



## The Oncology Family App

Providing families with cancer care information  
at their fingertips



Philippa Fielden CNC Oncology Liaison  
Penny Slater QPPHON Program Manager

# The need

- Families on holiday away from their usual area and needed urgent care - difficult to find paediatric oncology vital contacts...
- Families needed access to cancer care information
- Complement the Children's Health Queensland clinical flowchart to manage suspected neutropenic sepsis
- Idea !!! – Information available in an app form with 24 hr emergency & non emergency QPPHON contacts (Queensland Paediatric, Palliative Haematology & Oncology Network) for both Android and Apple devices
- 2014 Australian Mobile Phone Lifestyle Index ( AMPLI) 75 % people own a smart phone, predicted 90% by end of 2016.
- We identified 96% of oncology families had access to a smart phone or mobile device (unpublished data)
- <http://www.hapticgeneration.com.au/survey-tells-us-how-australians-use-smartphones-and-tablets/>

## Development

- Benchmarking – no other paediatric oncology app with an emergency / sick management plan & contacts worldwide found to date.
- Presented the idea to Oncology Patient, Family & Carer Network – interest, support & ideas from families.
- Prioritised features for stage 1 and stage 2
- Vendor chosen who had personal experience of a child with a chronic health condition
- Test version – 6 families were testers of the app, feedback was used to create new versions for testing

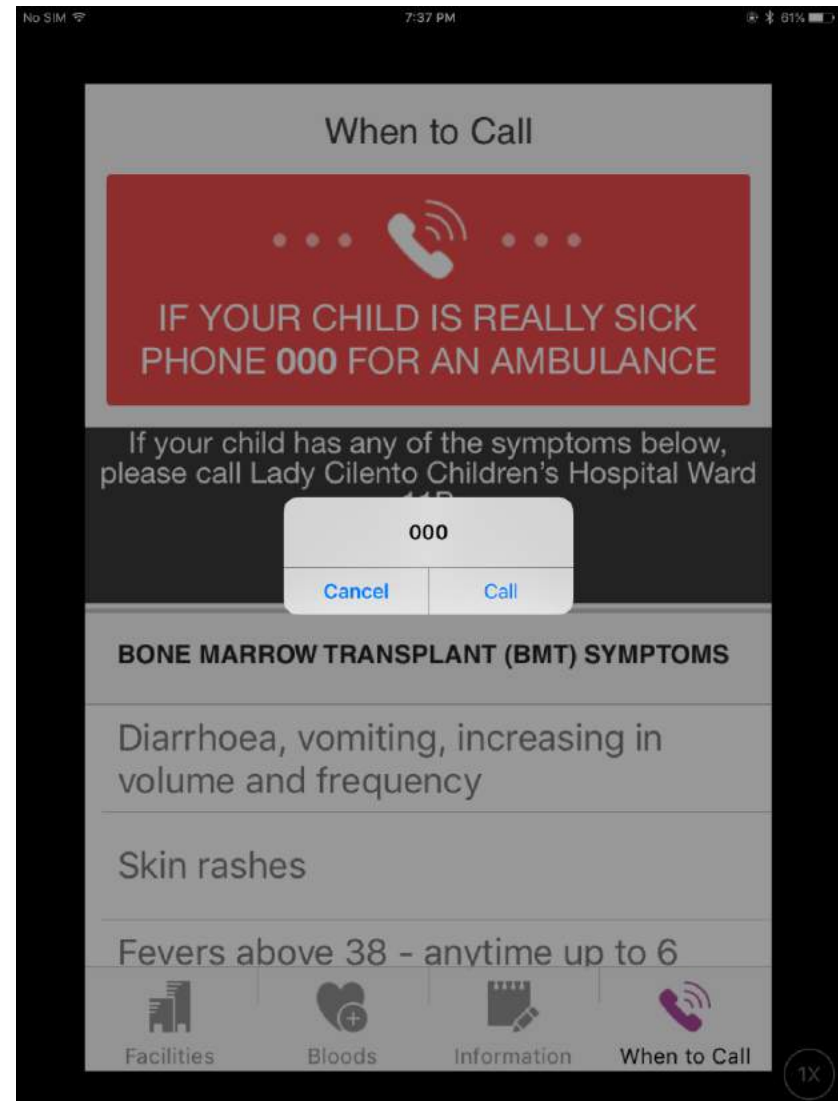
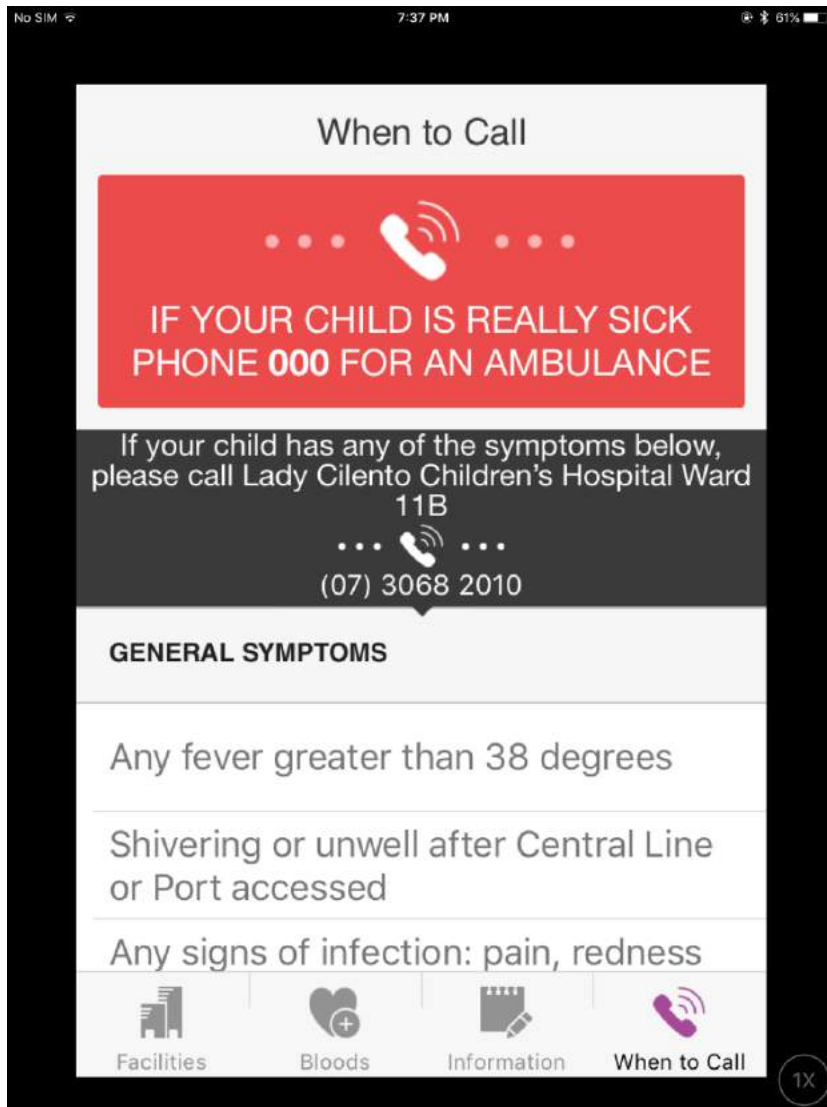
# Valuable feedback from the Oncology Patient, Family and Carer Network contributing to App Development

