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RESEARCH

Priority setting for supportive care research in children and young people with cancer

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Abstract

Introduction Supportive care for children and young people (CYP) with cancer describes services intended to manage the adverse effects of cancer and its treatments. We aimed to identify priorities for future supportive care research according to key stakeholders in order to enable researchers and research funders to target these areas.

Methods Nineteen unanswered supportive care research questions were identified from four more general CYP cancer priority setting partnerships. Over a 6-month period, five different priority setting activities were held, involving children and young people, their families, healthcare professionals, researchers, funders and the public. At each event, participants were asked to prioritise the questions in different ways.

Results Different stakeholder groups identified different priorities. For CYP being able to "live a normal life doing normal things" seemed particularly important. Professionals had a strong focus on infection prevention and management. Similarities were also identified, with management of pain, mental wellbeing, and gastrointestinal side effects (nausea, vomiting, diarrhoea, constipation, and mucositis) scoring highly for all groups.

Conclusion Using a range of different priority setting approaches with key stakeholders facilitated engagement with a wide audience, and resulted in rich information relating to supportive care priorities for CYP with cancer. These priorities should inform the development, funding, and performance of future work.

Keywords *Priorities* · Paediatric · Research · Supportive care

Introduction

In children and young people (CYP) with cancer, supportive care refers to those elements which relate to identifying, preventing and/or managing the adverse effects of the disease or its treatment. These can include infectious complications, gastrointestinal problems (e.g. nausea, vomiting, diarrhoea and constipation), pain, psychological difficulties (including common mental health disorders), as well as social and financial needs.

Establishing research priorities for healthcare enables key stakeholders to identify what to focus on in terms of resources, including time, personnel and finances. Priority setting partnerships (PSPs) follow a structured format to elicit research questions from key stakeholders, identify those questions which are unanswered, and then prioritise unanswered questions through purposively engaging groups who are important to the field. The process aims to inform the research agenda, and to allow all voices to be included. There have been various priority setting exercises in CYP cancer in recent years [1–4]. These have revealed that supportive care issues are important for children, young people, their families and the professionals who care for them.

The recent establishment of our Candlelighters Supportive Care Research Centre (CSCRC) was a stimulus to determine the key priorities in this area for all stakeholders, to inform our programme of work as well as that of the well-developed community of paediatric supportive care researchers. Aiming to reduce duplication of previous priority setting partnerships (PSPs), we drew relevant supportive care questions from the wider pool of submitted

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"unanswered questions" then used a variety of stakeholder engagement methods to develop the priorities.

Methods

Question identification

Four recent PSPs for CYP with cancer were identified and the full submitted sets of unanswered research questions (available at the respective PSP websites) were reviewed by two experienced clinical academics (BP, JEM) to identify those which addressed supportive care issues. [1–4] For the purpose of this exercise, supportive care was defined as any question related to managing the acute symptoms of the cancer or its treatment. Questions related to palliative or end of life care, or to the late effects of cancer treatment were not included. This was to fit with the CSCRC remit. Where questions were repeated across PSPs, these were amalgamated into one question for each issue addressed. In total 19 questions were identified, see Table 1.

Priority setting activities

Over a 6-month period, five different priority setting activities were performed, each seeking to engage a different audience, and each using different ways to assess priorities.

Face to face activities with CYP

We held two face-to-face activities with CYP with cancer and their siblings. These were held in Leeds, UK, at a location which provides support for CYP with cancer and their families. The building is run by a local charity well known to all families in the area and provides a homely, non-clinical environment. The two events were held approximately three months apart, and were open to any CYP with cancer experience and/or their siblings. The events were advertised on the local CYP cancer charity's social media, email updates, website and physical posters. Parents were welcome to attend the events but were involved in different activities. CYP were asked to read the survey questions and place them on a scale of 1–5 on a table, where 1 was the least important and 5 was the most important. The participants were then encouraged to discuss where they had

Table 1 Questions used in all adult priority setting exercises (which were then adapted for CYP, as seen in Fig. 1)

