (ICT) is care provided
    - ☐ With what quality & safety care is provided

Programs, services & drugs within health systems

- ☐ Prevention
  - ☐ Primary prevention
    - ☐ Condoms
    - ☐ Drug related (not harm reduction)
    - ☐ Education/training
    - ☐ Behavioural

    - ☐ Mass media/campaigns
    - ☐ Vaccines
    - ☐ Circumcision
    - ☐ Microbicides
    - ☐ Pre-natal/Perinatal
    - ☐ Pre & post-prophylaxis
  - ☐ Secondary prevention
    - ☐ Positive prevention
    - ☐ Indirect (e.g., through identification or treatment of other STIs)
  - ☐ Harm reduction
- ☐ Treatment & support
  - ☐ Anti-retroviral
    - ☐ Combination therapy (HAART)
    - ☐ Single drug therapy
    - ☐ Initiation of treatment
    - ☐ Changing/stopping/interrupting treatment
    - ☐ Salvage therapy
    - ☐ Gene therapy
  - ☐ Side effects
  - ☐ Complementary therapy
  - ☐ Nutrition
  - ☐ Psychological
  - ☐ Education
  - ☐ Psychosocial/behavioural
  - ☐ Opportunistic infections
  - ☐ Exercise/rehabilitation

4. <u>Implementation strategies</u>

- ☐ Consumer-targeted strategy
  - ☐ Information or education provision
  - ☐ Behaviour change support
  - ☐ Skills and competencies development
  - ☐ (Personal) Support
  - ☐ Communication and decision-making facilitation
  - ☐ System participation
- ☐ Provider-targeted strategy
  - ☐ Educational material
  - ☐ Educational meeting
  - ☐ Educational outreach visit
  - ☐ Local opinion leader
  - ☐ Local consensus process
  - ☐ Peer review
  - ☐ Audit and feedback
  - ☐ Reminders and prompt
  - ☐ Tailored intervention
  - ☐ Patient-mediated intervention
  - ☐ Multi-faceted intervention
- ☐ **Organization-targeted strategy**

Appendix 2 – Peer-relevance assessment question

How useful is the information presented in this summary to decision-making in your organization or jurisdiction?

Score	Criterion
☐ 5	Highly useful: I would definitely use this
☐ 4	Probably useful: I would likely use this
☐ 3	Somewhat useful
☐ 2	Probably not useful: I would likely not use this
☐ 1	Not useful: I would definitely not use this

Appendix 3 – Data collection instrument (secondary outcome measure)

Background

We have developed an evidence service for community-based organizations working in the HIV sector entitled SHARE (**S**ynthesized **H**IV/**A**IDS **R**esearch **E**vidence). SHARE provides access to records of syntheses of research evidence (systematic reviews, overviews of systematic reviews and treatment guidelines) that address topics related to HIV/AIDS in order to help organizations more easily find and use research evidence in their work.

Before you access the evidence service, we would like you to complete a brief survey that should take you approximately 5-10 minutes to complete.

Section A – Intention to use research evidence

Each question in this section refers to a scenario where you need to make a decision about programs and services delivered by your organization, brief or provide advice to another manager in your organization or when you are involved in advocacy, a policy debate or deliberations with policymakers and/or other organizations. <u>Please answer each question as though you are engaged in a typical decision-making process or advocacy initiative</u>.

1. I expect to use synthesized research evidence of the type contained in SHARE to help work through what I will decide or advocate for.

Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
1	2	3	4	5	6	7

2. I want to use synthesized research evidence of the type contained in SHARE to help work through what I will decide or advocate for.

Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
1	2	3	4	5	6	7

3. I intend to use synthesized research evidence of the type contained in SHARE to help work through what I will decide or advocate for.

Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
1	2	3	4	5	6	7

4. Using synthesized research evidence of the type contained in SHARE to help work through what I will decide or advocate for is…

Very harmful	Moderately harmful	Slightly harmful	Neutral	Slightly beneficial	Moderately beneficial	Very beneficial
1	2	3	4	5	6	7

Very bad	Moderately bad	Slightly bad	Neutral	Slightly good	Moderately good	Very good
1	2	3	4	5	6	7

Very unpleasant (for me)	Moderately unpleasant (for me)	Slightly unpleasant (for me)	Neutral	Slightly pleasant (for me)	Moderately pleasant (for me)	Very pleasant (for me)
1	2	3	4	5	6	7

Very unhelpful	Moderately unhelpful	Slightly unhelpful	Neutral	Slightly helpful	Moderately helpful	Very helpful
1	2	3	4	5	6	7

5. Most people who are important to me in my professional life think that…

I should definitely not	I should almost certainly not	I should probably not	Neutral	I should probably	I should almost certainly	I should definitely
1	2	3	4	5	6	7

…use synthesized research evidence of the type contained in SHARE to help work through what I will decide or advocate for..

6. It is expected of me that I use synthesized research of the type contained in SHARE evidence to help work through what I will decide or advocate for.

Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
1	2	3	4	5	6	7

7. I feel under social pressure to use synthesized research evidence of the type contained in SHARE to help work through what I will decide or advocate for.

Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
1	2	3	4	5	6	7

8. People who are important to me in my professional life want me to use synthesized research evidence of the type contained in SHARE to help work through what I will decide or advocate for.

Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
1	2	3	4	5	6	7

9. I am confident that I could use synthesized research evidence of the type contained in SHARE to help work through what I will decide or advocate for..

Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
1	2	3	4	5	6	7

10. For me to use synthesized research evidence of the type contained in SHARE to help work through what I will decide or advocate for is…

Very difficult	Moderately difficult	Slightly difficult	Neutral	Slightly easy	Moderately easy	Very easy
1	2	3	4	5	6	7

11. The decision to use synthesized research evidence of the type contained in SHARE to help work through what I will decide or advocate for.

Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
1	2	3	4	5	6	7

12. Whether or not I use synthesized research evidence of the type contained in SAHRE to help work through what I will decide or advocate for.

Strongly	Disagree	Somewhat	Neither	Somewhat	Agree	Strongly

disagree		disagree	agree nor disagree	agree		agree
1	2	3	4	5	6	7

The question below refers to how useful you found the information from the evidence service. **[used only in the follow-up survey]**

13. I found the information from the evidence service to be useful.

Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
1	2	3	4	5	6	7

Section B – Organization and participant characteristics [questions asked only at baseline or at follow-up noted in square brackets]

1. What is the title of your position? (open ended) **[asked only on baseline survey]**

2. Are you currently in a full-time or part-time position? **[asked only on baseline survey]**

3. Do you have previous training in research? **[asked only on baseline survey]**
   - ☐ Yes (if yes, please briefly describe – open ended box provided)
   - ☐ No

4. Did you participate in the workshop on finding and using research evidence provided by the Ontario AIDS Network (OAN) and the Ontario HIV Treatment Network at the OAN meeting of board chairs and executive directors in November 2009? **[asked only on baseline survey]**
   - ☐ Yes
   - ☐ No

5. In what province/territory is your organization located? **[asked only on baseline survey]**
   - ☐ British Columbia
   - ☐ Alberta
   - ☐ Saskatchewan
   - ☐ Manitoba
   - ☐ Ontario
   - ☐ Quebec

- ☐ New Brunswick
- ☐ Nova Scotia
- ☐ Prince Edward Island
- ☐ Newfoundland & Labrador
- ☐ Yukon
- ☐ Northwest Territories
- ☐ Nunavut

6. Where does your organization <u>principally</u> provide services (choose only one)? **[asked only on baseline survey]**
- ☐ Locally (i.e., within one city or town)
- ☐ Regional area (i.e., sub-provincial area)
- ☐ Entire province/territory
- ☐ National/multi-province/territory

