

The Oncology Family Forum: Collaborating With Families to Codesign Pediatric Oncology Services

Journal of Patient Experience
2020, Vol. 7(6) 1671-1677
© The Author(s) 2020
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/2374373520950977
journals.sagepub.com/home/jpx


Claire Radford, BA, MSpPath¹ ,
Penelope J Slater, BSc (Hons), PhD, Grad Dip Tertiary Ed, Grad
Dip Pub Pol Mgmt¹ , and Philippa Fielden, RN, RSCN, Dip Paed Onc¹

Abstract

The Oncology Services Group at Queensland Children's Hospital established an Oncology Family Forum in 2018 to enable codesign of service improvements. A total of 26 family members attended the first 4 Forums, with between 12 and 15 attendees at each. Attendees represented a range of diagnoses, were 85% female, 85% resided within 40 km of the tertiary center, and 26% were on-treatment. In a survey of attendees, 83% agreed that the Forum had improved families' service experience and 92% supported the codesign partnership and the exploration of their suggestions. A small proportion (25%) of attendees disagreed that there was enough time to share, 17% disagreed that all their questions were answered, and 17% disagreed that the Forum represented views of regional families. Respondents identified collaboration, improving understanding and communication as positive aspects of the Forums. Forums will continue to be offered regularly, augmented by videoconferencing (particularly during the COVID-19 pandemic), written responses to family questions and special interest discussion groups. The new collaborations and programs that have been initiated, codesigned, and progressed through these Forums will continue to be the focus of service delivery and quality improvements.

Keywords

codesign, consumer satisfaction, patient satisfaction, pediatric oncology, patient engagement, quality improvement

Introduction

The Oncology Services Group (OSG) at Queensland Children's Hospital (QCH) is the only tertiary referral center for pediatric oncology, servicing Queensland and Northern New South Wales in Australia. It sees around 200 new patients per year. Family engagement at all levels has been an important feature of the service. The Oncology Family Forum (the Forum) was added in 2018 in response to concerns voiced by families on various news and social media platforms and via the hospital complaints and compliments processes. There was a requirement for more direct engagement with families in a conversation around service improvement.

The Forum design was informed through family engagement during the move to the new QCH in 2014 and experiences at another children's cancer center. In collaboration with families, the Forum was implemented with the following objectives:

- Provide opportunities for families and service representatives to meet and discuss potential areas for service improvement.
- Codesign solutions in partnership with families to better meet their needs.
- Enhance the working relationship between staff and families.

Following the vision of the Children's Health Queensland (CHQ) Consumer and Community Engagement Strategy

¹ Oncology Services Group, Queensland Children's Hospital, Children's Health Queensland Hospital and Health Service, Brisbane, Queensland, Australia

Corresponding Author:

Penelope J Slater, Level 12b, Oncology Services Group, Queensland Children's Hospital, 501 Stanley Street, South Brisbane 4101, Queensland, Australia.
Email: penny.slater@health.qld.gov.au



2016 to 2020 (1), OSG was committed to ensuring that the child and family were at the heart of all we did in working collaboratively to improve health outcomes. The goal was to be a listening organization which engaged in building productive relationships with families.

The concept of consumer codesign in health care originated in maternity health care improvements in the post-World War II period and was further developed during the 1980s with a focus on chronically ill and hospitalized children (2). It is now included in most health care standards. Consumer or patient-family codesign enables patients and families to partner with the health care team and service² to improve care. This may include developing education, creating tools and policies, or informing service delivery and structural changes (3).

The patient and family experience is an important source of knowledge (4) and central to improving care and creating sustainable health care systems for the future (5,6). Improved service efficiency has been linked to improvements in patient experience (1), and research has demonstrated links between patient satisfaction and health professional satisfaction (7).

Workgroups, advisory groups/councils, brainstorming sessions, focus groups, and user panels were the top 5 methods for consumer participation in health care (8). Experience-based codesign is a health care-specific quality improvement approach (9) which utilizes the unique experiences of patients and their families (4).

