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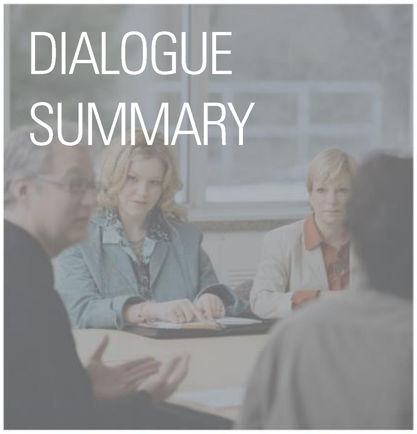

DIALOGUE
SUMMARY

ADVANCING THE DEVELOPMENT OF NATIONAL CHILDHOOD CANCER-CARE STRATEGIES IN LATIN AMERICA

8 JUNE 2015

EVIDENCE >> INSIGHT >> ACTION

Dialogue Summary:
Advancing the Development of National Childhood Cancer-care Strategies in Latin America

8 June 2015

McMaster Health Forum

For concerned citizens and influential thinkers and doers, the McMaster Health Forum strives to be a leading hub for improving health outcomes through collective problem solving. Operating at regional/provincial levels and at national levels, the Forum harnesses information, convenes stakeholders, and prepares action-oriented leaders to meet pressing health issues creatively. The Forum acts as an agent of change by empowering stakeholders to set agendas, take well-considered actions, and communicate the rationale for actions effectively.

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the dialogue summary. The funders reviewed a draft dialogue summary, but the authors had final decision-making authority about what appeared in the dialogue summary.

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Dialogue

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SUMMARY OF THE DIALOGUE

Dialogue participants agreed that the nature of the problem can be understood in relation to the four themes presented in the evidence brief: 1) Latin America faces a heavy (but inconsistently measured) burden of childhood cancer morbidity and mortality; 2) access to childhood cancer care is inconsistent and limited, with significant differences in outcomes within and between countries; 3) there is a need for more coordinated system-wide practices and policies to strengthen childhood cancer control in Latin America as part of broader efforts to improve child health and strengthen health systems; and 4) childhood cancer receives limited attention from policymakers despite its importance for reducing childhood mortality and improving health over the life course. In relation to these dimensions of the problem, participants focused on three overarching themes: 1) limited context-specific and comparative evidence constrains policy and program development; 2) the gap between knowing what policy responses are needed and implementing them; and 3) lack of awareness of childhood cancer as a pressing health-system issue has limited both the scope and effectiveness of collective action at national, regional and international levels.

Deliberations about the three elements of a potentially comprehensive approach to address the problem centred on whether a pan-regional task force to develop and oversee the implementation of national childhood cancer strategies in Latin America is needed, as well as what form it would take and the activities it could perform. While some participants initially questioned whether such a task force would be a worthwhile use of time and resources given the need for country-level action, all participants eventually agreed that there is a need for a pan-regional task force given that it would support collective action toward addressing shared issues (e.g., building cancer registries and enhancing access to diagnosis, medicines and allied treatment) and individual efforts at the national level, which would continue to be the main locus of action. Participants also emphasized that essential components for a pan-regional task force include developing a coherent statement of purpose, clearly articulated foundational values (e.g., focusing on children and families with a corollary emphasis on human rights), and strong governance. Deliberations about the second (developing health-system guidance) and third (building capacity for monitoring and evaluation) elements emphasized their intertwined nature. Most participants viewed them as related components of an iterative process, to be pursued in tandem and to inform one another. Ultimately, participants endorsed the utility of a framework to guide evidence synthesis and data collection, as well as to develop health-system guidance.

Four priorities for action emerged from participants during the deliberations about next steps that could be taken by different constituencies. These included: 1) building advocacy efforts for strengthening national childhood cancer care; 2) generating data and evidence; 3) fostering stakeholder engagement; and 4) building a pan-regional task force. Participants framed these next steps as complementary initiatives that should be pursued in tandem. Specific activities cited as interdependent included: linking all elements of a solution (i.e., task force activities, health-system guidance, monitoring and evaluation) to advocacy strategies; developing a matrix of childhood cancer system development to guide knowledge creation and assist with advocacy efforts; and the need to augment the involvement of key stakeholders in priority next steps, most notably task force planning and execution.

