




## ORIGINAL ARTICLE

## Managing low-risk febrile neutropenia in children in the time of COVID-19: What matters to parents and clinicians

Gabrielle M Haeusler,<sup>1,2,3,4,5,6</sup> Richard De Abreu Lourenco,<sup>7</sup> Cindy Bakos,<sup>8</sup> Tracey O'Brien,<sup>9,10</sup> Monica A Slavin,<sup>1,2,3,11</sup> Julia E Clark,<sup>12</sup> Brendan McMullan ,<sup>2,10,13</sup> Meredith L Borland,<sup>14,15,16</sup> Franz E Babl ,<sup>6,17,18</sup> Meinir Krishnasamy,<sup>2,3,19,20</sup> Marijana Vanevski ,<sup>1,2,6</sup> Karin A Thursky<sup>1,2,3,11,21</sup> and Lisa Hall<sup>2,22</sup>

<sup>1</sup>Department of Infectious Diseases, <sup>19</sup>Academic Nursing Unit, Peter MacCallum Cancer Centre, Departments of <sup>2</sup>NHMRC National Centre for Infections in Cancer, Sir Peter MacCallum Department of Oncology, <sup>3</sup>Sir Peter MacCallum Department of Oncology, <sup>11</sup>Medicine, <sup>18</sup>Paediatrics, Faculty of Medicine, Dentistry and Health Sciences, <sup>20</sup>Nursing, University of Melbourne, <sup>4</sup>The Paediatric Integrated Cancer Service, <sup>5</sup>Infection Diseases Unit, Department of General Medicine, <sup>17</sup>Department of Emergency Medicine, Royal Children's Hospital, <sup>6</sup>Department of Infectious Diseases, Murdoch Children's Research Institute, <sup>8</sup>Little Big Steps, <sup>21</sup>NHMRC National Centre for Antimicrobial Stewardship, The Peter Doherty Institute for Infection and Immunity, Melbourne, Victoria, <sup>7</sup>Centre for Health Economics Research and Evaluation, University of Technology Sydney, <sup>9</sup>Kids Cancer Centre, <sup>13</sup>Department of Immunology and Infectious Diseases, Sydney Children's Hospital, <sup>10</sup>School of Women's and Children's Health, Faculty of Medicine, University of New South Wales, Sydney, New South Wales, <sup>12</sup>Infection Management Service, Queensland Children's Hospital and Centre for Children's Health Research, CHQ, <sup>22</sup>School of Public Health, Faculty of Medicine, University of Queensland, Brisbane, Queensland, <sup>14</sup>Department of Emergency Medicine, Perth Children's Hospital, <sup>16</sup>Divisions of Paediatrics and Emergency Medicine, School of Medicine, University of Western Australia, Perth and <sup>15</sup>Emergency Department, Perth Children's Hospital, Nedlands, Perth, Western Australia, Australia

**Aim:** The Australian 'There is no place like home' project is implementing a paediatric low-risk febrile neutropenia (FN) programme across eight paediatric hospitals. We sought to identify the impact of the coronavirus disease 2019 (COVID-19) pandemic on programme implementation.

**Methods:** Paediatric oncology, infectious diseases and emergency medicine health-care workers and parent/carers were surveyed to explore the impact of the COVID-19 pandemic on home-based FN care. Online surveys were distributed nationally to health-care workers involved in care of children with FN and to parents or carers of children with cancer.

**Results:** Surveys were completed by 78 health-care workers and 32 parents/carers. Overall, 95% of health-care workers had confidence in the safety of home-based FN care, with 35% reporting changes at their own hospitals in response to the pandemic that made them more comfortable with this model. Compared to pre-pandemic, >50% of parent/carers were now more worried about attending the hospital with their child and >80% were interested in receiving home-based FN care. Among both groups, increased telehealth access and acceptance of home-based care, improved patient quality of life and reduced risk of nosocomial infection were identified as programme enablers, while re-direction of resources due to COVID-19 and challenges in implementing change during a crisis were potential barriers.

**Conclusion:** There is strong clinician and parent/carer support for home-based management of low-risk FN across Australia. Changes made to the delivery of cancer care in response to the pandemic have generally increased acceptance for home-based treatments and opportunities exist to leverage these to refine the low-risk FN programme.

**Key words:** cancer; COVID-19; febrile neutropenia; home-based care; low risk.

### What is already known on this topic

- 1 Home-based management of low-risk febrile neutropenia (FN) using a structured programme with appropriate follow-up and oversight is safe, improves quality of life and reduces health-care costs.
- 2 A formal low-risk FN programme is currently being implemented across many paediatric oncology centres in Australia.

### What this paper adds

- 1 The coronavirus disease 2019 pandemic has altered models of health-care delivery and parent/carer perceptions of care.
- 2 Home-based management of FN care is generally well accepted among clinicians and parents/carers provided appropriate infrastructure and safety nets are in place.
- 3 Behaviours and health-care system changes adopted during the pandemic may strengthen longer term acceptance of alternative models of care.

