



Original Research

Advancing the development of national childhood cancer care strategies in Latin America



Avram Denburg^{a,b,g,*}, Michael G. Wilson^{b,c,d}, Sonali Johnson^e, Tezer Kutluk^{e,f}, Julie Torode^e, Sumit Gupta^{a,g,h}

^a Division of Haematology/Oncology, Hospital for Sick Children, Toronto, M5G 1X8, Canada

^b Centre for Health Economics and Policy Analysis, McMaster University, Hamilton, L8S 4K1, Canada

^c McMaster Health Forum, McMaster University, Hamilton, M5G 1X8, Canada

^d Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, M5G 1X8, Canada

^e Union for International Cancer Control, Geneva, Switzerland

^f Division of Pediatric Oncology, Hacettepe University Medical School, Ankara, Turkey

^g Faculty of Medicine, University of Toronto, Toronto, M5S 1A8, Canada

^h Institute for Health Policy, Management, and Evaluation, University of Toronto, Toronto, M5T 3M6, Canada

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ABSTRACT

Background: Despite a rising burden of cancer among children in low- and middle-income countries (LMICs), few efforts to develop system-wide strategies to combat childhood cancer exist. Such efforts are hampered both by gaps in research evidence and by weak links among stakeholders spanning the trajectory from research and care to policy. Deliberative dialogues have emerged as a promising means of advancing evidence-informed policy, by providing a structured forum for key stakeholders to integrate and explore scientific and experiential knowledge about complex health system issues.

Methods: We convened a two-day deliberative forum with a broad array of stakeholders to collectively identify core problems, objectives, potential solutions, and key implementation considerations related to the development of national childhood cancer strategies in Latin America.

Results: from this deliberative process describe broadly endorsed elements of a solution to the challenges posed by childhood cancer in the region, both at the level of individual countries and through supra-national collaboration. Key findings include: the potential role for a pan-regional task force on childhood cancer in advancing collective goals; the import of structured health system guidance to national policy and program development on childhood cancer; and the crucial need for enhanced capacity to monitor and evaluate childhood cancer systems and policies.

Conclusion: The fruits of this deliberative process include novel policy-relevant research and advocacy endeavours, and enhanced relationships among diverse regional stakeholders to support evidence and policy development relevant to childhood cancer care in Latin America. Deliberative dialogues hold promise for advancing evidence-informed health system strategies on childhood cancer care in other LMIC contexts.

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1. Introduction

Outcomes for children with cancer in high-income countries (HICs) have improved significantly in the past several decades [1]. The same is not true for many low- and middle-income countries (LMICs), which carry 90% of the global burden of childhood

cancer [2]. As compared to 80% in HICs, survival rates from childhood cancer in LMICs range from 5 to 60%, in part due to variability in health-system capacity, political attention, and commitment within and between countries [3].

Considerable knowledge and efforts exist to address the childhood cancer burden in LMICs [4–6]. For example, a number of Latin American countries have led the development of local childhood cancer services towards improving survival rates [7–20]. However, in most cases, these advances have not been scaled up and integrated into system-wide approaches [11,12].

* Corresponding author at: Division of Haematology/Oncology, The Hospital for Sick Children, 555 University Ave, Toronto, Ontario, M5G 1X8, Canada.

E-mail address: avram.denburg@sickkids.ca (A. Denburg).

Designing an evidence-informed strategy for addressing health-system issues in childhood cancer requires the creative interplay of the best available scientific evidence with the knowledge and experiences of those involved in or affected by the issue [13]. To this end, we convened a dialogue with a broad array of stakeholders to collectively identify core problems, potential solutions, and key implementation considerations related to the development of national childhood cancer strategies in Latin America.

2. Methods

We convened a two-day deliberative forum, *Placing Childhood Cancer on the Global Child Health Agenda*, at the Brocher Foundation in Hermance, Switzerland on June 8–9, 2015. An evidence brief [14] was sent to participants prior to the dialogue. Our methods for preparing the brief are outlined in Table 1 and our approach to convening the dialogue is described below.

In collaboration with the steering committee, we identified and invited health-system stakeholders (government officials, inter-governmental organizations, NGOs, leaders of professional and patient organizations, clinicians and researchers) who could: 1) bring unique views and experiences to bear on the challenge; and 2) champion within their respective constituencies actions that would address the challenge. Participants were identified by reviewing government directories, the websites of relevant organizations, extant academic literature on childhood cancer care in Latin America, key informant interviews, and through suggestions from steering committee members.