There are a number of different evaluation tools in the literature that explore participant engagement, organizational commitment, services, systems, the influence on population health and overall cost-effectiveness (10). Frequently, a combination of qualitative and quantitative evaluation approaches are used (10). For example, Discovery Interviews with oncology families at QCH were a valuable and enlightening process for clinical teams as well as the parents/caregivers. It led to service improvements which encompassed family supports, service processes, and individual clinical practice (11).

Bombard et al reviewed 48 studies involving consumer engagement in health care improvement (3). Only 25% of these studies formally evaluated the experience of consumers, but where this was explored the results were generally positive, with reported increases in self-esteem and empowerment in the consumers.

In an evaluation of 2 pediatric experience based codesign projects, health professionals were initially uncomfortable with the consumers' new role in health care improvement. The consumers initially showed higher attendance and commitment to the process compared to the professionals (4). Time-poor health professionals may perceive that involving consumers in quality improvement initiatives is time-consuming (12,13), and that some consumer perspectives are a critique on the professional care they provided (4).

Codesign in health care has significant potential to make real change; however, it is not without its challenges,

especially when there is an ongoing care relationship between the consumer and professional (4). Careful consideration of the format, recruitment, method of consumer involvement, and leadership action is recommended to enable successful engagement and create a receptive environment (4). The organization needs to be ready for codesign, with support from senior managers and preparations to empower consumers to contribute (9).

Bombard et al describe 3 areas that influence consumer engagement in health care codesign: the patient (beliefs about the patient role, health literacy, education), the organization (policies, practices, and culture), and society (social norms, regulation, policy) (3). This summary of the facilitators and barriers of engagement was drawn upon during the development of our Oncology Family Forum.

Methods

The QCH Oncology and Executive Leadership Teams were committed to work effectively in partnership with our families. This included establishing clear structures, processes, shared principles, and goals in alignment with CHQ values.

In the spirit of partnering with families (the CHQ value of integrity), the aim of the Forum was to listen to each other (respect), look after each other (care), provide information around the oncology service, and explore innovative ideas and suggestions (imagination). The principles and goals (see supplementary material) were discussed at the commencement of each Forum to set the scene for productive collaboration.

The purpose and processes of the meetings were clearly articulated. Invitations were distributed in all clinical areas and shared electronically with family contacts for dissemination via their networks. Families were requested to indicate their intention to attend and submit questions or topics for discussion, which informed the agenda. Following the Forum, a summary of discussions and actions was approved through CHQ Communications and Engagement and distributed to families.

Coordination of the Forum (including compiling agenda items, summary notes, and reports) was the responsibility of the Program Manager, who was not directly involved in the care of patients and was a neutral party for the families to approach.

Key steps were taken to facilitate family attendance at the Forums:

- The Forums were scheduled outside of business hours (6-7:30 PM), so it would not conflict with hospital appointments, ward rounds, school hours, and so on. After-hours access to the Forum auditorium was negotiated with security.
- Free parking vouchers were provided, so that those costs would not be a barrier to families attending.

- Key leadership of the Oncology Service was represented at the Forum, including Medical, Nursing, Allied Health, and the Program Manager.
- The CHQ Executive Leadership Team was represented through the Executive Director of Hospital Services, which underscored the hospital's commitment to partnering with families. Where relevant to the agenda topics, other CHQ staff attended to provide information and/or field questions.
- Families were invited to submit questions and topics in advance, to inform the agenda. Responses were also prepared in advance by the staff, to ensure that the discussions were able to occur on the night with all the required information.