- “Information of what to do if there is a fever, an emergency /sick management plan.”
- “Need a record of blood counts, appointments and questions for the doctor ”
- “Need phone numbers for wards.”
- “Staff names and who’s who e.g. health care team, I want to put in names and contact details of my OT, physio, social worker...”
- “Reminders for appointments”
- “Going Home information including information on chemotherapy drugs.”
- “The app could help teenagers look after themselves and allow them to take more responsibility, as they always have their phone with them”

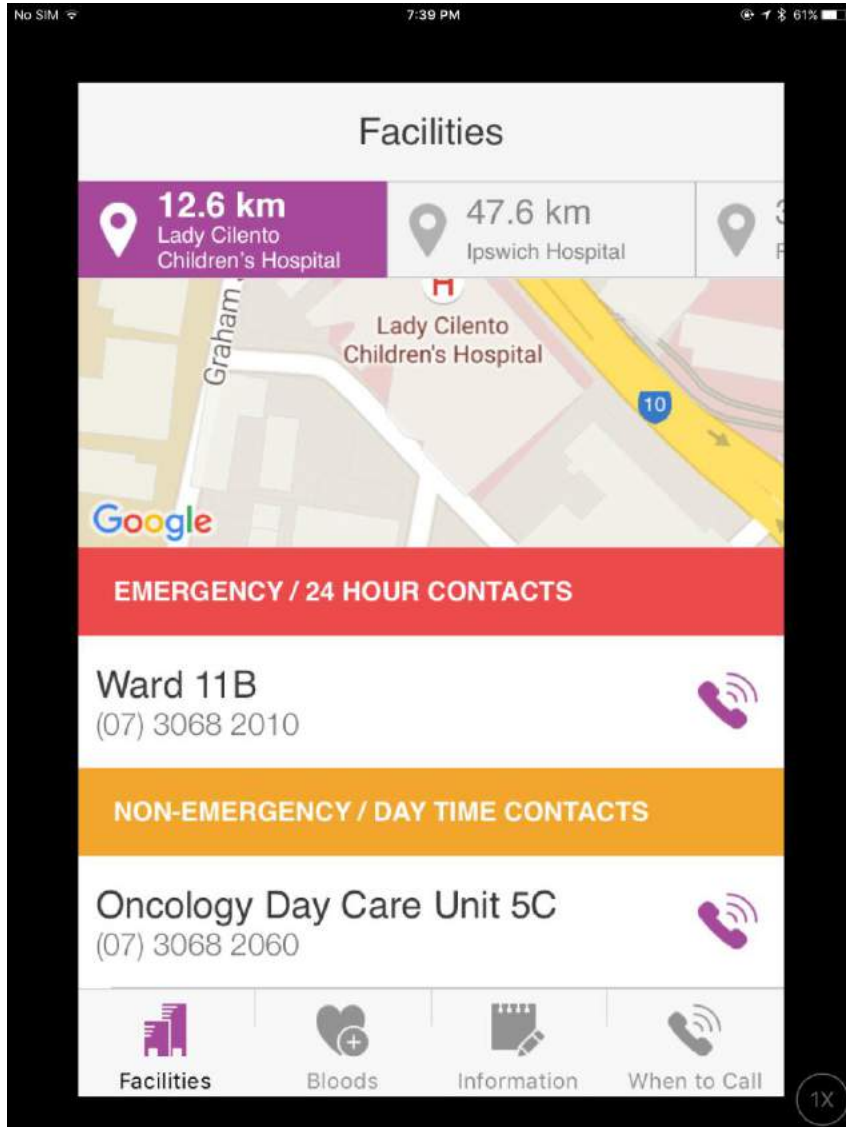
## Screen shots of released app - icon



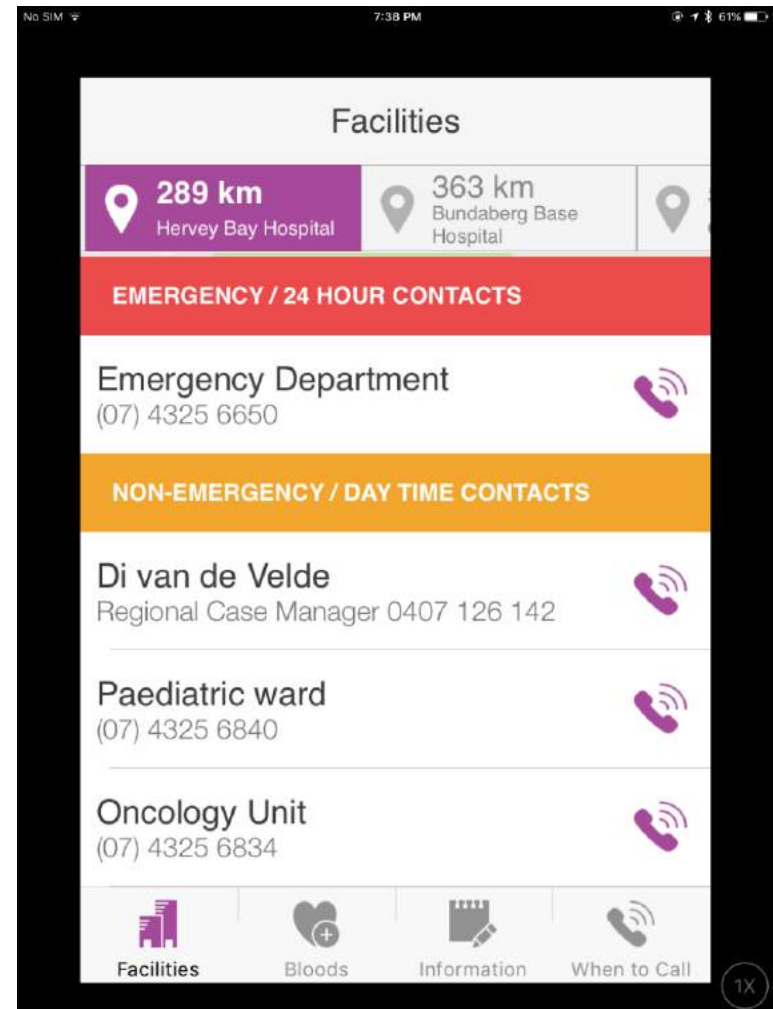
# First Page: When to call



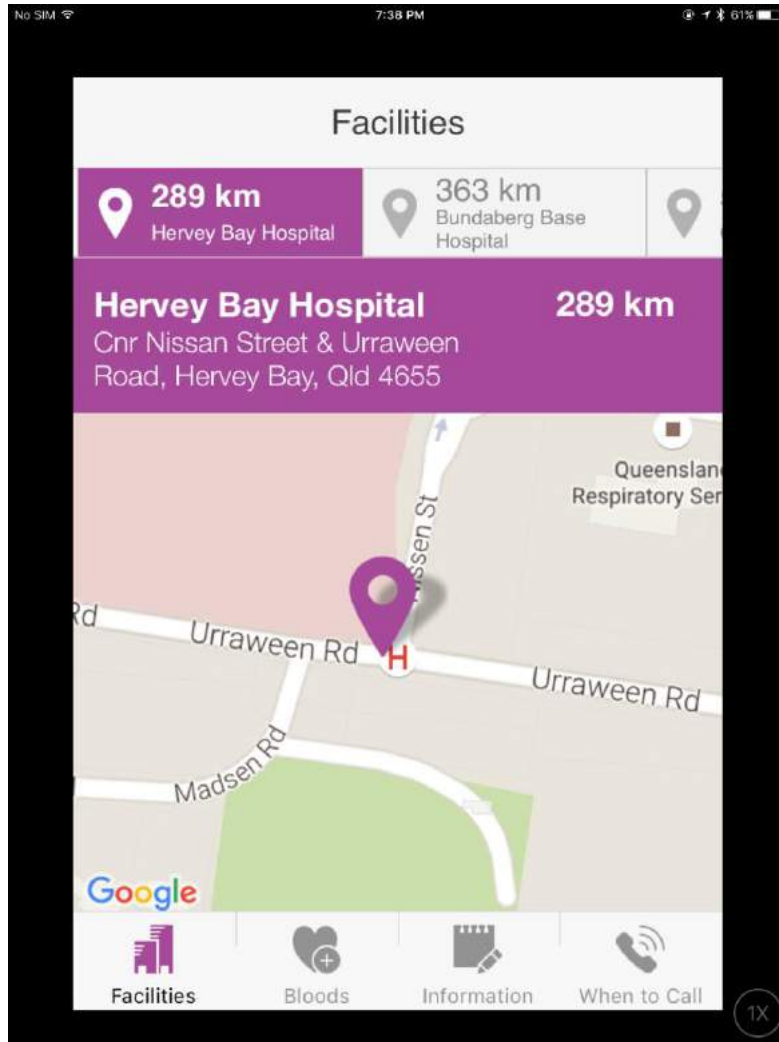
# Facilities



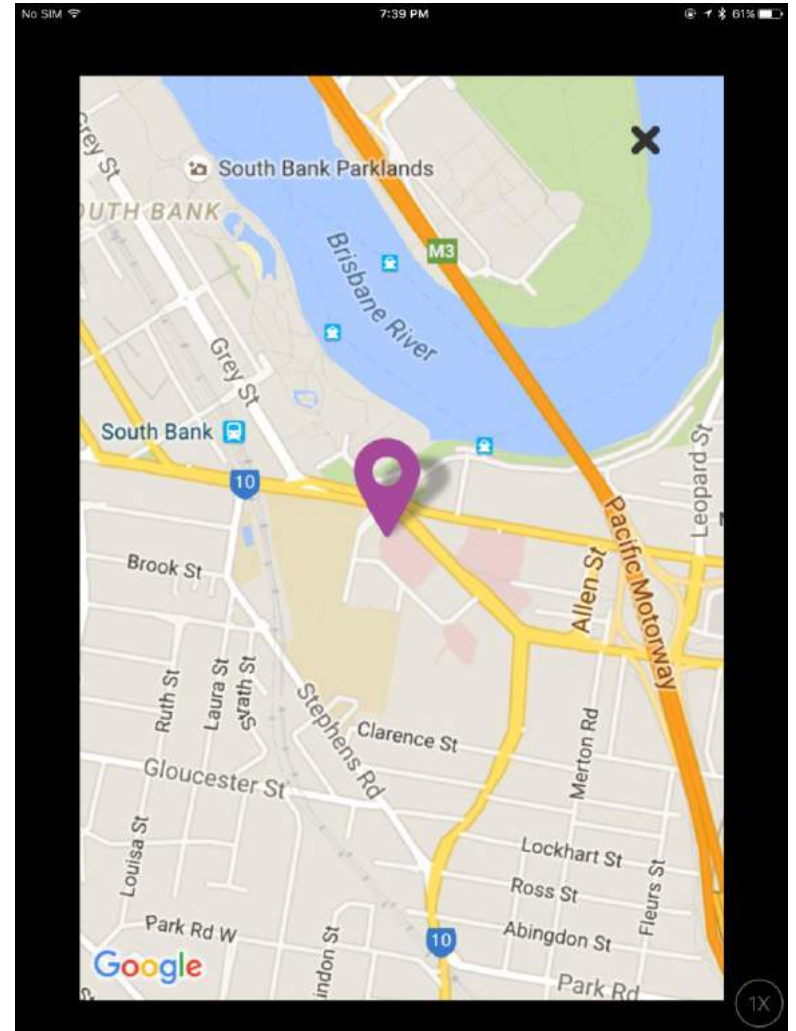
# Click to call



# Facilities



# Google maps





# Blood Results

10:26 AM 93%

Bloods

Weight	Height	Hb	WCC	Platelets	Neutrophils
26.9 <sup>kg</sup>	128 <sup>cm</sup>	110	2.6	258	1.7
