Table 1. Oncology Family Forum shared principles and goals

| Shared principles and goals |
|-----------------------------|
| 1. The care of the child remains at the centre of everything we do |
| 2. Respecting everyone’s time and effort to attend. |
| 3. Commitment to start and end on time, valuing this is family time for everyone here. |
| 4. Having the time to share information and feedback equally and respectfully. |
| 5. Understand the purpose and desired outcomes of the meeting. |
| 6. Our commitment to communicate to all our families (so everyone’s voice can be heard, and we reach our regional and remote families). |
| 7. Commitment to answer all your questions, however if we cannot cover everything today, we are committed to feeding back answers to you. |
| 8. This is not a complaint avenue but a method to hear the voices of our families, in a two-way conversation to understand and improve our service. For any individual concerns, patient experience feedback forms and contact details are on the table outside. |
| Forum   | Area                        | Topic                                                                 |
|---------|-----------------------------|----------------------------------------------------------------------|
| 1, 3    | Oncology service demand     | Delays to chemotherapy                                               |
| 1       |                             | Bed availability and discharge                                       |
| 1       |                             | Oncology patients in outlying wards                                  |
| 1       |                             | Room allocations and communication                                   |
| 1, 2, 3 |                             | Timeframes for treatment / processes and waiting times in Oncology Day Unit |
| 4       | Facility changes            | Redesign of Oncology Day Unit waiting area                           |
| 2, 3, 4 |                             | QCH Expansion Project – new Oncology beds                            |
| 1       | Family support              | Information and support for families                                 |
| 2       |                             | Counselling for families                                             |
| 2, 3 (written) |                       | Information re Centrelink entitlements                              |
| 2       |                             | Care after treatment                                                 |
| 4       |                             | Psychosocial support for families – representatives presenting from cancer support organisations: Cancer Council, Redkite, CanTeen, Childhood Cancer Support, Camp Quality and Leukaemia Foundation. |
| 4       |                             | Question and answer with the Director of Social Work and Director of Psychology. |
| 1       | Hospital processes          | Meal times                                                           |
| 1, 2, 3 (written) |                       | Car parking - cost and access                                        |
| 1       |                             | Pharmacy payments                                                    |
| 1       | Families / staff collaboration | Facebook parent support page                                         |
| 1       | Updates                     | Patient and family feedback and outcomes                             |
| 2       |                             | Previous Forum actions                                               |
| 2, 3 (written) |                       | Family Forum meeting processes                                       |
| 2       |                             | Access to genetic testing for children diagnosed with cancer          |
| 2, 3 (written) | Clinical information      | Procedure for heparin locking Central Venous Access Devices          |
| 3       |                             | Update on care provided at home - blood tests, line cares and post hydration |
| 3       | Written responses provided on outstanding and new agenda items       | Donations of equipment, Oncology Family App, Oncology Family Newsletter template, Freedom of Information requests |
Table 3. Positive themes about the Forum and the number of respondents represented in each theme.

| Positive aspects about the Forum                                      | Number |
|-----------------------------------------------------------------------|--------|
| Collaboration, trust, common cause                                    | 5      |
| Improving understanding                                               | 5      |
| Communication                                                         | 5      |
| Families listened to                                                  | 4      |
| Accountability, actions followed through                              | 3      |
| Improving relationships, breaking down barriers                       | 3      |
| Positive and welcoming, chairing                                     | 3      |
| Range of attendees                                                    | 2      |
| Ideas, improvements                                                   | 2      |
| Questions answered                                                    | 1      |
| Staff needs listened to                                               | 1      |
| Meeting other families                                                | 1      |

Table 4. Negative themes about the Forum and the number of respondents represented in each theme.

| Area                      | Negative aspects about the Forum                                      | Number |
|---------------------------|-----------------------------------------------------------------------|--------|
| Agenda                    | Time                                                                  | 7      |
|                           | Some agenda items discussed by email, survey                          | 2      |
|                           | Topics out of scope                                                   | 1      |
|                           | Cover topics for those who have travelled                             | 1      |
| Forum processes           | Advanced notice for date claimers                                     | 1      |
|                           | Delays in minutes                                                      | 1      |
|                           | Being able to hear discussion                                          | 1      |
|                           | Information between Forums                                            | 1      |
|                           | Invitation                                                             | 1      |
|                           | More staff and families attending                                     | 1      |
|                           | Offending staff                                                        | 1      |
|                           | Opportunity to speak                                                   | 1      |
| Range of families         | Regional voice                                                         | 2      |
|                           | On treatment perspectives                                              | 1      |
| Outcomes                  | Accountable actions not assigned to team member, deliverables         | 2      |
|                           | Measure return on investment                                           | 1      |
|                           | Timely changes                                                         | 1      |
### Table 5. General comments provided by respondents to the survey.

| Area       | Family comments                                                                                                                                                                                                                                                                                                                                 |
|------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Gratitude  | The Forum is a place where important issues are raised.  
I believe the Forums are a great avenue to communicate and resolve issues. We must ensure that ALL issues raised are dealt with in a timely manner (or at least an update provided) otherwise QCH staff will lose credibility with carers. Thank you so much for giving our kids and families a voice. Thank you. It's a great initiative that's needed. The Forum is a positive way to engage with the medical team.  
It's fantastic that a broad range of staff attend. I’m understanding the different roles and look forward to further opportunities to meet. Has been a positive experience hope it is something that will continue long term  
Thank you all for the time and effort staff have put into this and going above and beyond to hear the parents. I know that we are only trying to support the staff and hospital in helping us. |
| Processes  | Progression of issues and identification of solutions collaboratively is vague. Big issues like [family support, genetics] … need an interactive discussion space involving families, clinicians, researchers, policy makers and funders. The long-term success of the Family Forum will rely on these processes evolving.  
It would be great to see the Terms of Reference tightened up. When budgeting comes around, will some money be directed towards supporting this initiative? And once cost savings are identified from the process, will the money be reinvested back into Oncology, or into the general pot of QCH funds?  
I hope that a team member can be allocated to each item in future and return with a detailed response to the item. This helps to identify where a family needs to engage when working through an issue. |
| Topics     | Possibly a separate Forum for families currently on treatment and families post treatment - mainly accessing outpatient facilities now? Maybe break off into groups after the initial meet/greet?  
It would be great to see some delegates from outside support groups such as Redkite, Camp Quality, CCS, etc. They are imperative to the well-being of patients and carers.  
A rural Forum only - just as a trial to see if this brings up issues that don't necessarily affect Brisbane based families?  
It would be beneficial to have more representation of rural/regional parties, or recognition of agenda items raised by rural/regional parties.  
Roll on higher commitment to allied services especially welfare/social work dept so as continuation of service can be provided - staff rotations throughout QCH interrupt delicate and necessary support for patient and family especially in palliative/terminal cases |