7. What type of area(s) does your organization serve (please choose the one that best describes your area)? **[asked only on baseline survey]**
- ☐ Urban
- ☐ Rural
- ☐ Both urban and rural
- ☐ Northern and remote

8. Approximately how many <u>paid full-time equivalent staff for HIV-related work</u> are there in your organization? **[asked only on baseline survey]**
- ☐ 0-5
- ☐ 6-10
- ☐ 11-15
- ☐ 16-20
- ☐ 21-25
- ☐ 26-30
- ☐ 30+

9. Approximately how many people does your organization directly serve each year (i.e., not just HIV related) **[asked only on baseline survey]**
- ☐ 0-250
- ☐ 251-500
- ☐ 501-750
- ☐ 751-1000
- ☐ 1001-1500
- ☐ 1501-2000
- ☐ 2000+

10. Did someone other than participant enrolled in the study complete this survey? **[asked only on follow-up survey]**

- ☐ Yes
- ☐ No

11. What is the title of the position of the person who filled out the survey (if you answered ‘Yes’ to question 10) **[asked only on follow-up survey]**

12. Were you also the person that filled out the original survey? If no, please what is the title of the person who filled out the original survey? **[asked only on follow-up survey]**
    - ☐ Yes
    - ☐ No (open-ended response provided for title of position)

13. Did you provide your login ID and password to anyone else <u>outside</u> of your organization during the study in order to support their use of research evidence? **[asked only on follow-up survey]**
    - ☐ Yes (if yes, how many?)
    - ☐ No

14. Did you provide your login ID and password to anyone else <u>within</u> your organization during the study in order to support their use of research evidence? **[asked only on follow-up survey]**
- ☐ Yes (if yes, how many?)
- ☐ No

14. Since the trial began, did you change part-time versus full-time status or position within your organization? If yes, please describe the change. **[asked only on follow-up survey] [open ended response]**
    ☐ Yes (if yes, please describe – space for open-ended response provided)
    ☐ No

15. Since the trial began, did you take any vacation or leave that lasted more than two weeks? If yes, please describe the duration and timing of the vacation or leave **[asked only on follow-up survey]**
    - ☐ Yes (open-ended box provided for description of duration and timing of leave)
    - ☐ No

Conclusion

Principal findings

This thesis presents four original scientific contributions, each addressing a different yet important part of supporting the use of research evidence by community-based organizations. Chapter 2 presents a framework for community-based knowledge transfer and exchange that provides an outline of different activities that are important for supporting the use of research evidence. The framework focuses on: 1) 'linkage and exchange' that promotes the approach of producers and users of researchers engaging in a process of asking and answering questions together; 2) a greater emphasis on both producing and disseminating systematic reviews that address topics of interest to community-based organizations; 3) developing a large-scale evidence service consisting of both 'push' efforts and efforts to facilitate 'pull' that highlight actionable messages from community-relevant systematic reviews in a user-friendly way; and 4) and rigorous evaluations of efforts for supporting the use of research evidence.

The next three chapters build on and address different elements of the framework. The scoping review provides a comprehensive and systematic outline of the research literature related to community-based organizations in the health sector to help support the development of a better understanding of their characteristics and functions in the health sector. Through the review I identified 190 relevant articles and found that a large number of different terms have been used in the research literature to describe community-based organizations (e.g., voluntary organization, non-governmental organization, civil society organization or community coalitions/network/partnerships), which makes it difficult to develop a well defined outline of organizations and their roles in health systems. In addition, I found research literature related to a range of topics about community-based organizations (mandate, structure, revenue sources and type and skill of staff), the involvement of community members in organizations, how organizations contribute to community organizing and development, and how they function in networks with each other and with government (e.g., in policy networks).