27.2 <sup>kg</sup>	128 <sup>cm</sup>	110	1.7	125	1.0
26.9 <sup>kg</sup>	-	85	0.5	25	0.06
27.5 <sup>kg</sup>	128 <sup>cm</sup>	67	0.4	36	0.01

Facilities   **Bloods**   Information   When to Call

11:26

Cancel   Bloods   Done

Date   **Monday, August 10, 2015**

Height (cm)   **178**

Weight (kg)   **67**

Hb   **23**

WCC   **5.4**

Done

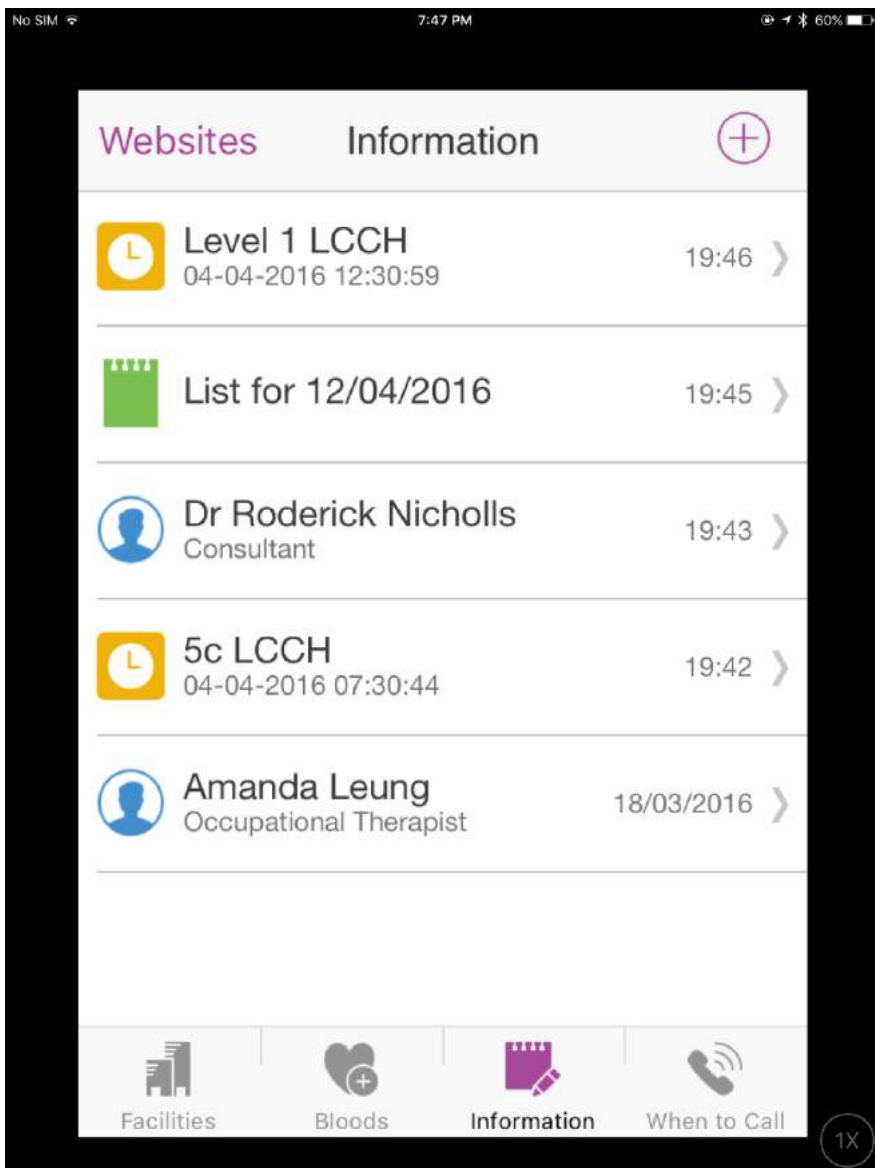
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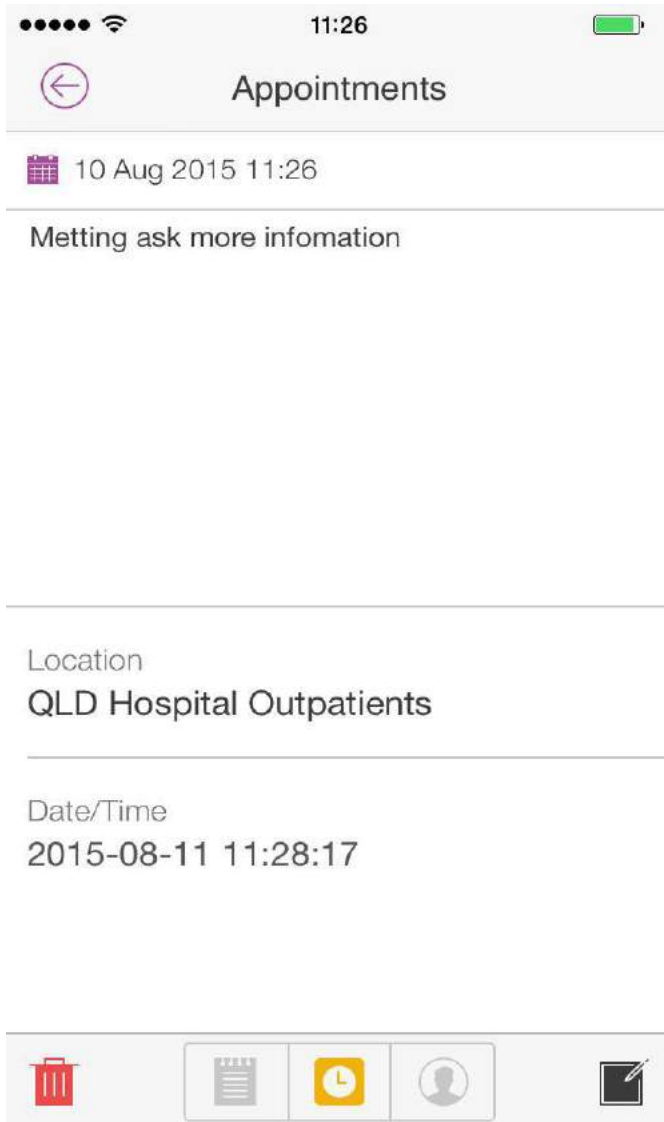
# Information