SUMMARIES OF THE FOUR DELIBERATIONS

DELIBERATION ABOUT THE PROBLEM

Dialogue participants generally agreed that the problem can be understood in relation to the four themes articulated in the evidence brief that informed the stakeholder dialogue:

1) Latin America faces a heavy (but inconsistently measured) burden of childhood cancer morbidity and mortality;
2) access to childhood cancer care is inconsistent and limited, with significant differences in outcomes within and between countries in Latin America, as a result of inequities in access to diagnosis and treatment;
3) there is a need for more coordinated system-wide practices and policies to strengthen childhood cancer control in Latin America as part of broader efforts to improve child health and strengthen health systems; and
4) childhood cancer receives limited attention from policymakers despite its importance for reducing childhood mortality and improving health over the life course.

Through in-depth deliberation about these dimensions of the problem, three overarching themes emerged, which together relate to the relationships between evidence, policy and action. Each theme involves the path from evidence to policy, with key limitations identified at points specific to policy development, implementation and advocacy.

Limited context-specific and comparative evidence constrains policy and program development

Participants agreed that variation in resources and infrastructure (e.g., cancer registries) among countries, coupled with a lack of understanding and/or documentation of the specific challenges faced by different countries, limits the ability to know what policies are needed where. A few participants noted that this broad regional state of affairs was compounded by the added complexity of intra-country ethnic diversity; regional inequities in health system governance, financing and delivery capacities; and varying stability and responsiveness of political institutions within and across jurisdictions. Many participants pointed to the lack of cancer registries as a central reason for the lack of context-specific data and evidence. Moreover, several other participants noted that the development of childhood cancer registries are complicated by the fact that implementation requires 'buy-in' from several levels. This includes physicians who need to

Box 1: Background to the stakeholder dialogue

The stakeholder dialogue was convened in order to support a full discussion of relevant considerations (including research evidence) about a high-priority issue in order to inform action. Key features of the dialogue were:

1) it addressed an issue currently being faced in Latin America;
2) it focused on different features of the problem, including (where possible) how it affects particular groups;
3) it focused on three elements of a comprehensive approach (among many) for addressing the policy issue;
4) it was informed by a pre-circulated evidence brief that mobilized both global and local research evidence about the problem, three elements of a comprehensive approach for addressing the problem, and key implementation considerations;
5) it was informed by a discussion about the full range of factors that can inform how to approach the problem and possible options for addressing it;
6) it brought together many parties who would be involved in or affected by future decisions related to the issue;
7) it ensured fair representation among policymakers, stakeholders and researchers;
8) it engaged a facilitator to assist with the deliberations;
9) it allowed for frank, off-the-record deliberations by following the Chatham House rule: "Participants are free to use the information received during the meeting, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed"; and
10) it did not aim for consensus.

We did not aim for consensus given our goal was to instead provide a space where diverging opinions could be shared and discussed, and to identify where synergistic efforts among stakeholders to address the problem might be possible.

Participants' views and experiences and the tacit knowledge they brought to the issues at hand were key inputs to the dialogue. The dialogue was designed to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. The dialogue was also designed to generate action by those who participate in the dialogue, and by those who review the dialogue summary and the video interviews with dialogue participants.

collect and give data to build robust data in registries as well as hospitals collaborating to link data in order to build population-level registries. Other participants noted that while evidence about health-system interventions that address key issues in childhood cancer (e.g., those aimed at reducing diagnostic delays and decreasing abandonment of therapy) is essential for supporting policy and program development, it is limited or focused on contexts that are different than those in Latin America. More generally emphasizing the importance of data and evidence for shaping context-specific policy and program development, one participant shared that there is a need to "know where we stand, to know where we want to walk and the path we will take to get there."