**Correspondence:** Dr Gabrielle M Haeusler, Department of Infectious Diseases, Peter MacCallum Cancer Centre, 305 Grattan Street, Melbourne, VIC 3000, Australia. Fax: +61 3 9656 1185; email: gabrielle.haeusler@petermac.org

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Home-based management of children with cancer and febrile neutropenia (FN) who are at low risk for serious infection is safe, improves quality of life (QoL) and reduces costs of care.<sup>1–3</sup> However, the clinical impact of low-risk FN programmes is contingent on the utilisation of a structured programme incorporating a validated risk stratification tool and appropriate safety nets.<sup>4</sup>

Similarly, low-risk FN programmes should be monitored for compliance and outcomes and to identify barriers to the delivery of timely and safe care.<sup>5</sup> The Australian 'There is no place like home' project is implementing a low-risk FN programme across eight tertiary paediatric hospitals in Australia (ACTRN12616001440415). This builds on the results of the Australian Predicting Infectious Complications in Children with Cancer (PICNICC) study and will enable children with cancer across the country to benefit from this model of care.<sup>6</sup>

The global pandemic caused by SARS-CoV-2, commonly referred to as coronavirus disease 2019 (COVID-19), has led to changes in the way many patients with chronic illness access health-care services. As the pandemic continues to evolve in Australia, these changes have been implemented rapidly, and the impacts on existing and emerging care pathways remain largely unknown. However, 'amidst the chaos there may be some seeds of opportunity',<sup>7</sup> including improving how home-based or ambulatory care is delivered, as well as understanding the acceptability of this model to clinicians and patients alike.

A key component of the 'There is no place like home' study is to identify barriers and enablers to the acceptability, adoption and feasibility of a low-risk FN programme across Australia.<sup>8</sup> This study objective was to characterise the impact of the COVID-19 pandemic on the implementation of this programme and explore how changes to the delivery of cancer care may enhance or hinder uptake and sustainability of a low-risk FN programme.

**Table 1** Health-care worker and parent/carer demographic information

	Number (%)
<b>Health-care worker responses (n = 78)</b>	
State	
Victoria	17 (21.8)
New South Wales	16 (20.5)
Queensland	5 (6.4)
South Australia	8 (10.3)
Western Australia	32 (41.0)
Speciality	
Oncology	42 (53.8)
Infectious diseases	4 (5.1)
Emergency medicine	28 (35.9)
HITH	2 (2.6)
Pharmacy	2 (2.6)
Medical and nursing level	
Medical consultant	37 (47.4)
Medical JRMO (fellow, registrar, resident)	11 (14.1)
Nursing (NUM/ANUM)	6 (7.7)
Nurse specialist	10 (12.8)
Registered nurse	11 (14.1)
NA/missing	3 (3.8)
<b>Parent/carer responses (n = 32)</b>	
State	
Victoria	10 (31.3)
New South Wales	10 (31.3)
Queensland	8 (25.0)
Unknown	4 (12.4)
Child's cancer diagnosis	
Acute leukaemia	15 (46.9)
Lymphoma	3 (9.4)
Solid tumour	14 (43.8)
Treatment status	
Active treatment	11 (34.4)
Completed treatment in last 6 months	6 (18.8)
Completed treatment 6–12 months ago	5 (15.6)
Completed treatment >12 months ago	10 (31.3)
Number of FN episodes	
0 episodes	1 (3.1)
1–2 episodes	2 (6.3)
3 or more episodes	29 (90.6)

ANUM, Associate Nurse Unit Manager; FN, febrile neutropenia; HITH, hospital in the home; JRMO, Junior Resident Medical Officer; NA, Not applicable; NUM, Nurse Unit Manager.

## Methods

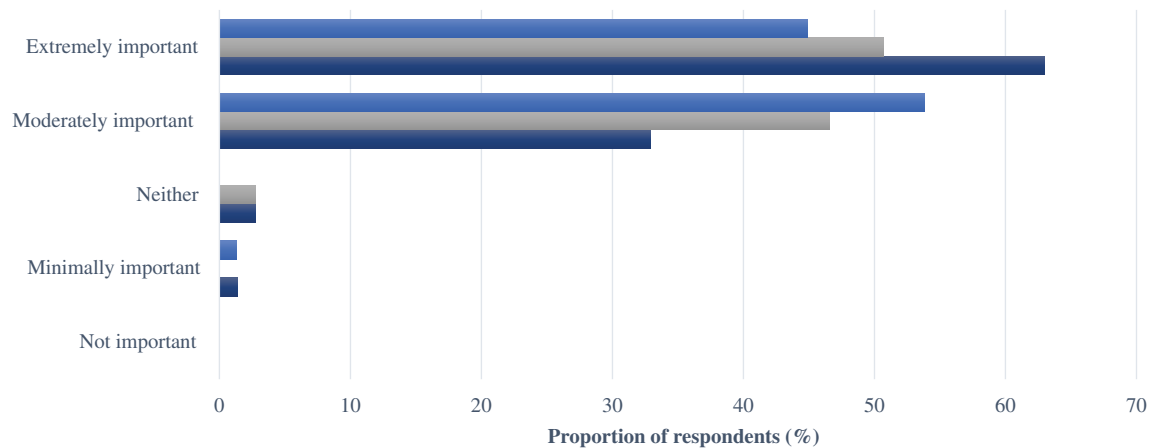
Separate surveys were developed for health-care workers and parent/carers of children with cancer. The health-care worker survey asked respondents to rate (5-point Likert scale) the perceived (i) importance of; (ii) confidence in, the low-risk programme prior to and during the COVID-19 pandemic; and (iii) the degree of difficulty in implementing the programme currently. Changes to the overall management of children with cancer and the impact of these on clinician acceptability of the low-risk programme were also explored via open-ended questions.

