

# Enhancing Patient/Family Education with Children's Oncology Group Tools and Resources

Elizabeth A. Duffy DNP, RN, CPNP  
Teresa Herriage DNP, APRN, CNP, CPHON®  
Wendy Landier PhD, CPNP, CPON®, FAAN

*COG Educational Track at APHON 2020*



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## Disclosure

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- Elizabeth Duffy, Teresa Herriage, and Wendy Landier have no industry relationships.
- Off label use will not be discussed.

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# Background



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## Patient/Family Discharge Education

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- Patient/family education is primarily nursing's responsibility
  - ◆ Landier, Leonard, & Ruccione. (2013). Children's Oncology Group's 2013 blueprint for research: nursing discipline. *Pediatr Blood Cancer*, 60(6), 1031-1036.
- Paucity of evidence to support current practices
  - ◆ Rodgers, Laing, Herring, et al. (2016). Understanding effective delivery of patient and family education in pediatric oncology. *J Pediatr Oncol Nurs*, 33(6), 432-446.
- Considerable variations occur in discharge practice
  - ◆ Withycombe, Andam-Mejia, Dwyer, et al. (2016). A comprehensive survey of institutional patient/family educational practices for newly diagnosed pediatric oncology patients. *J Pediatr Oncol Nurs*, 33(6), 414-421.

## Patient/Family Discharge Education

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- Expert consensus on key content essential for discharge education
  - ◆ Haugen, Landier, Mandrell, et al. (2016). Educating families of children newly diagnosed with cancer. *J Pediatr Oncol Nurs*, 33(6), 405-413.
  
- Parents preferred education process is not always the actual education process
  - ◆ Rodgers, Stegenga, Withycombe, et al. (2016). Processing information after a child's cancer diagnosis – how parents learn. *J Pediatr Oncol Nurs*, 33(6), 447-459.

## Receiving Consistent Information



“I would have fifty different doctors telling me things and every doctor’s got a different opinion. So I kind felt like sometimes I got fifty different opinions, you know?”

*(father of child with rhabdomyosarcoma)*

## COG Consensus Recommendation: *Standardize and Individualize*

- Standardize the content
  - ◆ Essential information only
  - ◆ Use of structured tools (e.g., checklists)
- Individualize the methods
  - ◆ Learning style
  - ◆ Language, literacy, culture
  - ◆ Emotional state (e.g., feeling overwhelmed)





# Fellowship Project




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# Fellowship Goals

Implement/evaluate an evidence-based practice change:  
*Integrate COG standardized new diagnosis education checklist into clinical practice and evaluate outcomes*

Article

## A Standardized Education Checklist for Parents of Children Newly Diagnosed With Cancer: A Report From the Children’s Oncology Group

Journal of Pediatric Oncology Nursing  
2018, Vol. 35(4) 235–246  
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Cheryl Rodgers, PhD, RN, CPNP, CPON<sup>®1</sup>,  
Vanessa Bertini, MSN, RN, CPN, CPON<sup>®2</sup>,  
Mary Ashe Conway, MSN, RN, CPHON<sup>®3</sup>, Ashley Crosty, RN<sup>4</sup>,  
Angela Filice, BScN, BA, RN<sup>5</sup>,  
Ruth Anne Herring, MSN, RN, CPNP-AC/PC, CPHON<sup>®6</sup> ,  
Julie Isbell, MSN, RN, CPON<sup>®7</sup>, E. Anne Lown, DrPH<sup>8</sup>,  
Kristina Miller, DNP, RN, PCNS-BC, CNE<sup>9</sup>,  
Margaret Perry, BSN, RN, CPHON<sup>®</sup>, CPN<sup>10</sup>,  
Paula Sanborn, BSN, RN, CPHON<sup>®</sup>, CPN<sup>11</sup>, Nicole Spreen, BScN, RN<sup>4</sup>,  
Nancy Tena, MSN, RN, CNS-BC, CPHON<sup>®</sup>, BMTCN<sup>®12</sup>,  
Cindi Winkle, BSN, RN<sup>6</sup>, Joan Darling, PhD<sup>13</sup>, Abigail Slaven, RN, CPHON<sup>®14</sup>,  
Jeneane Sullivan, MSN, RN, CPON<sup>®15</sup>, Kathryn M. Tomlinson, BSN, RN<sup>16</sup>,  
Kate Windt, BSN, RN, CPHON<sup>®17</sup>,  
Marilyn Hockenberry, PhD, RN, PPCNP-BC, FAAN<sup>1</sup>,  
and Wendy Landier, PhD, RN, CPNP, CPON<sup>®</sup>, FAAN<sup>18</sup>

**Table 2.** Primary Topic Checklist.

Topic	Learner	Prefs	Method	Eval	Date/initials	Final checkoff
Meeting with physician team for diagnosis and treatment plan						
Meeting with social worker to screen for immediate psychosocial needs						
Diagnosis (parents know how to convey this in an emergency)						
When to call for help						
Who to call for help						
Fever						
Temperature-taking						
Handwashing						
Preventing infection						
Treatment side effects to know before next appointment						
Home medication: Names and purpose						
Home medication: Dose and frequency						
Home medication: Administration						
Home medication: Storage						
Home medication: Prescriptions are filled or plan in place to fill them						
Home care company (contact information and supplies)						
Chemotherapy safe-handling/item disposal						
Follow-up appointments						
<b>For patients with external central line</b>						
Emergency care of central line						
Demonstration of central line flush						
<b>For CNS tumor patients</b>						
Symptoms of increased intracranial pressure, shunt malfunction, headache						
Seizures						
<b>If applicable</b>						
Postop/wound care						
Pain/pain management						
Topical anesthesia for port						

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J Pediatr Oncol Nur 2018 35(4):235-246

Journal of Pediatric Oncology Nursing  SAGE journals

## Implementation

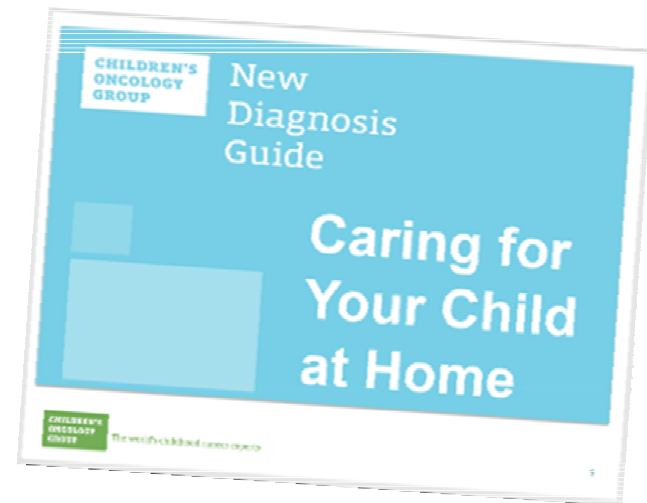
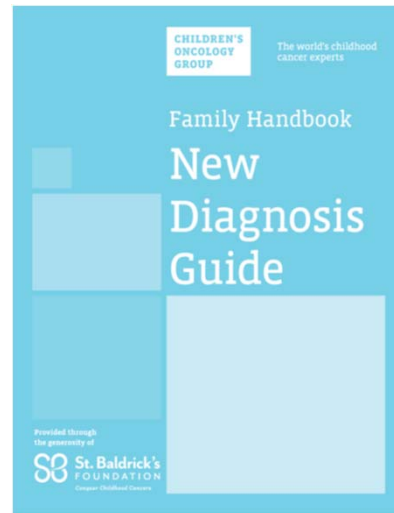
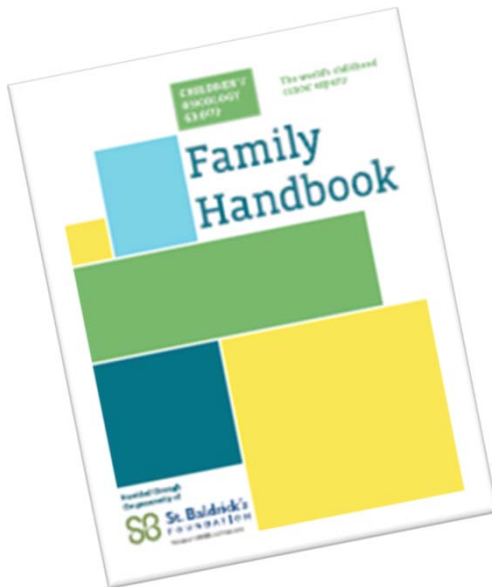
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- Two COG Institutions over 4-5 months
- Collected checklists (primary, secondary)
- Surveyed patients/families following discharge
- Online survey of nursing staff