There is a gap between knowing what policy responses are needed and implementing them

Participants from diverse health-system contexts noted that variations in political environments and available resources have constrained opportunities to translate grassroots programs into coordinated governmental policies on childhood cancer care. Some participants highlighted that considerable efforts to develop strategies to address system-level problems have largely not been able to catalyze policy implementation. For example, most agreed with one participant who indicated that while there have been efforts to develop statements and strategies that identify what is needed, there has been far less action on implementing the policies that are ultimately needed to strengthen childhood cancer care.

Several participants pointed to key gaps in knowledge and capacity as important reasons for the lack of policy implementation. In addition to the lack of evidence about health-system interventions that address key issues in childhood cancer noted above, one participant noted that the issue is further complicated by the significant heterogeneity between Latin American countries coupled with a lack of capacity to build understandings of the specific issues in each country, identify the policies that are needed, and to develop country-specific implementation strategies. Another participant similarly highlighted that evaluations of 'what's working' is essential for supporting policy development and implementation, but that this type of work has been neglected. Another participant emphasized that the gap between policy and implementation could be bridged, but "we need opportunities to learn from others' successes". In general, participants highlighted that no single approach to policy implementation is 'best' given important differences between settings that may otherwise seem similar using macro-level classifications (e.g., GDP per person and Gini coefficients). As a result, there is a need for policy responses to be flexible enough to adapt to context-specific realities.

Lack of awareness of childhood cancer as a pressing health-system issue has limited both the scope and effectiveness of collective action at national, regional and international levels

Many participants felt that lack of awareness of childhood cancer as a pressing health-system issue has limited both the scope and effectiveness of collective action at national, regional and international levels. Participants stressed that comprehensive and robust data is needed for effective advocacy, particularly as it relates to building the case for childhood cancer-care policy and programs as conduits to support broader health-system strengthening (i.e. a diagonal health-system intervention). In addition, most felt that the lack of focused and evidence-informed advocacy has constrained collective action, particularly at the national level, in most countries in the region. A number of participants contended that weak advocacy and political engagement from the global health community – in the form of international institutions involved in either child health or cancer control – has compounded barriers to local advocacy and political action on childhood cancer care in many countries across the region. Many perceived this as a missed opportunity to mobilize international political capital and resources to build sustained attention to the issue at national and regional levels, particularly given the tractability of the problem as compared with many other global health issues.

DELIBERATION ABOUT APPROACH ELEMENTS

During the deliberations about the three elements of a potentially comprehensive approach to address the problem, dialogue participants focused on whether the task force described in the first element is needed, as well as what form it would take and the activities it could perform. Deliberations about the second and third elements emphasized their intertwined nature. Specifically, most participants construed them as related components of an iterative process, to be pursued in tandem and to inform one another. Key themes related to each of the three elements are outlined below.

Element 1: Convene a multi-stakeholder, pan-regional task force with national working groups to develop and oversee the implementation of national childhood cancer strategies in Latin America

Most participants were supportive of pursuing this option and emphasized the strong rationale for, and potential benefits of, convening a pan-regional task force. However, some participants initially questioned whether such a task force would prove to be a worthwhile use of time and resources, given the necessity for action at the country level. For example, a few participants asserted that such a task force would not be helpful for addressing the goals of specific countries in a way that is aligned with their values. Specifically, one participant noted that the activities proposed as part of the task force (e.g., identifying a clear picture of the challenges faced across Latin America and engaging in processes to develop priorities as well as meaningful and achievable targets) need to be conducted within countries and in close collaboration with relevant government institutions in order to facilitate implementation of country-specific policy and programs. The same participant emphasized that limited resources need to be used in a way that will achieve the most impact, which they saw as fostering action within their country rather than across countries in the region. Building on this, other participants expressed concerns that a pan-regional task force would result in duplication of existing local and national efforts.

