



# **Co-Creating a Mental Health & Addictions Research Agenda for Ontario**

**Final Report - March 2011**

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*Brought to you by the  
Ontario Mental Health and Addictions Knowledge Exchange Network*

**OMHAKEN**

*creating together* Coordinators

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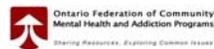
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## LETTER FROM THE SPONSORS

We are pleased to present the results of **creating together**: Co-Creating a Mental Health and Addictions Research Agenda for Ontario. **creating together** began in the spring of 2010, with a shared interest from the Ontario Mental Health and Addictions Knowledge Exchange Network (OMHAKEN), Co-sponsors and Supporters in consulting stakeholders across the province to jointly develop a research agenda. This unique opportunity was inspired by Canadian Health Services Research Foundation's Listening for Direction<sup>1</sup> national exercise. OMHAKEN and its partners<sup>2</sup> felt that the time was right for this important undertaking, as the Ontario government is introducing a comprehensive Mental Health and Addictions Strategy. The research agenda can be used to supplement and complement the report from the Minister's Advisory Group<sup>3</sup> by articulating the research needs associated with a transformation of our mental health and addictions systems.

**creating together** used a number of different approaches to gather priorities from stakeholders across the province, and was committed to involve all those with a stake in the results. We were pleased to receive almost overwhelming interest to participate in discussions on new knowledge needs that could be used to improve our mental health and addictions systems. Our report confirms the interest in research and knowledge translation and exchange and highlights the similarities in priorities across the province.

The process of collecting and reflecting upon the dialogue with participants has been a collaborative and educational activity among partners that we hope will continue over the coming months and years. The most valued contributions to this initiative are the goodwill and cooperation of those who participated. We hope that those of you who participated will read these findings with great interest and a sense of shared accomplishment. A special thank-you to the committees and volunteers of **creating together** for their effort and support in helping to bring this idea to fruition.

Readers are reminded that the intent is to identify priority areas for new knowledge and to fill knowledge to action gaps. Our findings can help guide decisions and shape new investments or their reallocation for research and knowledge translation and exchange in Ontario. They should also encourage researchers and other stakeholders to move forward in a collaborative fashion.

The work of the **creating together** partners is ongoing. Our participation in the creation of this research agenda represents our commitment to continue to develop research and knowledge in these areas, and ensure that it is applied to improve the health system and health outcomes for Ontarians. As Sponsors we are committed to use the findings to guide decisions about future research funding and other allocation decisions. We hope that these results will stimulate useful linkages and dialogue across the province as we work together to enhance mental health and addictions research and knowledge. OMHAKEN will continue to facilitate interactions that bring stakeholder worlds together.

Collaboratively yours,

Ontario Mental Health and Addictions Knowledge Exchange Network  
Centre for Addiction and Mental Health  
Institute for Clinical Evaluative Sciences  
Ministry of Health and Long-Term Care  
Ontario HIV Treatment Network  
Rainbow Health Ontario  
Schizophrenia Society of Ontario  
Seniors Health Research Transfer Network Collaborative

<sup>1</sup> Canadian Health Services Research Foundation (CHSRF). (2008) *Listening for Direction III, National Consultation on Health Services and Policy Issues*. Available at: [http://www.chsrf.ca/Libraries/Listening\\_for\\_Direction/LfDIII-FINAL\\_ENG.sftb.aspx](http://www.chsrf.ca/Libraries/Listening_for_Direction/LfDIII-FINAL_ENG.sftb.aspx)

<sup>2</sup> See Appendix 1 List of Co-sponsors and Supporters p. 41

<sup>3</sup> See Appendix 4 References p. 45

# Main Messages

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- *creating together* is strongly supported by fifteen provincial mental health and addictions organizations, seven of which have committed to using the results to inform their funding and resource allocation decisions about health services and population health research. Each organization contributed essential knowledge and expertise and many contributed funds and/or instrumental resources.
- Excellent participation rates were achieved for in-person and videoconference consultations (253 participants) and the online survey (1,431 completed surveys). The representation of mental health and addictions stakeholder groups was robust and broad-based for each group.
- There was a remarkable degree of consensus among the various groups about the research priorities. The synthesized research priorities that emerged included:
  - **Population health research is needed to better understand how to mitigate risk and build resilience (e.g., for children, youth, and families). This illustrates the importance assigned to health promotion and prevention.**
  - **Learning how to intervene to influence the social determinants of health (e.g., housing, income, employment) with a special focus on vulnerable populations. Economic evaluation and system monitoring should be employed to this end.**
  - **Research about continuity of care and access to care needs to be conducted in various settings (e.g., rural and remote, primary health care) and tailored to the needs of particular vulnerable populations (e.g., the elderly, Aboriginal communities, people with co-morbid disorders, people with low income, LGBT, women, etc.). Better data quality is crucial to this work.**
  - **Persons with lived experience and their families are particularly interested in being involved in research that is aimed at deepening understanding of, and addressing stigma and discrimination.**
- Further investment in effective knowledge translation and exchange (KTE) methods is needed to ensure that all mental health and addictions stakeholders receive research results in a timely fashion and through media that are accessible, tailored to their needs, and in user-friendly formats and language.
- Ontario has a rich resource base upon which to draw for building capacity in collaborative research and KTE. This base has been strengthened through the involvement of the *creating together* Co-sponsors and Supporters.
- Stakeholders expressed strong interest in being engaged in research on all topics and endorsed the greater involvement of persons with lived experience in mental health, problematic drug use, and other addictions and their family members in research activities. The consultations supported the need for developing capacity for community-based participatory research.
- The priority topics and the need for improved KTE practices that were identified in the consultations are consistent with the findings of other policy and research consultations in Ontario and across Canada.

# Executive Summary

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*creating together* has developed a research agenda for health systems and population health research focused on mental health and addictions<sup>4</sup> that will provide guidance for funders of research and stakeholders in Ontario. *creating together* also identified knowledge transfer and exchange (KTE) needs and capacity building approaches for greater collaborative research and effective KTE. The report is based on extensive consultation with provincial stakeholders. The release of this report coincides with the recent release of the report from the Minister's Advisory Group to the Minister of Health and Long-Term Care (MOHLTC), "Respect, Recovery, and Resilience: Recommendations for Ontario's Mental Health and Addictions Strategy" and fits well with the policy agenda.

*creating together* was initiated by the Ontario Mental Health and Addictions Knowledge Exchange Network<sup>5</sup> in collaboration with fifteen provincial organizations representing research funders, policy, service provision, persons with lived experience, family members, and the MOHLTC (see Appendix 1 List of Participating Organizations - Co-sponsors and Supporters, p.41). Each organization and individual participant has contributed valuable knowledge and expertise to *creating together* and several have provided funding and/or instrumental support. The seven Co-sponsors committed at the outset to use the *creating together* research agenda to guide research funding and allocation decisions.

## Research Agenda And Key Findings

*creating together* learned that research is very important to mental health and addictions stakeholders, that they want to participate in research and that they agree about what the priorities should be for new research. The participation rates were high for in-person and videoconference consultations (253 participants) and the online survey (1,431 completed surveys) and achieved good representation from all stakeholder groups in mental health and addictions. The topics that were consistently identified as priorities were synthesized to constitute the *creating together* Research Agenda. The six priority agenda topics are: Social Determinants of Health; Risk and Resilience; Health Promotion and Prevention; Stigma and Discrimination; Continuity of Care; and Vulnerable Populations.

### 1. Social Determinants of Health

Learning how to intervene to favourably impact the social determinants of health (e.g., housing, income, employment) while focusing upon disadvantaged subgroups was very strongly endorsed. The broader use of economic evaluation and system monitoring should be employed to this end and could support greater interest and activity in this area. Many agreed that given the broad research base in housing and employment addressing the social determinants of health in policy and practice could happen fairly quickly if robust KTE efforts were implemented.

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<sup>4</sup> The word 'addictions' is used in this report as an umbrella term for substance use problems, problem gambling and/or process addictions, e.g., internet.

<sup>5</sup> The OMHAKEN website is located in the Mental Health and Addictions section of [www.ehealthontario.ca](http://www.ehealthontario.ca).

## 2. & 3. Risk and Resilience, Health Promotion and Prevention<sup>6</sup>

More population health research is needed to better understand how to mitigate risk, build resilience (e.g., in children, youth and families, and build better communities). This illustrates the importance assigned to health promotion and prevention by stakeholders.

## 4. Stigma and Discrimination

Persons with lived experience in mental health and addictions and their families expressed particular interest in being involved in research that is aimed at further understanding and addressing stigma and discrimination. There is a clear perception that the impact of stigma and discrimination, although very important, is a neglected area that urgently requires more emphasis and action to both synthesize current research and disseminate and implement existing knowledge.

## 5. Continuity of Care

More research about continuity of care and access to care needs to be conducted in various settings (e.g., rural and remote, primary health care) and tailored to the needs of particular vulnerable populations (e.g., elderly, Aboriginal communities<sup>7</sup>, co-morbid). Better access to higher data quality is crucial to supporting this work. Consultation participants perceived access to care to be an ongoing issue within the mental health and addictions systems and would like to see more research into how best to improve access. A closely related topic is the impact of integrated systems on access.

## 6. Vulnerable Populations

The consultations also provided information about those populations deemed most vulnerable. They are: low-income families and individuals; children and youth; older adults/seniors; members of LGBT communities; women; persons with co-morbid/concurrent disorders; persons who are homeless; Aboriginal communities; persons with serious substance use problems; ethno-cultural groups/immigrants/refugees; and, persons with severe and persistent mental illness. Some of these groups fit naturally within the five agenda topics. All of them should be kept in mind when defining research questions and methods.

Most stakeholders expressed strong interest in being involved in research activities, in conducting research and/or in receiving research results. The greater involvement of persons with lived experience and family members in research activities was strongly endorsed in the consultations, as was greater capacity for community engaged research. Ontario is in a strong position to build capacity in collaborative research and KTE. The participating organizations in *creating together* have demonstrated knowledge and experience in these areas and are keen to build on this base which has been strengthened through the collaborative planning process.

These findings about priority research topics and the need for improved KTE are remarkably consistent and fit very well with those of other policy and research consultations in Ontario and across Canada. The areas of emphasis in the Ontario Minister's Advisory Group's recommendations for the mental health and addictions strategy on stigma and discrimination,

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<sup>6</sup> These two priorities are linked because they share common knowledge bases and research methods.

<sup>7</sup> The term Aboriginal communities is used throughout to refer to First Nations, Métis and Inuit.

early identification and intervention in mental health and addictions problems, healthy resilient communities (where the social determinants of health such as housing, employment and income support are fundamental), and integration of health and other services closely match the priority research and KTE topics of *creating together*. Both reports were also consistent in the identification of vulnerable populations.