Participants received the evidence brief two weeks prior to the dialogue, and were requested to read it in advance to ensure comparable foundational knowledge and a common starting place for detailed discussion. Day 1 of the dialogue included deliberations about each section of the brief, as well as a deliberation about next steps that could be taken by different constituencies. We did not aim for consensus, in order to provide a space for free exchange of varied views and perspectives. To promote and protect such exchange, the dialogue followed the Chatham House rule: information used during the meeting could be used, but neither the identity nor the affiliation of participants were to be revealed. The dialogue was therefore not recorded, but detailed notes were taken by the facilitator and study-team members; these were used to develop a thematic analysis of the deliberations.

Day 2 of deliberations began with a summary of Day 1 deliberations, followed by dedicated discussion of discrete topic areas (early detection, treatment and care, survivorship, and monitoring, evaluation and research). For each topic of focus, participants sought to identify challenges, solutions and good practice examples from the region in the domains of health system governance, delivery and financing. Themes from the preceding stakeholder dialogue informed the discussion. Deliberations were structured by the following agenda: 1) identifying key priorities and targets; 2) applying the elements addressed in the dialogue (pan-regional task force, health system guidance, monitoring and evaluation) to advance topic-specific goals; and 3) considering the dynamics and contextual realities of appropriate integration of efforts with existing health services. As with Day 1, we used notes from facilitators and study-team members to develop a thematic analysis of the deliberations.

3. Results

We present below a summary of the key findings from the evidence brief and the major themes of the Day 1 and 2 deliberations, which included 24 participants (two policymakers, one manager, six healthcare professionals, six researchers, and nine stakeholders

from across Latin America as well as from Canada, the United States and several global health organizations). Full versions of the evidence brief and dialogue summary are available on the McMaster Health Forum website (www.mcmasterhealthforum.org) [14,18].

3.1. Key findings from the evidence brief

Key messages from the evidence brief are summarized in Tables 2 and 3. Table 2 describes the main factors contributing to the problem of childhood cancer in Latin America, while Table 3 summarizes the three identified elements of a comprehensive approach to address it: 1) a pan-regional task force, 2) health system guidance, and 3) monitoring and evaluation.

As highlighted in the evidence brief, implementing these elements will hinge on: 1) making the case that childhood cancer is not a competing policy priority, but rather one integral to reducing childhood mortality, improving health over the lifecourse and strengthening health systems; 2) building regional and national buy-in for the objectives and design of a multi-stakeholder task-force; 3) engaging national and international organizations (e.g. child and adolescent health, non-communicable diseases, and cancer-specific networks) to encourage joint action on childhood cancer policies; and 4) building capacity for health-system guidance as well as monitoring and evaluation.

3.2. Thematic summary of day 1 stakeholder dialogue

Dialogue participants broadly agreed that the problems associated with childhood cancer policy in Latin America were effectively captured through the themes presented in the evidence brief (Table 1). In-depth deliberation about these dimensions of the problem yielded insights along three further overarching themes: 1) limitations in context-specific and comparative evidence for policy and program development; 2) gaps between existing knowledge and the capacity for policy implementation; and 3) constraints on advocacy related to problem awareness and framing. Relationships between knowledge, policy and action were at the core of the problem deliberations. Notably, participants identified key weaknesses in the evidence-to-policy trajectory at junctures specific to policy development, implementation, and advocacy.

Deliberations about the three elements of a comprehensive approach to addressing the problem centred on the nature, constitution, and functions of a pan-regional task force on childhood cancer policy. Participants agreed on the potential for a pan-regional task force to enhance collective action toward addressing shared issues (e.g., building cancer registries and enhancing access to diagnosis, medicines and allied treatment) and to support distinct efforts at the national level, which would continue to be the main locus of action. They highlighted the following features as integral to task force legitimacy and success: 1) a coherent statement of purpose; 2) clearly articulated foundational values; 3) strong governance; and 4) prioritization of activities that could benefit from pan-regional scope. Participants also cautioned that regional action should strive to recognize and integrate national efforts, and not seek to supersede them.