After reflecting on these concerns and further deliberation between participants, all dialogue participants (including those who initially expressed the concerns) ultimately supported the need for a pan-regional task force. The principal reason underlying this support is that participants viewed a task force as being useful if it were focused on addressing shared issues across countries where collective action is needed to support regional and country-level action, and towards building capacity. Specific activities that were identified by participants as being amenable to collective action across the region included:

- supporting existing international efforts to develop population-based cancer registries in Latin American countries;
- enhancing equitable access to medicines, through pan-regional approaches to drug procurement and quality assurance;
- realizing efficiencies in health human resource training;
- fostering collaboration for cross-national policy learning;
- linking and empowering local constituencies engaged in advocacy; and
- facilitating data collection, evidence synthesis and the development of health-system guidance

The above activities were seen as requiring collective action in order to maximize the potential for benefit by all countries in the region, which provided many participants with the explicit and well-founded justification they required for convening a pan-regional task force. Participants also articulated several additional components for a pan-regional task force that were seen as essential for it to have an impact. These included:

- *a coherent statement of purpose*
    - participants justified the need for a task force principally through reference to enhanced opportunities to support policy learning (what can we learn from each other) and political impact (collectively taking action);

- *clearly articulated foundational values*
  - participants emphasized keeping a lens trained on children and their families as the focal point, with additional emphasis on human rights (including explicit reference to legal and political levers connected to the United Nations Convention on the Rights of the Child); and
- *strong governance*
  - participants gave particular emphasis to the need to engage all relevant stakeholders (i.e., policymakers, NGOs, healthcare workers, researchers, and patient/family advocates) in task force constitution, deliberations and outputs.

Element 2: Develop health-system guidance to support the implementation of childhood cancer-care strategies based on national contexts, as well as integration with national cancer-care control programs

Participants initially expressed divergent views on the relative priority that should be accorded to developing health-system guidance. Some questioned whether sufficient data and evidence exists to pursue this as a core element of the solution, while others viewed efforts to develop health-system guidance as a crucial prerequisite to strengthening system capacities for data collection and evidence dissemination. Much of the debate about the relative importance and feasibility of developing health-system guidance turned on different perceptions of the nature and role of evidence in policymaking. Those grounded in and/or committed to scientific conceptions of evidence emphasized the need for robust and comprehensive data to measure disease outcomes and evaluate programs and policies. Participants that expressed this view saw efforts to develop health-system guidance as potentially premature, and instead emphasized the importance of first pursuing the collection of robust and comprehensive data. By contrast, those engaged in advocacy or policy development tended to stress the importance of drawing on the full range of evidence, including colloquial evidence and political context, to inform the development policy initiatives. These participants perceived such domains of evidence as crucial constituent parts of health-system guidance, and outlined that developing guidance would therefore be an important input into policy development. In addition, some participants noted that mobilizing the evidence required to develop health-system guidance would help foster opportunities for comparative policy learning in the region.

While participants initially held divergent views related to the need for health-system guidance, all endorsed the need for more and better-understood data and evidence (including colloquial evidence), and most eventually converged on a positive view of the role for health-system guidance. The convergence of views occurred as the deliberations progressed, and was informed by: 1) more nuanced views about the nature and roles of evidence in policymaking (e.g., because of a recognition of the importance of mobilizing a broad array of evidence and adapting it for use in specific health system and political contexts); and 2) enhanced perceptions of the need for integrated approaches to advancing evidence and policy on childhood cancer care in the region. As a result, most ended up agreeing that health-system guidance that is tailored to local realities and capacities could play an important role in strengthening childhood cancer care in the region. In this regard, many participants came to see health-system guidance as directly linked to the efforts and outputs of a task force, particularly as related to the role of stakeholder engagement and deliberative processes to inform the development of health-system guidance.

Element 3 - Build capacity for monitoring and evaluation to support efforts to continuously refine the implementation of national childhood cancer-care strategies

Many dialogue participants spoke to the need to approach elements 2 and 3 as twin components of an integrated process of knowledge synthesis and evaluation, with two major functions:

1. *knowledge synthesis*: the structured collection, organization and interpretation of evidence (scientific and colloquial) on childhood cancer policies and systems across the region; and

2. *monitoring and evaluation*: the iterative evaluation of child cancer policies and programs based on pre-defined endpoints, which would in turn further strengthen the available evidence base for developing and refining health-system guidance.