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## COG Educational Resources for Families and Nurses



## Primary Checklist Topics

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- Met with physician for diagnosis and treatment plan
- Met with social worker for psychosocial needs screening
- Diagnosis
  - ◆ Parents know how to convey this in an emergency
- When to call for help
- Who to call for help
- Fever
  - ◆ Temperature-taking
- Preventing Infection
  - ◆ Handwashing



## Primary Checklist Topics (continued)

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- Treatment side effects to know before next appointment
- Home medication:
  - ◆ Names and purpose
  - ◆ Administration
    - Dose and frequency
  - ◆ Storage/Disposal
  - ◆ Prescriptions are filled or plan in place to fill them
- Home care (contact information and supplies)
- Chemotherapy safe-handling and item disposal
- Follow-up appointments



## Evaluation

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- **Feasibility and fidelity**
  - ◆ Use of checklist by RNs
  - ◆ Completion of checklist items
  - ◆ Assessment to be completed by EBP fellow or research assistant
- **Patient/Parent Satisfaction**
  - ◆ Anonymous survey to evaluate discharge education process using Likert-type scale
  - ◆ Completed by parent/patient at the first clinic visit after discharge



## Checklist Data: Feasibility and Fidelity

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# Results



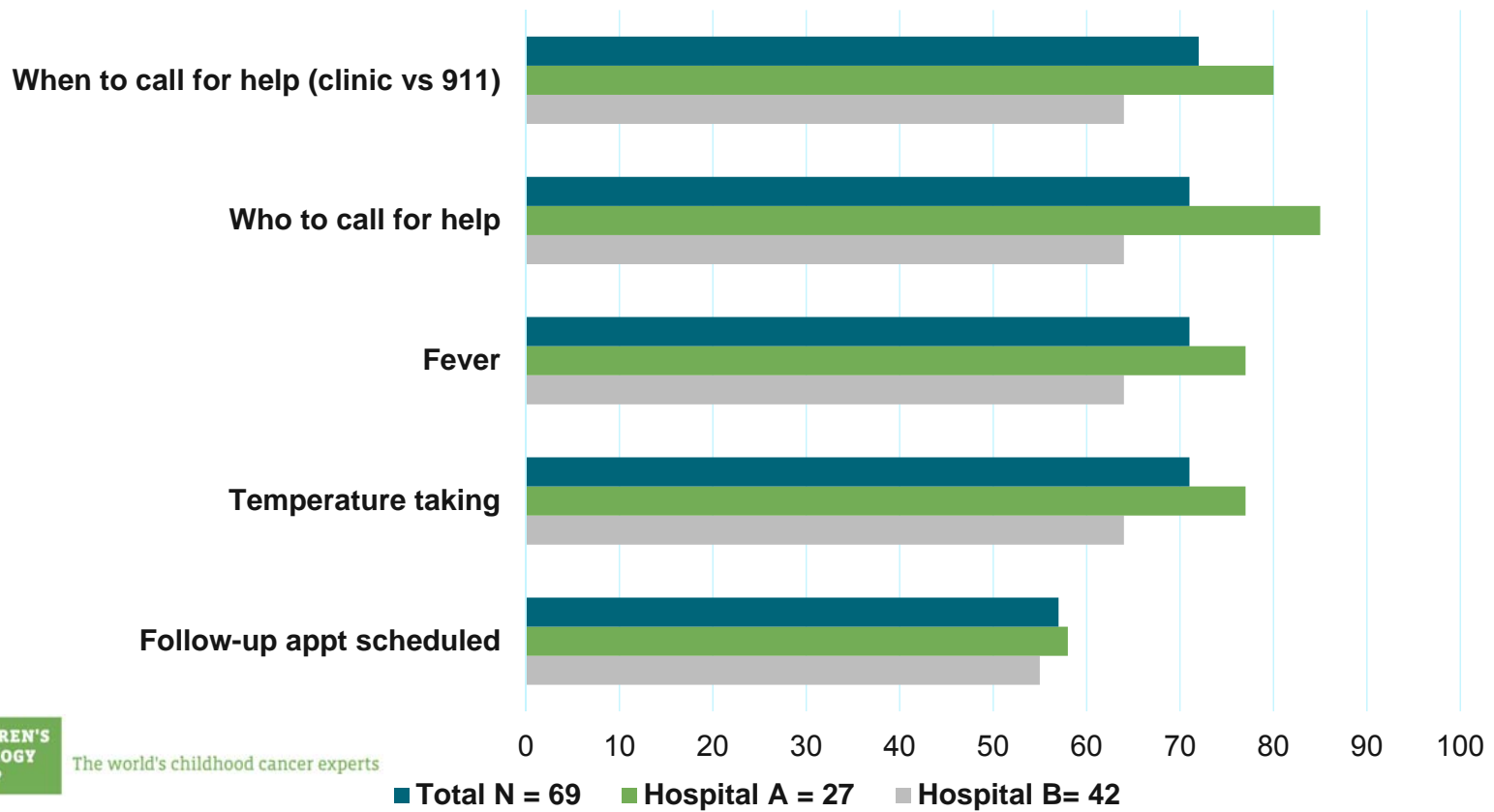
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## Clinical Data: Use of Checklist

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## Resources/Accessing Care- % Completed



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■ Total N = 69 ■ Hospital A = 27 ■ Hospital B = 42

## Parent Data: Patient/Parent Satisfaction

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## Figuring Out Life

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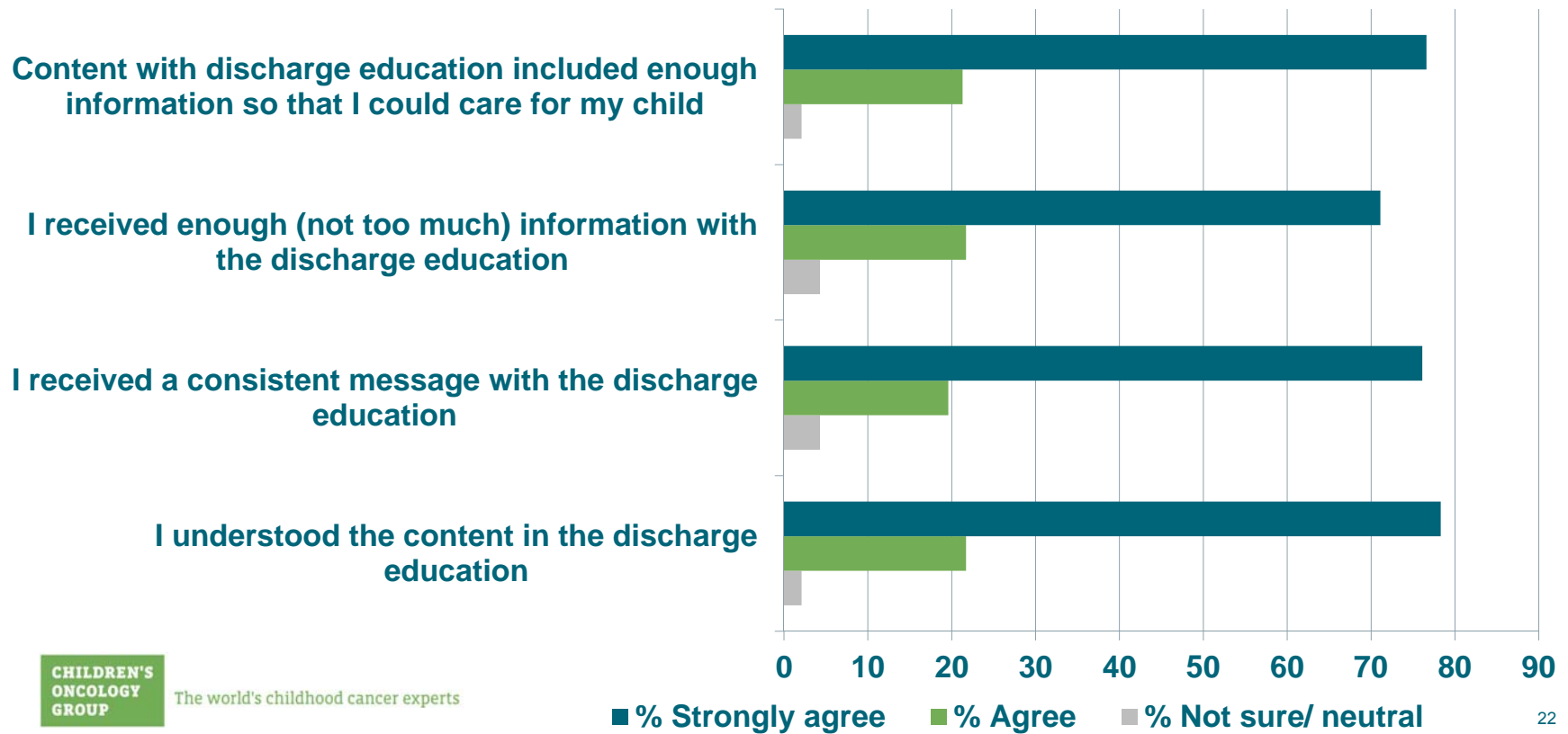


"That was my hardest experience just having to juggle the logistics with you know who can I shuffle car pool off with ... you know just like the little logistics that you don't think crowds you until it crowds you."