A second major component of the discussion about solutions related to the need for an integrated approach to health-systems guidance and monitoring/evaluation. Initial divergence of views about the feasibility and legitimacy of health-systems guidance – founded on discrepant notions of evidence and varying perceptions of data availability and quality – ultimately converged around the need for better evidence, and agreed upon priorities to that end. Participants endorsed the utility of a framework to guide evidence synthesis, data collection, and health-system guidance endeavours, and stressed the intertwined nature of these facets of a solution.

Table 1
Summary of the five stages used to develop the evidence brief.

Stage	Description
Convening a steering committee	<ul style="list-style-type: none"> • Convened an interdisciplinary steering committee with representatives from partner organizations and key stakeholder groups to ensure multiple perspectives and opportunities for expert guidance throughout the process. • The steering committee provided advice throughout the process of developing the evidence brief, which included refining a terms of reference for the brief (a preliminary outline of the brief), identifying key informants and dialogue participants.
Conducting key informant interviews	<ul style="list-style-type: none"> • Conducted key informant interviews (17 in total) with policymakers (from specific countries and from international or regional agencies/organizations), managers from healthcare institutions, stakeholders (e.g., from cancer agencies, interest groups and provider and patient associations) and researchers, who were actively engaged in the issue of childhood cancer in Latin America. • We used the feedback from key informants to iteratively revise the terms of reference to guide the writing of the evidence brief.
Identifying, selecting, appraising and synthesizing findings	<ul style="list-style-type: none"> • The inclusion of systematic reviews was prioritized (given that they provide a synthesis of the global pool of evidence about a given topic), which were supplemented with individual studies and reports to contextualize the findings. • Systematic reviews were identified from Health Systems Evidence (www.healthsystemsevidence.org)^a by searching topic categories related to the elements of a potentially comprehensive approach included in the brief (networks/multi-institutional arrangements, consumer & stakeholder involvement (all categories); quality monitoring and improvement systems, and organization-targeted implementation strategies), and reviewing the documents included in the disease category for cancer. • Targeted searches of PubMed were conducted using the health services research topic filter (using the terms (cancer AND (pediatric OR pediatric or child^a) AND (latin america^a)). • Grey literature was identified through the key informant interviews and by searching websites of relevant organizations.^b • The searches were reviewed for relevance by the lead authors of the brief (AED and MGW). • Each included systematic review, the focus of the review, key findings, the last year the literature was searched, methodological quality (based on available AMSTAR ratings in Health Systems Evidence)¹⁵, and context-specific information (the proportion of included studies that were conducted in Latin America, and the proportion of included studies focused on childhood cancer) were extracted.
Drafting the evidence brief	<ul style="list-style-type: none"> • Key findings from global and local research evidence were synthesized with a focus on concision and accessibility. • The structure of the brief consisted of a one-page summary of key messages followed by a detailed exposition of the problem, three elements of a potentially comprehensive approach, and challenges to implementation at various levels of health system organization.
Finalizing the evidence brief	<ul style="list-style-type: none"> • To ensure its scientific rigour and system relevance, the penultimate version of the brief was subjected to merit review by a policymaker, stakeholder and researcher, and suggested revisions were incorporated in the final product

^a Health Systems Evidence (www.healthsystemsevidence.org) is a continuously updated database containing more than 5000 systematic reviews and more than 2400 economic evaluations of delivery, financial and governance arrangements within health systems. Details regarding its development and continuous updating can be accessed in separate publications [16,17].

^b Websites revised included those for Cure4Kids, International Agency for Research on Cancer, International Network for Cancer Treatment and Research, International Society of Paediatric Oncology, Pan American Health Organization, NCD Alliance, UNICEF, Union for International Cancer Control, World Child Cancer and World Health Organization.

Dialogue participants addressed a number of important implementation considerations. 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 systems guidance. A few stakeholders counselled that priority actions should 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 spoke to a number of important barriers to advancing national childhood cancer strategies in Latin America. International engagement was a central theme in this regard. 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. Many underscored the importance of effective issue framing –

Table 2
Summary of key factors contributing to the problem.