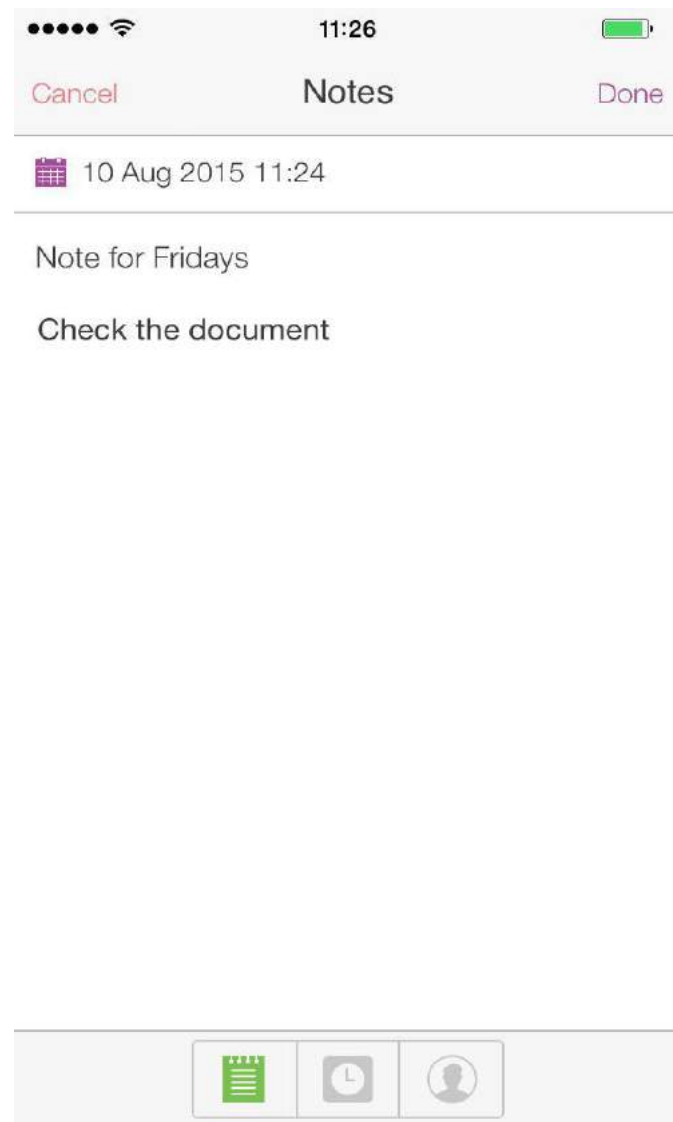
# Contacts



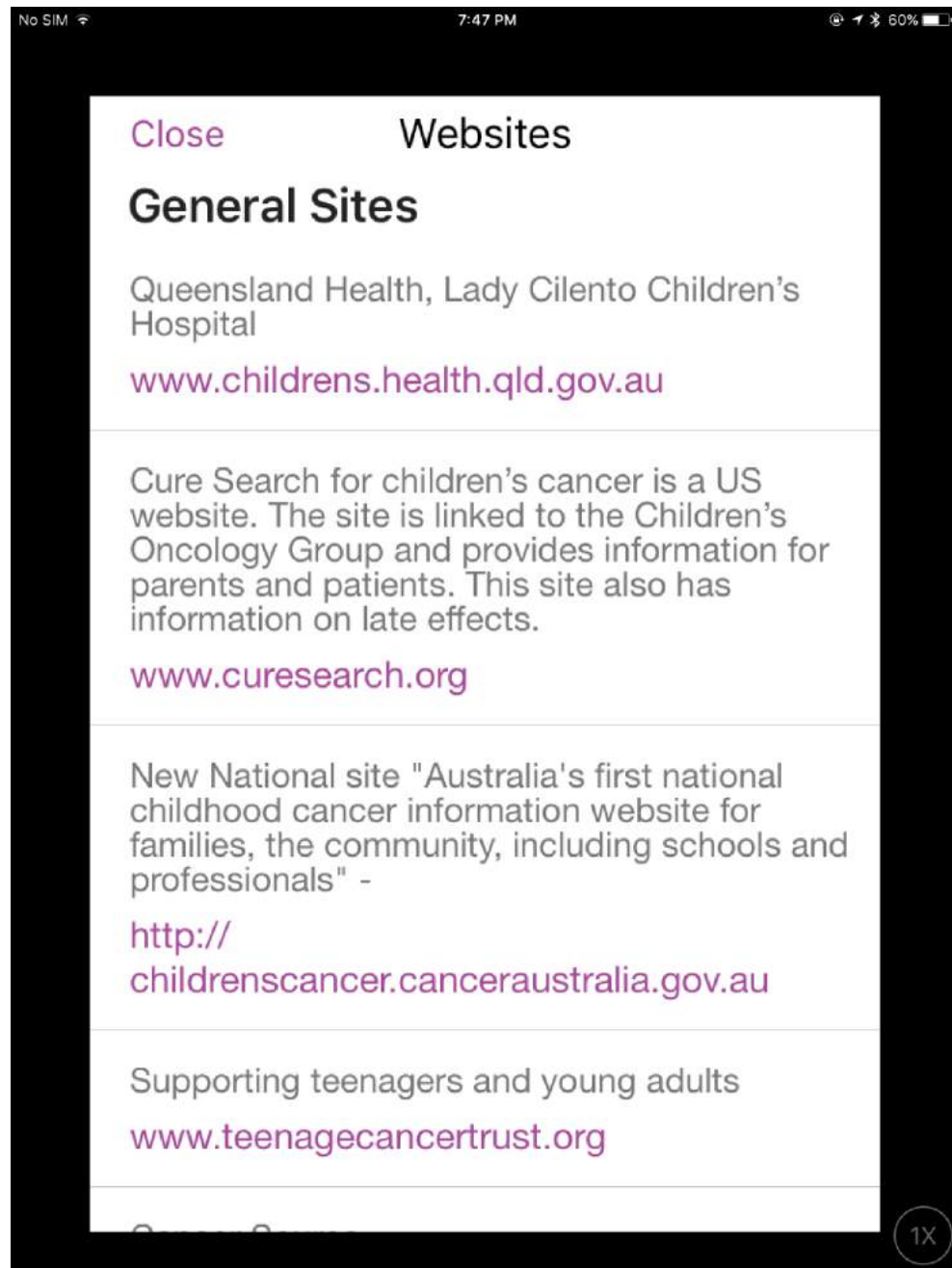
# Appointments



# Notes



# Websites



# Release of stage 1

- Android 17 November 2015
- Apple 25 November 2015

In-services to staff

Banner advertising

Flyers

App Information added to the Family Handbook Education Resource

Meet & greet families to demonstrate the app



# Evaluation



## PROJECT LOGIC – Dissemination to families

**Long term outcome:** The majority of oncology families are using the Oncology Family app to support the care of their child

**Short term outcomes:** Increasing % of families surveyed are using the Oncology Family app.

Adolescents reported to be taking more responsibility for their care.

**Outputs:** Number of app downloads - Apple and Android

## PROJECT LOGIC – Improved patient safety

**Long term outcome:** Families provided with safe and consistent care in regional areas

**Short term outcomes:** Improvements in timeliness of delivery of antibiotics in regional patients with febrile neutropenia.

Timely recognition, reporting and presentation of a deteriorating oncology patient.

Improved compliance with standards of care regardless of location.

**Outputs:** Available in the app:

Accurate and useful instructions of when to call the hospital.

Clinical pathways information for parents and health providers.

Guidelines available to clinicians at regional sites.



## PROJECT LOGIC – Access to information resources

**Long term outcome:** Improved support and education of parents

**Short term outcome:** Improved access to accurate, evidence based information and resources through the app

**Output:** Resource bank includes website links, Ryan's Rule, management of febrile neutropenia, Family Handbook, chemotherapy drug information sheets, home admin of oral chemo

## PROJECT LOGIC – Family information

**Long term outcome:** Families have ready access to their individualised information in one location.

**Short term outcome:** Ready access of families to vital information

**Outputs:** Recorded in the app:

Blood results, appointments, parents notes and reminders

To follow: Patient summary page

## PROJECT LOGIC – Shared care

**Long term outcome:** The state-wide model of care with treatment as close to home as possible is supported through the app.

### **Short term outcomes:**

Improved coordination of shared care

Improved communication for oncology families with their Regional Case Manager

Improved ability to locate clinical services throughout Queensland in the event of an emergent or non-emergent concern

**Outputs:** Accurate emergency and non-emergency statewide contacts.

Mapped location of the above centres with distance to hospital.

Individual staff contacts for family able to be stored in app

## PROJECT LOGIC – Family satisfaction

**Long term outcome:** The app is responsive to consumer needs and suggestions

**Short term outcomes:** Enhanced collaboration with consumers

Direct family input into future app development

Families are satisfied with the usefulness of the app in managing care

**Outputs:** Families able to provide feedback through the app

Family survey conducted on which sections are the most useful and suggestions for future stages

Funding sought and found for stage 3 of the app

# PROJECT LOGIC – Dissemination to other ANZCHOG hospitals and other units at LCCH

**Long term outcome:** QPPHON shares the development of the information app for oncology families in Australia and informs future apps in CHQ