*(mother of child with ALL)*

Rodgers et al., 2016

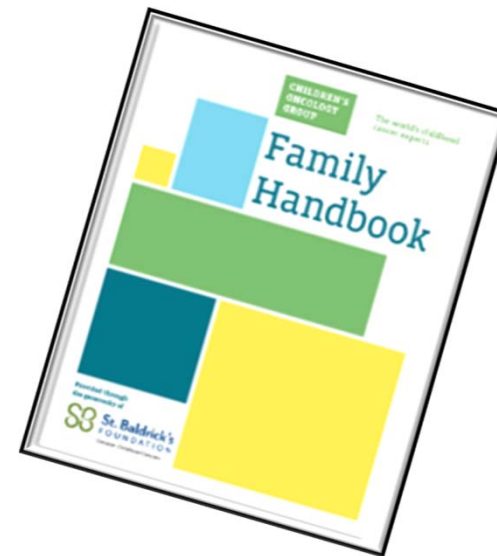
## Parent Satisfaction (N = 47)



## 1. What did you find helpful during the new diagnosis education process?

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- I felt that people (doctors, nurses, etc.) were wonderful, compassionate for us and what was placed in our life
- Always someone to ask a question; many people there to support
- Family Handbook explanation
  - ◆ The binder was great and organized



## Responding to the Diagnosis

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"I'd say the only thing is just trying to retain everything with the fog that you're in from being hit with it." *(mother of child with Ewing sarcoma)*

Rodgers et al., 2016



## 2. How can we improve our teaching process?

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- Don't give too much information too fast
- I have no new ideas, the process was great
- Nothing, everything was good
- Give more time before discharge



### 3. Additional comments:

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- We are very happy with the care our son is receiving
- Love this place - love the warmth of all our caregivers. Feels like a team.
- I want to stress how comfortable I felt asking questions. I also NEVER felt that anyone was short on time or on a run to get to the next patient. I felt well cared for.
- Thank you for all the support received from doctors, nurses, interpreters. Specially, for the support given our child. (Translated by Spanish interpreter)



## Pacing Information

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“Cause I know that first meeting was three hours and ... I'm sure that they told us three hours worth of information [but] I don't remember three hours worth of information.”

*(mother of child with ALL)*

Rodgers et al., 2016

## Nurse Data: Feasibility and Fidelity



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## Describe what worked well about the tool

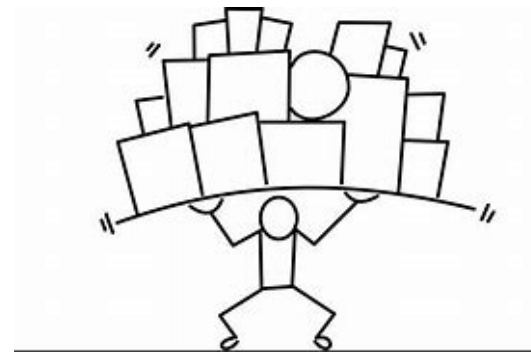
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- Prioritizing education, streamlined, looks nicer/easier to read. I love the revised form! From feedback parents gave me, it seemed **less overwhelming** to them.
- Limiting the amount of information to 'survival' decreases the amount of stress to our families.
- The tool is really nice for families who have a short first hospital stay. It allows them to feel confident utilizing their resources when they are at home without **overwhelming** them with other details.
- It's great! It will be the norm in time for teaching the basics to families, good initial content for safety when discharged.

## Standardization

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- I like how the slides corresponded with certain pages of the **new oncology family handbook**. It helped the flow of the teaching
- It makes sense **not to overload** the family with too much information up front and just keep the information to the basics for the initial teaching
- **Standardization** and knowing which topics to cover in each session.



## Describe any barriers you experienced using the tool: *Process*

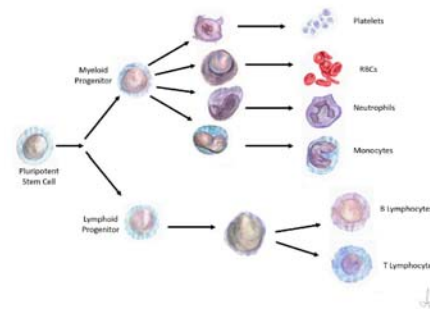
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- Great process
- Paper checklist and the process of obtaining it at discharge to scan in the medical record.
- Phase two seems to get lost when
  - ◆ there is a longer than expected first admission or,
  - ◆ if the patient is discharged home and readmitted shortly after.
- Come up with something so that the RN doesn't forget to get the checklist from the room before discharge.



## Describe how this process could be improved: *Primary Checklist Content*

- I really think that **blood counts** should be included in the primary teaching.
- Parents need to be aware of counts to understand the significance of fevers and the need to return immediately to the ER for antibiotics, etc.
- Sometimes hard for families since we don't go into details about the **cells**
- There have been topics that parents ask questions about that are not on the first session that have been placed on the second or third session.



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Illustration by Aimee Ermel, 2014

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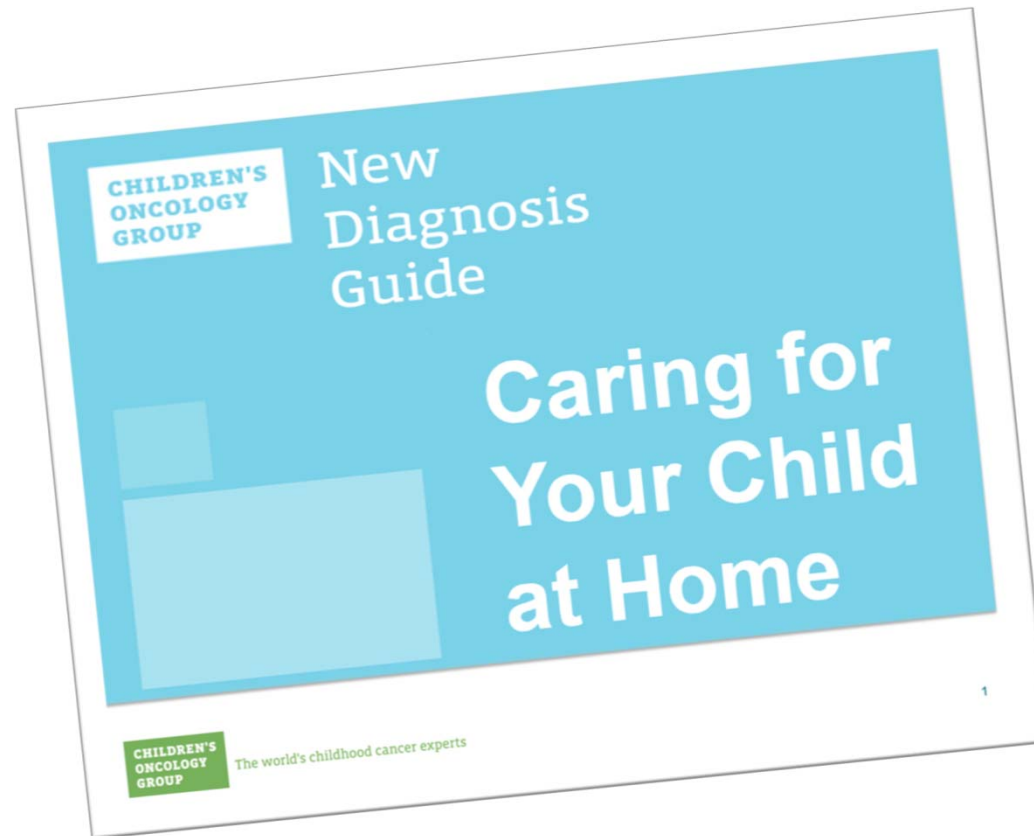
## Paper/EMR/Communication

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- The Cerner documentation should be the same as the paper form. I would love if the Cerner documentation appeared exactly as the paper form does.
- Process of coordination of education in the inpatient to outpatient and back.
- Documentation of each session in the EMR in a place that both outpatient/inpatient can see.
- Process for tracking phase one and two education within the EMR.