Issue	Factors contributing to the issue
Latin America faces a heavy (but inconsistently measured) burden of childhood cancer morbidity and mortality	<ul style="list-style-type: none"> • Reliable data on the incidence of and mortality from childhood cancers in most Latin American countries is rare because of a lack of comprehensive registry coverage [19], with the exception of some that have reasonably comprehensive cancer registries (e.g., Argentina, Brazil and Colombia) [20–22] • For childhood leukemia, we that survival rates are worse than in high-income countries, but there is substantial variation both in survival and in incidence rates with estimates of the latter ranging from 27.8/million/year in Brazil to 75.3/million/year in Mexico [23–26]. • For solid and central nervous system (CNS) tumours: <ul style="list-style-type: none"> ○ little is known about the epidemiology and burden in most Latin American contexts [27–29]; and ○ the treatment and outcomes for solid tumours in Latin American countries varies between the type of tumour and health-system contexts, with survival rates being significantly lower than in high-income countries [30,31].
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	<ul style="list-style-type: none"> • Key challenges for ensuring access to high-quality cancer care to children in Latin American countries include: <ul style="list-style-type: none"> ○ low overall investments in health, with corresponding limitations in health-system capacity; ○ competing public health and health care priorities [11]; ○ rural/urban divides and regional inequities in access to care [26]; ○ weak systems for childhood cancer detection and registration, resulting in delayed and sometimes missed diagnosis [23,32]; ○ unreliable supplies of chemotherapeutics [11,33]; ○ limited access to pediatric formulations of new cancer treatments as well as medical devices that support cancer care and treatment in childhood (e.g., because of policies that unnecessarily delay the inclusion of these formulations and devices on formularies) [11,34]; ○ barriers to accessing effective palliative care, including cultural stigma associated with the use of opioids, leading to limited drug access, inconsistent government support, lack of trained personnel, and lack of palliative care education [35–37]; and ○ refusal/abandonment of therapy (which affects up to 60% of children with cancer and often follows intensive phases of therapy and precedes radical surgery for solid tumours [38,39] is one of the principal causes of cancer-associated mortality in LMICs, and factors leading to abandonment include difficulties in accessing care because of low socioeconomic status, geographic distance, poor healthcare worker communication with families and poor supportive care leading to decreased quality of life.
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	<ul style="list-style-type: none"> • Many different health-system approaches to childhood cancers exist in Latin America, with some countries having little to no organized pediatric oncology services (while others have institution-specific programming with minimal to no government involvement), and few countries having a national policy on childhood cancer that guide system-level approaches. • Limited access to childhood cancer care has been addressed in many countries through ‘twinning partnerships’ (collaborations between institutions from high-income and low- and middle-income countries to improve outcomes for children with cancer) and while these have many benefits (e.g., improved infrastructure, enhanced access to drugs and diagnostic tests and access to trained clinicians), efforts to move from ad hoc partnerships to integrated, system-wide practices and policies remain a priority. • Efforts to shift to such system-wide practices and policies require addressing several challenges related to: <ul style="list-style-type: none"> ○ governance (e.g., developing and implementing processes to support the development of evidence-informed policy that accounts for the specific contexts of Latin American countries, monitoring and evaluating the effects of policies, providing opportunities for citizens and stakeholders to provide input into policy development processes, ensuring accountability and transparency in decision-making.); ○ financial (e.g., making difficult decisions about whether and how to extend financial coverage for children with cancer given cost constraints and many competing priorities); and ○ delivery arrangements (e.g., balancing the tension between reforms to delivery of care that focus on ‘vertical’ vs. ‘horizontal’ integration).
Childhood cancer receives limited attention from policymakers despite its importance for reducing childhood mortality and improving health over the life course	<ul style="list-style-type: none"> • Childhood cancer has rarely made it onto the global child health agenda due to a lack of awareness of the importance of childhood cancer (e.g., because of significant attention given to the high burden of adult cancer worldwide), misinformation about the existence of cost-effective solutions, and competing priorities in already resource-limited health systems [12]. • Global institutions and networks concerned with improved non-communicable disease outcomes have largely excluded childhood cancer from their policy discussions and advocacy efforts [40]. • Grassroots mobilization and advocacy by patient groups and foundations will be crucial for spurring strengthened infrastructure, service delivery and financing of childhood cancer care in Latin American countries, but while grassroots projects exist in many LMICs, the transition to a health-systems approach to childhood cancer has been slow, and childhood cancer services are poorly integrated with existing primary and secondary care. • Perhaps most crucially, the recognition and framing of policy on childhood cancer care as an opportunity for diagonal health-system strengthening (i.e., supporting both vertical and horizontal integration) is relatively recent, and stakeholders in both the global child health and non-communicable disease (NCD) arenas are only beginning to appreciate its promise [11].