How can we improve the quality of mental wellbeing and other social supports available to those on treatment for childhood cancer?
How do we improve learning and cognition (thinking) through and after treatment?
How can we make the experience of taking medicines better for children and young people (including having the choice of tablets or liquid medicine)?
How can we help children and young people to have as much time at home as possible?
What are the best ways of giving information about diet to children and their families during and after treatment and make decisions about support (e.g. NG tube and gastrostomies)?
During and after treatment, what issues prevent or encourage physical activity, what interventions are most effective?
How do we better predict, prevent, diagnose, and treat the tingling/numbness caused by some treatments (peripheral neuropathy)?
What is the best approach to giving information to children and parents about fertility, including the timing of discussions and support with decision making on fertility preservation?
What are the risks of aspects of a usual lifestyle (such as swimming, pets, attending birthday parties, soft play) for children who are on treatment?
How can experiences of having a Hickman line or Port-a-cath be improved for children with cancer?
How can we reduce mouth sores and diarrhoea/abdominal pain caused by mucositis?
Does a monitoring system for fevers (such as wearing a thermometer as a wristband) to give an alert if a child has a high temperature improve infection outcomes?
How can we best reduce pain in cancer treatment: headache, procedural (eg. needle) pain and body pain?
How can we better manage nausea, vomiting, constipation, and diarrhoea caused by cancer and treatment?
How can we most effectively manage appearance changes through treatment?
How can we reduce the likelihood and effect of infections in families affected by childhood cancer?
How can research into treatment side effects and the less common complications children experience be enabled (including for example, gathering information from online forums for parents/carers)?
How can sleep be improved for families impacted by childhood cancer?
Can we reduce the long-term effects of additional medications children with cancer may receive (such as antibiotics, pain killers, laxatives)?

placed the questions and to agree, as a group, their final placement. The activity continued until there was consensus among the group.

Virtual meeting with CYP cancer professionals

At a regular online meeting of CYP cancer professionals in the Leeds Principal Treatment Centre (PTC), professionals were invited to complete an anonymous online survey prioritising the questions (see Supplementary Material 1 for survey structure). Participants could also choose to add further questions or comments within the survey itself. The survey was conducted via Qualtrics, with consent implied by survey completion. Discussions within the online meeting were also encouraged and observations made relating to these interactions.

Survey responses were considered in two ways: "most top ranked" and "most valued". The "most top ranked" analysis considered the question which was placed as top priority by the most respondents. The "most valued" analysis used a sum of the position assigned by each participant to the question and those scoring lowest were considered most valued (e.g. a question ranked 1 st by fifteen participants would have a score of 15 and be considered most valued).

Online survey

The online survey used for the CYP cancer professionals was adapted for use by the general public, with demographic options available for CYP, parents/carers, other family members, researchers and "other". The survey was distributed via social media and via communications from well known children's cancer charity emails and social media channels. Other aspects of survey methodology and analysis were as for the CYP cancer professionals.

Research centre launch event

At the launch event for the Candlelighters Supportive Care Research Centre, we held various interactive activities for attendees, who included families with CYP cancer experience, healthcare professionals and researchers in children's cancer, research funders, and leaders of local businesses and enterprises. In the priority setting activity, each attendee was given five "Champ pounds" representing a unit of funding. They were then asked to place their "pounds" on the questions that they would spend their money on. The "pounds" were recorded then removed from the questions between each group of attendees, so that each group's opinions were not influenced by those who had answered before them. The number of "pounds" placed on each question were totalled and then ranked from most to least.

Results

Face to face activities with CYP

Fifteen CYP with cancer and their siblings attended the events. They had a range of experiences including leukaemia, solid tumours and brain tumours, as well as some who had received stem cell transplants. Some were still receiving treatment for their cancer and others were in follow-up, some many years from their diagnosis.

Figure 1 shows the placement of the priorities by the CYP. All priorities were placed at 3 or above, except for one group placed a question around schoolwork as unimportant (it had initially been put off the table!). Gastrointestinal symptoms were rated highly in both groups, as were infections and pain.