The parent/carer survey asked respondents to rate (5-point Likert): (i) how worried they were currently coming to hospital and (ii) how interested they were in home-based FN treatment prior to and during the COVID-19 pandemic. The survey also explored if parents/carers would now delay hospital presentation for FN and if there were any changes to care delivery they like to remain beyond the end of the pandemic. To provide additional context on parent/carer's risk perceptions of the COVID-19 pandemic, the 'Effective Communication in Outbreak Management for Europe (ECOM)' survey tool was adapted for use.<sup>9</sup> This survey explored parents' knowledge of COVID-19, understanding of risk and knowledge of effectiveness and willingness to perform preventative strategies.

Across both the health-care worker and parent/carer surveys, the option for additional comments and free text was provided. The project received ethics approval (HREC 62964) and completion of the surveys indicated consent to participate.

The health-care worker surveys were distributed electronically to clinicians involved in the care of children with cancer using a snowballing sampling technique. Survey links (REDCap) were sent to the primary investigator team at the eight FN programme implementation sites across Australia (between two and three people per site) with the request to also distribute to other relevant clinicians locally. Similarly, the parent surveys were distributed by the consumer representative (CB) using their own network or parents of children with cancer as well as local hospital consumer liaison channels (distribution list number unknown), with a request to distribute to other relevant contacts. The surveys were open for 1 month (12 June 2020–17 July 2020).

Summary statistics were used to represent demographic data and results of 5-point Likert scale questions. Comments and free-



**Fig 1** Importance of implementing or maintaining a low-risk febrile neutropenia programme (health-care worker perspective) (■, prior to pandemic; ■, during pandemic; ■, during pandemic (for patients)).

text fields were analysed thematically using an inductive approach to identify common themes.

## Results

Survey responses were received from 78 (complete 72, partial 6) health-care workers and 32 parents/carers (complete 28, partial 4). All eight low-risk FN programme implementation sites were represented in the health-care worker responses (median 7 responses/site, interquartile range 4–10). In contrast, parent and carer responses were only received from Victoria, New South Wales and Queensland (Table 1). Due to the snowballing sampling technique, a response rate was unable to be calculated.

### Health-care worker attitudes

Most health-care workers thought it was important to implement a low-risk FN programme, irrespective of the pandemic (Fig. 1). The perceived importance of this for their patients during the pandemic was rated highly, with 63% of health-care workers indicating they felt it was likely to be ‘extremely important’ to patients and families currently.

Regarding confidence in the suitability and safety of home-based care, irrespective of the COVID-19 pandemic, 14 (20%) health-care workers felt ‘completely confident’ and 54 (75%) felt ‘moderately confident’ (‘slightly confident’, 2; ‘impartial’, 2; incomplete, 6). Qualitative comments to this question are summarised in Table 2. The most common reasons cited for confidence in home-based care were availability of a structured programme, overall benefits to the patient being out of hospital, awareness of evidence to support this model and availability of an established hospital in the home (HITH) service. Factors negatively impacting confidence included lack of an HITH service or one with limited experience in managing oncology patients, being unaware of evidence to support home-based care and no anecdotal experience.

Twenty-five (35%) respondents reported changes to the overall management of children with cancer at their own hospitals in

response to the pandemic that made them ‘more comfortable’ with home-based care. Qualitative comments attributed this to increased availability and integration of telehealth and capacity of HITH or other ambulatory care services, efficiency of pathology or assessment pathways and acceptance of lower neutrophil thresholds for discharge. Only one respondent indicated that the changes made them less comfortable with home-based care and highlighted the potential limitations of telehealth for thorough and complete assessments.

Overall, 33 (42%) respondents thought it was now ‘easier’ and 13 (17%) now ‘more difficult’ to implement or maintain the low-risk FN programme (‘neither’, 26; incomplete, 6). Reasons for making it easier to implement included availability and acceptance of telehealth, increased acceptance of home-based care for oncology patients, executive-level support for innovative models of care and increased HITH capacity and resources available for programme. Reasons for the perceived increase in the difficulty to implement included a redirection of resources to COVID-19-related activities, requirement of change to practice during a crisis and limitations of telehealth for thorough and complete assessments.