Table 3

Summary of key findings from systematic reviews related to three elements of an approach to address the problem.

Element	Focus	Summary of key findings from systematic reviews ^a
1- Convene a multi-stakeholder, pan-regional task force with national working groups	<ul style="list-style-type: none"> ● Identifying a clear picture of the challenges across Latin American countries related to addressing childhood cancer by: <ul style="list-style-type: none"> ○ using high-quality data and evidence; and ○ systematically eliciting tacit knowledge, views and experiences of key stakeholders (e.g., policymakers, patients and families/caregivers, NGOs and the private sector); ● Engaging in priority-setting processes to develop: <ul style="list-style-type: none"> ○ short-, medium- and long-term priorities both within and across Latin American countries; and ○ meaningful and achievable targets that can be met and sustained in the long-term. 	<ul style="list-style-type: none"> ● A framework highlighted the importance of identifying the causes of a policy challenge at different levels (individual motivation, team-level tasks, professional roles, organizational rules and system-level strategies) [41]. ● A systematic review focused on deliberative dialogues as a mechanism that can be used to further understand the challenge by periodically convening by a multi-stakeholder taskforce to systematically elicit tacit knowledge, views and experiences of stakeholders, not only to identify a clear picture of the challenges faced in specific countries, but also to contribute to a broader stakeholder-engagement process to identify priorities and targets.¹³ ● None of the four reviews [42–45] we identified about priority-setting processes included an explicit assessment of benefits, harms and costs, but they did provide information related to key elements of such processes (e.g., use of formal or informal processes and the use of quantitative, qualitative and mixed techniques that can be used to elicit preferences from stakeholders).
2- Develop health-system guidance to support the implementation of childhood cancer-care strategies	<ul style="list-style-type: none"> ● Creating a continuously updated knowledge 'hub' with evidence on childhood cancer epidemiology, treatment approaches, and health-system arrangements that can be used in the development of guidance; ● Engaging the full spectrum of health-system stakeholders involved in cancer, child and adolescent health, and non-communicable diseases (e.g., global health governance institutions such as the WHO, non-governmental organizations, a cross-section of select national policymakers, stakeholders and researchers) and consumers to develop and refine guidance; and ● Developing 'workbooks' to support the implementation of the guidance in specific Latin American contexts through subsequent national-level deliberative processes 	<ul style="list-style-type: none"> ● An older systematic review assessed the available literature about collaborations between the primary care and public health sectors, and found such collaborations to have beneficial outcomes at the level of health systems (e.g., improvements in the delivery of health services) and health professionals (e.g., improved partnerships and team functioning) [46]. ● 10 systematic reviews point to benefits of stakeholder- and consumer-engagement processes, which include: ensuring that evidence is interpreted with the end user in mind, and developing final products that are readable and accessible; facilitating wider dissemination and uptake of the research findings; and supporting knowledge acquisition among stakeholders and consumers [47–56]. ● No systematic reviews relevant to developing 'workbooks' to support the implementation of health-system guidance were identified (see the results section for an example of such a 'workbook')
3- Build capacity for monitoring and evaluation	<ul style="list-style-type: none"> ● Building high-quality cancer registries ● Identifying relevant indicators and outcomes that can be tracked between countries to provide common benchmarks for analysis ● Monitoring and evaluating the extent of implementation using common benchmarks across countries, and adjust country-specific plans based on the results 	<ul style="list-style-type: none"> ● We did not identify any reviews that were directly relevant to this element (see the results section for additional considerations that could be relevant to this option). ● While not directly applicable to this element, lessons can be drawn from factors that have been found in systematic reviews to contribute to successful implementation of quality-improvement interventions, which include: <ul style="list-style-type: none"> ○ leadership from top management; ○ a supportive organizational culture (including support of board members); ○ availability of data infrastructure and information systems (in this case cancer registries); ○ experience with or years involved in quality improvement; ○ physician involvement; ○ motivation to change; ○ sufficient resources; ○ effective team leadership; and ○ use of multifaceted interventions [57,58].