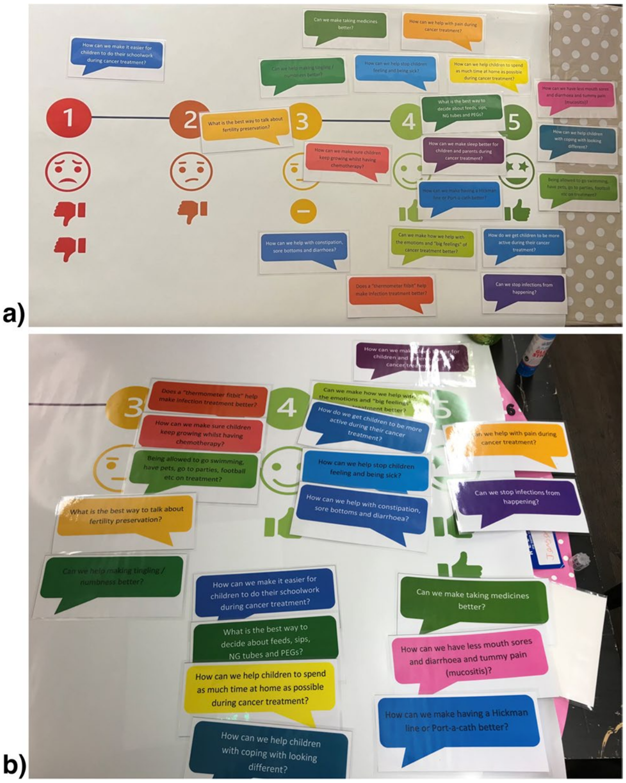

Fig. 1 **a**, **b** Supportive care priorities according to children and young people

One group scored highly the issues of spending time at home, being active and being able to do day-to-day activities. In discussions, this related to the desire to “live a normal life and do normal things”. Both groups rated promoting growth, paraesthesia, and the need for information about fertility preservation as among the least important questions for them.

Virtual meeting with CYP cancer professionals

Fifteen professionals completed the online survey, with another 13 opening the link but not providing any priorities. Of those who did provide data, eight were doctors, two nurses, two dieticians, one pharmacist, and two did not specify. 80% were female. Ten reported they were white, two Asian, one Black and two preferred not to say. Participants were of a range of ages, consistent with the make-up of the department.

The question that was most top ranked related to infections, followed by mental health, taking medications and time at home. The questions that were most valued related to mucositis, other gastrointestinal side effects, pain, physical activity, and mental health. The least valued questions were those around fertility preservation, changes to appearance, and side effects of supportive care medications.

Online survey

The online survey received 24 responses providing priority setting data, with 20 other responses not providing any priorities. Of these, 14 were parents/carers, six cancer survivors, three professionals (two researchers, one research nurse), and one other relative. For the non-professional respondents, most had experience of leukaemia or lymphoma, four of brain or spinal tumours, and two with other solid malignancies. The age at diagnosis had been < 1 to 17 years old, with a median of six years, consistent with that expected within paediatric services.

The question that was most top ranked by this group was related to pain, followed by mental health, and day-to-day activities. The questions that were most valued related to gastrointestinal side effects, pain, mental health, day-to-day activities and taking medications. The least valued questions related to research methodologies, dietary information, and central venous lines.

A number of respondents to the online survey, including CYP cancer professionals in the virtual meeting, provided additional questions or comments in their responses. These are provided in Table 2.

Research centre launch event

Sixty-four adult participants participated in the launch event activity. Some had experience of cancer in children and young people, either personally (as a patient or family member) or professionally (as a clinician and/or academic). Other attendees had limited experience but held other positions of influence socially, in politics, or in business. Groups of participants were pre-allocated to provide a range of experiences in each of the five cohorts.

The question that received the most “funding” related to mental health, followed by time at home, pain, gastrointestinal symptoms and adverse effects of supportive care medications themselves. The questions that received the least “funding” related to changes to appearance and dietary information.

Synthesis of findings

Throughout the process of performing our priority setting activities, we debated how best to draw the findings

Table 2 New questions or comments provided by participants in the virtual meeting with CYP cancer professionals and the online survey

How can siblings best be included and supported?
More support for those children that have to stay in the isolation rooms for long periods of time
How should families be best supported after their child’s death?
How can we improve the quality of mental wellbeing and other social supports available to survivors of childhood cancer (including older children, teenagers and adults living with the late effects of childhood cancer)?
How can we better understand children's worries and emotional experiences through the participatory arts?
How can we improve continuity for our patients in terms of nursing and medical staff?
How do early interventions (e.g. early school visit by keyworker, documented discussion, early visit to school) affect school attendance during and after ALL treatment?
How enable children and young people with brain tumours get back to school/work/normal life?
I would be interested in work around dietetic input at diagnosis—should we be more forward about what we expect with different treatments/be more proactive with those that will require our input?
How can we help young people going though treatment to hang onto/rediscover a healthy self-image that is not about being sick/a survivor/a fighter but about being a person?
If you improve time at home you improve the experience but also potentially reduce side effects