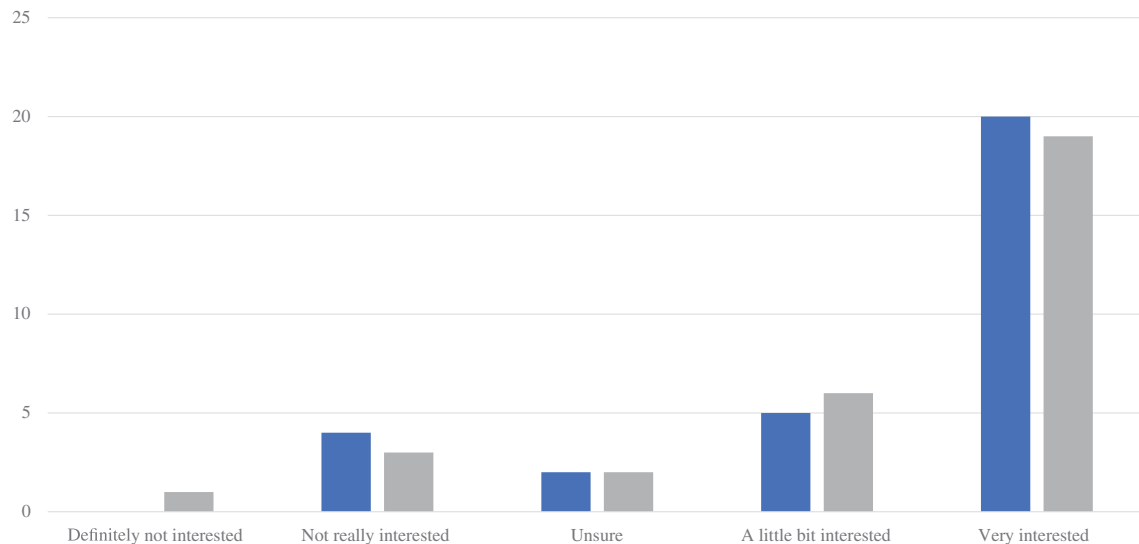
### Parent/carer attitudes

Compared to pre-pandemic, over half of the parent/carer respondents indicated they were now more worried about attending the hospital (38% much more worried; 25% a bit more worried; 31% about the same; 3% less worried; and 3% a lot less worried). The primary reason for this concern was a perceived risk of exposure to COVID-19 in hospital. Specific concerns were raised about asymptomatic carriers, close proximity of day-chemotherapy chairs, admission to dedicated COVID-19 wards, the higher prevalence of the virus in metropolitan areas and perceptions that other people were not adhering to preventative measures. Other reasons included the frequent COVID-19 testing of children causing high levels of distress and reduced support (i.e. only one carer allowed). Ten respondents felt ‘about the same level of worry’ due to confidence in their child’s hospital’s

**Table 2** Factors contributing to the overall health-care worker level of confidence in the suitability and safety of home-based febrile neutropenia (FN) care

Theme	Health-care worker quotes
Perceived benefits to patient and family	<ul style="list-style-type: none"> <li>• <i>It's always better to be managed at home than in hospital if it is safe to do so</i> (ED consultant)</li> <li>• <i>Home-based care may help to prevent hospital acquired infections and stress related to hospital admission</i> (ED resident)</li> <li>• <i>Important for patient quality of life to try and minimise hospital stay where possible</i> (oncology consultant)</li> <li>• <i>Reducing risk of nosocomial infections in susceptible patients</i> (ID consultant)</li> </ul>
Perceived benefits to the hospital	<ul style="list-style-type: none"> <li>• <i>I believe that a home based LRFN is extremely important whether there is a COVID-19 pandemic or not, as these children should be able to be easily managed in the safety and comfort of their home environment and not taking up valuable bed-space in a hospital setting</i> (oncology specialist nurse)</li> </ul>
Parent/carer health literacy	<ul style="list-style-type: none"> <li>• <i>Oncology parents are very motivated and usually well versed in medical lingo preparing them for at home management</i> (ED resident)</li> <li>• <i>Parents of high risk patients generally have a good insight on how sick their kids are and would be mostly able to make rational decision</i> (ED registrar)</li> <li>• <i>The parents would have difficulty monitoring regular observations and taking blood tests in the home environment in patients that are high risk for being unwell</i> (ED registrar)</li> <li>• <i>I would be concerned that patients won't re-present after they have been put on the home-based care due to their concern about COVID in the hospital</i> (oncology fellow)</li> </ul>
Health-care worker knowledge and understanding	<ul style="list-style-type: none"> <li>• <i>There has been extensive validation work done at my hospital and I am confident in the safety of the programme</i> (oncology consultant)</li> <li>• <i>International and national research has demonstrated safety</i> (HITH nurse)</li> <li>• <i>I know minimal information about what the home-based care of FN patients would look like</i> (ED consultant)</li> <li>• <i>I feel that our practice is lagging behind the evidence and the rest of the world</i> (ED consultant)</li> <li>• <i>I would need to know details about the programme and the resources provided to implement it</i> (ED consultant)</li> <li>• <i>I cannot be completely confident as I am aware I do not possess all the information. I realise people with more knowledge and experience have significant reservations</i> (ED consultant)</li> </ul>
Structured low-risk FN programme	<ul style="list-style-type: none"> <li>• <i>The programme is well thought out with clear guidelines and tools to use</i> (oncology specialist nurse)</li> <li>• <i>Safety criteria and guidelines in place to reduce inappropriate discharges</i> (oncology fellow)</li> <li>• <i>The staff in oncology and allied departments in the hospital are acquainted with study guidelines but need adaptation to suit local needs</i> (oncology consultant)</li> <li>• <i>With the correct oversight and safety measures/algorithms in place this would be a very useful programme</i> (ED consultant)</li> <li>• <i>The home based programmes safety net ensures that most positive BCs would have alerted before home discharge the risk of SBI in these patients is therefore minimal</i> (ID consultant)</li> </ul>
Hospital infrastructure	<ul style="list-style-type: none"> <li>• <i>Well established hospital in the home that is essential for this</i> (oncology consultant)</li> <li>• <i>[Requires] correct infrastructure and safety nets in place</i> (oncology consultant)</li> <li>• <i>We routinely engage HITH services for oncology patients for other indications</i> (HITH nurse)</li> <li>• <i>I still have a little concern about our ability to appropriately monitor all low risk children at home, given that we have no HITH</i> (ID consultant)</li> <li>• <i>HITH is not equipped currently to care for oncology patients, therefore I would be concerned about their level of care and assessment</i> (oncology nurse specialist)</li> </ul>
Communication between departments	<ul style="list-style-type: none"> <li>• <i>I think some minor improvements in the way our department and HITH work together would increase my confidence</i> (oncology fellow)</li> <li>• <i>Need to make sure we have good communication between our unit, RDNS/similar and the parents</i> (oncology ANUM)</li> </ul>
Stakeholder engagement	<ul style="list-style-type: none"> <li>• <i>Care needs to be taken with implementation, including engagement of staff from multiple disciplines and services, patients and families</i> (ID consultant)</li> </ul>
Anecdotal experience	<ul style="list-style-type: none"> <li>• <i>We have been using OP oral antibiotics for low risk FN for some time. Expanding the inclusion criteria is a good idea</i> (oncology consultant)</li> <li>• <i>We seem to have a lot of moderate and higher risk patients, so currently less eligible patients making it less of a priority for the healthcare team</i> (oncology specialist nurse).</li> <li>• <i>I think on reflection on our results of low risk febrile neutropenia admissions it would be safe</i> (oncology consultant)</li> </ul>