The Forums were intentionally “informal” in nature, to foster open discussion and collaboration between staff and families. The following strategies facilitated this:

- Light refreshments were provided 30 minutes prior to the Forum to enable families and staff to network. This also encouraged attendance from those who would not have had an opportunity to have dinner, given the hour the Forum was held.
- The meeting space was arranged to promote collaboration, through a semicircle of chairs with staff and families intermingled, to promote team work and to minimize any perception of “us and them.”
- The shared principles and goals were discussed or displayed at the start of each Forum to set the scene.
- The agenda was followed, but the Chair was adaptable and allowed discussions to go where they needed to go.
- Negotiations with families occurred regarding agenda items not covered due to time restraints, whether to hold them over to the next Forum or answer them in written form.
- Families had ample opportunities to ask further questions, suggest ideas, and clarify any issues.

Process Evaluation

Processes were evaluated through records of attendance and minutes, using the following measures:

- The number of times the Forum took place (ie, quarterly unless there was an agreed change in frequency).
- Items for discussion proposed by families and addressed by the agenda or rescheduled or answered in written form.
- The number of parents/caregivers attending Forum.
- The number of staff attending the Forum and representation of relevant areas.
- The official summary of minutes provided to parents/caregivers within 2 weeks following each Forum.
- Updates on actions arising provided to families in the Oncology Family News and/or at each Forum.

- Forum commenced and finished on time.
- Demographics of family attendees were representative of the patient population.

Impact Evaluation

A survey was circulated to 18 Forum attendees in February 2019, with responses referring to the first 2 Forums on October 23, 2018, and January 29, 2019. The questions were responded to via a Likert scale (1: strongly disagree, 2: disagree, 3: neutral, 4: agree, and 5: strongly agree).

In addition, the families were able to provide free text replies to the questions below:

- List up to 3 positive things about the Oncology Family Forum
- List up to 3 negative things about the Oncology Family Forum

Outcome Evaluation

The above survey provided an opportunity for the families to comment on whether they felt the Forum had improved the families' experience of Oncology Services. Outcomes of the discussion with families about changes in delivery of services were also measured through:

- A reduction in chemotherapy delays as measured through the chemotherapy prescribing system and the records of the Oncology Day Unit.
- A reduction in waiting times in Oncology Day Unit as measured through the electronic patient and appointment records.

Interviews regarding their experience with the Forum were conducted with 4 parents/caregivers (2 on-treatment families and 2 off-treatment families) in May 2019. Following written consent, one staff member asked the parents/caregivers the following questions in relation to oncology services and recorded and transcribed their responses:

- Describe some of the challenges you experienced.
- Describe any changes you've noticed.

Results

Four Oncology Family Forums were held in 2018 and 2019, including October 2018, January 2019, May 2019, and September 2019. The aim was to hold Forums 3 to 4 times a year, and dates were influenced by the availability of Executive and staff attendees and the auditorium.

Table 1 provides information about the attendees at the first 4 Forums. There were 26 individual parents/caregivers/grandparents who had attended at least 1 of the 4 Oncology Family Forums, including 4 males and 22 females (85% female). One attendee was a grandfather and the remainder were parents/caregivers. Twelve of the attendees attended only 1 Forum, 5

Table 1. Oncology Family Forums—Total Attendee Information.^{a,b}

Descriptor	Categories	October 2018	January 2019	May 2019	September 2019	Totals across 4 forums
Family attendance		12	14	15 (3 via video link)	12	26
Gender of parent	Female	11	12	13	9	22
	Male	1	2	2	3	4
Relationship to patient	Parent	12	13	15	11	25
	Grandparent		1		1	1
ASGS Remoteness area of family residence	Major cities	11	12	12 (2 via video link)	12	22
	Inner Regional	1	1	1		3
	Outer regional		1	2 (1 via video link)		1
Patients represented		11	12	15	11	23
Diagnosis	Leukemia /lymphoma	4	7	9	7	12
	Solid tumor	4	2	4	3	8
	Brain tumor	3	3	2	1	3
Patient age-group	0-4 years	0	0	1	1	2
	5-9 years	5	4	7	5	9
	10-14 years	4	5	5	3	8
	15-19 years	2	3	2	2	4
Stage of treatment	On treatment	4	4	4	4	6
	Finished treatment	8	8	11	7	17
	<12 months					9
	>12 months					8
Staff attendance		14 CHQ	19 CHQ 2 Ministerial	11 CHQ	12 CHQ 7 NGO	

Abbreviations: ASGS, Australian Statistical Geographic Standard Remoteness Areas 2016; CHQ, Children's Health Queensland.

