

# Identifying Priorities for Harmonizing Guidelines for the Long-Term Surveillance of Childhood Cancer Survivors in the Chinese Children Cancer Group (CCCG)

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## abstract

**PURPOSE** Survivors of childhood cancer often experience treatment-related chronic health conditions. Given its vast population, China shares a large proportion of the global childhood cancer burden. Yet, screening and treatment of late effects in survivors of childhood cancer remain underaddressed in most regions of China. This study aimed to identify high-priority late effects for harmonizing screening guidelines within the Chinese Children's Cancer Group (CCCG), as well as barriers and enablers of the implementation of surveillance recommendations in local practice.

**METHODS** To establish clinical consensus, 12 expert panelists who represent major institutions within the CCCG completed a Delphi survey and participated in a focus group discussion. The survey solicited ratings of the prevalence, severity, and priority for screening of 45 late effects. Major themes identified from the focus group were analyzed using thematic analysis.

**RESULTS** The Delphi survey identified eight high-priority late effects for harmonization within CCCG: osteonecrosis, osteoporosis, left ventricular dysfunction, secondary brain tumors, treatment-related myeloid leukemia, gonadal dysfunction, growth hormone deficiency, and neurocognitive deficits. The common barriers to implementing survivorship programs include lack of support and resources for clinicians to provide follow-up care. Patients were also concerned about privacy issues and lacked awareness of late effects. Many institutions also lacked rehabilitation expertise and referral pathways.

**CONCLUSION** By identifying obstacles related to the professional setting, patient behavior, and organization of care, our study identified resources and a framework for establishing collaborative strategies to facilitate follow-up care of childhood cancer survivors in China.

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## INTRODUCTION

Cancer survivorship is accompanied by a myriad of treatment-related complications that can persist or appear years after completion of therapy. Substantial published evidence indicates that these chronic morbidities can negatively affect emotional health, psychosocial adjustment, and health-related quality of life of childhood cancer survivors.<sup>1-3</sup> To facilitate early detection and opportunities for interventions to improve health, international working groups, such as the Children's Oncology Group (COG) and the International Late Effects of Childhood Cancer Guideline Harmonization Group (IGHG), support evidence-based screening for late effects in childhood cancer survivors.<sup>4-6</sup>

Risk-based care involves a personalized systematic program of regular screening, surveillance, and

prevention strategies based on the cancer type, treatment regimen and cancer experience.<sup>5,7</sup> The COG Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers were developed to promote risk-based, exposure-related recommendations for the screening and management of late effects in survivors.<sup>8</sup> Long-term follow-up (LTFU) services that provide medical and rehabilitation care for childhood cancer survivors have been internationally recognized as an essential component of quality cancer care.<sup>4,9</sup>

China, with a vast population, has the largest share of the global childhood cancer burden. An estimated 40,000 new cases of childhood cancer are diagnosed in mainland China each year.<sup>10,11</sup> Over the past decade, advances in treatment strategies and collaborations with international groups have substantially

## ASSOCIATED CONTENT

### Appendix

Author affiliations and support information (if applicable) appear at the end of this article.

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## CONTEXT

### Key Objective

What are the priorities and key barriers to the implementation of survivorship programs among institutions within the Chinese Children's Cancer Group (CCCCG)?

### Knowledge Generated

An expert panel identified cardiovascular, endocrine, and psychosocial outcomes as high-priority late effects that warrant harmonization of screening guidelines. The common barriers to implementing survivorship programs were clinician-related (lack of support and resources for providing follow-up care), patient-related (lack of awareness of late effects and concerns with privacy issues), and institution-related (lack of rehabilitation expertise and referral pathways).

### Relevance

The working group will review the existing guidelines and recommend the most feasible strategies for screening these high-priority late effects in CCCC institutions. Identifying barriers and enablers will help promote the successful development and implementation of quality survivorship services in China.

improved survival rates among children with cancer in China. Additional studies should focus not only on improving cancer treatment but also on surveillance of the emerging population of long-term childhood cancer survivors. Unfortunately, screening and treatment of late effects in survivors are inadequate in most regions of China. Specifically, no standardized and collaborative strategies for follow-up care have been developed to address the long-term effects in Chinese pediatric cancer programs.

In 1997, several large pediatric oncology centers across China initiated the Chinese Children's Cancer Group (CCCCG) to promote the provision of cost-effective therapies and multidimensional support to children with cancer.<sup>12</sup> Currently, this group comprises more than 20 major hospitals and medical centers with catchment area covering 65% of the Chinese population. This consortium has launched multiple national clinical trials for pediatric cancers, which have yielded promising results. For example, the CCCC Acute Lymphoblastic Leukemia-2015 protocol enrolled almost 6,000 patients and achieved a 3-year survival rate of 93.3%.<sup>13,14</sup> Government support, medical insurance, and donations from charitable organizations have greatly contributed to the reduction of treatment abandonment in China.<sup>14</sup> The existing collaboration among the CCCC institutions is expected to promote the successful development and implementation of quality and accessible survivorship services in the near future.

The objectives of this study were to identify high-priority late effects in childhood cancer survivors for harmonization of screening guidelines, as well as barriers to and enablers of the implementation of surveillance recommendations in local practice. Clinical consensus was sought from a panel of experts who represent major institutions within the CCCC.

## METHODS

A mixed-methods approach was used to develop consensus. First, the Delphi technique was used to obtain

consensus on the experts' opinions through two rounds of structured surveys.<sup>15</sup> This study methodology seeks to obtain consensus on the opinions of experts through a series of structured questionnaires. A panel of experts would complete the questionnaires anonymously. The responses from the first round of questionnaire would be analyzed and summarized to develop the next round of questionnaire. This is therefore an iterative multistage process designed to combine opinions into a group consensus.