ANUM, Associate Nurse Unit Manager; BC, Blood cultures; COVID-19, coronavirus disease 2019; ED, Emergency department; HITH, hospital in the home; ID, Infectious diseases; LRFN, Low-risk febrile neutropenia; OP, Outpatient; RDNS, Royal district nursing service; SBI, Serious bacterial infection.



**Fig 2** Parent/carer interest in receiving home-based febrile neutropenia care for their child (■, prior to pandemic; ■, during pandemic).

policies and procedures in managing COVID-19 and low levels of community transmission in their regions.

Nine parents/carers (28%) indicated they would now wait longer than usual before coming to hospital if their children developed a fever over 38.0°C. Of these, seven were parents of children off active treatment, indicating they would be comfortable to manage this at home or visit their local general practitioner. Other reasons for delaying presentation centred around a perceived increased risk of COVID-19 exposure, particularly in hospitals treating adult patients. Nineteen (60%) parents/carers would not wait longer than usual, universally citing a sense of urgency for medical review in the setting of immune suppression. Four (12%) were unsure.

The current COVID-19 pandemic did not appear to impact the level of parent/carer interest in receiving home-based FN care with over 80% of respondents indicating they were interested in this model (Fig. 2). Key themes contributing to this interest included a preference for home environment, improved QoL, reduced impact on family, perceived safety and positive anecdotal experiences (Table 3). Reasons for 'no interest' or being 'unsure' were linked to negative anecdotal experiences (i.e. the potential for patients with to deteriorate rapidly) and programme safety concerns.

Twenty-one (66%) parents/carers had attended their local hospital in the preceding 2 months. Of the eight (25%) parents/carers who had not attended hospital, five cited increased availability of telehealth as the reason. Key changes noticed by the parents/carers that they would like to see continue beyond the pandemic included telehealth where appropriate; limitations to visitors or sibling attendance, especially in clinic or day chemotherapy; enhanced health screening, hand hygiene and temperature checks; increased visibility of cleaning; and improved communication between departments.

Fourteen (44%) parents/carers completed the ECOM survey, with results for knowledge of the virus presented in Figure 3.

Compared to other illnesses relevant to children with cancer, more parents rated COVID-19 as 'very serious' (Fig. 4) and 13 (93%) were concerned their child was going to contract COVID-19 (slightly concerned in 4 and concerned/very concerned in 9). Regular handwashing ( $n = 13$ ) and social distancing ( $n = 11$ ) were considered likely to prevent COVID-19 by parents/carers and most thought their children could carry out these measures (handwashing in 10 and social distancing in 8).

Communication that parents wanted to receive about COVID-19 included information about 'chance COVID-19 is serious for child' ( $n = 7$ ), how is it treated ( $n = 7$ ), safe return to school ( $n = 5$ ) and illness prevention ( $n = 5$ ). Communication around, mode of transmission, incubation and symptoms were infrequently identified as important factors. All parents reported they preferred information provided by their oncologist, followed by state/federal governments. Qualitative comments highlighted a need to address the availability of information tailored to children with cancer including those off treatment, as well as more consideration given to return to school advice for regions with higher community transmission.