^an = 26.

^bParent = parent/caregiver.

attended 2 Forums, 5 attended 3 Forums, and 4 attended all 4 Forums. Three resided in outer regional areas, one in an inner regional area and the rest in major cities (85%).

The attendees represented 23 patients with diagnoses of leukemia/lymphoma (n = 12), brain tumors (n = 3), and other solid tumors (n = 8) and who were aged 0 to 4 years (n = 2), 5 to 9 years (n = 9), 10 to 14 years (n = 8), and 15 to 19 years (n = 4).

Additionally, 8 parents/caregivers represented 6 (26%) patients who were on-treatment, and 17 (74%) had finished treatment. At the time of their most recent attendance of their parent at a Forum, 9 of the related patients were less than 12 months off-treatment, and 8 were off-treatment for greater than 12 months. Of the latter group, 2 parents/caregivers represented patients who had finished treatment between 4 and 10 years previously and had remained engaged with the service for long-term follow-up.

Discussions in the first 4 Forums, either during the Forum meeting or via written responses, included a range of clinical, practical, structural, and administrative topics including service demand, facility changes, family support, hospital processes, family and staff collaboration, and clinical information (see supplementary material).

A link to the online survey was distributed to each of the 18 parents/caregivers/grandparents who had attended the 2 Forums conducted to February 2019. Twelve responses were received; a 67% response rate. Of the parents/caregivers who

responded to the survey, 8 had attended both Forums and 4 had attended only one Forum.

The survey (Table 2) revealed that 83% of respondents agreed or strongly agreed that the Forum had improved families' experience of oncology services overall. Of this, 92% agreed or strongly agreed that there was a partnership with families to codesign the service and that ideas and suggestions were explored together. A small number of parents (25% of respondents) disagreed that there was enough time in the Forum and 17% disagreed that all family questions were answered; 17% also disagreed that there was representation of all family voices, including regional perspectives.

Positive aspects of the Oncology Family Forum expressed by the families in the survey included improved collaboration, trust, understanding, communication, accountability, and relationships. Negative aspects were the time available and agenda management, forum processes, the range of families attending and accountability for outcomes (see supplementary material).

The survey also gave an opportunity for open comments about the Oncology Family Forum. Comments relayed gratitude for the Forum as well as suggestions regarding processes and agenda topics that were addressed in future Forums (see supplementary material).

Tables 3 and 4 show responses from the 4 parents/caregivers who participated in face-to-face interviews regarding the challenges they had experienced in the service and any changes they had seen.

Table 2. Family Responses to the Oncology Family Forum Survey n (%).^a

Question	Disagree	Neutral	Agree	Strongly agree
We maintained the care of the child/young person at the center of all we did.	0.0	1 (8.3)	6 (50.0)	5 (41.7)
There was a shared understanding of the purpose and desired outcomes of the Forum.	0.0	2 (16.7)	5 (41.7)	5 (41.7)
There was a partnership with families to codesign the service.	0.0	1 (8.3)	5 (41.7)	6 (50.0)
We listened to each other respectfully.	0.0	1 (8.3)	5 (41.7)	6 (50.0)
We looked after each other.	0.0	1 (8.3)	7 (58.3)	4 (33.3)
We provided information about Oncology Services.	0.0	1 (8.3)	5 (41.7)	6 (50.0)
We explored ideas and suggestions together.	0.0	1 (8.3)	5 (41.7)	6 (50.0)
We respected people's time in attending the Forum.	1 (8.3)	1 (8.3)	5 (41.7)	5 (41.7)
There was enough time to share information and feedback.	3 (25.0)	7 (58.3)	1 (8.3)	1 (8.3)
We heard the voice of all our families, including those residing in regional and remote areas.	2 (16.7)	5 (41.7)	2 (16.7)	3 (25.0)
All the families' questions were answered in the Forum or in follow-up.	2 (16.7)	5 (41.7)	2 (16.7)	3 (25.0)
I feel that the Oncology Family Forum has improved the families' experience of oncology services.	0.0	2 (16.7)	6 (50.0)	4 (33.3)