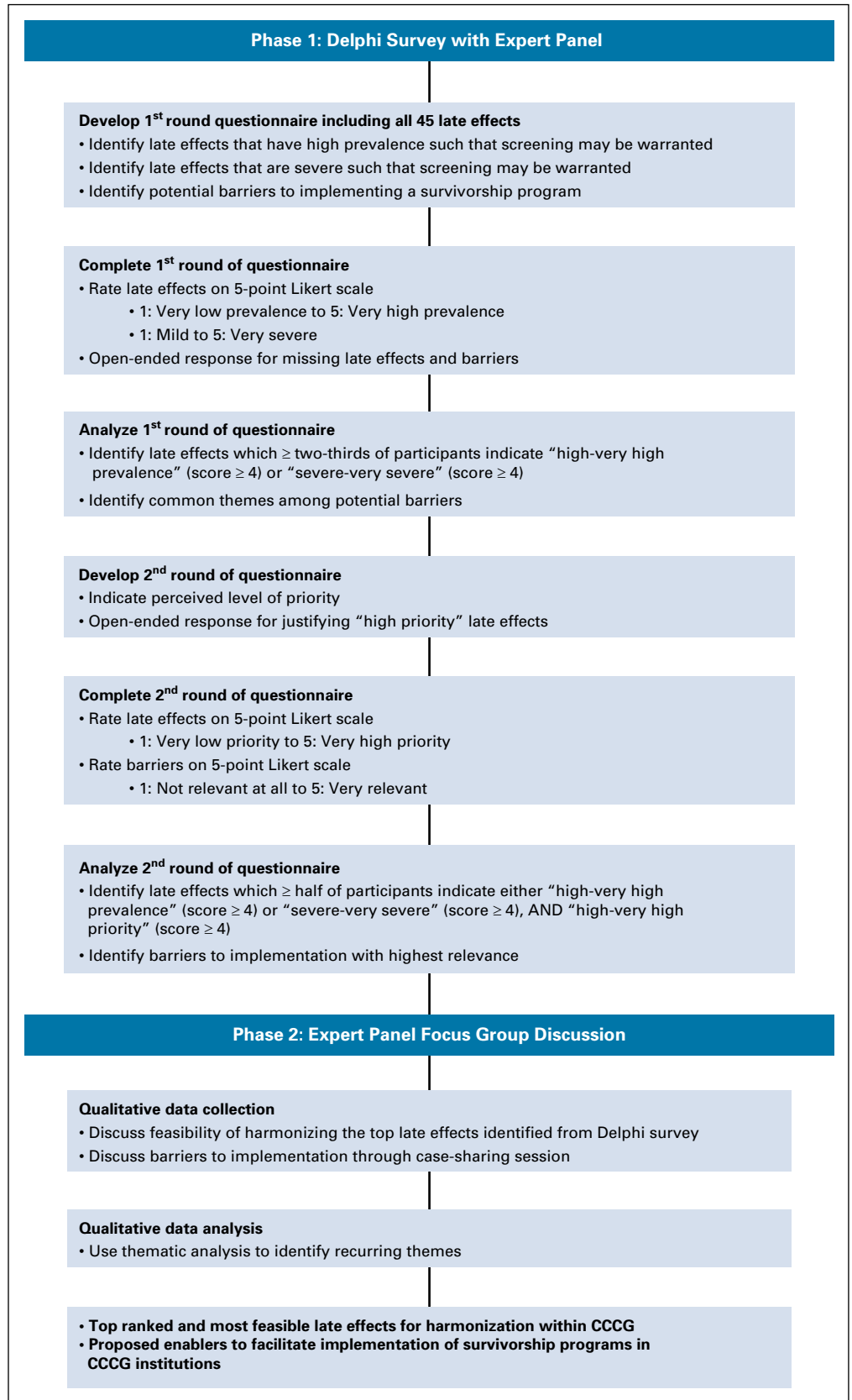
Second, an expert panel discussion was held as part of a regional pediatric oncology conference in Guangzhou, China. The Delphi process and study flow are summarized in [Figure 1](#). This study was approved by the Survey and Behavioral Research Ethics Committee of the Chinese University of Hong Kong (SBRE-18-636).

### Core Working Group and Expert Panelists

The core working group consisted of pediatric oncologist or hematologists who have organized clinical trials within the CCCC (H.Z., J.C., and C.K.-L.), methodologists with skills in evidence appraisal and synthesis (Y.T.C., L.W.P.A.-D., and L.S.Y.), and renowned international experts in cancer survivorship or pediatric oncology (M.M.H. and C.-H.P.). Functionally, the core research team designed the Delphi survey, liaised with the expert panelists, analyzed and summarized the results of each round of the Delphi survey, and directed the publication of the results and guidelines.

The core working group used a purposive sampling approach to recruit members of the expert panel. Fourteen eligible experts were approached by email. After excluding two experts from the same institutions, the participating experts comprised 12 representatives (response rate: 85.7%) from major CCCC-affiliated pediatric oncology institutions in Northern China (*hua bei*, n = 1), Eastern China (*hua dong*, n = 3), Western China (*hua xi*, n = 3), Central China (*hua zhong*, n = 2), and Southern China including

**FIG 1.** Workflow. CCCG, Chinese Children Cancer Group.



Hong Kong (*hua nan*,  $n = 3$ ). The representatives were pediatric oncologists or hematologists who (1) served as key medical care providers and active on-site investigators of CCCG clinical trials, (2) currently held leadership positions in their respective institutions or within the CCCG, and (3) were currently conducting or planning to conduct LTFU services in their respective institutions. The patient volume, survival rates, adverse reaction reporting rates, and clinical and research data comprehensiveness at the institutions were also considered during the formation of the expert panel.

### Development of the Delphi Survey

The Delphi survey was adapted from a report published by the International Late Effects of Childhood Cancer Guideline Harmonization Group.<sup>6</sup> Round 1 of the Delphi survey was conducted between July and November 2019. The expert panel was given a list of 45 late effects (Appendix Table A1) and asked to rate the following items separately for each late effect using a 5-point Likert scale: (1) prevalence (1: very low prevalence to 5: very high prevalence) and (2) severity (1: mild to 5: severe). The respondents were also asked to identify potential barriers to the implementation of long-term surveillance programs for childhood and young adult cancer survivors at their respective institutions (Appendix Table A2).<sup>16-19</sup> Open-ended questions were also included to allow the respondents to provide qualitative responses regarding the above-mentioned items.