### How We Got Here: *creating together* Process

Seven phases comprise the *creating together* process, five of which are complete. The two remaining will be completed following the release of this report. Phase I saw the creation of a master theme and topic list reflective of provincial research and KTE needs for the in-person consultations. To prepare the list, a scan of recent provincial consultation documents looking for identified research/KTE gaps and needs was conducted. A consultation process tailored to the *creating together*'s goals and objectives was outlined. To structure *creating together*, fifteen provincial organizations were invited to join as collaborators, resulting in two committees, Co-sponsors/Steering and Supporters. An Expert Advisory Panel was formed and staff from the Health Systems and Health Equity Research Group, Centre for Addiction and Mental Health (CAMH), acted as the initiative's Coordinating Centre.

A set of six consultations (Phase II) were conducted in-person (4: Thunder Bay, Toronto, London, and Ottawa) and through videoconference (2: focus on five communities each in Northern and Southern Ontario). A total of 287 people attended the sessions. Nine topics emerged as clear priorities ranging from vulnerable populations, stigma and discrimination to performance monitoring.

Phase III started with the creation of the online survey based on the findings from Phase II. The online survey consisted of sixteen defined research topics with a set of related sub-topics. Survey respondents were asked to rank order their top five research priority topics. A snowball sampling strategy was used where a core respondent group was identified and then asked to provide new names to build the sample population. This resulted in a list of approximately 1,292 potential respondents who received the survey directly. The survey was also circulated through the networks of *creating together*'s partners resulting in an even wider distribution. The survey was available in both French and English. The overall response to the online survey was robust with 1,431 people responding. Of these:

- 1,396 completed the survey in English;
- 35 completed the survey in French;
- In the English version, 79 people indicated they were French, 105 bilingual (English/French) and 24 other;
- 70 people indicated they were from Aboriginal communities; and,
- 115 respondents completing the survey had also participated in the in-person consultations.

In Phase III, six priority topics emerged separated by a wide margin from the other topics. Social Determinants of Health was the number one priority in rank weighted order, closely followed by Risk and Resilience. Health Promotion and Prevention appeared as a top priority in Phase III, although not in Phase II. There was consensus across both phases around the three remaining Phase III priority topics: Vulnerable Populations, Stigma and Discrimination, and, Continuity of Care. Again, a high level of agreement was achieved across stakeholder groups.

Phases IV and V involved synthesizing the data and formulating the research agenda. A comprehensive overview of the research agenda is found in the Key Findings section of this summary. The Expert Advisory Panel played a major role in developing the summary agenda and the final report. The synthesis of the vast amount of data collected through the consultations and online survey created a clear set of research priorities each of which has associated KTE synthesis and implementation needs, clearly identified vulnerable populations, and research methods.

To move the research agenda forward it will be essential to improve data quality and access, further connections between researchers and stakeholders, provide research training for service providers and enhance KTE.

The last two phases of *creating together*: Final Report Dissemination (VI), and Evaluation of *creating together* and Further Dissemination Activities (VII) are described briefly as they are scheduled to take place following the release of the report.

## What Comes Next

The results of the consultations will be used to guide decisions about investments in these research domains and KTE in Ontario. They should encourage researchers and others to move forward in a collaborative fashion. The results also identify areas that might require additional or reallocated resources to address the need for new knowledge and knowledge to action gaps. The research agenda can supplement and complement the report from the Minister's Advisory Group by articulating the research needs associated with a transformation of our mental health and addictions systems.

The full report is organized to first provide brief background information about *creating together* and its process (p. 10). Then the summary research and KTE agendas are presented (p.13). An example of a more focused consultation with the LBGT community is also described. What follows is a more complete description of the consultation activities and findings that formed the basis for the agenda. The appendices and website links provide more detailed information for interested readers.

# I Background

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*creating together* is sponsored by the Ontario Mental Health and Addictions Knowledge Exchange Network<sup>8</sup>. The goal of *creating together* is to create a research agenda and knowledge transfer and exchange (KTE) agenda for mental health and addictions<sup>9</sup> in Ontario through the direct involvement of stakeholders. It is co-sponsored and supported by fifteen provincial funding, policy, service provider, persons with lived experience and family organizations and the Ministry of Health and Long-Term Care (MOHLTC) (see Appendix 1 List of Co-sponsors and Supporters, p. 41). Each organization has contributed valuable knowledge and expertise and several have provided funding and/or instrumental support. The expected outcomes of *creating together* were defined at the beginning as:

- A health services and population health research agenda that will provide direction for future research investments and KTE activity in Ontario.
- Strengthened linkages between researchers and stakeholders to support future collaborative research and KTE.
- Direct benefit to persons with lived experience and family members resulting from the development and application of knowledge aimed at building better mental health and addictions systems in Ontario.

Recognizing that research agenda setting is an important part of the ‘knowledge to action cycle’ (Graham, I. et al., 2006<sup>10</sup>), *creating together* went directly to mental health and addictions stakeholders to ask them what their research and knowledge exchange needs and priorities were. The stakeholder groups approached were: persons with lived experience; family members; researchers; service providers; allied professions and sectors; and, policy makers, system planners, funders and provincial organizations. In departing from the standard practice of funders and researchers defining the research needs and agendas, *creating together* generated a clear set of research priorities, based on a broad consensus across stakeholder groups.

*creating together* received commitment at the outset from the Co-sponsor funding organizations that the findings will be used to guide decisions about future research funding and other allocation decisions. This might also extend to Supporters of *creating together* and other research funders.

Seven distinct phases (see Section II Phases and Timelines, p.11) comprised the *creating together* process and this report covers the first five, ending with the Research Agenda. The last two phases, Report Dissemination, and, Evaluation Report and Dissemination, will take place upon completion of this report.

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<sup>8</sup> The OMHAKEN website is located in the Mental Health and Addictions section of [www.ehealthontario.ca](http://www.ehealthontario.ca).

<sup>9</sup> The word ‘addictions’ is used in this report as an umbrella term for substance use problems, problem gambling and/or process addictions, i.e., internet.

<sup>10</sup> See Appendix 4 References p. 45

The research scope of *creating together*, health systems and population health research, is based on the areas of research funded by the MOHLTC, a *creating together* Co-sponsor and funder. Other funding was provided by the Canadian Institutes for Health Research/Canadian Health Services Research Foundation Chair award of Dr. Paula Goering. The Centre for Addiction and Mental Health (CAMH) Provincial Services staff provided direct in-kind services and along with the other Co-sponsors and Supporters, offered invaluable advice and technical assistance at each stage of *creating together*.

## II Phases & Timeline

<p><b>Phase I: Planning and Development</b>  <b>March – May 2010</b></p> <ul style="list-style-type: none"> <li>• Formed <i>creating together</i> advisories: Expert Advisory Panel, Co-sponsors/Steering Committee and Supporters Committee</li> <li>• Reviewed documents developed for the Mental Health and Addictions Strategy, the Select Committee and Minister’s Advisory Group (23 + transcripts)</li> <li>• Reviewed report from Institute for Clinical and Evaluative Sciences, Mental Health and Addictions Research Initiative</li> <li>• Identified common themes and topics around knowledge needs. Developed a draft list of knowledge themes and topic areas. Reviewed with Expert Advisory Panel for input</li> </ul>
<p><b>Phase II: Stakeholder Consultations (In-person and Videoconference)</b>  <b>June – August 2010</b></p> <ul style="list-style-type: none"> <li>• Six provincial consultations - four in-person (Thunder Bay, Toronto, London, and Ottawa) and two videoconference consultations (focused on Northern and Southern Ontario communities involving a total of five cities in each region)</li> <li>• Developed reports for each consultation and an Integrated Report<sup>11</sup> for all consultations</li> <li>• Reviewed with Expert Advisory Panel and <i>creating together</i> committees</li> </ul>
<p><b>Phase III: Online Survey Stakeholder Consultation</b>  <b>August – November 2010</b></p> <ul style="list-style-type: none"> <li>• Select members of Expert Advisory Panel advised on form and content of the online survey</li> <li>• Circulated revised form to Expert Advisory Panel members, Co-sponsors/Steering and Supporters committee members. Incorporated feedback into the final version</li> <li>• Contracted with an online survey specialist to craft the survey, receive results and provide SPSS data tables</li> </ul>

<sup>11</sup> See [www.creatingtogether.net](http://www.creatingtogether.net) for full Integrated Report.

<ul style="list-style-type: none"> <li>English language version posted October 8 and French translation November 2</li> <li>Both surveys closed on November 15</li> </ul>
<p><b>Phase IV: Expert Advisory Panel &amp; Synthesis</b>  <b>November – December 2010</b></p>
<ul style="list-style-type: none"> <li>Reviewed data and analysis with Expert Advisory Panel to develop outline of report</li> </ul>
<p><b>Phase V: Research Agenda</b>  <b>November 2010 – March 2011</b></p>
<ul style="list-style-type: none"> <li>Developed a research agenda for mental health and addictions based on the synthesis of the survey results and the Integrated Report from Phase II</li> <li>Developed draft final report and reviewed with Expert Advisory Panel and committees</li> <li>Production of final report for dissemination</li> </ul>
<p><b>Phase VI: Final Report Dissemination</b>  <b>March – May 2011</b></p>
<ul style="list-style-type: none"> <li>Dissemination to all stakeholders; participants; members of provincial parliament; OMHAKEN listserv; post on <i>creating together</i> and OMHAKEN websites</li> </ul>
<p><b>Phase VII: Evaluation Report &amp; Dissemination</b>  <b>March 2011 - tbd</b></p>
<ul style="list-style-type: none"> <li>Evaluation of <i>creating together</i> process</li> <li>Further Knowledge Translation via webinars, conferences, dialogues</li> </ul>

### III Research Agendas, Capacity Building, & KTE

The *creating together* research, capacity building and KTE agendas for mental health and addictions is based on the synthesis of the online survey results and the consolidated findings from the in-person and videoconference consultations, found in the Phase II *creating together* Integrated Report. The findings are presented in table form by priority topic (or topics in some cases). New research/knowledge needs, KTE synthesis and implementation needs, the most relevant vulnerable populations, and research methods are identified. Vulnerable Populations is a priority topic that is necessary to consider within each of the other priority topics to make it meaningful. As such, it is not represented in its own table but woven throughout the others instead. A short section on what needs to take place to ‘move forward’ is included for the priority topics.