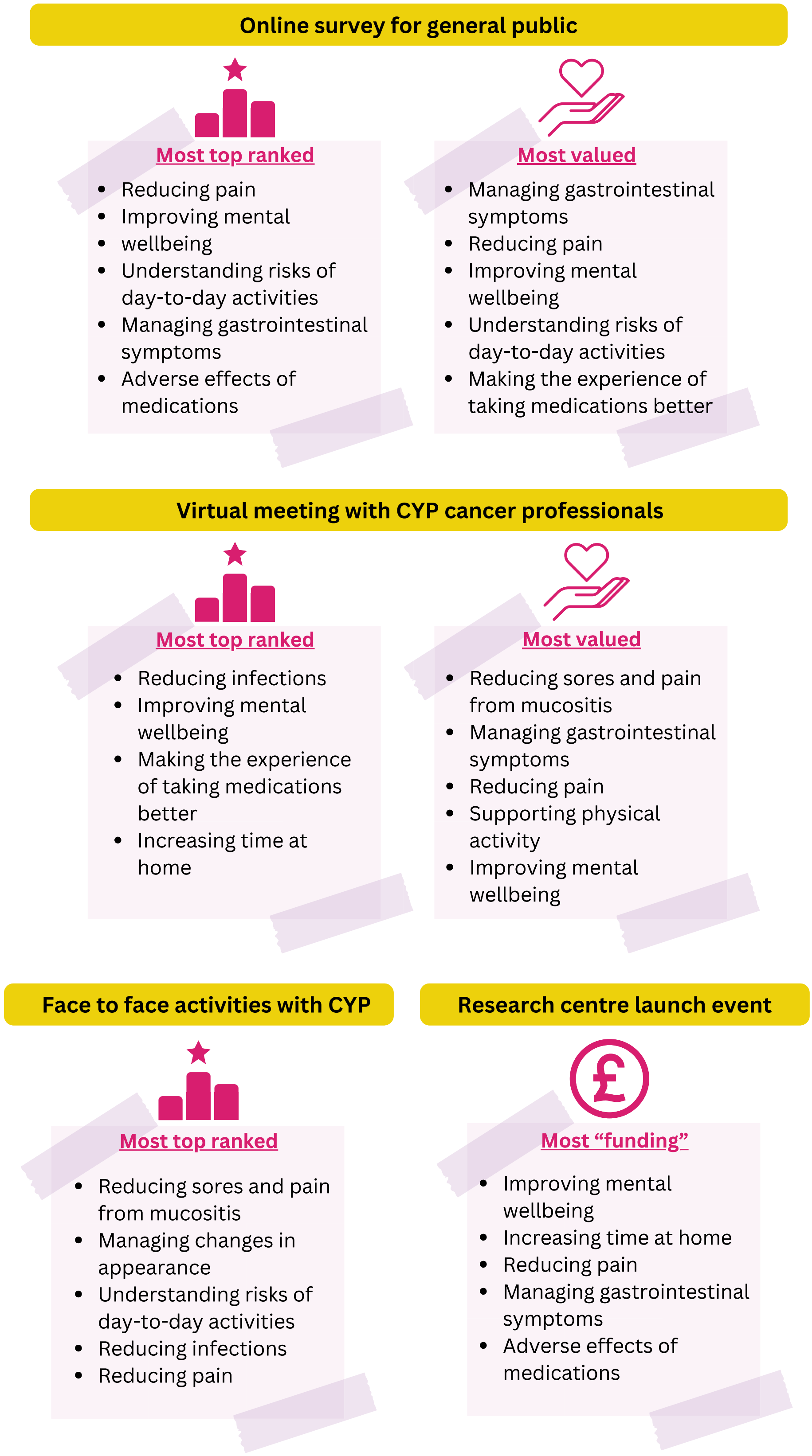

Fig. 2 Infographic presenting supportive care research priorities

Online survey for general public

Most top ranked

- Reducing pain
- Improving mental
- wellbeing
- Understanding risks of day-to-day activities
- Managing gastrointestinal symptoms
- Adverse effects of medications

Most valued

- Managing gastrointestinal symptoms
- Reducing pain
- Improving mental wellbeing
- Understanding risks of day-to-day activities
- Making the experience of taking medications better

Virtual meeting with CYP cancer professionals

Most top ranked

- Reducing infections
- Improving mental wellbeing
- Making the experience of taking medications better
- Increasing time at home

Most valued

- Reducing sores and pain from mucositis
- Managing gastrointestinal symptoms
- Reducing pain
- Supporting physical activity
- Improving mental wellbeing

Face to face activities with CYP

Most top ranked

- Reducing sores and pain from mucositis
- Managing changes in appearance
- Understanding risks of day-to-day activities
- Reducing infections
- Reducing pain

Research centre launch event

Most "funding"

- Improving mental wellbeing
- Increasing time at home
- Reducing pain
- Managing gastrointestinal symptoms
- Adverse effects of medications

Note that these phrases represent simplified descriptors of the original research questions as presented in Table 1 together. The idea of a final "top 5" is very attractive, providing a structured way to consider the work still to be done in this area. However, philosophically this has failed to sit well with us, given that this would require giving greater "weight" to specific voices, or to specific methods, and would lose the multi-dimensional strength of the data. Instead, we have decided that a considered narrative synthesis that considers the nuances between the various stakeholders, methods, and analyses is more appropriate (see Fig. 2 for infographic).