Round 2 of the Delphi survey was conducted in November 2019. This round only included late effects that received a score of high-very high prevalence (prevalence score  $\geq 4$ ) or severe-very severe (severity score  $\geq 4$ ) from at least 66.6% (two-thirds) of the respondents, as well as consensus from the core investigators. The expert panel indicated their perceived priority with respect to harmonizing each late effect (1: very low priority to 5: very high priority). They also rated the relevance of the barriers to implementation in the contexts of their respective institutions (1: not relevant at all to 5: highly relevant).

Finally, the most important late effects were defined as those indicated as either high-very high prevalence (prevalence score  $\geq 4$ ) or severe-very severe (severity score  $\geq 4$ ) and high-very high priority (priority score  $\geq 4$ ) by at least 50% of the respondents. Similarly, the most important barriers were those indicated as relevant-highly relevant (relevance score  $\geq 4$ ) by more than 50% of the respondents.

### Focus Group Discussion At the St Jude-VIVA-NCMCS Pediatric Hematology/Oncology Forum

An in-depth focus group discussion was conducted at the St Jude-VIVA-NCMCS meeting on November 9, 2019, in Guangzhou, China.<sup>20</sup> This 90-minute meeting was attended by both the core working group and expert panelists. Two core working group members (H.Z. and J.C.) facilitated

focus group discussion. The expert panelists shared information about the survivorship care models adopted by their institutions and addressed potential barriers to implementation. The panelists also discussed the feasibility of harmonizing the top late effects identified from the Delphi survey and deliberated on the barriers and enablers to establishing survivorship programs within CCCG institutions.

The focus group meetings were conducted in Mandarin and audio recorded. Two bilingual investigators first transcribed the recordings in Mandarin, and then translated the transcriptions into English (L.S.Y. and L.W.P.A.-D.). Two other bilingual investigators (H.Z. and C.Y.) reviewed the final transcripts.

### Data Analysis

Descriptive statistics (frequencies and proportions) were used to summarize the quantitative results from the Delphi survey. These analyses were performed using IBM SPSS 25. Two investigators (L.S.Y. and L.W.P.A.-D.) read and coded all the transcripts independently. Coding was performed in two cycles. The first cycle involved the creation of codes and assignment of data segments to the codes. The second cycle involved validation of the code lists and application of the lists to the remaining data. The codes were then cross-checked and reviewed by a third researcher (Y.T.C.). Next, the coding and themes were discussed by the research team, and a coding framework was developed and applied to all the transcripts. The qualitative data were analyzed using Archiv für Technik, Lebenswelt und Alltagssprache (ATLAS.ti 8 qualitative data-analysis software (Scientific Software Development GmbH, Berlin, Germany)).

For reporting purposes, we combined the results of the Delphi survey and major themes identified from the focus group to demonstrate data consistency in both methodologic approaches. The COREQ 32-item checklist was used to report the qualitative findings (Appendix Table A3).<sup>21</sup>

## RESULTS

### Theme 1: Current Models of Care

The expert panel discussed the survivorship services currently available at their respective institutions. Representative quotes are presented in Table 1. Most institutions had adopted the oncology specialist care model, where follow-up care occurs in an oncology setting and is provided by an oncology treatment team. A few institutions engaged multidisciplinary teams, which typically involved specialty providers with expertise in cardiology, endocrinology, neurology, audiology, nutrition, and developmental-behavioral pediatrics. The panelists shared that the approaches were largely reactive rather than preventive. Most acknowledged that the screening efforts were insufficient and that survivors who developed symptoms of late effects were then referred to subspecialists.

**TABLE 1.** Major Themes and Selected Quotes

Theme	Quotations
Current models of care	<p><i>“Our protocols for long-term follow-up service are still not comprehensive... For example, we do not know what medications or treatments to offer for certain late effects... And sufficient screening isn't provided for patients.”</i> (Expert panelist 2)</p> <p><i>“In our pediatric hospital, we see our patients until they turn 18 years old, maximum 20 years old. After that, we need to refer them to specialties from other community hospitals... that's how we lose them (to follow-up).”</i> (Expert panelist 5)</p> <p><i>“We use QQ and WeChat (online messaging platforms) to arrange for follow-up appointments... very effective and popular, simple for everyone.”</i> (Expert panelist 8)</p> <p><i>“We prepared questionnaires to ask about survivors' health and psychosocial status, very much similar to what's done at St Jude (referring to St Jude Children's Research Hospital, Memphis).”</i> (Expert panelist 12)</p>
Identification of high-priority late effects	<p><i>“If one institution has the infrastructure in place and has no problem performing screening for all late effects... that is great! However, other institutions can also decide which late effects they want to prioritize, or they can choose to forego certain late effects if they find that the screening strategies are hard to implement. This harmonized set of guidelines may help us make these decisions.”</i> (Expert panelist 2)</p> <p><i>“We can look at some projects (on late effects) that we could do together, even though each unit (institution) may have a different structure or setting. For example, we are a specialized unit and we are strong in a particular area. However, there are other units with different focuses. I hope that we can share a standard version of a (guideline) for monitoring late effects. It need not be too comprehensive; otherwise, many units may not be able to follow it. It would be good if the guideline were simple so that everyone can try to do it. Institutions can do a lot of meaningful work based on this table (Delphi survey results), and it could be implemented in several phases...”</i> (Expert panelist 4)</p> <p><i>“Blood tests and surveys are relatively easier to manage, as compared to imaging tests.”</i> (Expert panelist 9)</p>

Most institutions targeted pediatric survivors, as well as other survivors, within 5-10 years post-treatment, regardless of the cancer diagnosis. Some experts were concerned that their institutions could only provide care until the survivor reached 18 years of age, after which there was no system in place to provide continual care for adult survivors. During follow-up visits, the most frequently provided assessments included blood tests to evaluate endocrine function, cardiac imaging, audiologic evaluation, and bone mineral density assessments.