#### Research and KTE Needs for Priority Topics

##### 1. Social Determinants of Health

New Knowledge	KTE: synthesis & implementation	Vulnerable Populations	Research Methods and Topics
<p>Intervention research to understand and assess the impact of social determinants of health on health and well-being.</p> <p>Evaluation research on existing and new models of practice that address the social determinants of health such as housing case management and cross-sectoral approaches.</p>	<p>Immediate action is needed to transfer existing knowledge with particular attention to policy makers.</p>	<p>Persons with low income was identified as the most vulnerable population. This fits well with social determinants of health as the top priority topic. (See Table 12 Vulnerable Populations in Rank Weighted Order, p.39)</p> <p>Other specific vulnerable populations named frequently in the comments were:</p> <ul style="list-style-type: none"> <li>• Persons who are homeless</li> <li>• Racialized sub-populations</li> </ul>	<p><b>Health economics:</b> priority sub-topic around costs of failing to address social determinants of health.</p> <p><b>Performance Monitoring:</b> sub-topic regarding incorporation of performance monitoring for the social determinants of health and health outcomes.</p>

New Knowledge	KTE: synthesis & implementation	Vulnerable Populations	Research Methods and Topics
		<ul style="list-style-type: none"> <li>• Persons with physical disabilities</li> <li>• LGBT sub-populations</li> <li>• Gender, e.g., men and mental health; trans community redefining gender</li> </ul>	

***Moving Forward:***

Many stakeholders suggested adding social engagement/social networks/healthy communities and their opposite, isolation/unhealthy communities, to the list of social determinants of health subtopics. Many agreed that that given the broad research base in housing and employment addressing the social determinants of health in policy and practice could happen fairly quickly in the presence of robust KTE efforts.

## 2. & 5. Risk and Resilience and Health Promotion & Prevention (HPP)

Among the six priority topics of interest, Risk and Resilience ranked second, and Health Promotion and Prevention, fifth. They are linked because they share common knowledge bases and research methods. As a result, they are presented sequentially next to each other here. Whereas research in risk and resilience studies the things that make people most vulnerable, health promotion and prevention research applies what is known to the design and evaluation of interventions (e.g., programs and policies to decrease risk and enhance resilience for people and/or communities).

New Knowledge	KTE: synthesis & implementation	Vulnerable Populations	Research Methods and Topics
<b>Risk and Resilience:</b>			
<p>Factors placing individuals and communities at risk.</p> <p>Building capacity for personal resilience.</p>	<p>Improved dissemination of existing information on risk and resilience.</p> <p>Best practices in resilience building.</p> <p>Transfer resilience building techniques to service providers.</p>	<p>Children and youth was the second most frequently named vulnerable population. (See Table 12 Vulnerable Populations in Rank Weighted Order, p.39)</p> <p>The other vulnerable populations in the top eleven were frequently mentioned.</p>	<p><b>Physical and Natural Environments</b> where the top sub-topic addresses “Research into the effect(s) of community spaces on <b>resiliency</b>, personal recovery and success.”</p> <p><b>Health Human Resources</b> where the third sub-topic identifies “<b>building workforce resilience</b>,” as a research need.</p>

New Knowledge	KTE: synthesis & implementation	Vulnerable Populations	Research Methods and Topics
<b>Health Promotion and Prevention:</b>			
<p>Intervening at the individual level, especially with children and youth, and at the community level.</p>	<p>Increased access to HPP materials. Educate staff in allied sectors about mental health and substance use prevention. Disseminate Canadian examples of cost savings from prevention research such as in the area of HIV infection.</p>	<p>Prevention of mental illness/substance abuse for:</p> <ul style="list-style-type: none"> <li>• People with chronic disease</li> <li>• at risk children and youth</li> <li>• high risk groups (e.g., substance users, sex workers, persons who are homeless, gay men).</li> </ul>	<p><b>Population-based Research</b> top sub-topic was, “The need for <b>preventive interventions</b> that are population-based and relevant to unique characteristics based on geography, language, economic status, culture, literacy levels, gender.” <b>Program Evaluation</b> of existing HPP programs.</p>

**Moving Forward:**

Survey respondents expressed particular interest in the relationship between culture and risk and resilience. Frequent mention was also made of the importance of knowing how to build resilience in young children and how to support parents. Finally, a wide array of suggestions was offered for how to conduct and evaluate health promotion activities (see section IV – E Health Promotion and Prevention, p. 38).

Further research and KTE efforts are needed in the near and long term for risk and resilience and health promotion and prevention. There is a perception that the root causes of substance abuse are fairly well known and this is accompanied with broad support for applying this to policy and practice.

### 3. Stigma and Discrimination

New Knowledge	KTE: synthesis & implementation	Vulnerable Populations	Research Methods & Topics
<p>Reducing stigma and discrimination within the contexts of culture, and, healthcare settings.</p>	<p>Synthesis and improved dissemination is needed on:</p> <ul style="list-style-type: none"> <li>• the negative effect of stigma</li> <li>• stigma reduction material.</li> </ul> <p>Knowledge from other fields should be applied to stigma and discrimination such as communications- as well as knowledge from other countries around what works to reduce stigma.</p>	<p>Several groups were mentioned as having issues with stigma:</p> <ul style="list-style-type: none"> <li>• People with HIV/AIDS</li> <li>• Substance users</li> <li>• Women who are single parents and may be CAS involved</li> <li>• Seniors</li> <li>• People with multiple/complex health and social conditions</li> <li>• People from Aboriginal<sup>12</sup> communities</li> </ul>	<p>More research driven by persons with lived experience.</p> <p><b>Health Economics</b> to assess the social and economic costs of stigma and discrimination.</p> <p><b>Program Evaluation</b> of exiting programs for stigma and discrimination.</p>

#### Moving Forward:

It was repeatedly emphasized that persons with lived experience and their families should be involved as collaborators and equal partners in all research and KTE activities, especially for stigma and discrimination (see section Building Capacity and Research for KTE, p. 19)

There is a clear perception that stigma and discrimination, although very important, is a neglected area that urgently requires more emphasis and action on both the synthesis of current research and the dissemination and implementation of existing knowledge. One example of existing activity aimed at addressing this is the recently launched Mental Health Commission of Canada Anti-stigma/Anti-discrimination Initiative, ‘Opening Minds.’ This ten-year plan is oriented to reduce the stigma of mental illness and to build a research base in this area. The first phase is twofold: targeting youth for early intervention; and, targeting healthcare professionals for perceived stigma and discrimination of people with mental health and substance use problems. Reducing stigma and discrimination in the workplace is a priority for the Commission’s Workplace Advisory Group.

<sup>12</sup> Aboriginal communities is used to denote First Nations, Inuit and Métis.

## 4. System Level Research:

- **Continuity of Care**
- **Integration & Systems Design**

Continuity of Care is the fourth priority. In the synthesis it is linked with Integration and Systems Design, priority number twelve because the two topics overlap, sharing a focus on understanding problems with access to care and improving access. They both require systems level research and, in particular, research into the effects of system level change on clients and families.

New Knowledge	KTE: synthesis & implementation	Vulnerable Populations	Research Methods & Topics
<b>Continuity of Care:</b>			
Access to care and the factors affecting access, (e.g., geography, wait lists and funding). Impact of poor/good service access on outcomes.	Application of Best Practice Guidelines in continuity of care for: <ul style="list-style-type: none"> <li>• Substance use/abuse</li> <li>• Co-occurring medical and substance use/mental health problems.</li> </ul>	Particular populations: female victims of abuse with substance use problems; youth aged 16-17 years old; the elderly; people with complex problems.	<b>Performance Monitoring</b> around access to services.  <b>Health Economics</b>
<b>Integration &amp; Systems Design:</b>			
Improving service access through integration.  Models of system integration and their effect on services and client outcomes.	Need to integrate more mental health and substance use knowledge into primary care.  More inter-professional knowledge sharing and collaboration.  Share promising practices/success stories for integration.	People in rural and remote settings, especially Aboriginal communities.	<b>Data quality,</b> linkage and standards across organizational and geographic boundaries.

### **Moving Forward:**

Stakeholders perceive access to care as an ongoing issue for the mental health and addictions systems and would like to see more research into how best to improve access and on the impact of integrated systems on access. Stakeholders highlighted the need to expand the settings in

which the research is conducted to remote and rural areas and to adapt the research methods to the needs of particular groups (e.g., Aboriginal communities).

## Building Capacity for Research & KTE

Ontario has already done some work when it comes to knowing how to build capacity for collaborative research and KTE. These have been ongoing areas of interest of the fifteen provincial organizations that supported *creating together* and collectively these organizations possess a great deal of expertise around the conduct of collaborative research and the effective translation of new knowledge. The *creating together* collaboration represents a unique capacity building exercise resulting from the deepening of relationships occurring through participation in the process.

Areas that need to be addressed to build capacity are:

- Data quality and access;
- Creation of research-based linkages between researchers and stakeholders;
- Health human resources and organizational capacity; and,
- Commitment to KTE.

This section draws on work of *creating together* Co-sponsors and Supporters to illustrate some of the innovation currently taking place around the above areas in Ontario.

## Data Quality and Access

Data quality is integral to excellence in research. Some areas identified for quality improvement were:

- Coding practices;
- Outcome measures;
- Availability of standardized/comparable data; and,
- Data linking.

Longitudinal research is hampered by the lack of consistent information across the lifespan. Another example is a CAMH initiative that is focused on improving data quality and exploring links between the provincial Drug & Alcohol Treatment Information System (DATIS) and other data sources such as the Ontario Common Assessment of Need (OCAN) and data sources at the Institute for Clinical Evaluative Sciences (ICES). Making data more accessible and putting it into user-friendly formats would support stakeholder interest and involvement in research together with developing more effective means of putting research results into practice. The *creating together* findings are supported by the results of the recent ICES Symposium where ‘data quality, validation and linkage’ was named as the top priority and, similar to *creating together*, the issue of broadening access to data for policy makers, organizations and the public was identified.

## Creating Research-Based Linkages Between Researchers and Stakeholders

The need for improved linkages and connections between stakeholders and researchers was clearly identified. Stakeholders strongly endorsed conducting more Community-Based Research and Participatory Action Research as a means to strengthen their relationships with researchers. The Ontario HIV/AIDS Treatment Network (OHTN), for example, has created a funding stream for this type of research. Another example is the Development and Dissemination fund at CAMH that offers support for collaborations between researchers and community groups to develop and mobilize evidence around strategic priorities for mental health and addictions.

There was a strong sentiment expressed that stakeholders need formal mechanisms by which to connect with researchers, to know what their research areas are and whether they are open to being approached. This calls for a comprehensive, current database, something similar to what OMHAKEN has been working on and one recently made available by ECHO: Improving Women's Health in Ontario. These connections can also be made when organizations act as 'brokers,' pairing researchers and interested stakeholders. For example, Rainbow Health Ontario hosts forums to bring together its network of academic researchers with community-based researchers and community members.