In chapter 4 I describe how I conducted five focus groups in three sectors (HIV/AIDS, diabetes, and mental health and addictions) with 31 executive directors and program managers, as well as follow-up interviews with 16 focus group participants, in order to develop a better understanding of the key characteristics of community-based organizations and their views about and experiences with systematic reviews and approaches to user-friendly summaries and peer-relevance assessments of systematic reviews. Key characteristics of community-based organizations that were identified include the involvement of community members in the formation, governance and functioning of the organization, as well as being guided by a mission, vision and set of values and having mandates that are typically shaped by the populations and geographic regions they serve. In addition, there was strong support for a structured user-friendly summary of systematic reviews that includes a plain-language summary, a succinct outline of the ‘take-home messages,’ and a summary of the benefits, harms and costs of the intervention/topic being addressed. Lastly, there was also support for assessing the relevance of systematic reviews by categorizing them by topic and population addressed and for providing scores from peer-relevance assessments of the review.

Chapter 5 presents a protocol for a randomized controlled trial (RCT) that will be used to evaluate the effects of an evidence service (SHARE – Synthesized HIV/AIDS Research Evidence) on community-based AIDS service organizations’ use of research evidence. The RCT will compare a “full serve” version of SHARE (an online searchable database, email updates and access to user-friendly summaries and peer-relevance assessments) with a “self-serve” version (a listing of relevant systematic reviews with links to records on PubMed and worksheets that help community-based organizations find and use research evidence) by measuring the mean number of logins/month/user and participants’ intention to use research evidence. In addition, 30 participants from the trial (15 from each study arm) will be purposively sampled for a qualitative study investigating their views about and their experiences with the evidence service they received, how helpful it was in their work, why it was helpful (or not helpful), what aspects were most and least helpful and why, and recommendations for next steps.

Study meaning

The four original scientific contributions presented in this thesis collectively begin to fill an important gap in supporting the use of research evidence in health systems. While community-based organizations provide numerous, often highly valued programs and services to the members of their community, they have received little attention in the health policy and knowledge transfer and exchange literatures. The scientific contributions advances a novel area of research in knowledge transfer and exchange and provides a framework, resources, and practical tools for those interested in supporting the use of research evidence by community-based organizations to draw upon. In addition, the four chapters demonstrate a cumulative progression of understanding about supporting the use of research evidence by community-based organizations. For instance, chapters 3-5 build on different elements of the framework presented in chapter 2, chapter 4 builds on the findings of the scoping review (chaper 3) by developing a better understanding of the key characteristics of community-based organizations, and the RCT protocol (chapter 5) incorporates the user-friendly summaries and peer-relevance assessments examined in chapter 4.

I have also drawn on existing theory and findings in the knowledge transfer and exchange literature to inform the research presented in this thesis. Specifically, in the chapter 2 (Community-based knowledge transfer and exchange: Helping community-based organizations link research to action), I developed a framework for supporting the use of research evidence by community-based organizations by adapting an existing framework for health system managers and policymakers (1) through a comparison of the framework to the principles of community-based research. I also developed the approaches for user-friendly summaries and peer-relevance assessments by drawing on similar approaches that have been used for health system managers and policymakers (2;3) and clinicians (4-7). Also, the RCT protocol that I have developed to evaluate the effects of an evidence service (SHARE – Synthesized HIV/AIDS Research Evidence) for community-based AIDS organizations draws on methods used for a similar trial completed in the clinical sector (6) and will be conducted in parallel to a similar trial evaluating the effects of an evidence service for policy staff in the Ontario Ministry of Health and Long-Term Care (8).