Technology has been adopted to facilitate the follow-up process and thus optimize survivorship care. The patients' appointments are arranged using QQ or WeChat, the two most popular communication and social media platforms in mainland China. One institution had developed a designated mobile application to help survivors coordinate their follow-up care.

### Theme 2: Identification of High-Priority Late Effects

Based on the Delphi surveys, five types of high-priority long-term effects were identified: (1) musculoskeletal (osteonecrosis and osteoporosis), (2) cardiovascular (left ventricular dysfunction), (3) secondary malignant neoplasms (treatment-related CNS tumor and acute myeloid leukemia), (4) endocrinopathy (gonadal dysfunction and growth hormone deficiency), and (5) neurocognitive deficits (Table 2).

Several areas of interest and strategies for implementation were discussed by the focus group (Table 1). Generally, the panelists advised that the working group should initially target only three to five late effects for harmonization. Preferably, these late effects would be those for which the surveillance methods were familiar to clinicians and could be administered feasibly in a clinical setting. Subsequently, harmonization could be extended gradually to additional long-term effects (Table 1).

Panelists indicated that collaborations between hospitals could be feasible. Collaborations that involve the CCCG network would warrant approval from the scientific committee. Cardiovascular, endocrine, and psychosocial outcomes were identified as high-priority late effects based on the collective consensus of the panel.

### Theme 3: Barriers to Implementing Survivorship Programs

After the first round of the Delphi survey, the panel identified 15 barriers to survivorship care (Fig 2).

**Clinician-related barriers.** The Delphi survey revealed that the rehabilitation teams in the panelists' institutions or healthcare systems lacked expertise in LTFU care of childhood cancer survivors ( $n = 10/12$ , 83.3%) (Fig 2). Additionally, the oncology teams did not have adequate time to coordinate and provide this type of care ( $n = 7/12$ , 58%). One of the strongest barriers was the lack of time to provide LTFU care as the experts already carried a heavy patient load in addition to teaching and administrative commitments (Table 3).

**Patient-related barriers.** Concerns about privacy issues, a lack of awareness of late effects, and a failure to appreciate the importance of LTFU care were identified as major patient-related barriers (Fig 2). Half of the expert panelists perceived that the patients' lack of awareness of late effects affected their motivation to participate in surveillance care. This phenomenon was especially apparent in survivors who were asymptomatic. Others expressed concern that survivors avoided visiting their physicians because they were afraid of being diagnosed with late effects. Additionally, high default rates were noted at the LTFU clinics. Another panelist also related that some survivors' family members went to great lengths to move on with life and avoid being contacted by the treating oncology team. Patients who live

**TABLE 2.** Final Delphi Survey Results (N = 12)

Late Effects Identified From Round 1 of Delphi Survey	Prevalence <sup>a</sup>	Severity <sup>b</sup>	Priority <sup>c</sup>
	High-Very High (4-5)	Severe-Very Severe (4-5)	High-Very High (4-5)
<b>Cardiovascular disease</b>			
Arrhythmias	7 (58.3)	4 (33.3)	4 (33.3)
Carotid artery disease	0	5 (41.7)	4 (33.3)
Left ventricular dysfunction <sup>d</sup>	3 (25)	9 (75)	10 (83.3)
<b>Secondary malignant neoplasms</b>			
Acute myeloid leukemia <sup>d</sup>	2 (16.7)	8 (66.7)	7 (58.3)
CNS tumor (malignant) <sup>d</sup>	2 (16.7)	9 (75)	7 (58.3)
Colorectal cancer	0	7 (58.3)	4 (33.3)
<b>Bone abnormalities</b>			
Osteonecrosis <sup>d</sup>	1 (8.3)	10 (83.3)	10 (83.3)
Osteoporosis <sup>d</sup>	10 (83.3)	5 (41.7)	6 (50)
<b>Endocrine abnormalities</b>			
Gonadal dysfunction (ovarian) <sup>d</sup>	3 (25)	6 (50)	7 (58.3)
Gonadal dysfunction (testicular) <sup>d</sup>	3 (25)	6 (50)	7 (58.3)
Growth hormone deficiency <sup>d</sup>	0	6 (50)	6 (50)
Insulin resistance	2 (16.7)	6 (50)	4 (33.3)
Thyroid dysfunction	2 (16.7)	5 (41.7)	5 (41.7)
<b>Pulmonary toxicity</b>			
Diffusion capacity impairment	2 (16.7)	5 (41.7)	7 (58.3)
Obstructive lung disease	2 (16.7)	3 (25)	5 (41.7)
Restrictive lung disease	1 (8.3)	4 (33.3)	8 (66.7)
<b>Renal toxicity</b>			
Glomerular injury	1 (8.3)	4 (33.3)	4 (33.3)
Tubular injury	1 (8.3)	3 (25)	4 (33.3)
<b>Ocular toxicity</b>			
Retinopathy	0	6 (50)	4 (33.3)
Hearing disabilities	2 (16.7)	5 (41.7)	4 (33.3)
<b>Psychosocial problems</b>			
Behavioral disorders	3 (25)	4 (33.3)	6 (50)
Fatigue	3 (25)	2 (16.7)	4 (33.3)
Mental health disorders	2 (16.7)	4 (33.3)	7 (58.3)
Neurocognitive deficits <sup>d</sup>	1 (8.3)	7 (58.3)	6 (50)

<sup>a</sup>Rating scale of 4 (high prevalence) to 5 (very high prevalence).

<sup>b</sup>Rating scale of 4 (between moderate to severe) to 5 (severe).

<sup>c</sup>Rating scale of 4 (high priority) to 5 (very high priority).