Community networks, such as the OHTN Community Network Committee, are another way for organizations to foster relationships. Its purpose is to build relationships between researchers and community organizations. The Centre for Excellence in Children's Mental Health at Children's Hospital of Eastern Ontario (CHEO) provides a consultation service that assists stakeholders with planning and implementing research, as well as those wishing to conduct their own program evaluation.

## Health Human Resources and Organizational Capacity

*creating together* has learned that provincial stakeholders are keenly interested in participating in research but do not always feel equipped to do so, making research training critical. For stakeholders to learn how to read research and interpret results they need to have access to courses or receive mentoring in research methodology, design and interpretation. There are many activities taking place that support education and training of stakeholders of research. CHEO for example offers webinars on various aspects of research and, for those wishing to conduct their own program evaluation, they provide online learning modules. For persons with lived experience the Mental Health Commission of Canada has created the Consumer, Peer Research Network Development, designed to help persons with lived experience engage in research. To our knowledge nothing like this is being done for persons with lived experience of substance use, except through individual researchers.

It was suggested that organizations build capacity from within by identifying an individual(s) to take on a research related/KTE role and thereby increase research literacy. Organizations can also share resources and ‘pair up’ smaller organizations with larger ones that have a research capacity.

The ICES Mental Health Research Initiative Strategy Symposium (Jan 2010) suggested that improvements to ‘user support’ from research groups were needed, such as having a resource document to refer to, a resource person to answer inquiries, and clarification of research processes.

## Commitment to KTE

KTE is integral to the translation, access and use of research. Stakeholder feedback affirmed that KTE was of the utmost importance and that more, higher quality KTE is needed. Stakeholders are especially concerned with those areas where a robust research base exists but is not widely known due to insufficient KTE (e.g., the social determinants of health). Organizational commitment to KTE is necessary and that commitment will vary according to the type of organization. For example, a granting agency might require KTE plans and an evaluation plan for their effectiveness in research proposals. They might also provide funds for this work. CHEO is a research funder with an explicit and tangible commitment to KTE through its resourcing of a knowledge exchange centre. The Centre’s mandate is to build cross-sectoral KTE capacity and to see that credible evidence is used. Rainbow Health Ontario has two communication coordinators who work to translate research into plain language materials, and following that, they sponsor dissemination campaigns to get the word out. Two other examples of research funding organizations with KTE mandates are Echo: Improving Women’s Health in Ontario and the Ontario Problem Gambling Research Centre. The lead sponsor of *creating together*, OMHAKEN (coordinated through CAMH) while not a funder, is closely tied with researchers from around the province to support KTE efforts. In addition to increasing the commitment to KTE, there is a need to continually evaluate KTE efforts to understand the impacts and how to target these resources appropriately.

## Considerations for Funders & Researchers: “Organizing to do the work”

Through the process of conducting the *creating together* stakeholder surveys a great deal has been heard about the need to conduct research and KTE that is highly relevant to funders and researchers. Stakeholders wish to see research done in ways that involve them. They see themselves as active participants in research and KTE and they value models like Community-Based Research, Participatory Action Research and qualitative research. Persons with lived experience and family members believe that they have important contributions to make to research, whether it is in defining questions, conducting research or interpreting results. This view is shared by the other stakeholder groups.

Stakeholders were clear that research with longer trajectories and that studied people through significant transitions and over the lifespan would inform their work in new and important ways. Emerging opportunities in the province will include the Ontario Common Assessment of Need which will generate a longitudinal database documenting assessment experiences with community mental health programs.

The use of mechanisms and strategies for pairing researchers with communities are considered essential to fostering collaborative research.

*creating together* learned that stakeholders want KTE to be done differently too, where, for example, funders wear two hats and participate as advisory committee members for research projects and where KTE planning is embedded in the research. In situations where knowledge exists but has not been adequately translated, steps need to be taken to disseminate the knowledge to concerned stakeholders, as well as to the interested public. This report has identified some of these areas providing some direction for the allocation of KTE funds and/or syntheses.

## Tailoring the Process to Further Understand Research Priorities: An LGBT Consultation

One limitation to the *creating together* approach is that it focused on consensus of priorities across the continuum of stakeholders of mental health and addictions in the province. The design does not allow for an in-depth exploration of research and KTE needs that may be specific to particular communities. Rainbow Health Ontario is a co-sponsor of *creating together* and was particularly interested in ensuring that people identifying as Lesbian, Gay, Bisexual and/or Transgender were represented in the process generally, but also interested in exploring the specific research needs of their communities. To accomplish this, *creating together* and Rainbow Health Ontario partnered to offer an in-person consultation on the research and KTE needs of LGBT communities. The session was held on September 13, 2010 in Toronto. This section does not go into detail of the findings of that consultation (LGBT consultation report is available at [www.creatingtogether.net](http://www.creatingtogether.net)). Instead, it focuses on the process and lessons learned that we gathered from the process for those interested in repeating the process for a particular group of mental health and addictions stakeholders.

Since this is the first time this has been offered, the planning committee did not know what to expect in terms of interest and attendance. Rainbow Health Ontario sent a communication about the purpose and details of the consultation to LGBT friendly organizations and via LGBT focused listservs. We were surprised at the overwhelming interest in participating and the half-day consultation session filled up very quickly and a long waiting list was generated. This speaks to the interest from LGBT communities in mental health and addictions and also the credibility of the organization sending the invitation. The format of the consultation was similar to that of the broader *creating together* in-person consultation session where we presented draft themes and topics based on a review of recent documents and noting reference to research and KTE needs. In hindsight, it may have been helpful to tailor or include more LGBT-specific background material, although the feedback from participants was quite positive and

overall, there was a remarkable consistency in the priorities identified at this consultation and the overarching priorities. The biggest difference we noted in the priorities was the level of specificity and detail that this added consultation provided. For example, to understand the impacts of mental health related stigma and discrimination in LGBT communities, it is critical to understand that LGBT people with mental illness are dually stigmatized by both perceptions about their sexual orientation and/or gender identity as well as by mental health or addictions issues. Addressing stigma entails both supporting people on an individual level to cope with mental health challenges as well as addressing systemic forms of oppression. For those who might be interested in gaining a more in-depth understanding of research and KTE needs, holding a more focused consultation is certainly a good first step.

## What Comes Next

The results of the consultations will be used by researcher funders and other stakeholder organizations, to guide decisions about investments in these priority research domains and KTE in Ontario. The results should encourage researchers and others to move forward in a collaborative fashion. They also identify areas that might require additional new or reallocated resources to address the need for new knowledge and to fill knowledge to action gaps. The research agenda can be used to supplement and complement the report from the Minister's Advisory Group by articulating the research needs associated with a transformation of our mental health and addictions systems. After all, the intention of *creating together* is not just to understand what the research needs are of those who touch the mental health and addictions systems, but to act on those needs.

Research, evaluation and KTE are integral parts of a high performing, well-serving system of services and supports for those who encounter mental health, problematic substance use and/or other addiction challenges. If we don't continue to invest in research and KTE in Ontario, we limit our ability to demonstrate the needs of individuals or the impacts our programs and services have on improving outcomes for Ontarians. An evidence-informed system is also one that allows us to target existing funds to services, supports and systems that demonstrate positive outcomes and to identify and address gaps. Now that *creating together* has identified research and KTE needs, the focus shifts to our partner organizations and other leaders in Ontario to address these needs. OMHAKEN will disseminate and communicate this report and address ways in which it can meet some of the KTE needs identified herein. OMHAKEN will also follow-up with the partners and other stakeholders over the coming year to see how the report has been used, and investigate new opportunities to weave the findings into future research granting and KTE initiatives. It is our hope that Ontario will undertake a similar research needs assessment in 2-3 years to respond to the shifting needs and priorities of the system.

## IV How We Got Here

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### Phase I Planning and Development

Planning and development for *creating together* encompassed four steps. The first involved reviewing collaborative research agenda setting activities in other jurisdictions. The second involved scanning a large number of recent consultation documents produced in Ontario for the development of a provincial 10-year mental health and addictions strategy for mention of research or KTE needs. This process resulted in a draft master theme and topic list reflective of provincial research and KTE needs that could be used for the stakeholder consultations. Using what was found from the first two steps, the Coordinating Centre created a consultation process and structure that was tailored to the particular goals and objectives of *creating together*. Finally, *creating together* garnered support by inviting provincial organizations to join as Co-sponsors, Supporters and/or Expert Advisory Panel members.

#### Step 1 – Jurisdictional Review

Collaborative priority setting for research is recognized as an integral part of healthcare systems in many jurisdictions. These examples offered guidance to *creating together* on how to involve stakeholders in setting research agendas. The Coordinating Centre conducted an in-depth review of similar exercises and these included:

- England (1999-2000) by National Health Service’s Service Delivery & Organization Research and Development Program
- New Zealand (1999-2004) Mental Health Research & Development Strategy by Ministry of Health & Health Research Council
- USA (1996) National Institute for Occupational Health and Safety
- Canada:
  - Listening for Direction, CHSRF (2001, 2004, 2007) by five national organizations
  - Nova Scotia (2002) by Nova Scotia Health Research Foundation
  - British Columbia (2009) by Smith, N., Mitton C., Peacock S., Cornelissen E., MacLead, S. Identifying Research Priorities for Health Care Priority Setting: A Collaborative Effort Between Managers and Researchers. BMC Health Services Research. 9:165.

#### Steps 2 and 3 – Review of Recent Consultation Documents

To assist in identifying current research and KTE needs the Coordinating Centre reviewed documents developed as background for the 10-year Mental Health and Addictions Strategy and the Select Committee’s report (23 + transcripts). In addition, the report from ICES Mental Health & Addictions Research Initiative (2010) was reviewed. The findings were used to develop a Draft Themes and Topics list for the consultations. The list of themes and topics focused on

the mental health and addictions systems, health systems and population health research related topics. Three major themes emerged: Social Determinants of Health; Health Systems/Services Research; and, Research Resources. Within each theme there were a number of related topics, in total thirteen, to guide discussion (see Appendix 5 Draft Themes and Topics List, p.47). The purpose of the list was to help but not limit participants in thinking about research/knowledge needs that could be addressed through further research and/or KTE.

#### **Step 4 – Developing creating together Structure**

The structure developed for *creating together* had four components:

- Coordinating Centre;
- Co-sponsors/Steering Committee: provided guidance, problem solving, and strategic advice;
- Supporters Committee: connected *creating together* to stakeholders and provided strategic advice and support; and,
- Expert Advisory Panel: assisted in synthesizing and interpreting the findings and was comprised of researchers, other experts.

(See Appendices 2 and 3 for committee members and organizational structure, p. 42-44)

## **Phase II Stakeholder Consultations**

(In-person and Videoconference)

### **Provincial Consultations**

The in-person and videoconference consultations took place between June 17 and July 26, 2010. Four in-person consultations were held in Thunder Bay, Toronto, London, and Ottawa. The two videoconference consultations were focused on Northern and Southern Ontario involving a total of five cities in each region (North – Kenora, North Bay, Sault Ste. Marie, Sudbury, Timmins; South – Cambridge, Hamilton, Kingston, Wellington, Windsor).