^aNote that no responses were recorded in the "strongly disagree" category.

The positive aspects of the Forum reported by families included having a common cause, building collaboration and trust, being listened to, increasing understanding and communication, following through actions, and meeting other families. The negative aspects were related to the ability to address all the agenda items raised by families and the different priorities of on-treatment and off-treatment families.

Discussion

The survey showed that the greatest concern of families was having enough time to share information and feedback, answering all the questions asked, and hearing the voice of the range of families, including those living in regional areas. The latter concern was improved through the addition of dial in

Table 3. Interview Quotes in Response to the Question: Describe Some of the Challenges You Experienced.

Parent	Comments
1	Some of the issues we faced leading up to the development of the Forums was the lack of communication between both parents and families and ward and outpatients.
2	Being here as a patient and with a child, and you almost live here during that time, you actually see things that you know could be done better. But where could you go and put that, because it wasn't a complaint. You do feel alone and you learn about things when you've finished, and I really would like to make a difference to families going through it, to help walk them through the process because your mind is not where it would normally be.
3	We did find that before we had these Forums that we had extremely long waiting times as outpatients.
4	Before the Forums started, it was a bit isolating. People, well I didn't know how things were going. It was hard to communicate, you didn't know who to communicate with.

Table 4. Interview Quotes in Response to the Question: Describe Any Changes You've Noticed.

Parent	Comments
1	So the Forums have really allowed us to air some of our concerns, really given us a place to even lobby for things that we need. Some of the ongoing challenges I think is just finding time—the written responses that were given to us by the Program Manager has been great because it does mean that we get more presentations as opposed to just question and answer. And people being patient focused as opposed to holistic program focused, which I think is important.
2	Having this Forum gives us the opportunity to tweak all those things that make everyone's life easier as they go through this difficult time. And even having the opportunity to talk about all the structural things that are going on around the hospital and how we can improve that.
3	There has definitely been an improvement in shorter waiting times, so where we have been here for 6-7 hours, we are now down to maybe 2-3 hours, so that's a huge improvement for our little people who are waiting around for long periods of time.
4	But since then [the Forums], it's been really fantastic. We've been able to learn more. It's been positive, the communication with staff, and understanding the hospital function better.

videoconference facilities. Three families used this in the third Forum and this was positively received. Time concerns were alleviated by providing written responses to some of the families' questions that were distributed at the Forum and to the email group. Although most Forums kept to the agenda and time frames, it was important to be flexible enough to address discussions that the families wanted to pursue.

New Collaboration Initiatives

The Forum gave a voice to the families in the codesign of service initiatives, including home support for post chemotherapy hydration and low-risk febrile neutropenia, improved discharge procedures, education of more staff to administer chemotherapy, and an increase in outpatient-based chemotherapy. These strategies saved 65-bed days from October 2018 to February 2020, which has substantially reduced the number of chemotherapy delays due to the lack of bed availability.

Success of the Forums would not have been possible without the families who attended and actively engaged with our service. The engagement from leaders across our organization was well received by families, and this was demonstrated to our families that staff were committed to partnering with them to improve our service.