## Discussion

Our national survey identified strong support for home-based management of low-risk FN among paediatric oncology, infectious diseases and emergency medicine health-care workers across Australia and a clear interest in receiving this care among the parents/carers. While the current COVID-19 pandemic has had little impact on this level of confidence and interest, it has contributed to changes in the management of children with cancer that has generally improved acceptability and implementability of this model of care. An exploration of barriers and enablers to home-based care highlighted the importance of safety, hospital infrastructure, communication and knowledge of evidence as key drivers for health-care workers. In addition to

**Table 3** Factors contributing to parent/carer level of interest in home-based febrile neutropenia (FN) care

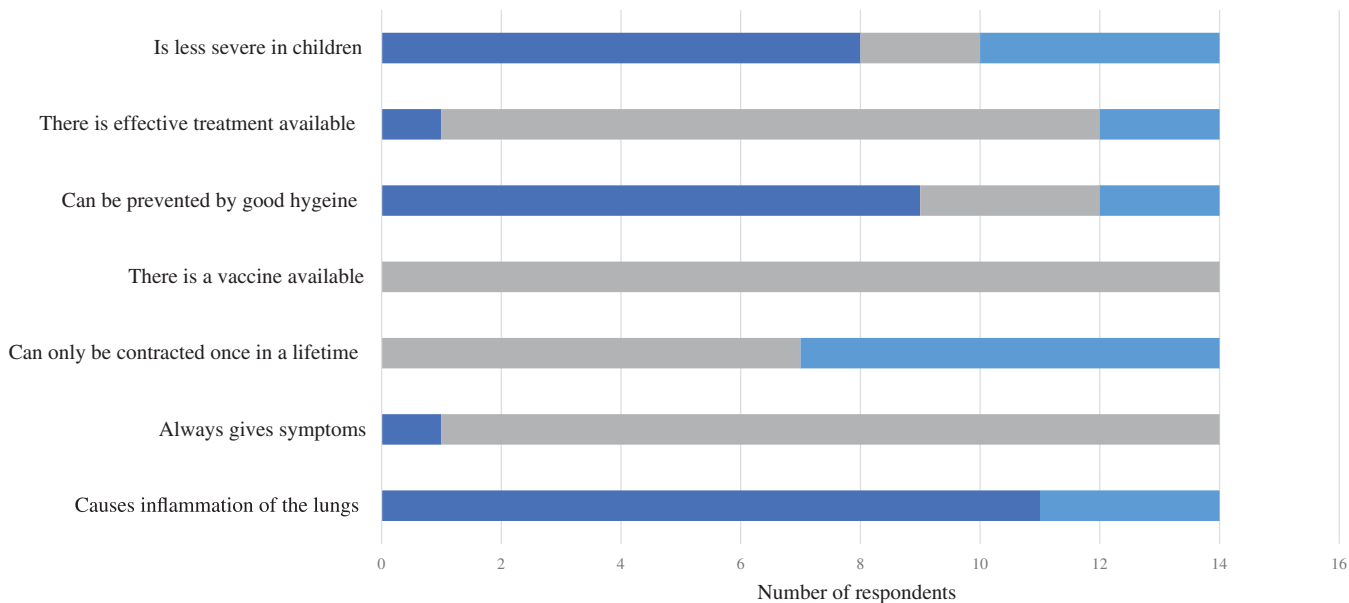
Theme	Parent/carer quotes
Environment	<ul style="list-style-type: none"> <li>• <i>My child is much happier in their own environment, they eat and sleep better than the hospital helping recovery</i></li> <li>• <i>It's not very pleasant being on the ward when you have already spent a lot of time in hospital. I feel like my child recovers more slowly when bedridden and hooked up to IV pole</i></li> <li>• <i>Always better to be home. Kids prefer their own bed</i></li> <li>• <i>Our daughter was in a trial while she was undergoing treatment. At first I thought it was ridiculous &amp; it felt unsafe, however being able to be at home, having a nurse visit to change the Baxter &amp; check on our daughter turned out to be fantastic. Being able to stay at home was wonderful. She was happy to be at home with our family &amp; loved that she could stay with our pets</i></li> <li>• <i>Hospital sucks... more germs, no privacy...limited sleep</i></li> <li>• <i>I would not have been confidence caring for a child so unwell at home. We are 40 minutes drive from the nearest treating hospital</i></li> </ul>
Impact on QoL	<ul style="list-style-type: none"> <li>• <i>Because it's less upsetting and traumatic for him to stay at home-as long as treatment could happen in a timely &amp; efficient manner</i></li> <li>• <i>Being admitted to hospital was not good for our mental health</i></li> <li>• <i>The more treatment done in the comfort of the home, the better. Less anxiety for children, less upheaval for families</i></li> </ul>
Impact on family	<ul style="list-style-type: none"> <li>• <i>...it's easier with our younger child not to have to leave home</i></li> <li>• <i>My son is more comfortable at home and it makes the logistics of other kids easier on the family. Less time away from work for other parent</i></li> <li>• <i>Treatment at home would allow family time instead of the upheaval that occurs when in hospital</i></li> </ul>
Safety	<ul style="list-style-type: none"> <li>• <i>I would be fairly interested, but concerned my child would be unwell at home. Safer in hospital</i></li> <li>• <i>It concerns me somewhat that something is more likely to be missed with at home treatment. When in cancer treatment; infections can come on fast. I fear that something could not be dealt with fast enough</i></li> <li>• <i>The situation can change so rapidly, and it is hard at home to make judgment calls about what is needed. In hospital the child is monitored and changed (eg another temperature spike) are picked up rapidly, and results of blood and other pathology tests are obtained rapidly</i></li> </ul>
Structured programme and hospital infrastructure	<ul style="list-style-type: none"> <li>• <i>It would require a much improved system of in call communications and in home support</i></li> <li>• <i>As long as medical monitoring is appropriate I would highly support it</i></li> <li>• <i>As long as my child had seen a dr and a treatment plan was in place I would be happy for my son to receive treatment at home</i></li> </ul>
Nosocomial infection risk	<ul style="list-style-type: none"> <li>• <i>I do not believe novel coronavirus would pose any extra risks compared to other pathogens</i></li> <li>• <i>Because it would reduce my son's exposure to other people and other illnesses in the hospital and he would not have to leave the comfort of his family when he is unwell</i></li> </ul>
Parent/carer anecdotal experience	<ul style="list-style-type: none"> <li>• <i>Perhaps one out of three episodes the management of FN in hospital wasn't that different to what we'd do at home</i></li> <li>• <i>No better place than home. I find it difficult to be in hospital with a curious and active two year old. He has fevered once while getting a blood transfusion and had to stay in hospital for 48 hours due to this. It was very difficult to keep him in his hospital bed as he was otherwise well however we had to keep him in hospital until the 48 hours had passed</i></li> <li>• <i>...most of her FN admissions she was well within 24 hours but had to continue IVAB</i></li> <li>• <i>Often there is no infection and we are made to wait it out until cultures come back negative</i></li> <li>• <i>All depends on stability of symptoms I have had my child be stable and then decline quickly</i></li> <li>• <i>The benefit would need to be made very clear to me. My daughter had 4 FN admissions in 2019, and she was critically ill at some point in all of those admissions</i></li> </ul>