### **Stakeholder Participation**

Potential participants were identified through the networks of CAMH Provincial Services staff, local addictions and mental health system leaders, and members of the Expert Advisory Panel, and the Co-sponsors/Supporters Committees. A total of 287 people attended six sessions. Twenty-four of these participants were also breakout group facilitators. Participant representation is shown in Table 1.

**TABLE 1: PARTICIPANTS BY GROUP AND LOCATION\***

Locations/ Participants	Thunder Bay	Northern Ont. videoconference	London	Toronto	Ottawa	Southern Ont. videoconference	Total	%
Persons with lived experience and family members**	2	6	4	2	4	5	23	9.1
Service providers	9	26	16	15	15	18	99	39.4
Allied professions and sectors	4	4	6	2	2	13	31	12.3
Policy makers, system planners, funders and provincial organizations	1	4	5	13	7	8	38	15.1
Researchers	3	5	5	7	10	7	37	14.7
Other	3	2	2	1	2	15	25	9.9
Total	22	47	38	40	40	66	253*	100

\*The number, 253, is based on the evaluation form and is lower than the attendance number as some participants left early and/or did not fill out the form.

\*\*In future phases, persons with lived experience and family members were separated into two groups so we could better understand their distinct needs and experiences

### Consultation Process

The in-person consultations used a structured process involving breakout groups, facilitators and recorders. A modified process was used for the videoconference consultations suitable to that medium. Participants were asked by the facilitators to discuss the Draft Themes and Topics List and to identify any new research needs and KTE needs. The purpose of the list was to help but not limit participants in thinking about research/knowledge needs that could be addressed through further research and/or KTE.

After reporting back, the facilitators took the feedback from the groups and created a new elaborated version of the Draft Themes and Topics List. Participants were then asked to select their top five priority research topics.

Draft site reports were prepared and circulated to the participants for validation purposes. They were then revised and finalized. The six site reports were consolidated to become the ‘*creating together* Integrated Report’. The purpose of the Integrated Report was to provide the Expert Advisory Panel with a summary of the results from the consultations that would enable them to advise on Phase III, the creation of the online survey.

## Consultation Results

Generally, the consultations were very well received. They had excellent attendance and good representation from all stakeholder groups. Participation rates were high resulting in a high volume of input. Service providers were the largest group of attendees. The numbers for persons with lived experience and family members and researchers were lower than anticipated. There was good representation from allied professions and sectors.

The themes and topics areas were generally accepted. It was suggested that Health Promotion and Prevention be classified as a theme rather than a topic under Health Systems/Services Research. Formal and informal feedback from participants indicated their continuing interest in *creating together*. The number of research topics expanded from thirteen to twenty-six through the consultations. New topics generated in the consultations included physical and natural environment; rural and low density communities and planning for the social determinants of health. For a complete list of new topics see Appendix 6 Revised Draft Themes and Topics List, p.48.

## Priority Topics

Nine topics emerged as clear priorities (see Table 2 below). Beyond that there was a large drop off in ratings. Participants specified a range of vulnerable populations: persons with acquired brain injury, fetal alcohol syndrome and Alzheimer's Disease; persons with developmental delay; transient populations; persons with opiate use and mental health problems; individuals with trauma history; seniors/aging population; Francophone population; Aboriginal communities; immigrant/ethnic/refugee communities; Lesbian, Gay, Bisexual and Transgender (LGBT) communities; families, children and youth; men.

**TABLE 2: PHASE II TOP NINE PRIORITY TOPICS**

Top 9 Priority Topics Identified	#/195 votes	%
1. Vulnerable Populations	114	58.5
2. Capacity Building	82	42.1
3. Risk & Resilience	80	41.0
4. Continuity of Care	79	40.5
5. Stigma & Discrimination	73	37.4
6. Program Evaluation	71	36.4
7. Performance Monitoring	67	34.4
8. Knowledge Transfer & Exchange (KTE)	64	32.8
9. Integration	63	32.3

The excellent qualitative data generated through the consultations provided guidance for the selection of sub-topics for the online survey, Phase III. For example, for the topic Capacity Building, participants emphasized the need to involve persons with lived experience in research

and the need for service providers to have better access to data and data analysis. Similarly for the topic Risk and Resilience, they stressed the importance of having better understanding of what contributes to resilience, how resilience is affected by transitions and how the social determinants of health play into it. There was a strong sense that more research into stigma and discrimination, driven by persons with lived experience, was needed and that healthcare professionals and some systems, such as criminal justice, were demonstrating high degrees of both stigma and discrimination toward people with mental health issues and people with current substance use experience. Similarly for the other topics, the qualitative data provided clear direction for Phase III.

Two KTE areas garnered significant attention: the difficulty stakeholders have in accessing and understanding research; and, the lack of application of research to policy. Participants also offered useful suggestions for improved KTE methods and tools.

### ***Priorities By Stakeholder Group***

Priorities were also broken down by stakeholder group (Table 3, p. 29). There was a high degree of consistency for priorities identified across the stakeholder groups.

### **Phase II Summary Findings**

1. Participants stated they want to be engaged in all areas of research, including conducting their own research. There was a strong and repeated emphasis on the importance of increased involvement of persons with lived experience in research.
2. Vulnerable populations are being seen by mental health and addictions service providers and are of major concern to them. These individuals are often characterized by multiple, co-occurring, complex problems.
3. The social determinants of health are of vital interest and there is a strong expressed interest in using research to demonstrate to policy makers their positive impact on mental health and problematic drug use (e.g., cost effectiveness of housing, employment and the other determinants). This likely would have been selected as a priority topic had it been listed as a topic rather than as a theme.
4. Participants expressed high interest in knowing more about lifespan/transitional changes and challenges. This interest spans the continuum of interventions from health promotion to service delivery.
5. System organization/design/integration and researching the effects of different 'system designs' received broad support from participants.
6. Participants would like to see more research into comparative analyses of different program models and their effectiveness.
7. Participants would like to know more about how to effect practice and policy change.
8. Participants offered detailed suggestions for improving methods for knowledge translation and exchange.
9. Overall, participants stated they want to see positive change in policy for mental health and addictions services and systems. They recommend placing greater emphasis on the application of research findings, (e.g., 'research to policy') and on the provision of strategic advice to increase their ability to influence policy makers.

**TABLE 3: PHASE II STAKEHOLDER PRIORITIES  
IN-PERSON & VIDEOCONFERENCE CONSULTATIONS**

Stakeholder Priorities In-person/Videoconference Consultations						
Stakeholder Group	1st Priority	2nd Priority	3rd Priority	4th Priority	5th Priority	6th Priority
Persons with Lived Experience & Family (N = 15)	Risk & Resilience (9)	Stigma & Discrimination (8)	Vulnerable Populations (6)	Continuity of Care (6)	Health Promotion & Prevention (6)	Capacity Building (6)
Mental Health & Addictions Service Providers (N = 77)	Vulnerable Populations (45)	Capacity Building (34)	Continuity of Care (30)	Integration (28)	Stigma & Discrimination (27)	Knowledge Transfer & Exchange (25) Performance Monitoring (25)
Allied Professions & Sectors (N = 15)	Vulnerable Populations (11)	Risk & Resilience (8)	Stigma & Discrimination (8)	Continuity of Care (8)	Integration (8)	Knowledge Transfer & Exchange (7)
		These priorities are tied				
Policy Makers, Systems Planners, Provincial Organizations (N = 35)	Vulnerable Populations (22)	Data Quality & Analysis (18)	Continuity of Care (16)	Program Evaluation (15)	Performance Monitoring (14)	Knowledge Transfer & Exchange (14)
Researchers (N = 32)	Capacity Building (18)	Vulnerable Populations (17)	Program Evaluation (15)	Performance Monitoring (13)	Continuity of Care (13)	Data Quality & Analysis (13)
Other (N = 21)	Risk & Resilience (17)	Vulnerable Populations (15)	Stigma & Discrimination (13)	Integration (10)	Program Evaluation (10)	Health Human Resources (8)

## Phase III Online Survey Stakeholder Consultation

### Background To Online Survey

The Phase II *creating together* Integrated Report was the starting point for the Expert Advisory Panel to consider the form and content of the survey. Committee members offered advice on how to structure themes and topics from the revised Draft Themes and Topics List, as well they provided specific suggestions for improving the survey.

For the online survey the themes from the original Draft Themes and Topics List were eliminated leaving sixteen topics with a set of related sub-topics. The social determinants of health was made into a topic. For clarity, definitions were developed for each topic and similarly for the sub-topics. To ensure that language was accessible and non-stigmatizing the survey was reviewed and revised by a plain language expert. The online survey was also available in French.

The committee chose a ranking method where participants were asked to rank order their five top research topics and then, for each priority topic, rank the sub-topics from most to least important. The one exception was vulnerable populations where respondents were asked to identify the three top vulnerable populations from their perspective. A 'comments' section was attached to each topic to allow respondents to provide additional qualitative feedback. The revised survey was circulated to the *creating together* committees and panel members resulting in further refinements.

The *creating together* team contracted with an online survey specialist to develop the survey, receive results and provide SPSS data tables. Before the launch, the survey was beta tested by *creating together* staff and members of various *creating together* committees. Feedback from reviewers was generally positive, further refinements were made, and a final version was produced (see [www.creatingtogether.net](http://www.creatingtogether.net)). The English language version was posted on October 8, 2010. The French translation was posted on November 2, 2010. Both surveys closed on November 15, 2010.

### Stakeholder Participation

To identify survey respondents, a snowball sampling strategy was used, resulting in the survey being sent to over 1,292 people. Co-sponsors, Supporters, and key stakeholders assisted in identifying potential survey respondents. Co-sponsors and Supporters also circulated the survey to their networks. They provided specific assistance with expanding the recipient list to enhance representation from Aboriginal and Francophone communities, stakeholders in population health/public health, persons with lived experience in mental health and addictions, family members and researchers. In addition, the survey instructions invited respondents to send it to other interested stakeholders resulting in distribution to several listservs and networks.

## Survey Findings

### Profile of Survey Respondents

The overall response to the online survey was robust with 1,431 people responding (1,396 completed the survey in English and 35 in French). In the English version, 79 people indicated they were French, 105 bilingual (English/French) and 24 other; 70 people indicated they were from Aboriginal communities; and 115 indicated that they had participated in the in-person consultations. A breakdown by stakeholder group is reported in Table 4.