^a A more detailed description of the findings from systematic reviews is available in the evidence brief [14].

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 LMICs; 2) serve as a 'diagonal' approach [11,59] to health-systems 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 on leveraging its Strategic Fund [60] to enhance access to quality childhood cancer medicines; 2) creating cross-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 [61]; 3) achieving regional consensus on pediatric age limits to clarify childhood cancer system remit; and 4) including human rights dimensions of childhood cancer treatment and care in advocacy efforts in the context of the United Nations Convention of the Rights of the Child and human

rights framing in the global non-communicable diseases agenda [62].

Looking forward, participant priorities for action fell in the following four domains: 1) advocacy efforts; 2) data and evidence generation; 3) stakeholder engagement; and 4) task force planning. Participants framed next steps in these areas as complementary, and discussed optimal ways to pursue them 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.

3.3. Summary of day 2 deliberation

Day 2 deliberations focused on the continuum of cancer management from early detection and referral, through treatment and care to survivorship. Monitoring, evaluation and areas for further research were also considered. Each moderated discussion addressed key challenges, solutions and good practice examples from countries in the region. The three elements identified in Day 1 were used as a framework throughout Day 2 deliberations. Participants agreed that in order to identify key advocacy priorities for the region it is essential to map existing knowledge and practice in the domains of financing, governance, management and delivery of childhood cancer services. Relatedly, they endorsed the development of a health-system matrix for the region as a potential repository of information to guide context-appropriate interventions across different levels of resource and capacity. Table 4 summarizes the key health-system challenges and solutions identified under each domain, as they relate to the broader elements of a solution adopted in Day 1 deliberations.

4. Discussion

4.1. Implications for policy

The findings from this evidence-informed deliberative forum justify the need for, and power of, a health-system approach to childhood cancer care in Latin America – and arguably beyond. A central theme of relevance to stakeholders engaged in the policy process is the importance of context specificity in problem definition and response, and of health-system strategies adapted to the level of development and jurisdictional realities. At the same time, our findings support the value of cross-national approaches to specific domains of substance and process, including access to medicines, cancer registration, health human resource training and planning, and international advocacy. Broadly endorsed stakeholder support for a pan-regional task force underscores the utility of cross-country collaboration, and implies a corollary need to generate and sustain momentum toward convening such a forum. In addition, clear and repeated calls by participants to focus upfront efforts on improving bases of evidence for policy, through enhanced capacities to monitor and evaluate current and future childhood cancer programs and policies, suggest knowledge generation, synthesis, and guidance as another priority domain for policymakers.

4.2. Implications for research

The emphasis on better knowledge for policy as a central theme of the deliberative forum implies a number of existing research gaps and opportunities to fill them. Few systematic reviews of direct relevance to the health system and policy aspects of childhood cancer care exist; formal evaluations of specific policies or programs

related to the governance, financing and delivery of childhood cancer services in most LMICs, including those in Latin America, are also scant [14]. An explicit and well-supported research agenda focused on the health system and policy dimensions of childhood cancer in LMICs is of critical necessity to develop and refine national and regional strategies aimed at improving cancer outcomes among children. Research priorities within such an agenda could include: economic evaluations of the costs of discrete programs of care and the outcomes of various financing strategies; comparative policy analysis of childhood cancer strategies across select jurisdictions, to understand the drivers of and barriers to agenda setting, policy development, and policy implementation; and enhanced systems for accurate childhood cancer epidemiology in LMICs. The need for context-specific evidence also suggests the heuristic and practical value of an evidence-informed matrix for level-appropriate childhood cancer strategies.

4.3. Strengths and limitations

To our knowledge, this represents the first attempt at a deliberative approach to evidence-informed policymaking on childhood cancer in LMICs. Indeed, ways to embed evidence in national or regional policy on childhood cancer has not enjoyed prominence in any jurisdiction around the globe, irrespective of resource level [11,12]. Though this project focused on Latin America, its approach and machinery are readily transferable to other contexts, HIC and LMIC alike. Certainly, stakeholder dialogues of this sort have proven valuable in various other policy contexts [63]. That this extension of the method proved both tractable and constructive in the context of childhood cancer is compelling, given the nascent state of childhood cancer policy in most LMIC settings, where the bulk of the disease burden is concentrated and the need for policy-oriented solutions most acute.