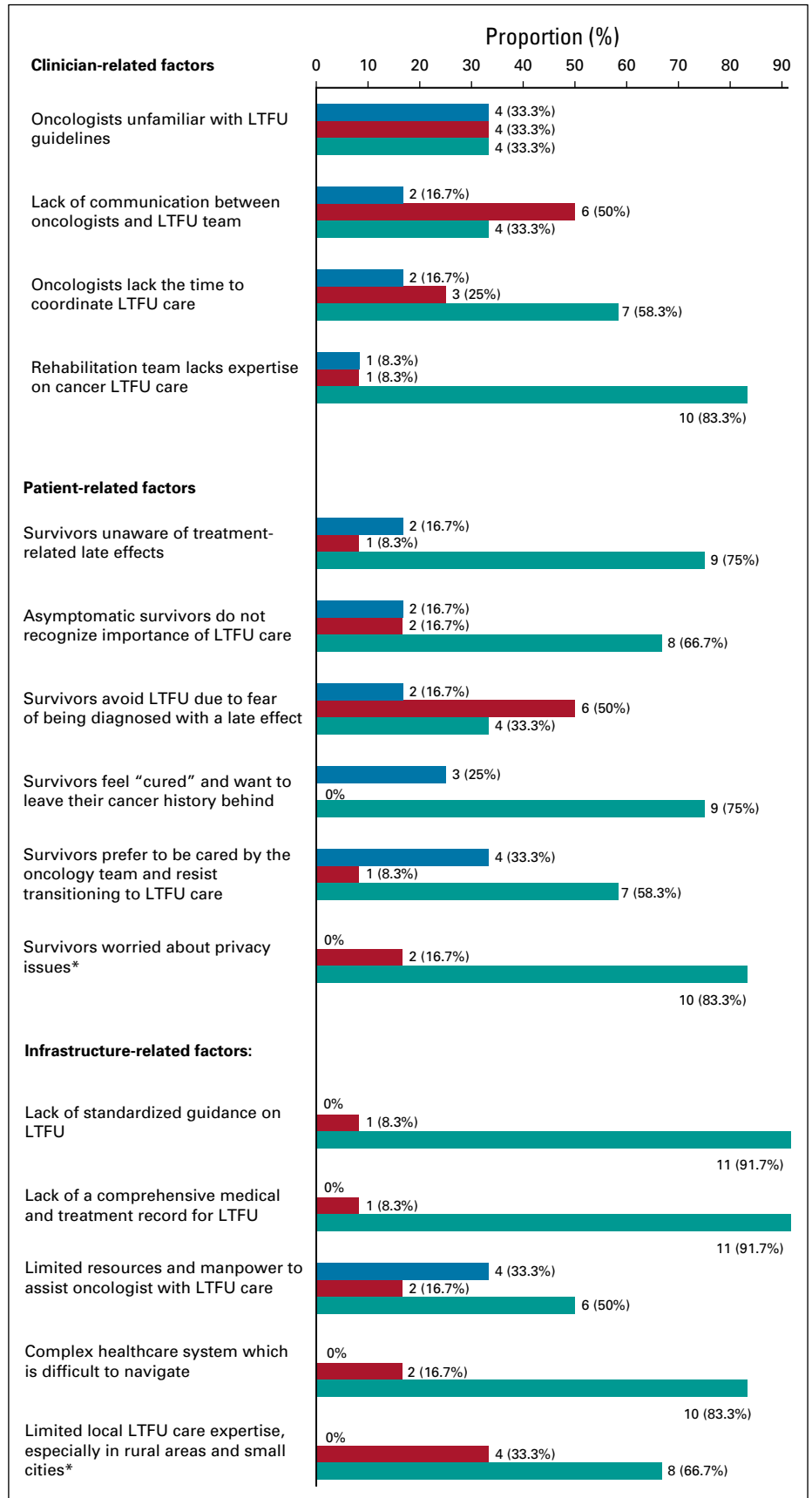
<sup>d</sup>Refers to late effects that  $\geq 50\%$  of the respondents indicated either high-very high prevalence (prevalence score  $\geq 4$ ) or severe-very severe (severity score  $\geq 4$ ); AND  $\geq 50\%$  of the respondents high-very high priority (priority score  $\geq 4$ ).

in rural areas may have financial hardships that prevent them from attending an LTFU clinic (Table 3).

**Infrastructure-related barriers.** Almost all experts indicated that a lack of standardized guidance for monitoring late effects in cancer survivors (n = 11/12, 91.7%) and a lack of comprehensive medical records (n = 11/12, 91.7%) were the major challenges to the implementation of a cancer survivorship program. These barriers were followed by

challenges imposed by complex healthcare systems, which are difficult to navigate (n = 10/12, 83.3%).

Clinicians found it difficult to provide LTFU care to survivors who resided in other cities related to lack of access to a patient's complete medical records. There is no existing infrastructure to help clinicians with the retrieval of patients' medical information from other institutions. Furthermore, other institutions may not be willing to release patient



**FIG 2.** Barriers to implementation of survivorship program (N = 12). Blue bars: barriers not relevant at all to my local practice. Red bars: barriers somewhat relevant to my local practice. Turquoise green bars: barriers highly relevant to my local practice. LTFU, long-term follow-up. \*These barriers were newly identified after the first round of Delphi survey.