## COG New Diagnosis Guide Slide Deck

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# COG New Diagnosis Guide Slide Set

## How is cancer treated?

Table of Contents

Each type of childhood cancer is treated differently.

Your child's treatment may include one or a combination of the following:



Chemotherapy  
Immunotherapy



Surgery

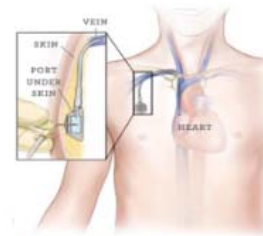


Radiation

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## Central Venous Line: Port

Table of Contents



PORT  
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Table of Contents  
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## Emergency Help

Table of Contents



Call **911** immediately if your child:

- Is not breathing or has severe difficulty breathing
- Has skin and/or lips that look blue
- Is having a seizure
- Does not wake up after you have tried to wake them



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## When to Call for Immediate Help

Insert your hospital/clinic  
phone numbers here:

### Fever:

Insert your hospital/clinic  
fever guidelines here

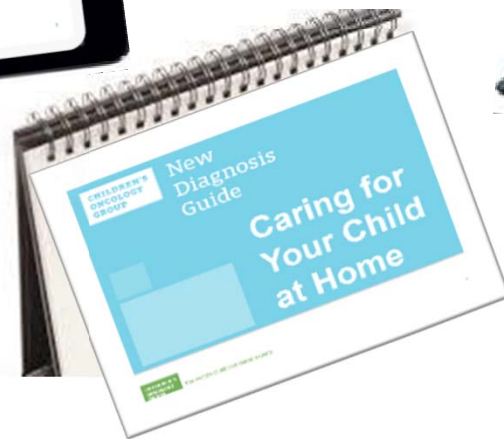
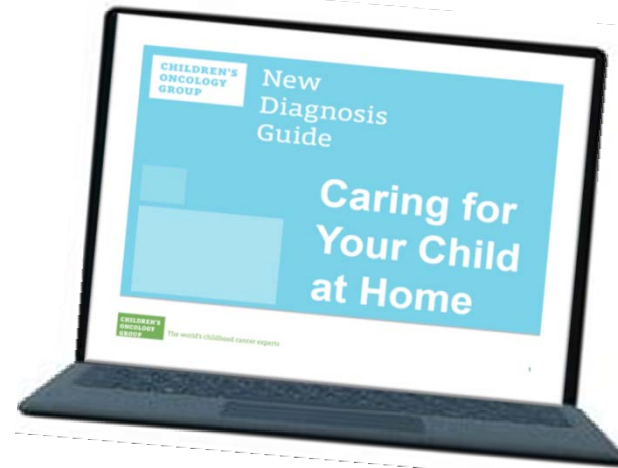
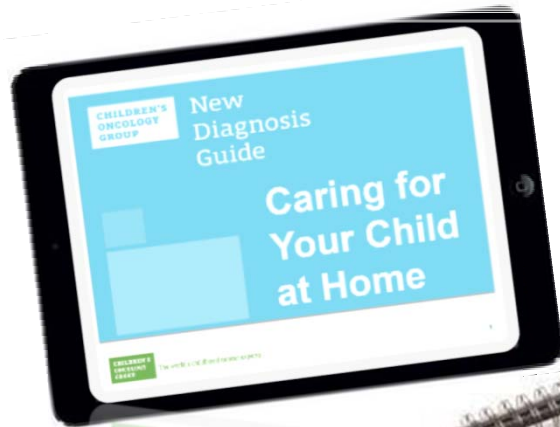


### Chills (shivering)

Do not wait until the clinic opens

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## Teach from tablet, laptop, flip book



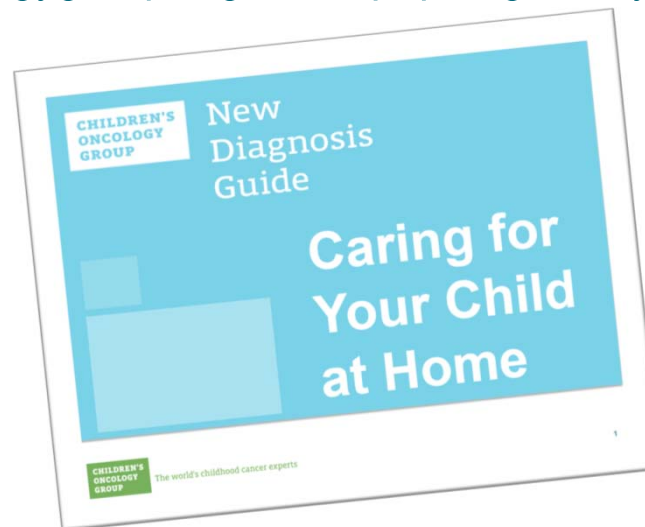
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## COG New Diagnosis Guide Slide Deck

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- How do I obtain the NDG Slide Deck?
- Can I add my own hospital specific information?
- Is there a cost?
- <https://www.childrensoncologygroup.org/index.php/cog-family-handbook>



# Smartphone App Project



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## Background

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- Smartphones are ubiquitous among adults of parenting age
  - ◆ >88% of 18-49 year-olds own a smartphone
- Smartphone apps provide a significant opportunity to meet the educational needs of parents across a wide spectrum of:
  - ◆ Literacy levels
  - ◆ Economic circumstances
  - ◆ Information needs
  - ◆ Learning preferences
- Smartphone apps allow for incorporation of audio, graphics, and video into educational content



## Project: Brief Summary

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- **Goal:** Develop a smartphone app for use by parents of children newly diagnosed with cancer that:
  - ◆ Delivers high-quality information, and is
  - ◆ Functional, aesthetically pleasing, and engaging
- Content informed by the COG expert consensus recommendations
- Key stakeholders involved at each stage of development
  - ◆ Parents
  - ◆ Clinicians
  - ◆ App developers
  - ◆ Research team
- Iterative process for development, incorporating stakeholder feedback at each step
- Evaluation for usability and acceptability by parents of pediatric oncology patients