IV, intravenous; IVAB, intravenous antibiotics; QoL, quality of life.

these factors, impacts on QoL, family functioning and avoidance of nosocomial infections were important by parents/carers.

Implementation of a national paediatric low-risk FN programme in parallel with the COVID-19 pandemic has opened the door to new models of care and increased clinician and patient acceptance for home-based treatment and remote patient assessments. We have identified a number of changes made to the general management of children with cancer across Australia in

response to the pandemic that align with the model of home-based FN care.<sup>4,10</sup> In particular, the increased availability and acceptance of telehealth was acknowledged as a positive change by health-care workers and parents in our study. The augmented HITH capacities in many hospitals, expanded government-funded access to telehealth and executive-level support for innovative models to reduce unnecessary patient traffic through hospitals should be leveraged for home-based FN care. In particular, when

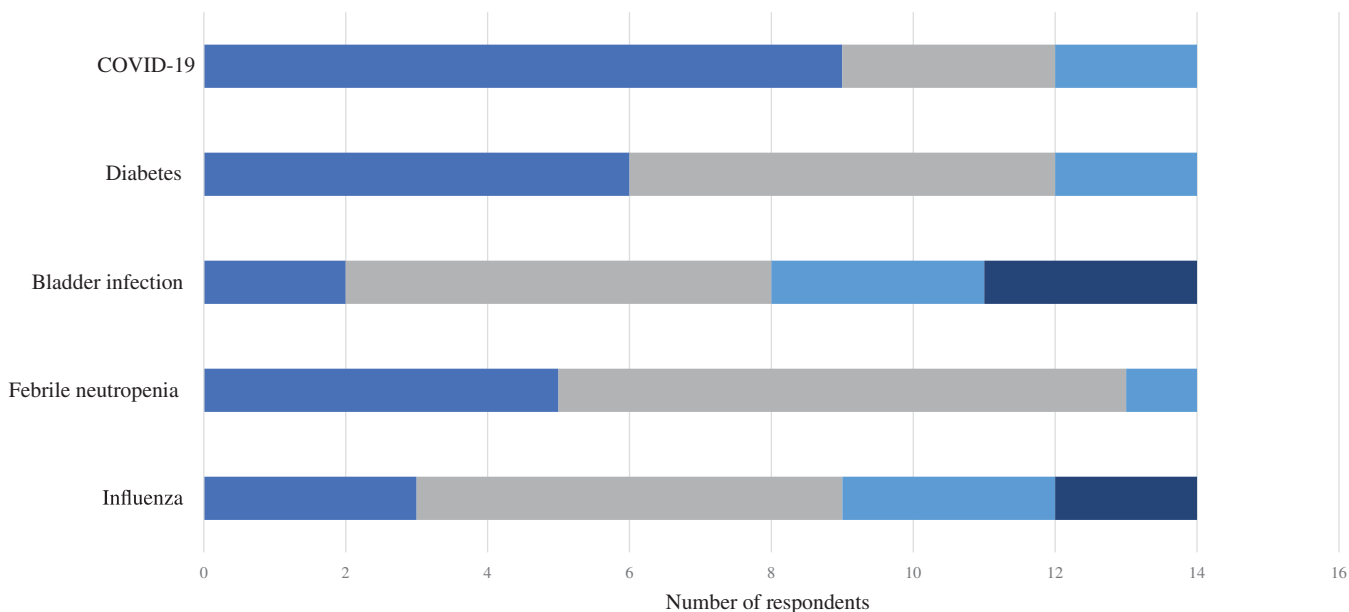


**Fig 3** Parent/carer knowledge of coronavirus disease 2019 (■, true; ■, false; ■, unsure).

embedded into a structured low-risk FN programme with appropriate limitations, telehealth has the potential to optimise efficiency, patient safety and QoL.

Not surprisingly, most parents/carers of children with cancer indicated they were more worried about attending hospital due to a perceived increased risk of exposure to COVID-19. Reassuringly, this did not appear to translate to a potential delay in

attendance if their child was febrile for those on active cancer treatment. In contrast, of the 28% that indicated they would wait longer at home before attending hospital, most were parents of children who had completed active cancer treatment. This is in keeping with results from a study that found more than one-third of parents delayed seeking any medical attention for their child with infective symptoms.<sup>11</sup> Of the changes made to hospital



**Fig 4** Parents feelings towards child developing the following illnesses or infections in the next 12 months (■, very serious; ■, serious; ■, slightly serious; ■, not serious).

access and care delivery in response to the pandemic, parents were keen to see the enhanced infection prevention measures remain. The concern about nosocomial infection was one of the drivers for interest in home-based FN care and has previously been identified as an important factor in parent and patient preferences.<sup>12</sup>

Overall parent/carer knowledge of SARS-CoV-2 and the associated COVID-19 illness, treatment, preventive strategies and vaccine availability was reflective of current evidence. While the abundance of information available in the mainstream media likely contributes to this, the high drop-out rate for the ECOM survey may have biased towards views of more motivated and health literate parents. Nevertheless, parents indicated they wanted to receive more information on severity of the disease in children with cancer, an area where evidence is lacking. While data from international surveillance studies of COVID-19 in children with cancer are forthcoming, early reports indicate an overall illness spectrum similar to that of the general paediatric population.<sup>13–15</sup> Parents also indicated a preference to receive information about school safety for their child, resources for which have been made available elsewhere.<sup>16</sup>