**TABLE 3.** Subthemes and Selected Quotes for the Major Theme “Barriers to Implementing Survivorship Programs”

Subthemes	Quotations
Clinician-related barriers	<p>“There is insufficient manpower. Our hospital has more than 160 beds spread across four floors in the hospital, but there are only 15 attending clinicians. We must also undertake teaching and outpatient duties. There is just no time for survivorship services.” (Expert panelist 2)</p> <p>“Our clinics are so packed. We see more than 50 patients and survivors within one afternoon. We will definitely give more time to patients (versus survivors). There is no time to counsel them (survivors) about lifestyle modification or good health behaviors... Just have to assume that they know.” (Expert panelist 9)</p> <p>“We are a specialized medical institution. Our colleagues do not do much survivorship care. We need to refer our patients out. But where to refer them to?” (Expert panelist 11)</p>
Patient-related barriers	<p>“The family members of the childhood cancer survivors may avoid the fact that their child has a history of cancer. Some of them will change his/her name and phone number after completing the treatment... then we are not able to contact them... Financial problems are also one of the barriers; many patients are from other cities or rural areas...where they are particularly poor. They may have to spend more than a thousand yuen (USD 150) to come to our institution for a follow-up...” (Expert panelist 2)</p> <p>“... They (family members of the survivors) don't want to be contacted again after they have completed all the chemotherapy treatments. In one retrospective study that we did recently, we found that only 110/274 (40.1%) were willing to come back for monitoring and evaluation after completing chemotherapies. They were afraid to face the reality that something bad might happen to them... for example (some late effects), or second malignancies or some endocrine disorders... that is why we cannot enroll all patients in our survivorship program.” (Expert panelist 4)</p> <p>“Very tough to get patients to pay for something that they see as ‘non-essential’ (referring to screening tests for asymptomatic health conditions)...” (Expert panelist 7)</p>
Infrastructure-related barriers	<p>“As our hospital is a specialized hematology hospital, we do not have centers or equipment for the management of other problems such as cardiac problems. We need to refer these patients to other hospitals. I think that is a big problem for us... Besides, most of our patients come from other cities (not from local areas), so when they have new health problems, we cannot get the exact details about what had happened to them” (Expert panelist 3)</p> <p>“The support from my institution is not strong... Our leaders assume that they have invested a lot of resources and money to support our hematology and oncology department, but in fact, these resources do not factor in survivorship services. We are not able to monitor all patients because we do not have specific monitoring machines or other instruments for these patients.” (Expert panelist 4)</p>

Abbreviation: USD, US dollars.

records to the LTFU care team. Most of the expert panelists agreed that limited resources and a lack of standardized guidelines are major barriers to implementing survivorship services. Some oncology centers have limited subspecialty services and would need to refer some patients to other tertiary institutions. A lack of leadership support also creates additional challenges when developing LTFU services (Table 3).

## DISCUSSION

Childhood cancer is increasingly recognized as an emerging healthcare issue by the Chinese government and researchers, and efforts to improve the survival rates of children with cancer have achieved a notable degree of success. Despite the many challenges identified in this study, several factors in China favor the provision of quality survivorship care and the achievement of research advances in this field. The working group proposes the following four enablers for the successful implementation of comprehensive survivorship programs in China. These enablers include (1) prioritizing specific late effects that warrant screening and harmonization, (2) establishing collaborations between treating oncologists and general practitioners within the community, (3) harnessing technology, and (4) educating survivors about the health benefits of survivorship care.

The first enabler is to prioritize the specific late effects of interest. Existing constraints within the current clinical

setting and healthcare system limit the implementation of all aspects of risk-based guidelines. Several important factors should be considered, including insurance reimbursement policies for screening tests, available resources, and labor constraints in the healthcare field.<sup>22</sup> For example, cardio-oncology research has demonstrated that survivors who had been exposed to moderate to high cumulative doses of anthracyclines do not manifest clinical symptoms of cardiovascular abnormalities until later in life.<sup>23</sup> Accordingly, the public healthcare system may rate such asymptomatic individuals as low priority, and an echocardiography procedure may not be scheduled for months or even years. This problem is especially prevalent in Hong Kong, as the highly subsidized medical services by the government have resulted in heavy patient load at public hospitals. One potential solution is to broaden medical insurance coverage and promote public-private partnership<sup>24</sup> such that survivors of cancer can undergo essential screening tests in private institutions without weighing down public facilities. In a resource-limited setting, the working group also considered prioritizing more intensive LTFU for subgroups of survivors who are at the highest risk for developing late effects,<sup>25</sup> such as survivors who underwent cranial radiation or hematopoietic stem cell transplantation.

We have successfully identified cardiovascular, endocrine, and psychosocial complications as high-priority late effects that are either clinically prevalent or sufficiently severe to



warrant harmonization. Moving forward, the working group will review the existing guidelines and recommend the most feasible strategies for screening these late effects. For example, most endocrine late effects could be screened systematically across institutions at reasonably low financial and labor expenditures using endocrine laboratory tests and physical examination. However, the current lack of certified neuropsychologists and heavy patient load in China may hinder the implementation of related cognitive screening strategies.<sup>26,27</sup> To address this limitation, we propose to translate and culturally adapt self-reported measures, such as the Childhood Cancer Survivor Study-Neurocognitive Questionnaire,<sup>28,29</sup> which has been used widely for screening neurocognitive impairment in large epidemiologic studies involving survivors of childhood cancer in the United States.<sup>30,31</sup> Additionally, subsequent work should also target at policymakers and negotiate for the reimbursement of other screening tests by the national healthcare insurance system in China, such as echocardiogram for high-risk survivors who underwent cardiotoxic therapies (anthracycline dose of more than 250 mg/m<sup>2</sup>, total body irradiation, and radiation with potential impact to the heart).

The second enabler is to establish collaboration between treating oncologists and designated general practitioners within the community. Many institutions within the CCCC are specialized oncology centers or tertiary public hospitals located in the large cities of China. However, the patients treated at these institutions may reside in small cities or rural areas. Often, it is not practical for survivors and their families to travel several hundred miles for LTFU care. Therefore, the working group proposes that survivorship care should be delegated to primary care providers (PCP) or general practitioners, rather than oncology providers. PCPs may play important roles in conducting primary screening for late effects, promoting protective health behaviors, and referring survivors for more specialized care when required.

Many international oncology groups now emphasize the importance of early integration of PCPs into the provision of survivorship services.<sup>32-34</sup> As the expert panel highlighted Chinese survivors' reluctance to transition to long-term care, the concept of shared care should be introduced early during the active treatment phase, and the unique roles and responsibilities of the primary oncology team and PCP should be delineated. One recent study on 200 parents and survivors of childhood cancer in Hong Kong revealed that most respondents preferred to discuss survivorship issues at the time of cancer treatment initiation rather than after the completion of treatment.<sup>35</sup> To facilitate the programmatic success of this model, the COG has even developed templates and guidelines to better equip PCPs to address the health needs of survivors.<sup>36</sup> Notably, China has been working toward improving the quality of rural health services since the late 2000s.<sup>37</sup> Policy-makers and stakeholders can facilitate this progress by establishing

sustainable collaborations between oncology centers and community-level institutions.