In this context, participants identified four principal benefits of a commitment to advancing an agenda that integrates efforts to develop health-system guidance and build capacity for monitoring and evaluation:

1. developing a framework for gathering, documenting and making sense of data on health-system approaches and challenges relevant to childhood cancer in the region;
2. fostering attention to level-sensitive, and ultimately context-specific, policy guidance;
3. leveraging evidence for political advocacy; and
4. establishing Latin America as a leader in health systems and policy knowledge on childhood cancer.

Ultimately, participants pointed to the need for a framework that integrates concepts from elements 2 and 3 to guide the development, evaluation and refinement of childhood cancer-care systems and policies that are sensitive to the varying levels of program development and system capacity in the region. Many felt this would optimally take the form of a conceptual model distinguishing tiers of development, by which level-appropriate policies and system structures could be recommended, while still recognizing that alternative approaches might be appropriate within a single tier. To inform the development of such a framework, participants emphasized the need for an inventory of country-level strengths and limitations in the domains of childhood cancer system governance, financing and delivery. It was felt that, combined, this conceptual and practical knowledge could assist in the prioritization of strategies at the national level. Most participants felt that any such framework, and allied health-system guidance, should undergo iterative refinement based on evidence from monitoring and evaluation of policies and programs across the region.

Considering the full array of options

As noted above, many participants affirmed that the discrete elements proposed in the evidence brief, and entertained at length in the dialogue, represented component parts of a comprehensive strategy, to be pursued together. The creation and convening of a pan-regional task force was seen to be contingent on, and enriched by, a framework for knowledge synthesis, which in turn would depend on and enhance systems for data collection, program monitoring and system evaluation. Relatedly, a number of participants cautioned that subsequent recommendations and actions take care not to duplicate existing initiatives and resources. In this context, participants enumerated existing areas of strength in the region, and identified domains where duplication of efforts should be avoided. Principal among them were: the implementation of population-based cancer registries, under the leadership of the International Agency for Research on Cancer (IARC); and the development of clinical guidelines and institution-specific models of care, as led by cooperative clinical groups such as the Asociación de Hemato-Oncología Pediátrica de Centro América (AHOPCA) and the International Society of Pediatric Oncology (SIOP).

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

A number of important implementation considerations were addressed by participants. The need for sensitivity to country context regarding policy design and implementation was an enduring theme throughout the dialogue. Relatedly, participants spoke to the potential for comparative analysis to contribute to cross-national policy lessons and advocacy strategies, and to the corollary value of venues and platforms to facilitate such analysis, including a pan-regional task force and a framework for health-system guidance. A few stakeholders counselled that priority actions incorporate consideration of barriers related to institutional memory, including the impact of potential changes in governmental buy-in as institutional make-up evolves over time (i.e., through changing stakeholders and/or political contexts).

Participants also discussed a number of important barriers to advancing national childhood cancer strategies in Latin America. International engagement was a central theme in this regard. Participants cited the manifold and oft-conflicting priorities of key institutional actors involved in global health governance and advocacy, and expressed concern that childhood cancer is situated in a gap between institutional remits, which undercuts its political interest. Specifically, many felt that neither the global child health community nor the global cancer community had taken sufficient ownership of the childhood cancer issue to date. A number of participants also considered the difficulties of securing national commitment to addressing childhood cancer in the context of competing health system priorities. By way of response to perceived inattention at both national and international levels, many underscored the importance of effective issue framing – specifically, the potential of childhood cancer plans to: 1) generate impressive, real-world gains in child health in the context of a mounting epidemiologic transition in low- and middle-income countries; 2) serve as a potent 'diagonal' approach to health-system strengthening, with a view to greater health equity in the region; and 3) translate health policies into powerful political stories of lives saved.