We encountered a number of both generic and specific limitations attached to the deliberative process. As with most deliberative attempts to embed research evidence in policymaking, issues related to stakeholder representation were apparent. Throughout both the development of the evidence brief and conduct of the deliberative forum, questions surrounding appropriate processes for, and decisions about, participant selection arose. In most deliberative fora, and on the majority of topics requiring deliberation, exhaustive and universally accepted stakeholder representation is near impossible. Processes for participant inclusion and exclusion are inevitably imperfect, dampening some voices and amplifying others [64]. In many ways, this reality recapitulates the power dynamics of the policy process itself. An optimal deliberative approach attempts to minimize these intrinsic imbalances in voice by inviting and invoking multiple perspectives, some of which would not otherwise find a seat at the policy table [65]. A strength of our process – noted by a number of participants during the forum – is that it did just this. A specific limitation of our dialogue was suboptimal representation of policymakers, given the number of jurisdictions at the table, and the fact that it was conducted in English rather than Spanish.

Relatedly, concerns regarding outcome and impact were forefront and explicit in the dialogue. The relationship between policy-relevant evidence synthesis and policy uptake is inadequately understood, and contingent on political context and climate [63]. The degree to which the knowledge and momentum generated from deliberative dialogues translate into real-world policy impact, or that subsequent policy reforms can be reasonably attributed to such processes, is likely to vary significantly across both jurisdictions and issues. This was compounded in our context by the lack of systematic reviews specific to the topic, creating challenges with respect to the quality of evidence for policy debate. Research into the relationships between evidence synthesis, delib-

Table 4
Day 2 deliberations: From childhood cancer health system challenges to solutions.

Health System Dimensions	Elements of a Solution				
	Key Barriers	Pan-Regional Task Force	Health System Guidance	Monitoring and Evaluation	Regional Exemplars
Early Detection and Referral	<ul style="list-style-type: none"> • PHC access and disease recognition • Poor integration of referral mechanisms across health system tiers • Weak diagnostic capabilities at referral centres 	<ul style="list-style-type: none"> • Define core diagnostic capacities for referral centres of excellence • Articulate opportunities for interface between national, regional and international child health platforms and childhood cancer detection/referral 	<ul style="list-style-type: none"> • Integrate training on presentation and referral of childhood cancer into existing programs for PHC facilities and staff • Establish clear referral pathways and mechanisms to accredited treatment centres 	<ul style="list-style-type: none"> • Develop procedures and checklists to track referrals • Introduce accountability measures to reduce time delays for referral 	<p>Chile:</p> <ul style="list-style-type: none"> • Incentives for appropriate referral to specialized treatment centres • Legislation on referral timeframes and treatment initiation <p>Mexico, Paraguay:</p> <ul style="list-style-type: none"> • Public campaigns on early warning signs • Training for staff in primary care and satellite clinics
Treatment and Care	<ul style="list-style-type: none"> • Variable treatment financing • Unreliable drug procurement and access • Inconsistent accreditation standards and practices • Lack of legislation on right to treatment • Poor quality data on epidemiology and outcomes • Political and cultural barriers to palliative care (e.g. opioid use) 	<ul style="list-style-type: none"> • Engage civil society to enhance financial and psychosocial support for families • Collaborate on supra-national approach to drug price negotiation, procurement and supply • Provide expert input into matrix of health system tiers to direct national targets and priorities for childhood cancer care • Develop consensus on domains and standards for accreditation of treatment centres 	<ul style="list-style-type: none"> • Establishment of tiered treatment guidelines based on centre resources and capacities • Develop national standards and guidelines for evaluation of treatment centres • Implement PAHO procedures for national drug procurement planning and supply management for oncologics 	<ul style="list-style-type: none"> • Strengthening childhood cancer registries for accurate incidence and mortality data • Monitoring of outcomes and treatment abandonment by centre/region 	<p>Mexico, Chile:</p> <ul style="list-style-type: none"> • Earmarked national funds for childhood cancer coverage • Release of funds to tertiary centre on suspicion of cancer, to incentivize prompt referral and diagnosis <p>PAHO/WHO:</p> <ul style="list-style-type: none"> • Recent addition of childhood cancer medicines to Model List of Essential Medicines • Regional mechanism for bulk drug purchasing through PAHO <i>Strategic Fund</i>
Survivorship	<ul style="list-style-type: none"> • Lack of data on late effects in LMIC childhood cancer populations • Weak consensus on resource allocation to survivorship care • Rigidity of age limits for pediatric systems of care 	<ul style="list-style-type: none"> • Partner with civil society to raise awareness on cancer survivorship • Advocate for enhanced capacity for survivorship care in the region • Establish resource-appropriate late effects screening guidelines 	<ul style="list-style-type: none"> • Develop basic educational packages to engage survivors on risk of late effects, health promotion activities, and ongoing health care engagement • Identify opportunities to integrate survivorship care with existing PHC programs 	<ul style="list-style-type: none"> • Fund development of longitudinal cohorts to track the burden and risks of late effects among survivors (resources permitting) 	<p>Argentina:</p> <ul style="list-style-type: none"> • CCI-affiliated national survivors group, coordinated by Fundacion Natali Dafne Flexer
Monitoring and Evaluation	<ul style="list-style-type: none"> • Poor comparability and consistency of data reporting across countries • Variability in scope and practice of cancer registration 	<ul style="list-style-type: none"> • Foster collaboration on regional approaches to cancer registration • Establish registry standards, including common data definitions, to facilitate comparison across jurisdictions 	<ul style="list-style-type: none"> • Develop guidelines and responsibilities for the collection of national data on incidence, mortality, survival, abandonment and refusal, and metrics of treatment delay • Create 'dashboards' to track progress on key performance indicators at institutional and national levels 	<ul style="list-style-type: none"> • Develop consensus indicators to enable comparative analysis of system outputs and outcomes across jurisdictions • Create framework of health system and institutional tiers to guide performance evaluation 	<p>Regional:</p> <ul style="list-style-type: none"> • RINC-UNASUR hub of GICR