Strengths and limitations

Together, the four original scientific contributions presented in this thesis have several strengths. First, by focusing on a relatively neglected group of stakeholders in health systems and in the knowledge transfer and exchange literature, I have taken important initial steps towards not only developing a new area of research but also to practically supporting the use of research evidence by this key group of stakeholders. As such, this thesis provides a unique and important contribution to the literature. Another related strength is that I have used a mix of approaches and methods to begin to build this area of research, which contributes to a greater depth of understanding. For instance, the focus groups and following one-on-one interviews provide in-depth feedback from executive directors and program managers of community-based organizations in three sectors, which enhanced the applicability and transferability of the findings. In addition, by using a mixed methods approach for the RCT protocol presented in chapter 5, I will be better able to understand whether and how the evidence service affects the use of research evidence by community-based organizations in the Canadian HIV/AIDS sector. Lastly, the RCT protocol presented in chapter 5 is the first designed (to my knowledge) to evaluate the effects of an evidence service for community-based organizations and one of only a very small number of completed or planned RCTs evaluating knowledge translation intervention for other stakeholders (6;8;9). Therefore, once completed, the RCT will contribute to an emerging evidence base about the effects of knowledge transfer and exchange interventions that can contribute to the findings of future systematic reviews.

There are also some limitations of this thesis that should be considered. First, all of the original scientific contributions, except for the scoping review, focus (although not exclusively) on the Canadian context and are somewhat limited in terms of sector and/or sample size. The framework presented in the chapter 2 draws on many examples from the Canadian HIV/AIDS sector. However, based on the fact that both knowledge transfer and exchange and community-based research are recognized by many funders and organizations outside of Canada, the descriptions and conclusions are likely relevant to other communities that are also engaged in community-based research. Similarly, the sample for the focus groups and one-on-one interviews in the chapter 4 are limited to participants from community-based organizations in one Canadian province (Ontario) and to some extent from one of the major urban areas in the province (the Greater Toronto Area). Further, the response rate was low for the focus groups and interviews, and despite sampling from three sectors (HIV/AIDS, diabetes, and mental health and addictions) the majority of the sample for the follow-up interviews was drawn from the HIV/AIDS sector. In addition, the RCT presented in chapter 5 will be conducted only in the Canadian HIV/AIDS sector, which provides a fixed and potentially limiting sample size. With respect to the scoping review, all relevant literature related to the key characteristics of community-based organizations may not have been captured as we only found minimal literature related to the cardiovascular disease, cancer and diabetes sectors despite each having large networks of charitable and community-based organizations. Similarly, we found a lack of literature related to community-based organizations involved in social movements, which further indicates that our search strategy may not have identified all relevant areas of the literature.

Future research

There are several general and specific areas for future research that have emerged from the chapters presented in this thesis. First, to complement the planned RCT, there is a need for long-term evaluation of efforts to support the use of research evidence by community-based organizations. Such evaluations will provide additional insight into whether, how and under what conditions community-based organizations use research evidence. This information can also be used to contribute to enhanced theories about how research evidence is used by community-based organizations and in health systems more generally, which could contribute to the development of more refined measurement tools for future evaluations. In addition, further evaluations of knowledge transfer and exchange interventions are important for continuing to develop an evidence base that can eventually be synthesized in a systematic review that assesses the effects of efforts to support the use of research evidence, thereby helping the field to have a better idea of 'what works' in knowledge transfer and exchange.

Additional potential areas for future research include deliberative dialogues and capacity building for community-based organizations. Deliberative dialogues (i.e., constructive multi-stakeholder dialogues about a priority health system issue/problem) could be an important strategy both for supporting the use of research evidence by community-based organizations and for including them in health system decision-making processes and promoting constructive discussion between multiple stakeholders. However, for community-based organizations to engage in such dialogues and to increase their use of research evidence more generally, capacity building initiatives will likely be needed to help them acquire, assess, adapt and apply research evidence to inform their programs, services and advocacy. This could involve conducting assessments of specific areas where community-based organizations in different settings require capacity building and then partnering with organizations (or networks of organizations) to develop materials (e.g., online interactive tutorials) and provide interactive workshops.

In the short-term, key areas of research that I plan to pursue include completing the RCT and the follow-up qualitative study and continuing the development of SHARE. Specifically, I plan to produce additional user-friendly summaries and, continue identifying and categorizing systematic reviews, and eventually to incorporate quality appraisals of systematic reviews included in SHARE.

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