**Short term outcomes:** Number of LCCH units implementing the modified app

App customised for other ANZCHOG centres

**Outputs:** Business Plan developed for app packages.

Presentation and trade table at ANZCHOG June 2016

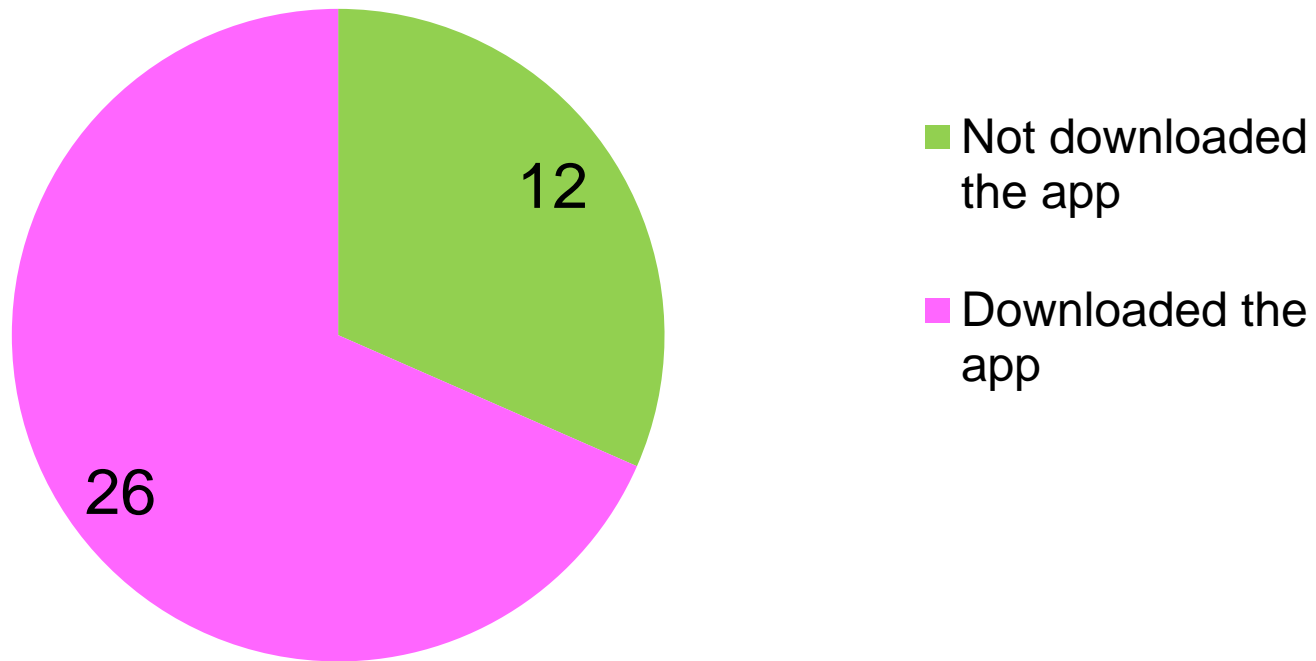
App development at CHQ progressed

# Oncology Family App Survey April 2016

- ✓ 38 oncology families surveyed
- Have you downloaded the app?
- What features do you use the most ?
- 26 families downloaded the app = 68%
- 12 families not downloaded the app
- Family survey before resources page & survey platform were added to stage 1