The third enabler is to harness technology to optimize survivorship care. In recent years, China's ability to exploit technology for public health agendas and healthcare delivery has been exceptionally effective. In one excellent example, China deployed artificial intelligence to track and report transmissions during the recent COVID-19 outbreak.<sup>38,39</sup> One report highlighted the successful establishment of internet hospitals that cover 21 municipalities in the Guangdong province.<sup>40</sup> At an institutional level, the systematized and digitized collection of health data may also address the expert panel's concerns regarding incomplete treatment records and the sharing of medical information between oncologists and PCPs.

At the patient level, many studies have demonstrated the benefits of harnessing technology to promote cost-effective methods for the delivery of medical information, social support, and interventions to large numbers of cancer survivors.<sup>41-43</sup> The benefits of such mobile health initiatives could be applied to the emerging field of patient-reported outcomes (PRO) in cancer survivorship. The cumulative evidence suggests that routine PRO monitoring with timely feedback enhances patient-provider communications and improves cancer-related symptom detection.<sup>44,45</sup> China has a high rates of internet penetration and digital literacy among adolescents and young adults and is therefore a fertile ground for testing the effects of telehealth on patient health behaviors.

The fourth enabler is to educate patients and families about late effects and health benefits of survivorship care. A large majority of the expert panel members highlighted patients' reluctance to participate in follow-up because of a limited awareness of the potential late effects. These phenomena were particularly evident in asymptomatic patients during the early phase of survivorship. These barriers are concerning, as poor surveillance may render survivors at risk of missing the early signs of a cancer recurrence and/or secondary malignancy. Although few reports have discussed the health behaviors of childhood cancer survivors in China, the existing data obtained from the adult cancer population are alarming. One study involving 1,632 Chinese male survivors of cancer determined that 45% were current smokers at a mean follow-up of 5.3 ( $\pm$  4.8) years after the cancer diagnosis.<sup>46</sup> The rate of tobacco smoking in China is among the highest in Asia.<sup>47,48</sup> This observation underscores the importance of engaging patients in educational and risk-reduction programs during the post-treatment period and the transition to survivorship.<sup>49,50</sup>

We propose that a strategy to improve cancer survivorship-related knowledge among Chinese survivors should first involve taking advantage of existing resources developed by the COG and IGHG. In May 2020, the working group (led by H.Z. and Y.T.C.) collaborated with the COG and launched

traditional and simplified Chinese versions of the Health Links patient education materials.<sup>8</sup> To the best of our knowledge, this is the first set of publicly available authoritative resources on late effects available in a native Chinese language. The second approach should leverage support from nongovernmental organizations (NGOs) that play active roles as patient advocates in China. Specifically, NGOs promoted educational talks, provided psychosocial support, and implemented basic screening services at sites that are easily accessible to survivors.

The findings of this study have several limitations. First, this study only included a small number of expert panelists. The CCCG includes more than 20 institutions, and therefore, the purposive sampling approach to recruitment has certainly overlooked some programs. We deliberately selected representatives from major institutions, as these city-level hospitals would likely have a stable infrastructure to organize regional survivorship programs and provide resources to smaller district-level hospitals. Given the nascent state of the field, we speculate that the identified barriers and enablers are generally reflective of the current state of the discipline in China on a macro level. However, we expect institutions within the urban and rural healthcare systems to differ in terms of resources, clinical workload, and accessibility to medical technology. As smaller institutions are often underrepresented in studies, more efforts should be targeted at unveiling the specific challenges and needs of the district-level hospitals and medical centers in the rural areas. The Delphi survey provides us preliminary direction on high-priority late effects; future work includes gaining consensus from a larger group of clinicians with different specialties in hematologic malignancies, solid

tumors, pediatric surgery, radiology etc. Respondents rated the prevalence and severity of late effects based on their clinical experience; epidemiologic studies are needed to quantify and characterize adverse outcomes related to specific therapies in Chinese survivors of childhood cancer. Furthermore, social desirability might have influenced each expert's description of the survivorship program at their institution during the focus group discussion. However, our findings revealed that the representatives were forthcoming in their discussions of the challenges to programmatic success, likely related to their desire improve the current state of childhood cancer care within the region.

Finally, we acknowledge that China is a geographically large region, and differences in resources and constraints must inevitably exist across institutions within the CCCG. Therefore, we emphasize that the development of this clinical consensus does not necessarily mean that this guideline must or will be implemented in practice by every institution. Each institution should be given the autonomy to modify or adapt the guideline according to its own timeline and setting. However, on a macro level, we hope that this type of initiative can help to optimize the implementation of future guidelines by first identifying obstacles related to the professional setting, patient behavior, organization of care, and available resources.

In conclusion, the initiation of this national endeavor toward guideline harmonization represents the first step in optimizing the collaborative process of guideline development within China. We anticipate that this approach will reduce duplication of effort and facilitate opportunities for research collaborations aiming to improve the quality of care for childhood and adolescent cancer survivors.

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Y.T.C., H.Z., and J.C. contributed equally to the work.