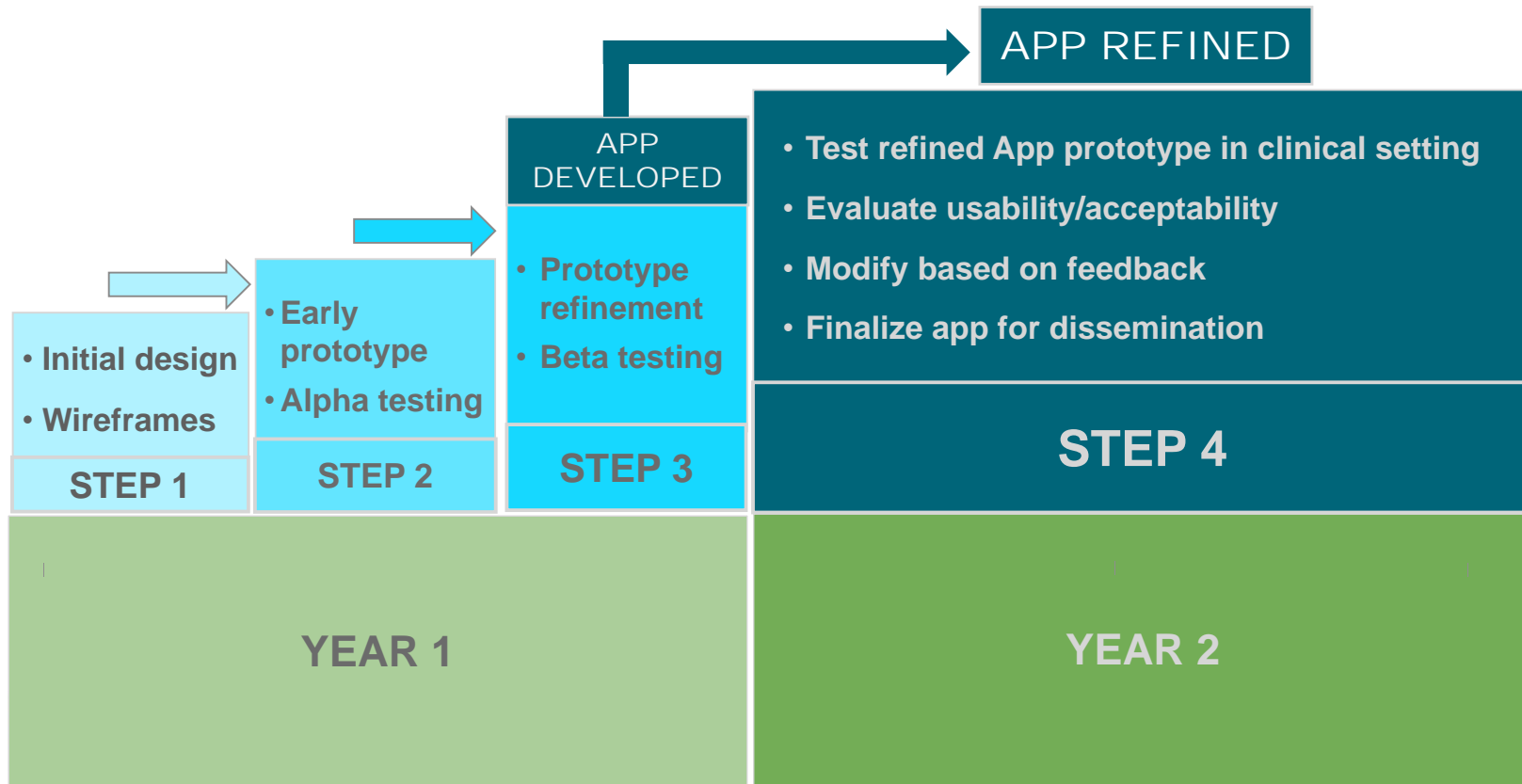
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Funding: Kaul Pediatric Research Institute, Children's of Alabama





# App Development Process



## Step 1: Initial Design/ Wireframes

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### ■ Who?

- ◆ Stakeholders (parents, clinicians)
- ◆ App development team (programmers, graphic designers; iOS/Android)
- ◆ Research team

### ■ What?

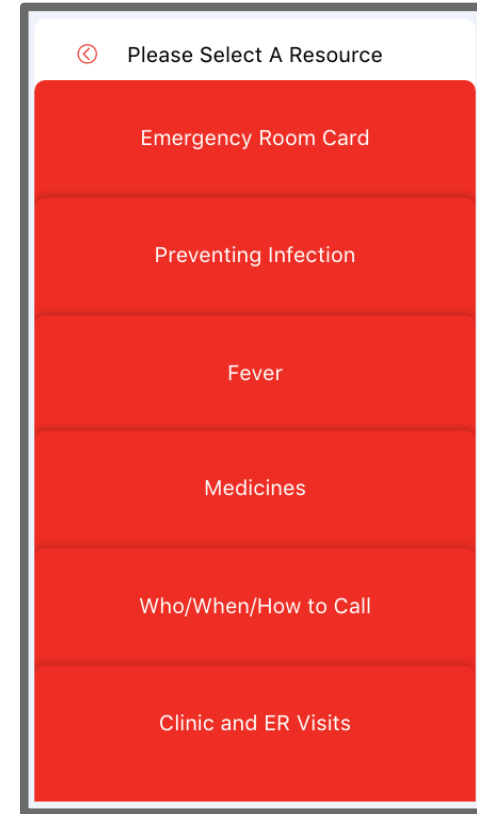
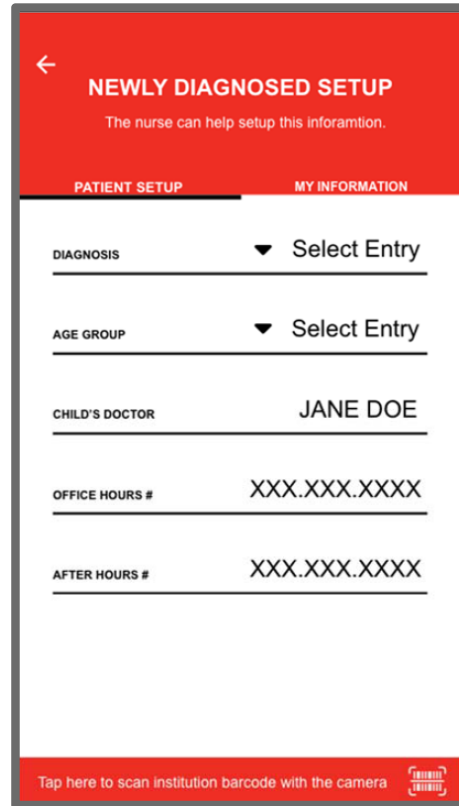
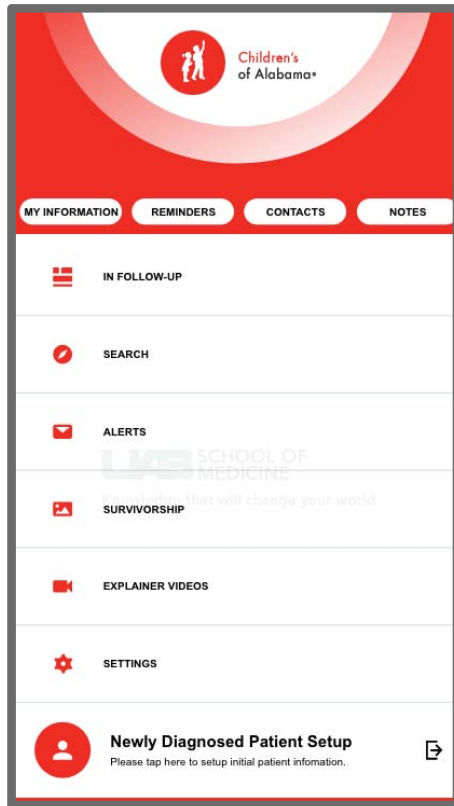
- ◆ Identify key content for inclusion
- ◆ Determine preferred layout and aesthetic features

### ■ How?

- ◆ Develop wireframe (blueprint/mockups)
- ◆ Defines structure, content, and functionality of App



# Step 1: Wireframes



## Step 2: Alpha Testing of Early App Prototype

### ■ Who?

- ◆ Clinicians (Nurses, NPs, physicians)
- ◆ Parents of children diagnosed at least 1 year ago