**TABLE 4: STAKEHOLDER GROUP (N = 1,431)**

Stakeholder Group	Single Identification	Any Identification / Mention	Total	% of Total Mentions
Persons with Lived Experience	78	188	266	14.52
Family Members	60	176	236	12.88
Service Providers	551	178	729	39.79
Allied Profession and Sectors	220	119	339	18.5
Policy Maker, Service Planner, Funder or Provincial Organizations	81	37	118	6.44
Researchers	86	58	144	7.86
Other	355	-	355	19.38

To read Table 4 - Stakeholder Group, column two 'Single Identification' represents all those who identified within one stakeholder group. The third column 'Any Identification/Mention' represents all those who used the 'Other' category and identified with more than one stakeholder perspective (e.g., clinician AND researcher, persons with lived experience AND service provider). The fourth column is the total number of mentions in both 'Single Identification' and 'Any Identification/Mention' category, and the fifth column displays the percentage of the total number of stakeholder identifications for each group.

Phase III succeeded in achieving higher percentages of persons with lived experience and family members, 27% in total compared to 9.1% in Phase II. The large numbers of persons with lived experience and family members who identified as having multiple roles is striking especially when compared with those who identified singularly. Similarly the 'other' category received approximately 20% of the mentions which reflects the 'multiple hats' all stakeholder groups are wearing. Although the number of people identifying as researchers is 144 in total, the percentage of researchers fell in Phase III to 7.86% from 14% in Phase II. This might reflect a proportionately lower percentage of researchers compared to the other stakeholder groups.

Allied professions and sectors increased in percentage from 12% in Phase II to 18.5% in Phase III. They were drawn from a wide range of sectors, including: education, justice, housing, hostels, primary care including family health teams and general practitioners.

### Online Stakeholder Survey Results

Tables 5 and 6 present the six, most highly rated, priority topics in rank weighted order and the top six priority topics by individual stakeholder group. This is followed by a thematic analysis of five of the top six priority topics. For these, all qualitative data were reviewed. Topics with repeated mentions and research areas previously unidentified are reported on. The section ends with a discussion of the sixth priority topic, Vulnerable Populations. The discussion of findings for Vulnerable Populations differs from the others because of the use of an open-ended question that asked respondents to name the top three vulnerable populations.

### Phase III Priority Topics

Participants were asked to choose their top five priority topics for research. The results of this ranking process showed that out of the original list of sixteen topics, six topics were most commonly identified. The other ten topics were identified much less as a top five choice. Table 5 below lists the top six priority topics in rank weighted order from most votes (1) to least (5).

**TABLE 5: PHASE III TOP SIX PRIORITY TOPICS**

Topics	1	2	3	4	5	Total
Social Determinants of Health	1095	828	621	250	99	2893
Risk & Resilience	1070	780	447	304	118	2719
Stigma & Discrimination	835	668	474	254	105	2336
Vulnerable Populations	980	468	315	224	110	2097
Health Promotion & Prevention	690	548	390	268	102	1998
Continuity of Care	580	452	348	338	135	1853

In Phase III, Social Determinants of Health was the number one priority in rank weighted order and was closely followed by Risk and Resilience. There is consensus across Phases II and III around four of the priority topics: Vulnerable Populations, Risk and Resilience, Stigma and Discrimination, and, Continuity of Care.

### Stakeholder Priorities

Table 6 shows the top six priority topics for each stakeholder group.

Of the Phase III top six selected priority topics, four were selected by all six respondent groups: Social Determinants of Health, Risk and Resilience; Vulnerable Populations; and Health Promotion and Prevention. Both persons with lived experience and family members ranked Stigma and Discrimination higher (2nd) than the other groups. Continuity of Care was a priority for all groups except researchers. The only stakeholder group that identified Integration and System Design as a priority was that of policy makers, system planners and provincial organizations.

**TABLE 6: PHASE III PRIORITIES BY STAKEHOLDER GROUP IDENTIFIED THROUGH ON-LINE CONSULTATION**

Stakeholder Group	1st	2nd	3rd	4th	5th	6th
Persons with Lived Experience (N = 78)	Social Determinants of Health (50)	Stigma & Discrimination (49)	Risk & Resilience (48)	Vulnerable Populations (34)	Health Promotion & Prevention (33)	Continuity of Care (32)
Family Members (N = 60)	Continuity of Care (31)	Stigma & Discrimination (30)	Health Promotion & Prevention (30)	Risk & Resilience (29)	Social Determinants of Health (29)	Vulnerable Populations (27)
		These priorities are tied		These priorities are tied		
Mental Health & Addictions Service Providers (N = 551)	Risk & Resilience (335)	Social Determinants of Health (330)	Stigma & Discrimination (285)	Continuity of Care (260)	Vulnerable Populations (252)	Health Promotion & Prevention (250)
Allied Professions & Sectors (N = 220)	Social Determinants of Health (141)	Risk & Resilience (133)	Continuity of Care (111)	Vulnerable Populations (110)	Stigma & Discrimination (100)	Health Promotion & Prevention (92)
Policy Makers, Systems Planners, Provincial Organizations (N = 81)	Social Determinants of Health (49)	Risk & Resilience (34)	Vulnerable Populations (33)	Health Promotion & Prevention (31)	Continuity of Care (30)	Integration & System Design (29)
Researchers (N = 86)	Social Determinants of Health (50)	Vulnerable Populations (44)	Stigma & Discrimination (39)	Risk & Resilience (38)	Program Evaluation (37)	Population-Based Research (35) Health Promotion & Prevention (35)
Other (N = 355)	Risk & Resilience (211)	Social Determinants of Health (207)	Stigma & Discrimination (193)	Health Promotion & Prevention (170)	Continuity of Care (162)	Vulnerable Populations (140)

## A Closer Look At The Priority Topics

### A) Social Determinants of Health

**TABLE 7: SOCIAL DETERMINANTS OF HEALTH SUB-TOPICS  
IN RANK WEIGHTED ORDER**

Social Determinants of Health Sub-topics	Total
Impact(s) of social determinants of health (both positive and negative) on health and well-being.	2311
Research on existing and newly developing models of practice for addressing social determinants of health (e.g., housing case management and cross-sectoral approaches).	2225
Research on how to get policy developers and service providers to attend to social determinants of health.	2131
Research on employment and housing service models to see what is most effective.	1903

The rank ordering of all the sub-topics is quite close with no one sub-topic standing out as being more important than the others. In reviewing the extensive comments for this topic there was a clear perception that in spite of there being a substantial body of research in this area it was not being applied in practice and at policy levels. In particular, respondents want to see the social determinants of health reflected in mental health and addictions policy.

Many respondents wanted more attention paid to the role of social engagement, social networks, caring/uncaring communities in mental health and substance use problems. Similarly, economic status, social class, low income were frequently mentioned. Respondents also drew attention to the importance of spirituality; safe/unsafe neighborhoods; physical health/access to fitness facilities/training; race, gender, sexual orientation, physical disability; and food security.

Some additional research questions/areas related to Social Determinants of Health put forward for discussion were:

- How does public policy influence health and the opportunity for health?
- How does culture strengthen the social determinants of health?
- What is the impact of shortcomings in the social welfare system?
- Research is needed on: the relationship between treatment effectiveness and the social determinants of health; the use of Indigenous knowledge to improve social determinants of health; the impacts of early childhood on family trauma and poverty.

**B) Risk and Resilience**

**TABLE 8: RISK AND RESILIENCE SUB-TOPICS IN RANK WEIGHTED ORDER**

Risk and Resilience Sub-topics	Total
Understanding the factors placing people at risk for mental health and/or substance use/abuse, problem gambling, and/or process addictions (e.g., Internet) problems (e.g., frailty, social isolation, history of trauma and/or violence, risky environments, early drug use and risk prevention).	2842
Building capacity for personal resilience (e.g., impact(s) of: informal supports; family; community; social networking sites on personal resilience).	2775
Building capacity for resilient communities (e.g., how to strengthen communities).	2323
Understanding the nature of resilience.	2249
How social determinants of health affect risk and resilience (e.g., housing, income).	2231

The first two sub-topics stand out as priorities: understanding contributing factors and building capacity for personal resilience. In addition, many communities/groups were identified as being of interest for developing more knowledge around risk and resilience, the majority of which are contained in the list of vulnerable populations identified in the survey (see section IV - F Vulnerable Populations, p. 39).

Many respondents were interested in knowing more about the effect of culture on risk and resilience, and whether some cultures are more resilient than others. Other areas of interest were: how to develop resilience in very young children; how the health system is promoting/not promoting resilience; how to best support parents in building resilience; and, how to make professionals more knowledgeable about resilience building techniques.

Some additional research questions/areas put forward for discussion were:

- Holistic healing methods of Aboriginal communities and their impact on resilience;
- The effects of oppression on risk and resilience;
- Brain mapping for areas controlling addictions and bio-genetic/psychosocial risk factors;
- Relationship between resilience and recovery;
- Understanding the pathways of trauma and their possible impact on resilience;
- Program evaluation for capacity building programs; and,
- The role of informal supports in reinforcing self-destructive behaviour, and its corollary, how peer support builds resilience and reduces risk.

**C) Stigma and Discrimination**

**TABLE 9: STIGMA AND DISCRIMINATION SUB-TOPICS IN RANK WEIGHTED ORDER**

Stigma and Discrimination Sub-topics	Total
Assessing the impact of stigma, labeling, and language on people with mental health/or developing problems with using/abusing substances, gambling, and/or process addiction (e.g., internet) problems across the lifespan.	1963
Reducing stigma: understanding what works in trying to reduce stigma.	1950
The context of stigma and discrimination: may relate to: different conditions (e.g., substance use); different communities; and different systems (e.g., justice, health care, police, employment).	1772
Understanding the components of stigma and discrimination.	1555

The first two sub-topics for stigma and discrimination are very close in ranking and suggest most of the research interest is focused here. Related to the sub-topic ‘understanding the components of stigma and discrimination’, respondents noted that the two are different concepts and that service providers often do not make the distinction. The third sub-topic, the ‘context for stigma and discrimination’ was elaborated on by respondents as follows:

- Different conditions: people with HIV/AIDS and drug/substance users were mentioned frequently; women who are single parents; women who are dealing with Children’s Aid; seniors; and, people with multiple conditions are likely to suffer from multiple stigma;
- Communities: religious; racialized communities – African/Caribbean, East Indian, and Aboriginal communities were specifically mentioned;
- Systems: Medical system, and within that, emergency room workers and doctors were frequently mentioned; universities; service providers; criminal justice system, law enforcement and courts were seen as criminalizing substance users; shelter/housing services; employers; and, the media.

The concepts of self-stigmatization and internalized oppression within different sub-populations and multiple stigmatization were frequently mentioned as problems needing to be more completely understood. Several respondents noted the negative effect of stigma on the ability to access healthcare and community services (e.g., housing and employment).