Participants also highlighted windows of opportunity to advance certain goals that would benefit from pan-regional approaches to stakeholder engagement and health-system guidance. These included:

1. engaging the Pan-American Health Organization (PAHO) on leveraging its Strategic Fund to enhance access to quality childhood cancer medicines;
2. creating supra-national strategies to maximize efficiencies in health human resource training related to childhood cancer care, in light of World Health Organization attention to related issues;
3. achieving regional consensus on pediatric age limits to clarify childhood cancer system remit; and
4. buttressing advocacy on the human rights dimensions of childhood cancer burden and care, in the context of the United Nations Convention of the Rights of the Child (UNCRC) and human rights framing in the global non-communicable diseases (NCD) agenda.

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

Four priorities for action emerged from participants during the deliberations about next steps that could be taken by different constituencies. They are: 1) building advocacy efforts for strengthening national childhood cancer care; 2) generating data and evidence; 3) fostering stakeholder engagement; and 4) building a pan-regional task force. Participants framed these next steps as complementary initiatives that should be pursued in tandem. Specific activities within these four areas that were cited as being interdependent included: linking all elements of a solution (i.e., task force activities, health-system guidance, monitoring and evaluation) to advocacy strategies; developing a matrix of childhood cancer system development to guide knowledge creation and assist with advocacy efforts; and the need to augment the involvement of key stakeholders in priority next steps, most notably task force planning and execution.

Building advocacy efforts for strengthening national childhood cancer care

Participants emphasized a number of actions and priorities related to advocacy for strengthening national childhood cancer care. They spoke to the importance of identifying priorities and opportunities for targeted advocacy efforts at national and international levels, and reached broad agreement on the need to support evidence-informed advocacy. Many also highlighted the benefits of linking each of the other elements of a solution (i.e., task force activities, health-system guidance development, and monitoring and evaluation) to advocacy strategies. Those with experience in advocacy efforts emphasized the power of focusing advocacy messages on strategies related to 'heart, pocket, and mind', as well as the related importance of incorporating patient stories, economic reasoning, and robust evidence into advocacy strategies. Finally, most participants agreed on the political value of incorporating a country-specific focus into advocacy efforts, to identify and capitalize on local advocacy opportunities and abilities.

Generating data and evidence

Based on the deliberations about evidence described above, participants endorsed priorities for actions related to evidence generation and use. There was broad consensus on the importance of developing a framework to identify the types and sources of information necessary for health-system guidance. Emphasis was placed on the value of a level-specific matrix of system development, to both guide further knowledge creation and evaluation, and to assist with advocacy efforts. Participants also saw the need to map existing childhood cancer-care strategies and policies in the region. In this context, emphasis was placed on: 1) the value of collecting information on solutions as well as problems; and 2) the need to generate a full picture of available information by engaging appropriate country stakeholders in its collection to prevent the duplication of efforts. A number of participants also endorsed the need to collate existing evaluative evidence on childhood cancer policies and systems in the region, with specific prioritization of economic evaluation and evidence on disease burden (in particular, through enhanced childhood cancer registration). Finally, virtually all participants saw value in identifying persistent gaps in knowledge and evidence as a means to advancing the development of evidence-informed childhood cancer policies in the region.

Fostering stakeholder engagement

The crucial importance of engaging the full spectrum of relevant stakeholders arose at multiple points throughout the dialogue, and was reiterated in deliberations about next steps to be taken. Participants highlighted the need to identify and involve legitimate institutions and stakeholders to convene a pan-regional task force, optimize buy-in from national governments, and capitalize on existing international and national advocacy capacity and networks. Many cited the importance of developing the conceptual and evidentiary products prioritized above (i.e., a framework for health-system guidance and a regional inventory of childhood cancer systems and policies) prior to the formal planning of broader stakeholder outreach.

Building a pan-regional task force

Finally, practical considerations related to advancing plans for a pan-regional task force were discussed. Priority actions identified in this domain included: 1) the need to develop terms of reference as a requisite first step for further task force planning; 2) the involvement of country representatives who participated in the stakeholder dialogue as leaders in the assembly of country teams for task force participation (with initial representation from the six countries represented at this dialogue); 3) framing of the task force as a forum to develop and refine a blueprint for level-appropriate cancer-care strategies in Latin America; and 4) concerted efforts to identify and engage the most appropriate potential convener of such a task force.

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