### ■ What?

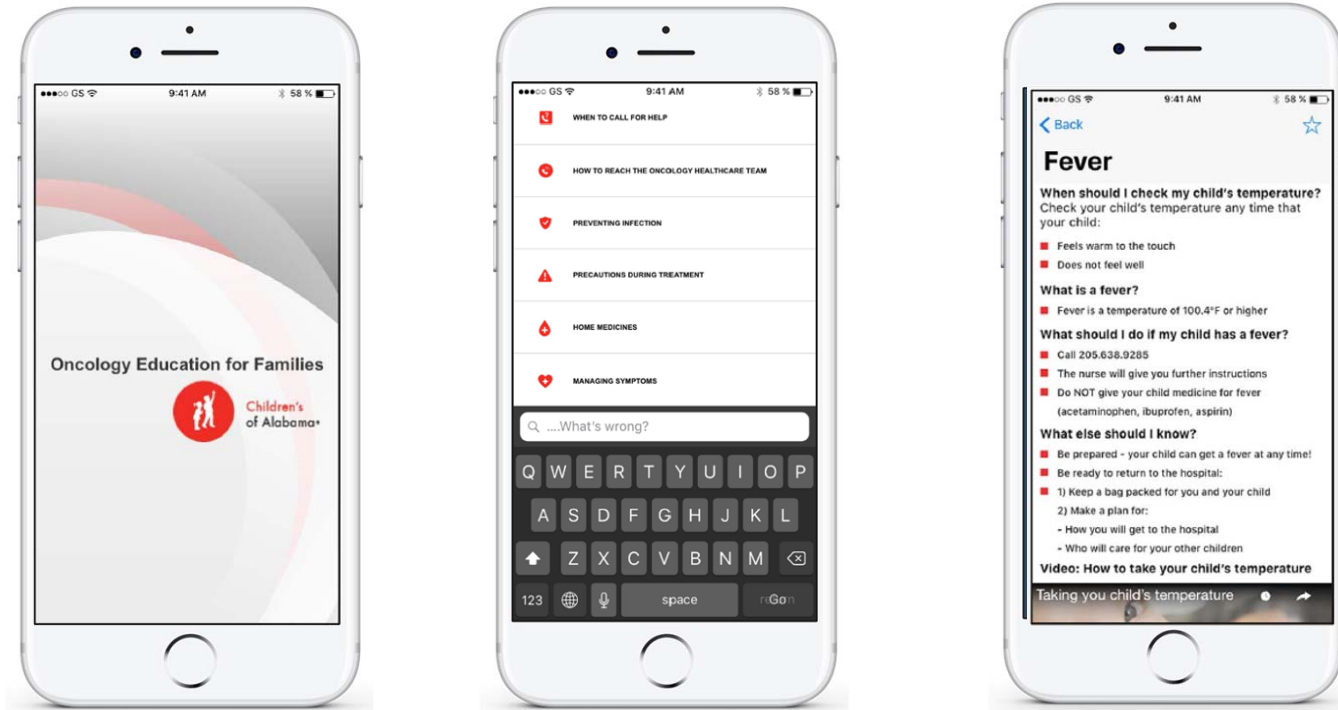
- ◆ Identify initial design problems

### ■ How?

- ◆ Research team presented scenarios and asked participants to perform tasks using the app
- ◆ Participants were observed performing tasks, and their actions mapped in order to understand the app's functionality and intuitiveness (cognitive walkthrough)
- ◆ Qualitative interviews were conducted to determine overall feedback
- ◆ Aggregate findings presented to Stakeholder Advisory Board



## Early App Prototype



## Alpha Testing: Results

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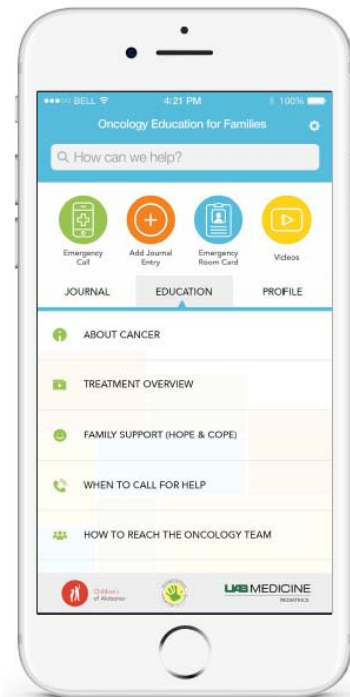
- Needs design and functionality changes to keep parents engaged
  - ◆ Journaling: Ability to keep personalized records
    - Labs
    - Weight, height, vitals
    - Notes
    - Treatments
  - ◆ Appointment tracker
  - ◆ Quick access to emergency information
  - ◆ Enhanced searchability of content
  - ◆ One-touch dialing to reach healthcare team



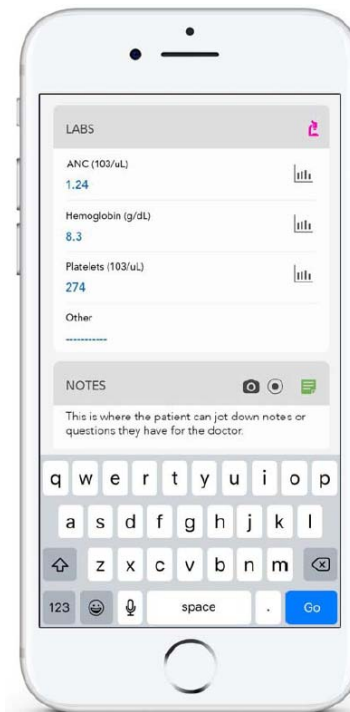
## Refined App Prototype



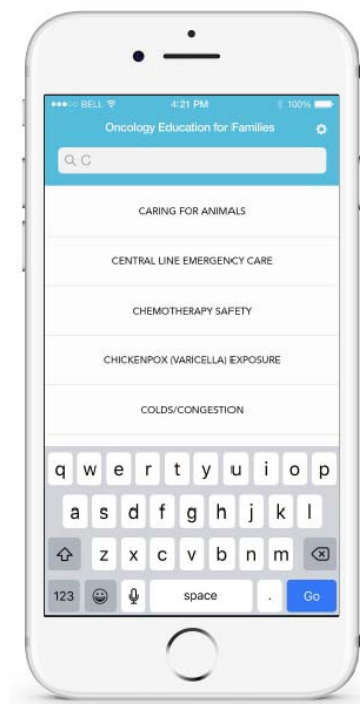
**Design**



**Functionality**



**Journaling**



**Searchability**

## Step 3: Beta Testing of Refined App Prototype

### ■ Who?

- ◆ Clinicians (Nurses, NPs, physicians)
- ◆ Parents of children diagnosed at least 1 year ago

### ■ What?

- ◆ Assess overall quality of app

### ■ How?

- ◆ Participants explore app over 1 hour to evaluate overall content, functionality, and app intuitiveness
- ◆ Asked to think of questions that they had (or for clinicians, questions parents had) when their child was newly diagnosed, and use the app to find answers to these questions
- ◆ Rating of App on Mobile Application Rating Scale (MARS) / Qualitative interviews
- ◆ Aggregate findings presented to Stakeholder Advisory Board
- ◆ Prototype further refined





## Results: Year 1

### PARENTS (N=12)

Characteristic	N	%
<b>Child's Diagnosis</b>		
Leukemia	6	50%
Lymphoma	3	25%
Solid Tumor	3	25%
<b>Time from Diagnosis</b>		
Months: Mean/SD	24.9	±4.3
<b>Relationship</b>		
Mother	9	75%
<b>Parent Age</b>		
≥40 years	9	75%

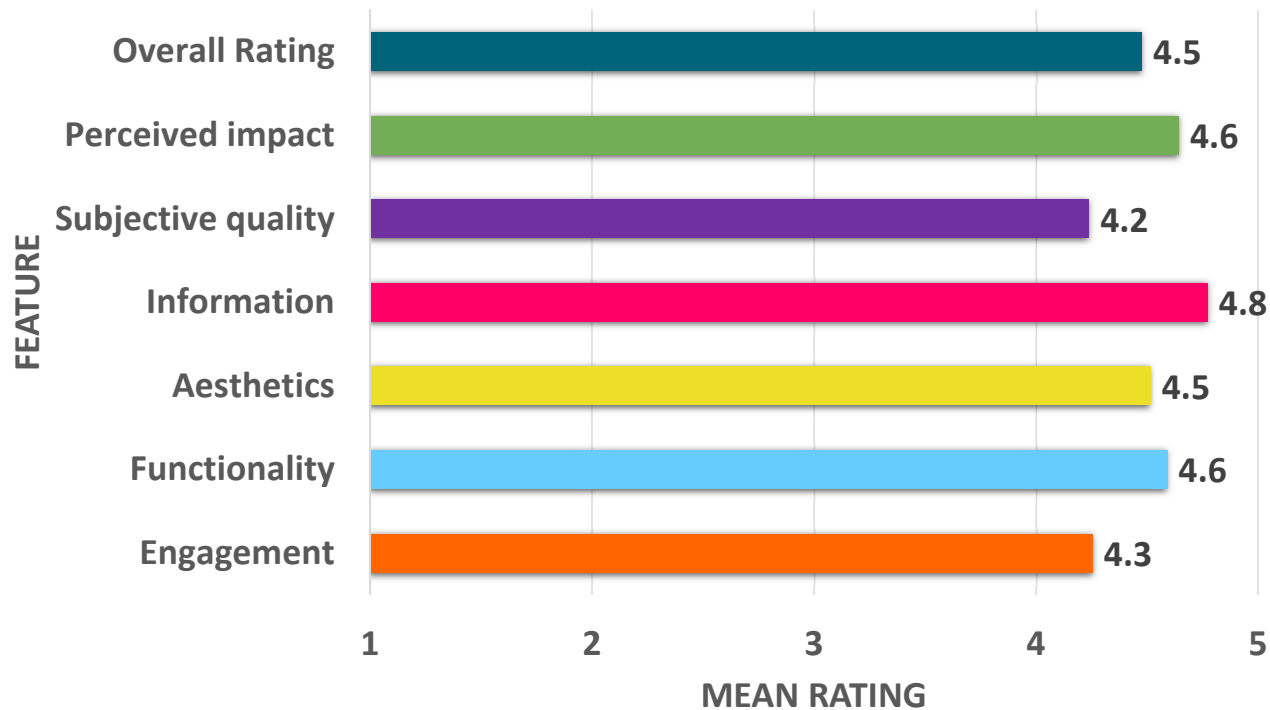
### CLINICIANS (N=17)