The Forum gave an opportunity for greater linkages and collaboration with nongovernment partners and charities such as Redkite and the Leukaemia Foundation. It also fostered increased engagement with the parent advocacy group Queensland Paediatric Oncology Support (QPOS) Network, which enabled greater promotion of OSG programs, activities and resources and new opportunities for support. For example, the QCH Social Workers were invited to attend the QPOS Women's Retreat to facilitate a session on peer support which was very well received. Based on family feedback, the Oncology Family Resources web page was established, to allow family access to a one-stop-shop of resources, many of which were developed at the specific request of families.

The Oncology Family News was established in June of 2019 and is now routinely distributed in the month prior to each Forum to summarize the last Forum's actions, invite families to the next Forum, and circulate other news items that were relevant to the families. Dissemination of the newsletter was an opt-in subscription process and required specific consent for the use and electronic storage of personal email addresses. Promotion of the newsletter, subscription processes, and upcoming Forums is advertised in all clinical areas, to the family email distribution list, the QPOS Facebook page and by word of mouth between the families.

The Queensland Minister for Health and Ambulance Services (The Honorable Dr Steven Miles) requested an invitation to the January 2019 Forum with the purpose to listen and understand family concerns. This visit informed the Queensland State Government's subsequent decision to bring forward the QCH Expansion Project, with works on an additional ward and oncology beds planned to be completed by the end of 2020. Family representatives were included in the codesign of this project, including membership on committees and participation in a family survey regarding the design.

Future Directions

The ongoing plan is to continue quarterly Oncology Family Forums, with both families and staff agreeing that this was

an appropriate time frame. Some of the Forum processes will be improved, such as the promotion of each Forum and the timeliness of the summaries from each Forum.

It would be ideal to have a balanced representation between families that had experienced all stages of cancer care, including those that had recent on-treatment experience and those that had finished treatment. On-treatment families had low representation at the Forum (27% of attendees), most likely due to their available time and energy to attend and be involved in discussions. One survey respondent suggested breaking the Forum up into groups that would focus on the areas of interest or experience of those attending. When it is felt that more focused input is required, the structure of the Forum can be refined to discuss the various questions raised.

Due to the restrictions associated with the Coronavirus pandemic, the Forum for August 2020 will be entirely provided through videoconferencing. There are a large number of families that have indicated that they will attend this Forum, and they represent a broader range of families that those attending previous Forums. This is partly due to a concerted effort in March 2020 to rapidly expand the family email distribution list. This email list is now a key strategy to share information with oncology families with through regular service updates related to the pandemic.

Future promotion of the Forum to families will also occur through the oncology family app (14), which is currently being updated and merged into the hospital wide MyQCH app, the CHQ Facebook page and directly through the families' Oncology Clinical Nurse Consultant/Liaison Nurse.

Conclusion

Given the positive feedback received, QCH OSG plans to continue to offer quarterly Oncology Family Forums with a newsletter issued the month prior. Attendance via videoconference and written responses will continue to be offered to facilitate access for families who are unable to attend in person. We will consider the success of the August 2020 Forum which was conducted successfully via videoconference with an attendance of 38 families and 15 staff. The service will continue to actively engage in this collaboration to ensure ongoing family engagement and partnership and to ultimately improve the experience of patients and families within our service.

Authors' Note

This study complied with standards of a quality activity and formal ethics approval was not required from the Children's Health Queensland Human Research Ethics Committee.

Acknowledgments

Gratitude goes to the families and CHQ staff who supported collaboration via the Oncology Family Forum and the subsequent implementation of service improvements. The authors specially thank the Co-Chairs of the Forum, Dominic Tait (Executive Director Clinical Services, QCH) and Dr Wayne Nicholls (Director, OSG, QCH), Fionnagh Dougan (CHQ Chief Executive), Juliana Buys (Nursing

Director, Division of Medicine, QCH), Karen Gatehouse and Belinda Taylor (CHQ Communications and Engagement Team), leadership of the CHQ Division of Medicine, and CHQ Facilities Management.


Declaration of Conflicting Interests


The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Study received funding from Queensland Paediatric Palliative care, Haematology and Oncology Network.