Respondents offered many solutions for reducing stigma: legislative change; using a ‘social inclusion’ lens; increasing public awareness; attracting people with ‘star power’ to speak out; attending to the most marginalized; providing assistance to immigrant communities; changing language around stigma; providing one-on-one education with clients; and, advocacy.

Some additional research questions/areas put forward for discussion were:

- What is the impact of stigma on employment?
- What is the impact of economic status on systemic barriers?
- How do the social determinants of health affect stigma and discrimination?

**D) Continuity of Care**

**TABLE 10: CONTINUITY OF CARE SUB-TOPICS IN RANK WEIGHTED ORDER**

<b>Continuity of Care Sub-topics</b>	<b>Total</b>
Access to care research studies the differences in access to services due to, e.g., geography, wait lists, funding differences. It also studies the impact of poor/good access on service user recovery/outcomes.	1849
Service provider/program types studies how different service provider roles and practices enable (or do not enable) continuity of care.	1649
Understanding service user pathways into services/supports within and across systems.	1525
Lifespan, life transitions research to better understand the life course of an illness and see how people's needs are expressed differently at different stages of the lifespan.	1467

Access to care was the most highly ranked research need by a large margin. Access to care research focuses on two areas: barriers to access and the impact of poor/good access. Several populations were noted as having particular difficulty with continuity of care due to service gaps: the deaf (need for translators); the elderly/psychogeriatric; youth ages 16-17; and women with substance use problems who are victims of domestic violence. Added detail regarding the barriers to continuity of care was provided: living in rural and/or northern settings, in particular being a member of an Aboriginal communities; people with complex problems and multiple service needs; and, the organization of services into disconnected silos (e.g., mental health and addictions).

Respondents offered many useful suggestions for how to improve continuity of care: structuring health care systems to incorporate continuity of care; helping services to work together more effectively through inter-organizational service agreements; understanding continuity of care from the perspective of persons with lived experience; providing home visits to the elderly; implementing models of care that promote continuity; and, offering central case management.

Some additional research questions/areas put forward for discussion were:

- What are the most effective practices supporting continuity of care?
- More research into continuity of care from the client perspective;
- How do length of service limits (e.g., inpatient treatment) affect long-term service use?
- What are the impacts of ‘first contact’ and thorough assessments on continuity of care?

**E) Health Promotion and Prevention**

**TABLE 11: HEALTH PROMOTION AND PREVENTION SUB-TOPICS IN RANK WEIGHTED ORDER**

Health Promotion and Prevention Sub-topic	Total
Health promotion: how best to intervene at earlier stages in the lifespan, e.g., in the schools and over the course of illness.	1525
Understanding prevention: e.g., research into prevention of mental illness, substance use/abuse, problem gambling, and/or process addictions (e.g., internet) problems.	1234
Evaluations of health promotion and prevention programs to measure the impact of programs to see what works, for whom and where (e.g., cities, rural, remote).	1087

The first topic ‘how best to intervene at earlier stages...’, achieved significantly higher priority than the others, and this echoes a theme that was heard in the in-person and videoconference stakeholder consultations. Several respondents to the online survey reiterated the message that more needs to be done to apply existing knowledge to relevant policy, as one respondent said, ‘that will promote transformative change.’ There was a sense, that the root causes for substance use problems are known but government policies do not reflect the knowledge base.

Related to the sub-topics there was interest in preventing mental illness in people with chronic disease; learning more about what prevention strategies work for at risk youth; and in taking proactive measures for high risk groups (e.g., sex workers, substance users, homeless, and gay/bisexual men).

To enable health promotion, respondents made several suggestions: promote positive parenting; use mental health promotion for seniors; institute family planning and genetic counseling; provide health promotion and prevention programs for immigrant groups; incorporate cultural competency into health promotion; and provide more for Aboriginal communities.

Some additional research areas put forward for discussion were:

- Develop evaluation tools to provide timely health promotion and prevention information;
- Research the intersection between physical and mental health;
- Research crisis prevention techniques;
- Research on what are effective messages for prevention programs;
- Research on the role that good mental health plays in preventing other issues; and,
- More research for and with Aboriginal communities.

### F) Vulnerable Populations

Vulnerable Populations was ranked overall as the fourth priority topic. Table 12 below shows the top eleven vulnerable populations from the online survey in rank order from most mentioned to least. Participants were asked to include their top three vulnerable populations in rank order.

**TABLE 12: VULNERABLE POPULATIONS IN RANK WEIGHTED ORDER**

Vulnerable Populations	1	2	3	Total
Low Income	327	190	99	616
Children/Youth	249	166	51	466
Older Adults/Seniors	225	104	47	376
LGBT	204	114	33	351
Women	141	102	68	311
Co-morbid/Concurrent Disorders	123	98	40	261
Homeless	87	52	53	192
Aboriginal Communities	102	54	28	184
Substance-Use Problems	78	58	39	175
Ethno-Cultural/Immigrant/Refugee	57	74	41	172
Mental Health Problems	72	68	22	162

Of the top eleven, low income received the highest weighting. Problems identified for children and youth encompassed mental health, substance use, being in care of CAS, being in unstable home environments, and being victims of abuse. Older adults/seniors were noted as having problems with dementia, mental illness, and prescription drugs. Women as the broad category, includes women who may be pregnant, sex trade workers, and/or have problems with substance use. Co-morbid disorders include people with concurrent disorders (defined as co-occurring mental health and addictions problems); dual diagnosis; people with co-occurring mental health and physical health problems; FASD and other conditions. Mental health and substance-use problems are separated because they are not necessarily concurrent and that reflects how respondents interpreted this question. There were no recorded examples of either problem gambling and/or process addictions. Substance use problems span the range of illicit drug use, injection drug use, cocaine, alcohol, and prescription drugs. Most mental health problems were related to serious/severe conditions and schizophrenia was the most frequently mentioned diagnosis. The ethno-cultural/immigrant/refugee group identified immigrants with mental health problems, those who were from developing countries, and who were recently arrived or non-status as being most at risk.

## Summary of Findings - Phases II & III

While respondents were asked specifically to identify any other research needs pertaining to a selected priority topic, respondents tended to use the 'comments' section as a spot to provide additional information related to the topics and sub-topics. Respondents offered advice on how best to improve continuity of care, health promotion efforts, and, how to build resilience. They identified many pertinent issues associated with stigma and discrimination and identified high risk groups that need to be targeted.

Respondents provided broad-based support for greater application and implementation of existing research, particularly at the policy level. Associated with this was their expressed interest in knowing more about how to effect change at the policy level. Respondents also offered numerous fresh suggestions for further research for each of the top six priority topics. In-depth findings from Phase II and Phase III are available as supplemental reports on the *creating together* website.

Areas that were strongly endorsed by participants and respondents in both consultation phases were the importance of: translating research into practice and policy; having access to high quality research; and, needing policy congruent research that is more closely aligned with the needs of stakeholders. In Phase II there was also a great deal of support for:

- Stakeholder participation in research;
- Stakeholder access to data;
- Stakeholder directed research;
- Involvement of persons with lived experience in research; and,
- Peer and family support programs.

These areas did not stand out to the same degree in Phase III. The Phase III qualitative data was less explicit than that of Phase II, making some of it difficult to use. Overall, a great deal of interest for this process was expressed as evidenced by the exceptional response rate to the online survey and the high volume of feedback. There was good confirmation from the online survey of the in-person and videoconference consultation findings.

# Appendices

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## APPENDIX 1      **List of Co-sponsors and Supporters**

The following Co-sponsors and Supporters are partnering with OMHAKEN on *creating together*.

### *Co-sponsors/Steering Committee*

(Co-sponsors have agreed to use the results of the process in some way to influence their own research activities):

- Centre for Addiction and Mental Health
- Institute for Clinical Evaluative Sciences
- Ministry of Health and Long-Term Care
- Ontario HIV Treatment Network
- Rainbow Health Ontario
- Schizophrenia Society of Ontario
- Seniors Health Research Transfer Network Collaborative

### *Supporters*

(Supporters are organizations that support the *creating together* process in various ways):

- Addictions Ontario
- Canadian Mental Health Association, Ontario
- Echo: Improving Women's Health in Ontario
- Ontario Common Assessment of Need
- Ontario Federation of Community Mental Health and Addictions Programs
- Ontario Mental Health Foundation
- Ontario Peer Development Initiative
- Provincial Centre of Excellence for Child and Youth Mental Health at the Children's Hospital of Eastern Ontario

## APPENDIX 2 List of Committee Members

### Co-sponsors/Steering Committee:

Charles Shamesh Nico Baker	Ontario HIV Treatment Network
Deborah VanOosten Caroline Lonsdale	Ministry of Health and Long-Term Care
Deirdre Luesby Ken LeClair Robin Hurst Saskia Sivananthan	Seniors Health Research Transfer Network Collaborative
Jennifer Bennie Paul Kurdyak	Institute for Clinical Evaluative Sciences
Loralee Gillis	Rainbow Health Ontario
Michelle Gold Scott Mitchell	Canadian Mental Health Association, Ontario
Raymond Cheng	Ontario Peer Development Initiative
Robert Moore	Centre for Addiction and Mental Health
Vani Jain	Schizophrenia Society of Ontario

### Supporters:

Alex Greer	Ontario Mental Health Foundation
David Kelly	Ontario Federation of Community Mental Health and Addictions Programs
David Smith	Ontario Common Assessment of Need
Deb Sherman Raymond Cheng	Ontario Peer Development Initiative
Ian Manion Mylene Dault	Provincial Centre of Excellence for Child and Youth Mental Health
Janis Cramp	Addictions Ontario
Jessica Kwik	Canadian Mental Health Association, Ontario
Leigh Hayden Shelly Cleverly	Echo: Improving Women’s Health in Ontario