Characteristic	N	%
<b>Role</b>		
Physician	4	23%
RN	6	35%
NP	4	23%
Psychosocial Team	3	18%
<b>Sex</b>		
Female	13	76%
<b>Clinician Age</b>		
≥40 years	6	35%

49

## Results: Year 1 – Mobile Application Rating Scale (MARS)

- Assessment of App quality during the design/development phase  
*1=lowest quality level; 5=highest quality level (Perceived impact is rated only by clinicians)*

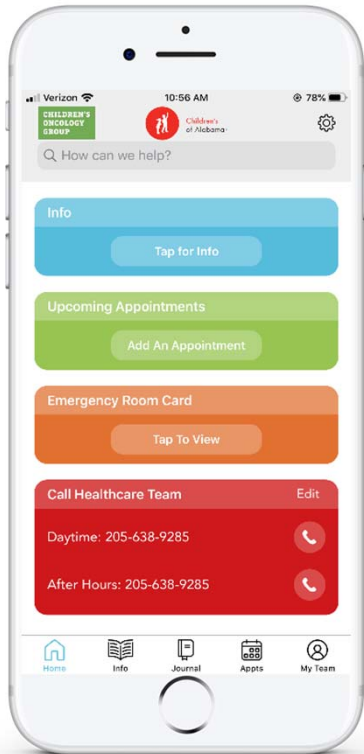


## Results: Year 1 – Qualitative Interviews

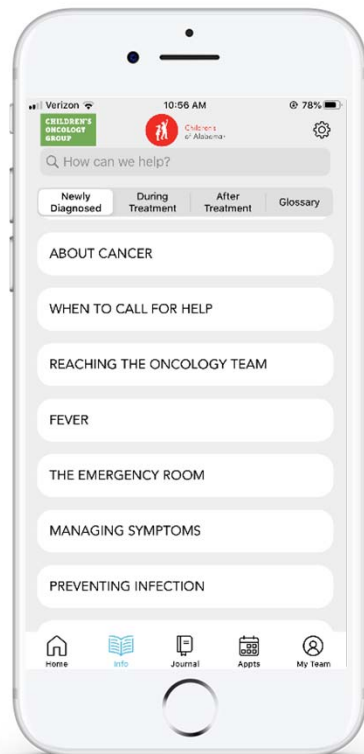
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- Many positive features: Emergency Room Card, quick access to critical information, journaling feature to track lab values and vital signs
- Opportunities for improvement:
  - ◆ Content: Additional details to ER card; Additional team members to contacts; Display labs and measurements as per hospital standard; Add med list and reminders; Add content beyond new dx
  - ◆ Layout:
    - Change order of educational topics
    - Curate content based on time from diagnosis
    - Move controls to bottom of screen
  - ◆ Functionality: Improve appointments, search bar, flagging, adding notes; sync w/EMR

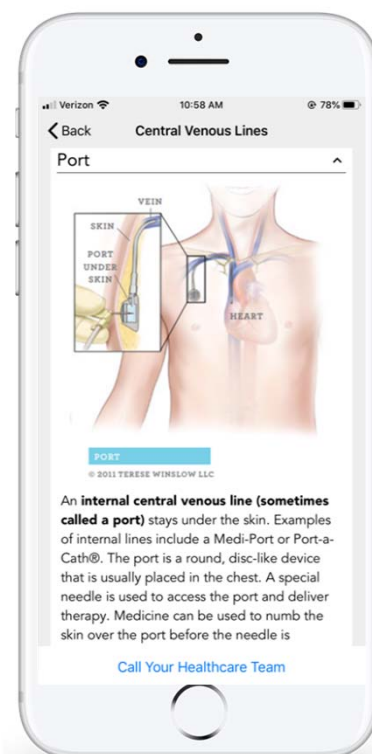
# Year 1 Feedback Incorporated



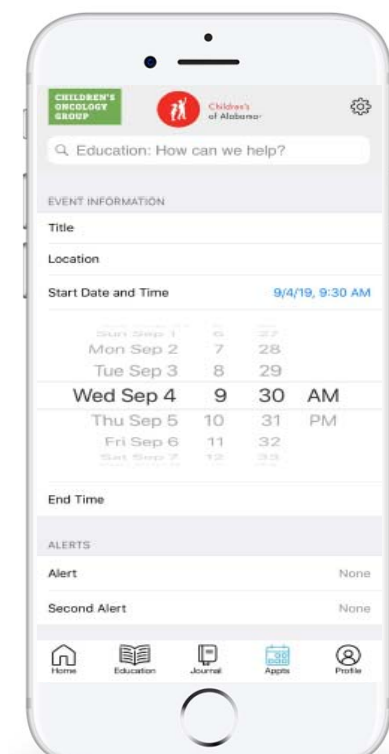
**New Home Page**



**Content Curated by Time from Dx**



**COG Content Incorporated**



**Appointment Functionality Improved**

## Step 4: Pilot Testing

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### ■ Who?

- ◆ Parents of children diagnosed at least 2 months ago

### ■ What?

- ◆ Evaluate and refine the app in a clinical setting

### ■ How?

- ◆ Download the app on their own phone
- ◆ Asked to complete defined tasks in-person, then to use at home x 2 weeks
- ◆ After using app x 2 weeks, parents completed Systems Usability and Acceptability Scales (SUS/SAS) and completed qualitative interview
- ◆ Aggregate findings presented to the Stakeholder Advisory Board
- ◆ Final recommendations for refinements made to App developers



## Results: Year 2

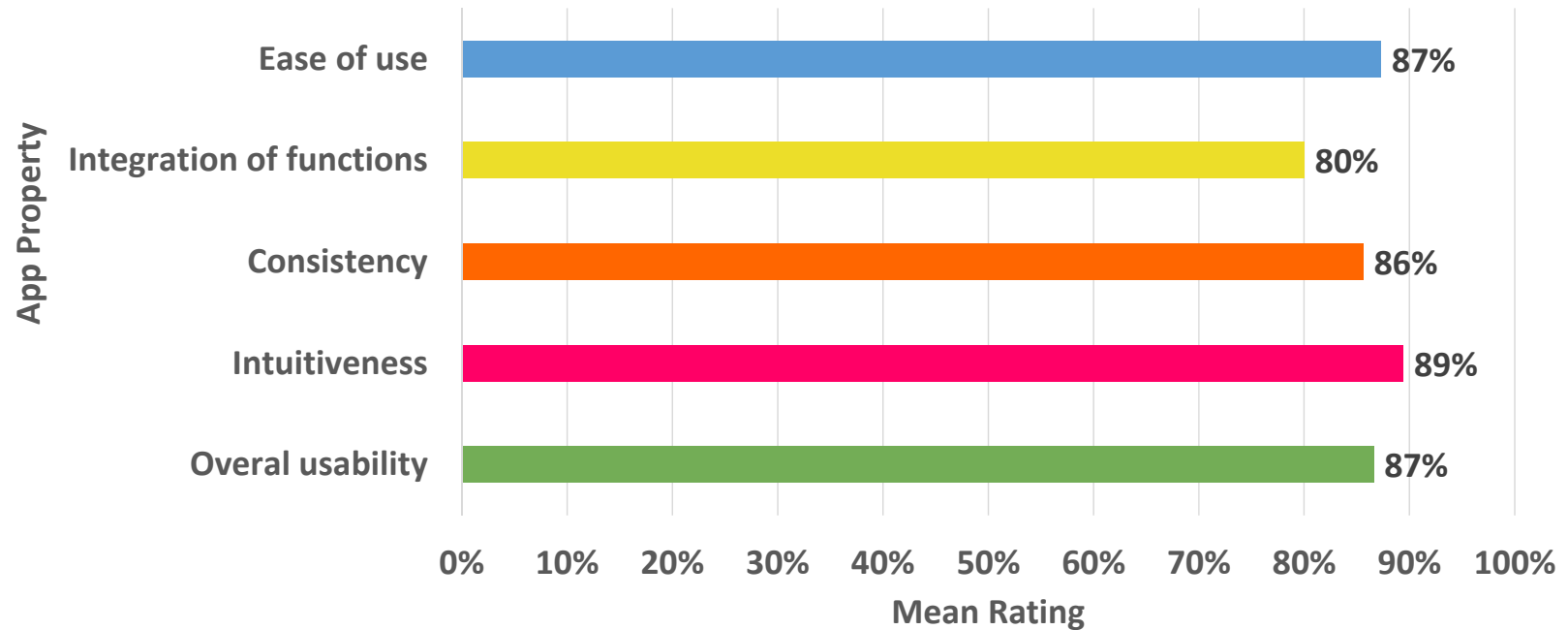
### PARENTS (N=20)