Various stakeholders in the paediatric oncology community contributed their views. The differences between groups demonstrate the varied perspectives – professionals, who are used to seeing the most acutely unwell children, prioritised infection management. They might also have been influenced by their knowledge of our current ongoing research. Young people meanwhile highlighted the importance of "being able to live a normal life and do normal things", whilst adults (including family members and the public) focused more on issues such as pain and gastrointestinal side effects, with known treatments that are not always effective. Mental health scored highly for all adult groups. Whilst this was important for the young people's groups, it was less highly rated.

When contemplating the different methods of data collection, we considered that in person activities exhibited some degree of social influence, with participants discussing and debating what might be more important. We attempted to reduce the impact of this by stressing the fact that there is no "right answer" to a prioritisation question and, in the survey launch activity, removing the previous groups' responses from the boards. Furthermore, the findings in the launch event might have been influenced by surrounding activities which demonstrated areas of research already ongoing at our centre. Several participants stated towards the end of the event that they might make a different decision once they had visited all other activities.

The use of online survey methods reduced the geographical limitations of having to be "in the room" to take part in the exercises, but there remain barriers to engagement. We are always aware of the decision to participate in such calls of engagement could draw people with particular experiences or backgrounds.

We have also reflected that different forms of analysis of the survey data could result in different ordering of priorities. The two approaches, "most commonly ranked in first place" vs "summed ranks", provide different ways of viewing the data – neither is definitively right or wrong, but they instead capture discrete concepts. For those using the priority setting data, it is perhaps best to consider whether they are looking for "the issue that is ranked most important most often" or "the question that more generally captures the average ranking in the view of the overall population".

The concept of variation within groups also influenced our thinking in this synthesis. Considering this, we noticed that for many of our activities, participants commented on their difficulties in ranking the questions—repeatedly we were told "but they're all important!". While we did not ask people to repeat the exercise, the five cohorts in the Launch Event demonstrated the influence of the surrounding activities, where researchers shared about supportive care issues such as mucositis and febrile neutropenia.

Discussion

In summary, we provide the outcomes of multiple priority setting activities for paediatric supportive care, from which readers can access the most appropriate for their situation. We included a range of stakeholders with a variety of experiences of children's and young people's cancer, including inclusion of patients themselves. The stakeholders participated in a variety of activities, each demonstrating a range of preferences in terms of priorities for paediatric supportive care research. This clearly shows the challenges for researchers and research funders in terms of selecting research questions to prioritise, but also supports a wide-ranging programme of research, with each question having the potential to importantly improve the care of these children and young people.

One key strength of the work lies in the use of multiple approaches to gathering and analysing data. This draws from the concept of triangulation of participants and data collection approaches within a qualitative paradigm, where the use of a range of approaches adds rigour and credibility to findings [5].

Our work does have a UK focus, with many activities taking place in the north of England. However, when informally sharing our findings with colleagues nationally and internationally, they hold face validity with those working more broadly, and thus demonstrate transferability to other settings, particularly for those in high income settings. For us, the particular focus on priorities for those in our local area has built strong relationships with our research centre and promoted the work to a wider audience.

Moving forward we continue to work with the community locally, nationally and internationally to map current paediatric supportive care research, including completed, ongoing, and planned projects and programmes. We hope this mapping will reduce duplication of research and facilitate collaborations in areas not yet being addressed. Taking into account these priority setting findings and the future mapping work, we will develop a structured plan for paediatric supportive care research in our own centre. We will also share this information with other researchers and research funders to encourage collective efforts to address important unanswered questions through specific funding calls targeting paediatric supportive care research priorities.

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Author contributions JEM and RSP contributed to the study conception and design. Material preparation, data collection and analysis were performed by JEM and RSP. CE designed the infographic. The first draft of the manuscript was written by JEM and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability Most data provided within included Supplementary Material, further anonymised data available by contacting corresponding author.

Declarations

Ethics approval Not required—research priority setting exercises.

Competing interests The authors declare no competing interests.

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