ORCID iD

Claire Radford, BA, MSpPath  <https://orcid.org/0000-0002-3300-2630>

Penelope J Slater, BSc (Hons), PhD, Grad Dip Tertiary Ed, Grad Dip Pub Pol Mgmt  <https://orcid.org/0000-0002-3621-4815>

Supplemental Material

Supplemental material for this article is available online.

References

1. Children's Health Queensland. CHQ consumer and community engagement strategy 2016–2020 (Version 3); 2017. Retrieved April 11, 2020, from: www.childrens.health.qld.gov.au/wp-content/uploads/PDF/our-strategies/chq-consumer-comm-strat-16-20.pdf
2. Rawson JV, Moretz J. Patient-and family-centered care: a primer. *J Am Coll Rad.* 2016;13:1544-9.
3. Bombard Y, Baker GR, Orlando E, Fancott C, Bhatia P, Casalino S, et al. Engaging patients to improve quality of care: a systematic review. *Implement Sci.* 2018;13:98.
4. Gustavsson SM, Andersson T. Patient involvement 2.0: experience-based co-design supported by action research. *Act Res.* 2019;17:469-91.
5. Lifvergren S, Huzzard T, Hellström A. Action research and healthcare. *Act Res.* 2015;13:3-8.
6. Williamson L. Patient and citizen participation in health: the need for improved ethical support. *Am J Bioeth.* 2014;14:4-16.
7. Blizzard R. Engagement unlocks patient satisfaction potential, part II. Gallup Poll Tuesday Briefing; 2003. Retrieved April 11, 2020, from: www.gallup.com/poll/8695/engagement-unlocks-patient-satisfaction-potential-part.aspx
8. Wilgenhof JF. An Inquiry into the Ways in Which Patients can be Included in the Implementation of Healthcare Innovations. Master's Thesis. Enschede, Netherlands: University of Twente; 2018.
9. Tomlin EM. Patients at the Centre of Design to Improve the Quality of care; Exploring the Experience-Based Co-Design Approach within the NHS, Doctoral Dissertation. Leeds, United Kingdom: University of Leeds; 2018.
10. Dukhanin V, Topazian R, DeCamp M. Metrics and evaluation tools for patient engagement in healthcare organization- and system-level decision-making: a systematic review. *Int J Health Policy Manag.* 2018;7:889.
11. Slater PJ, Philpot SP. Telling the story of childhood cancer: an evaluation of the discovery interview methodology conducted within the Queensland children's cancer centre. *Patient Intell.* 2016;8:39.
12. Donetto S, Tsianakas V, Robert G. Using Experience-Based Co-Design (EBCD) to Improve the Quality of Healthcare: Mapping Where we are now and Establishing Future Directions. Report, King's College; 2014.
13. Larkin M, Boden ZV, Newton E. On the brink of genuinely collaborative care: experience-based co-design in mental health. *Qual Health Res.* 2015;25:1463-76.
14. Slater PJ, Fielden PE, Bradford NK. The oncology family app: providing information and support for families caring for their child with cancer. *J Pediatr Oncol Nurs.* 2018;35:94-102.

Author Biographies

Claire Radford is allied health clinical lead for the pediatric oncology service within Children's Health Queensland and a speech pathologist with 15 years experience in pediatric oncology and rehabilitation. Her role is to support coordination of care and development of clinical pathways for children and their families, with a focus on improving access to psychosocial and functional services.

Penelope J Slater is program manager for the Oncology Services Group at the Queensland Children's Hospital. Her remit includes planning, evaluation, consumer engagement, staff wellbeing, quality and safety, project management and statewide network management.

Philippa Fielden is a clinical nurse consultant with over 25 years experience in pediatric oncology. She has a special interest in understanding the experience of oncology families to guide innovation and service improvement to provide the best possible outcomes for children and their families within Children's Health Queensland.