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## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The following represents disclosure information provided by authors of this manuscript. All relationships are considered compensated unless otherwise noted. Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. Relationships may not relate to the

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**APPENDIX**

**TABLE A1.** Late Effects Included in the Delphi Survey

Late Effects <sup>a</sup>
Cardiovascular disease
Arrhythmias
Cardiac valvular abnormalities
Carotid artery disease
Coronary artery disease
Pericardial disease
LV dysfunction
Secondary malignant neoplasms
Breast cancer
Acute myeloid leukemia
Bladder cancer
Cervical cancer
CNS tumor (benign)
CNS tumor (malignant)
Colorectal cancer
Endometrial cancer
Kidney cancer
Lung cancer
Melanoma
Nonmelanoma skin cancer
Oral cancer
Prostate cancer
Testicular cancer
Thyroid cancer
Bone abnormalities
Osteonecrosis
Osteoporosis
Endocrine abnormalities
Adrenal dysfunction
Gonadal dysfunction (ovarian)
Gonadal dysfunction (testicular)
Growth hormone deficiency
Insulin resistance
Thyroid dysfunction
Pulmonary toxicity
Diffusion capacity impairment
Obstructive lung disease
Restrictive lung disease
Renal toxicity
Glomerular injury
Tubular injury

(Continued in next column)

**TABLE A1.** Late Effects Included in the Delphi Survey (Continued)

Late Effects <sup>a</sup>
Hepatic toxicity
Biliary tract disease
Cellular liver injury
Ocular toxicity
Cataract
Retinopathy
Hearing disabilities
Dental abnormalities
Psychosocial problems
Behavioral disorders
Fatigue
Mental health disorders
Neurocognitive deficits

Abbreviation: LV, left ventricle.

<sup>a</sup>The Delphi survey (late effects) was adapted from a report published by the International Late Effects of Childhood Cancer Guideline Harmonization Group.

**TABLE A2.** Barriers to Implementation of Survivorship Program

Barriers
Clinician-related factors
Oncologists themselves may be unfamiliar with the ongoing needs of cancer survivors, including cancer-related health risks, screening guidelines, and risk-reduction methods.
Barriers to communication between the oncology team and the external care team may inhibit the provision of quality survivorship care.
Oncologists often lack the time to coordinate needed for long-term follow-up care.
The extended rehabilitation community may lack education and expertise or awareness of cancer survivorship issues.
Patient-related factors
Survivors may be unaware of late- or long-term effects of cancer treatment and unlikely to seek follow-up care.
Asymptomatic survivors may not realize the importance of ongoing follow-up care.
Patient fear of another cancer diagnosis or of being diagnosed with a serious late effect of treatment may stop them from seeking appropriate follow-up care.
Many patients desire to feel cured and to leave the cancer diagnosis in the past, which may inhibit a survivor from seeking follow-up care.
Survivors at low risk of recurrence and late effects may overestimate the need for ongoing oncology care and find it difficult to transit to the primary care practitioners.
Infrastructure-related factors
There is a lack of standardized guidance for the assessment and management of long-term and late effects.
There is a lack of standardized guidance for modes of communication and medical record technology.
There may be limited local resources to assist oncologists and others in the care team with providing follow-up care.
The healthcare system requires independence and self-advocacy skills to effectively navigate it and secure services. Not all individuals are equipped with these abilities and skills.

American Society of Clinical Oncology: Challenges to Implementing a Survivorship Program. <https://www.asco.org/practice-policy/cancer-care-initiatives/prevention-survivorship/survivorship/survivorship-4>.

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**TABLE A3.** The COREQ 32-Item Checklist for Reporting Qualitative Studies

	Item	Description	Page
Domain 1: research team and reflexivity			
Personal characteristics			
1.	Interviewer or facilitator	H.Z. and Y.T.C.	4
2.	Credentials	Team consists of researchers with credentials: MBBS, MD, PhD, B(Pharm), and B(Public Health). Presented in title page	Title page
3.	Occupation	Teams consists of pediatric oncologists and hematologists, pharmacists, and research methodologists	2
4.	Sex	Not relevant to the study objectives.	NA
5.	Experience and training	Team consists of researchers with training in pediatric oncology and hematology, pediatric cancer survivorship, clinical pharmacy, biostatistics, and research methodology (quantitative and qualitative)	2
Relationship with participants			
6.	Relationship established	No relationship between the researchers and the participants was established before study commencement. However, participants and researchers do know each other on a professional level.	NA
7.	Participant knowledge of the interviewer	Participants and interviewers do know each other on a professional level.	NA
8.	Interviewer characteristics	The general aim of the study was briefly made known to the participants before the focus group discussion.	4
Domain 2: study design			
Theoretical framework			
9.	Methodologic orientation and theory	Grounded theory was used.	4
Participant selection			
10.	Sampling	Purposive sampling was adopted.	2
11.	Method of approach	Approached via email and met face-to-face for focus group discussion.	2
12.	Sample size	12	2
13.	Nonparticipation	All preidentified expert panelists agreed to participate in the study.	2
Setting			
14.	Setting of data collection	Focus group discussion was held in a closed-door meeting.	4
15.	Presence of nonparticipants	Only the participants and interviewers were present.	4
16.	Description of sample	Inclusion criteria presented in Methods section.	2
Data collection			
17.	Interview guide	Questions were asked based on the Delphi survey findings.	4
18.	Repeat interviews	No repeat interviews.	NA
19.	Audio or visual recording	Audio recording was used.	4
20.	Field notes	Field notes were made by the interviewers.	4
21.	Duration	90 min	4
22.	Data saturation	Not applicable.	NA
23.	Transcripts returned	Transcripts were not returned to participants. However, the report was shared with the participants.	NA
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	2 independent data coders and 1 third coder to resolve discrepancies.	4
25.	Description of the coding tree	Described under "Data analysis."	4
26.	Derivation of themes	Themes were derived from the data.	4
27.	Software	(ATLAS).ti 8	4
28.	Participant checking	The report was shared with the participants.	NA

(Continued on following page)

**TABLE A3.** The COREQ 32-Item Checklist for Reporting Qualitative Studies (Continued)

	<b>Item</b>	<b>Description</b>	<b>Page</b>
	Reporting		
29.	Quotations presented	Participant quotations were presented to illustrate the themes or findings. Participants were identified by a participant number.	Results section
30.	Data and findings consistent	There is consistency between data and findings. We also identified consistency between the qualitative data and the Delphi survey results.	Results section
31.	Clarity of major themes	The 3 major themes were presented as subsections (“theme 1,” “theme 2,” and “theme 3”) in the narrative.	Results section
32.	Clarity of minor themes	Minor themes were presented under the 3 major themes in the narrative.	Results section

Developed from [ref. 21](#).