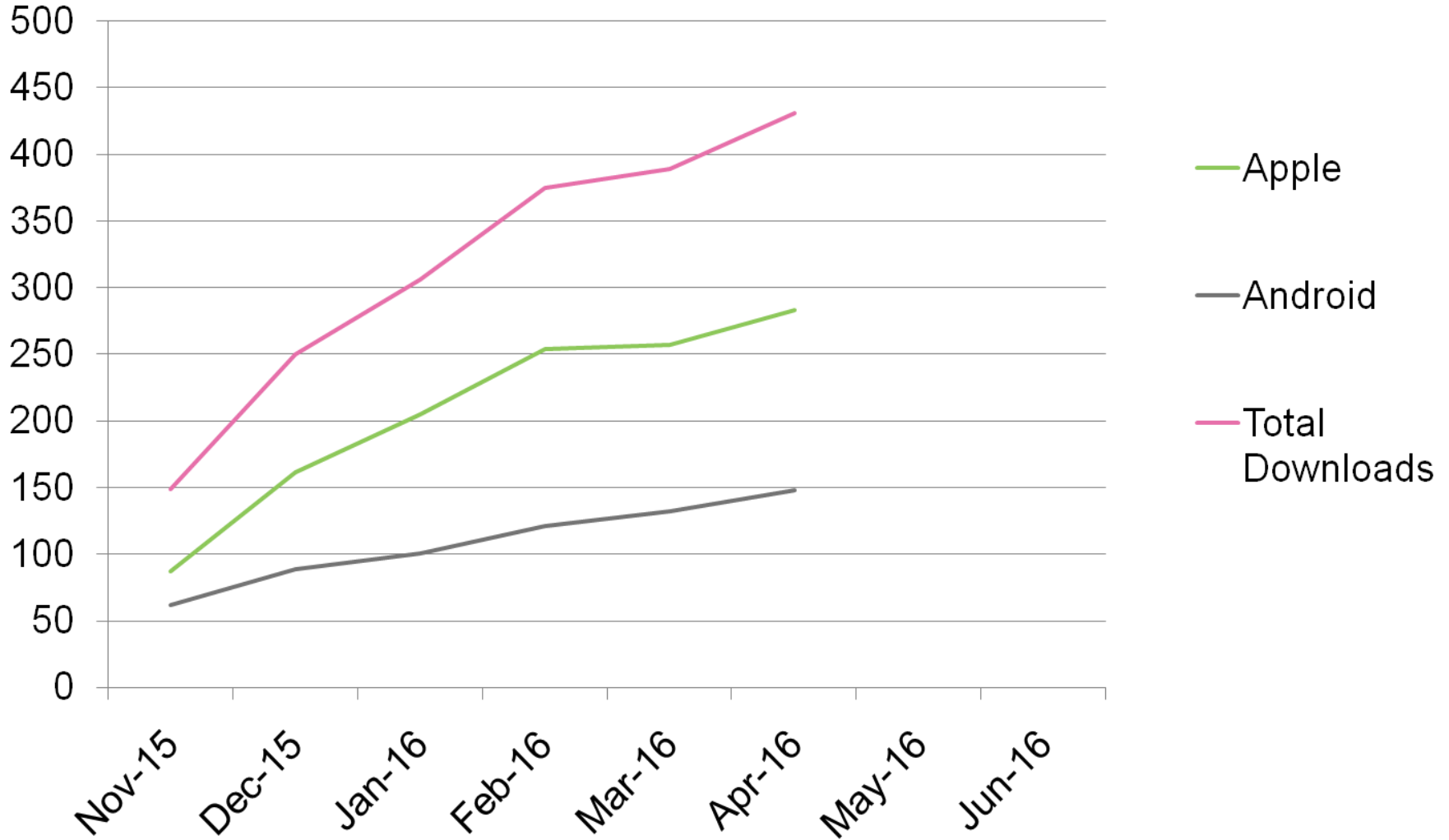
# Oncology Family App Survey April 2016

**Total families downloaded the app (38 surveyed)**



# Oncology Family App Download Stats

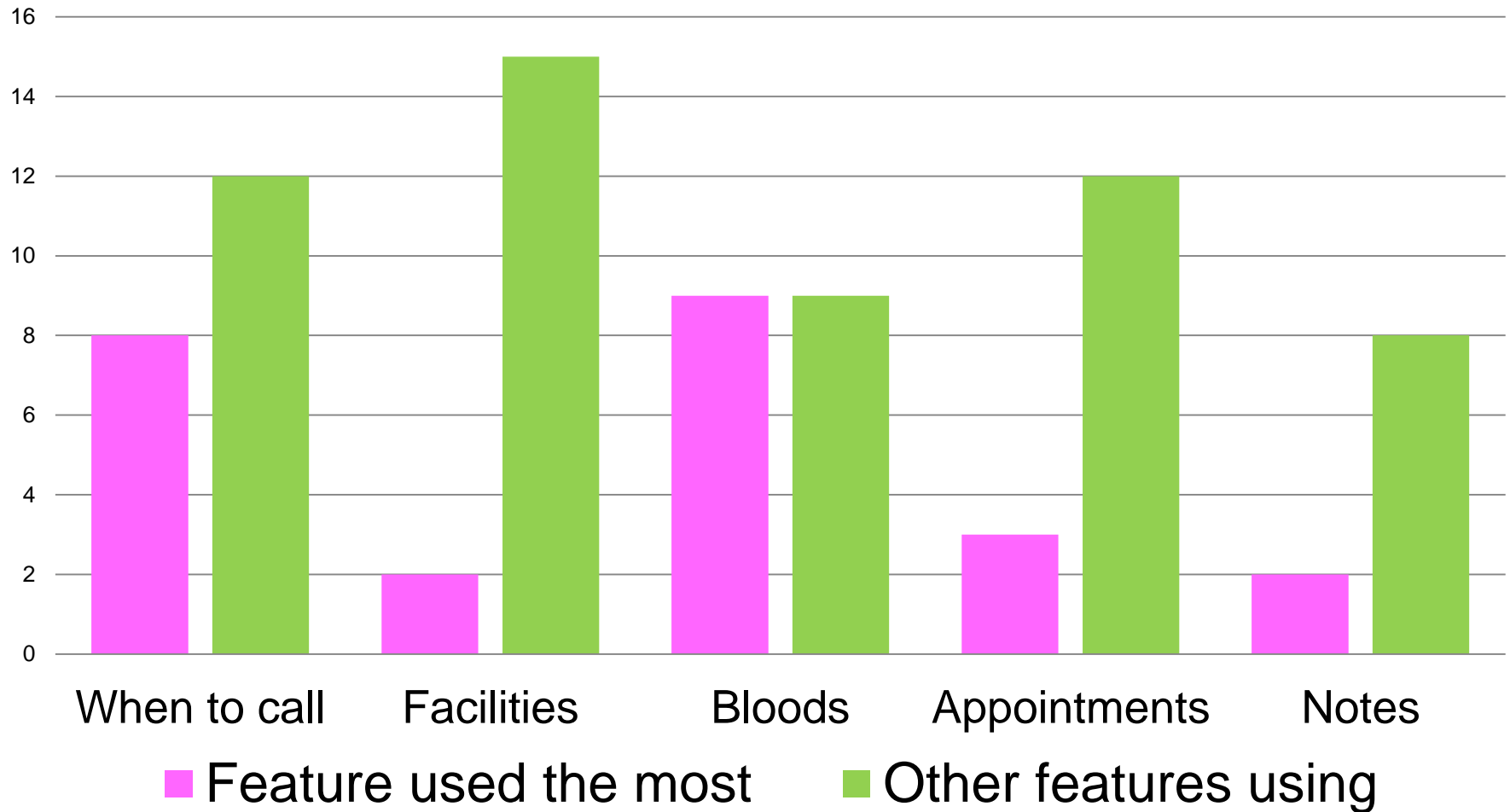
## Total 431 as of 12/04/16





# Oncology Family App survey

Features of the app used by families (38 surveyed)



## Oncology Family App Survey

- “I used the app to check on my child’s symptoms, as I wasn’t sure if to call the hospital as they didn’t have a fever. Read “change in behaviour & pale with no energy” & thought ‘yes, I should call.’ It was good to have all the information. I used click to call & phoned the 24 hour number, and received advice to present to Emergency.”
- “The app is excellent – we are able to go back & forwards between chemos to Sunshine Coast. I use the Nambour contacts in the app as I’d lost the piece of paper with them on. The app is great for that, keeping all information together & always at hand.”
- Teenage patient: “I love the app to track my blood results and weight, and record appointments and questions for the doctor”.

# Families talking about the Oncology Family App

Video link



## Priorities for next version directed by family feedback

- One line of free text under each blood count –eg post chemo, had a blood transfusion etc
- ‘Need to be able to enter height or weight independently on blood table,’
- ‘Appointments to be displayed in order of date of upcoming appointment, not order they are entered.’
- ‘Appointment title to be displayed’
- Summary page of child’s history – diagnosis date, surgery date etc