Our survey has identified important barriers to home-based care as well as opportunities to address these in the national low-risk FN implementation process. Reservations due to a lack of awareness about the evidence to support this model and the availability of an implementation tool kit<sup>17</sup> will be addressed through targeted education of relevant health-care workers and updates to national online FN resources.<sup>18</sup> While hospital resourcing and infrastructure barriers are more challenging, concerns about capacity for home-based monitoring of patients may, in part, be alleviated by use of telehealth, enhanced communication between departments and adaption of HITH assessment criteria for oncology patients. The importance of inter-departmental communication and appropriate patient monitoring were echoed in the parent/carer responses. Concerns about the safety of home-based FN care were also highlighted by both clinicians and parents. Programme safety remains paramount and this issue has similarly been identified as a critical component of home-based FN care in a national survey of clinical practice.<sup>19</sup> Results of randomised controlled trials also show no increased risk of adverse outcomes in low-risk patients treated at home on oral or intravenous antibiotics as compared to standard inpatient management.<sup>2</sup> To optimise safety, the low-risk programme incorporates a validated risk stratification tool and additional safety-net criteria including mandatory periods of in-hospital observation and clear directives for medical review and readmission.<sup>4,6,20</sup> While apparent to most clinicians in this survey, the presence of these safety nets need to be better addressed in patient facing information.

Although our sample sizes are modest, we did achieve good health-care worker representation across all implementation sites. In contrast, only three states were represented in the parent/carer surveys. However, while these states account for the majority of Australian COVID-19 cases at close of survey, the results are likely to be translatable to other states with low rates of community transmission given the national COVID-19 media coverage. In addition to the limitations that the sample size may have on the conclusions of this study, results should also be interpreted in the context of the pandemic stage and state and

territory restrictions for when it was completed and, depending on the duration of these measures, further surveys will be required to quantify and qualify the longer term impacts on cancer patients.

## Conclusion

In 2020, there has been a paradigm shift in the delivery of health care across Australia and the world. Whilst many are eagerly awaiting the 'return to normal', we have a unique opportunity to reassess how our health-care system is accessed and how care is delivered both within and outside the hospital walls. Concurrent implementation of a paediatric low-risk FN programme during the pandemic has highlighted a number of these opportunities and will inform modifications to enhance safety, efficiency and acceptability of this model of care.

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Me Flying a Kite by Max Farrell (5) from Operation Art 2020