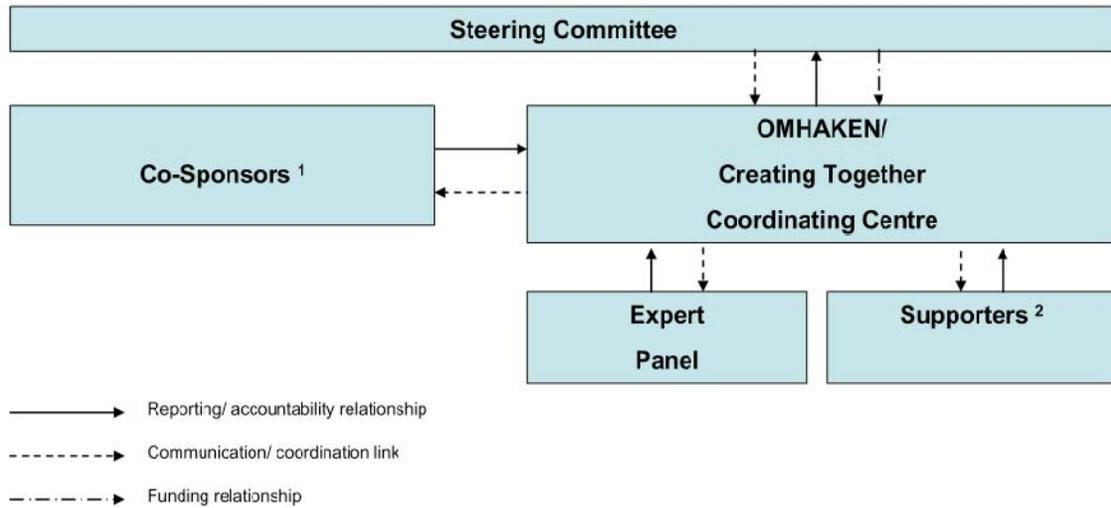
**Expert Advisory Panel:**

Nimira Lalani Rick Blickstead	Wellesley Institute
Brian Rush Carol Strike Lori Ross Nigel Turner Paula Goering (Chair)	Centre for addiction and Mental Health
Bruce Minore	Centre for Rural and Northern Health Research
Caroline Lonsdale Deborah VanOosten Chris Higgins	Ministry of Health and Long-Term Care
Charles Shamesh Sean Rourke	Ontario HIV Treatment Network
Geoff Nelson	Wilfred Laurier University
Kate Pautler Susan Marshall	Ontario Common Assessment of Need
Leigh Hayden	Echo: Improving Women’s Health in Ontario
Lindsey George	McMaster University
Michelle Gold	Canadian Mental Health Association - Ontario
Raymond Cheng	Ontario Peer Development Initiative
Terry Krupa	Queen’s University
Tim Aubry	University of Ottawa
Vani Jain	Schizophrenia Society of Ontario
Walter Cavalieri	Canadian Harm Reduction Network

# APPENDIX 3

# creating together Structure

Creating Together Committee Structure



1. Co-Sponsors: Centre for Addiction and Mental Health \*, Institute for Clinical Evaluative Sciences, Ministry of Health and Long-Term Care \*, Ontario HIV/AIDS Treatment Network, Rainbow Health Ontario \*, Schizophrenia Society of Ontario, Seniors Health Research Transfer Network Collaborative

Note: Organizations marked with an \* are making a direct financial contribution to Creating Together.

2. Supporters: Addictions Ontario, Canadian Mental Health Association Ontario, Echo: Improving Women's Health in Ontario, Ontario Common Assessment of Need, Ontario Federation of Community Mental Health and Adciction Programs, Ontario Mental Health Foundation, Ontario Peer Development Initiative, Provincial Centre of Excellence for Child and Youth Mental Health at CHEO

## APPENDIX 4                      References

### Background scanning materials:

#### *MAG Theme Papers:*

Materials supporting the development of the MAG's paper - Respect, Recovery, Resilience: Recommendations for Ontario's Mental Health and Addictions Strategy (2010) (full reference is listed below)

#### *Other Theme Papers:*

CMHA, Ontario: Mental Health and Addictions Issues for Older Adults: Opening the Doors to a Strategic Framework (2010)

Employment and Education for People with Mental Illness: A Discussion Paper (2010)

Improving Mental Health Services for Immigrant, Refugee, Ethno-Cultural and Racialized Groups - Issues and Options for Service Improvement (2009)

#### *Documents provided by MOHLTC:*

Mental Health & Addictions: The Ontario Landscape - Executive Summary to Landscape Report (2009)

Key System Design Elements A Survey of Ontario's Local Health Integration Networks Regarding Mental Health, Addictions and Problem Gambling Services (2009)

#### *Literature reviews/ provided by MOHLTC:*

A Rapid Literature Review on National Mental Health and Addiction Workforce Strategies (2009)

Literature Review Prepared for the Ministry of Health and Long-Term Care Healthy Communities Theme Group - Promoting Mental Health and Well-Being (2009)

Literature Review Prepared for the Ministry of Health and Long-Term Care Early Identification and Intervention Theme Group - Early Identification and Intervention of Mild to Moderate Mental Illnesses in Primary Health Care (2009)

Engaging People with Lived Experience for Better Health Outcomes: Collaboration with Mental Health and Addiction Service Users in Research, Policy, and Treatment - A Review of Literature Pertaining to Peer / Consumer Involvement in Mental Health and Addiction Policy (2009)

A Rapid Literature Review on Inter-professional Collaborative Mental Health Care (2009)

A Rapid Literature Review on the Social Determinants of Health and Mental Health and Addictions (2009)

#### *Best Practice / Prepared by HSRCU:*

A Rapid Literature Review of Best Practices in Mental Health Service System Policy and Programs Phase I (2009)

Best Practices in the Delivery of Services and Supports to People with Substance Use/Gambling-related Problems: A Review of the Literature (2009)

Phase II Report: The Design of an Evidence-Informed Integrated Mental Health, Substance Use and Problem Gambling Service System for Ontario (2009)

### **ICES**

ICES Mental Health Research Initiative Strategy Symposium – Workshop Summary – January 25, 2010

### **CAMH/ Select Committee on Mental Health and Addictions**

CAMH summaries of Select Committee Hearings (2009)

Select Committee on Mental Health and Addictions – Interim Report – March 2010

Select Committee on Mental Health and Addictions – Exhibit List (2010)

Transcripts from Select Committee on Mental Health and Addictions (2009)

### **Other**

Graham, I., Logan, J., Harrison, M.B., et al. (2006). Lost in Knowledge Translation: Time for a Map? *The Journal of Continuing Education in the Health Professions*, 26:13-24

Minister’s Advisory Group on the 10-Year Mental Health and Addictions Strategy (2010).

Respect, Recovery, Resilience: Recommendations for Ontario’s Mental Health and Addictions Strategy. Available at:

[http://www.health.gov.on.ca/en/public/publications/ministry\\_reports/mental\\_health/mentalhealth\\_rep.pdf](http://www.health.gov.on.ca/en/public/publications/ministry_reports/mental_health/mentalhealth_rep.pdf)

## APPENDIX 5 Draft Themes & Topics List

### *Draft Themes and Topics List For Discussion*

#### **I Social Determinants of Health**

These are the social factors, e.g., housing, employment, income and income distribution, that affect health and well being.

- Vulnerable populations may include but is not limited to: Gay/Lesbian/Transgender/Bisexual people, people with HIV/AIDS, Aboriginal communities, Francophones, vulnerable groups of men and women.
- Risk and Resilience: Understanding what places people at risk and what constitutes resilience that enables people to deal with uncertainty, change and risk across the lifespan.
- Stigma and Discrimination: Reducing the barriers to service use and community inclusion.

#### **II Health Systems /Services Research:**

This is research that tells us how services and systems are working, how well matched they are to the needs of people who use them and their abilities to access them.

- Performance Monitoring: The routine collection of information on the system, e.g., number of emergency room visits, length of stay.
- Health Economics: Tells us what the costs and benefits are of services.
- Health Human Resources: The right people in the right place at the right time with the right skills and values.
- Continuity of Care: The journey through the systems and transitioning out of it.
- Integration: The organization of the system, e.g., the absence of silos and creation of organizational linkages.
- Program Evaluation: Learning about how to achieve better outcomes.
- Health Promotion and Prevention: What we need to know to improve health, wellness and to prevent mental health, addictions and/or gambling problems.

#### **III Research Resources**

- Data Quality/Analysis: Accurate, accessible, relevant information for research.
- Knowledge Transfer and Exchange: Conducting research that is relevant, gets to users for action and is informed by user needs.
- Capacity Building: Training and other activities that support research uptake.

## APPENDIX 6                      Revised Draft Themes & Topics List

The following list was generated following the In-person and Videoconference consultations)

### *Theme 1: Social Determinants of Health*

Vulnerable populations  
Risk and resilience  
Stigma and discrimination  
Physical and natural environment\*  
Measurement of outcomes\*  
Policy & Planning of Social determinants of health\*  
Other (social determinants of health)\*

### *Theme 2: Health Systems/Services Research*

Performance monitoring  
Health economics  
Health human resources  
Continuity of care  
Integration  
Program evaluation  
Health promotion and prevention  
Rural/low density communities\*  
System/regional level effectiveness\*  
Models of care/service delivery models\*  
Policy and planning (policy formulation)\*  
Solvent use and harm reduction\*  
Change management\*  
Other\*

### *Theme 3: Research Resources*

Data quality/analysis  
Knowledge transfer and exchange  
Capacity building  
Facilitating change in practice\*  
Other\*

\*Indicates new topics included from in-person/videoconference consultations.

## APPENDIX 7 Phase III Topics

The following list of topics was generated through the online survey:

- **Vulnerable groups of people:** Provides information about the health status and needs of people who may be most likely to experience problems.
- **Population-based research:** Provides guidance about what works to prevent poor health and to promote well-being and flourishing for communities.
- **Risk and resilience:** There are numerous factors which contribute to a person's risk for mental health, substance use/abuse, problem gambling, and/or process addictions (e.g., internet) problems. Other factors give people the ability to deal with uncertainty, change, and risk (resilience).
- **Stigma and Discrimination:** Provides information about stereotypes of and hostility towards certain groups and how these things affect access and use of services.
- **Social Determinants of Health:** understanding the social factors (e.g., housing, employment, income, education, social supports) that affect health and well-being.
- **Health Promotion and Prevention of Disease/Illness:** Tells us what we need to know to improve health and wellness and to prevent mental illness, substance use/abuse, problem gambling, and/or process addictions (e.g., internet) problems.
- **Physical and Natural Environments:** Tells us how the places in which we live may affect our mental health and/or developing problems with using/abusing substances, gambling, and/or process addictions (e.g., internet) problems.
- **Performance Monitoring:** The routine collection of information on the health services system (e.g., number of emergency room visits, length of stay in hospital or community programs).
- **Health Economics:** Tells us about the costs and benefits of services being provided and the costs of illness.
- **Health Human Resources:** Provides guidance to make sure that the right people with the right skills and values are in the right place at the right time.
- **Continuity of Care:** Provides information about whether the system is able to provide service users with the right services at the right times.
- **Integration and System Design:** Tells us how health systems are organized, how they work together and how they are connected to each other.
- **Program Evaluation:** Provides information about what should be done at the program level to achieve better outcomes for service users.
- **Data Needs:** Provides information about how best to gather accurate, accessible, relevant information for research.
- **Knowledge Transfer and Exchange (KT and E):** Tells us how to conduct research that is relevant and how to get it to researcher users in a timely way. It also guides us in how to involve research users in research.
- **Capacity Building:** Provides guidance for planning training and other activities that support the use and application of research.