- Resources pages on a bookshelf including Ryan’s Rule, Family Handbook, Safe handling, chemo sheets, febrile neutropenia pathway, NGOs and supported provided....
- Act on feedback re aesthetics of the app to encourage families to ‘play around’ with all the features - bigger brighter ‘buttons’, clearer sections

## Second level priorities

- Appointment reminders on phone calendar
- Medication list with reminders
- Blood count trends – graphed trends on all the different blood count types
- Oral chemo sheets – daily tick sheets – see specifications already sent
- Syncing with other devices in the same household so parents and older children can share information.
- Google navigation to QPPHON hospitals so it will direct them to the chosen hospital

## Resources to be added in next version

- Family Handbook for Children with Cancer (Going Home) education resource
- Information on safe handling of cytotoxic medications at home
- Chemotherapy drug information
- Information on clinical pathway - Management of Suspected Neutropenic Sepsis
- Ryan's rule information empowering parents to escalate any concerns
- Non-government organisations and support available to families (websites)

## Awards

- Children's Health Queensland People's Awards 2015  
Board Chair Award Innovation Excellence
- Finalists eHealth Awards – Queensland Government May 2016



# Acknowledgements

- ❖ Oncology parents of QPPHON
- ❖ QPPHON executive
- ❖ Prof Ross Pinkerton
- ❖ Arri Khan, Appfluential
- ❖ CHQ IT Team; Fiona Parker, David Kelly, Todd Wilson, John Rudkin
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- ❖ Comms and Engagement; Damian Pointin
- ❖ Patient Safety and Quality Unit; Jake Whitby