PHC = primary health care; PAHO = Pan-American Health Organization; WHO = World Health Organization; RINC-UNASUR = Network of National Cancer Institutes of the Union of South American Nations; GICR = Global Initiative for Cancer Registry Development; CCI = Childhood Cancer International.

erative process and policy outcome, and the factors that influence variation therein, is in its early stages [66]. Our project reaffirms the need for more research in this critical space at the juncture between health systems evidence and policy.

Finally, the fact that multiple countries were party to the deliberations is at once a strength and a limitation of our approach. It allowed for the assimilation of multiple perspectives and experiences, facilitating comparative health system and policy learning. However, it also limited the degree of depth achieved with respect

to any single country context, and, as a result, the potential for specific policy reform in a given jurisdiction. Striking the right balance between scope and depth on complex health system issues with supranational dimensions is a delicate matter. Achieving the desired system outcomes is likely to require structured dialogue within various policy worlds, some tightly bound and others more expansive.

4.4. Progress and next steps

This deliberative forum has fostered relationships and intentions that have already begun to bear fruit with respect to childhood cancer policy research and advocacy in Latin America. On the strength of insights and commitments from across the two days of deliberation, collective efforts to map the health-system dimensions of childhood cancer care in Latin America are underway, with formal endorsement from the Network of National Cancer Institutes (RINC) of the Union of South American Nations (UNASUR). Dialogue participants are now engaged in survey design and implementation to this end, and are leading efforts in their respective countries to engage key stakeholders towards its completion. Synthesizing the scientific and colloquial evidence from the deliberative dialogue process with context-specific health system knowledge will inform the development of a matrix for a systems and policy approach to childhood cancer, sensitive to levels of health system development. Momentum from the forum has likewise prompted allied proposals for policy-relevant research endeavours, including economic evaluations of existing childhood cancer programs and country-level analyses of childhood cancer policy. Finally, dialogue participants are engaged in preliminary discussions around the constitution and convention of a pan-regional task force on childhood cancer in Latin America.

Contributors

All authors conceived of the study idea and design. AD, MW, SJ, and SG did the analyses.

All authors were involved in the data interpretation and crucial revisions of the report, and approved the final version. AD is the guarantor of the report, had full access to all the data, and had final responsibility for the decision to submit for publication.

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Declaration of interests

We declare no competing interests.

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