Characteristic	N	%
<b>Child's Diagnosis</b>		
Leukemia/Lymphoma	17	85%
Solid Tumor	3	15%
<b>Time from Diagnosis</b>		
Months: Mean/SD	10.4	±7.0
Median/Range	10	3-30
<b>Relationship</b>		
Mother	16	80%
<b>Parent Age</b>		
≥40 years	4	20%



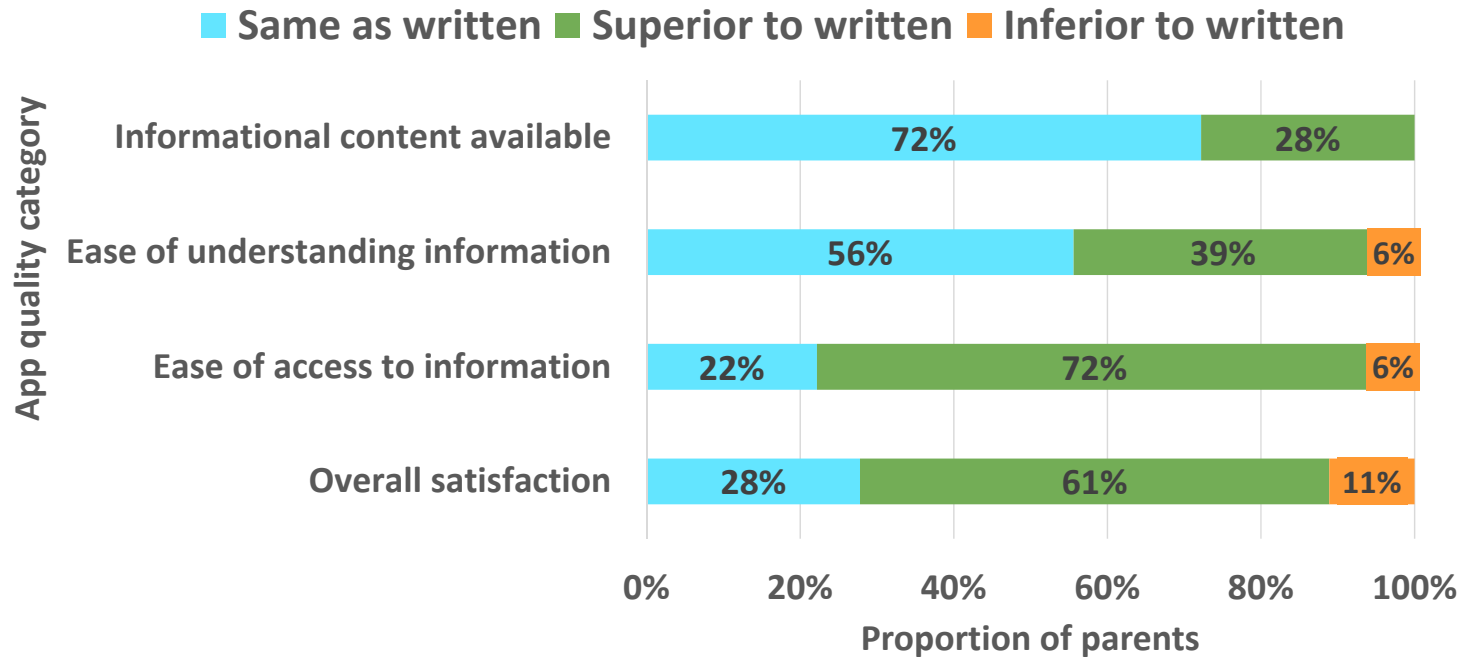
## Results: Year 2 – System Usability Scale (SUS)

- Rates app on ease of use, integration of functions, consistency, intuitiveness, and overall usability (>70%="good")



## Results: Year 2 – System Acceptability Scale (SAS)

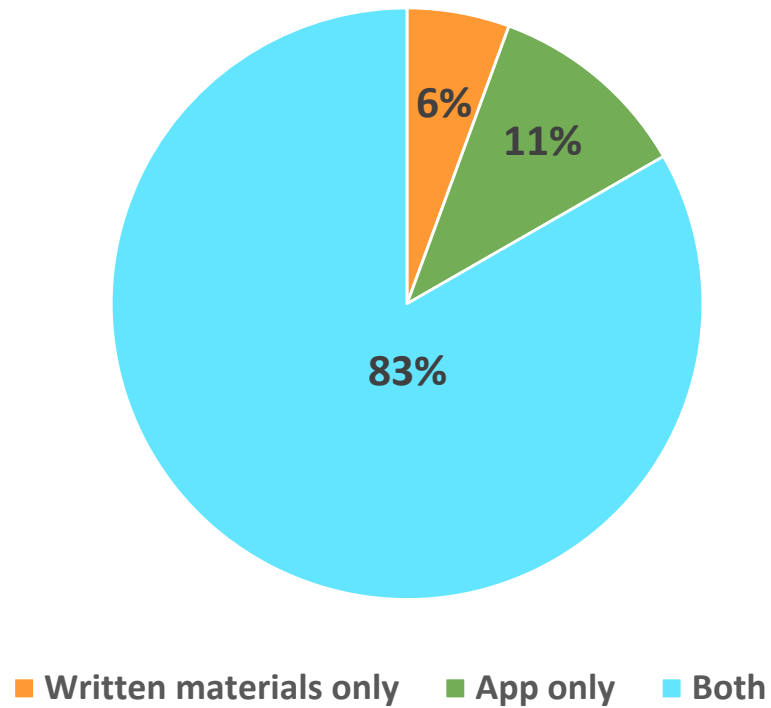
- Compared to written educational materials that you have received about your child's care in regard to the following qualities, the app is:





## Results: Year 2 – System Acceptability Scale (SAS)

- *Parental preference for educational materials about their child's care:*



## Results: Year 2 – Qualitative Interviews: Positive App Qualities

**“It is the same information [as the written materials], it was just easier to find...going through the app was less time consuming. Easier to find the information.”**

**“I love the emergency room card. That’s like one of my favorite things... I found it very helpful, the fact that it is right there, is convenient. Plus there is like little tabs, and you can click and scroll instead of frantically flipping through pages trying to find it, it is like right there.”**

**“I am very fond of [the app]. I am very much into my cell phone. I do like a paper copy of everything but to be one hundred percent honest with you, I didn’t read any of it. But once I got the app, it opened my eyes to what I didn’t read in the paper.”**

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## Results: Year 2 – Qualitative Interviews: Positive App Qualities

**“I like the ease of access...it was very user friendly, very easy to use. I like the different things like where I can put the appointments in, information like his weight and stuff, so I can keep up with it.”**

**“I think it is real easy to use. I like it. It actually gave me a reminder last night to come here [clinic] today. I mean I remembered, but I was like, ‘what is this?’ It came up on my watch and everything. It was helpful.”**

**“When you are first diagnosed I was thinking ‘I wish somebody had given me this and told me all of this.’ It eased my mind a lot. Plus you are stuck in that hospital room upstairs. You don’t want to sit and read a book when you are upset. So you want to play on your phone, yeah, so if I had [the app] to like mindlessly scroll on, it would have been very beneficial.”**

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## Results: Year 2 – Qualitative Interviews: Not for Everyone

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“I guess I thought it was too cumbersome to be worthwhile. When it comes to the information that was in the binders, I liked that I could read, highlight, take notes on what the information was....I’m more of a book-in-hand kind of person, so I prefer that....for people who are more into technology, it is good. But, I just don’t feel like...I feel like this information is so important it deserves a book. It deserves notes and highlights and tabs, and stuff like that which, I mean, I couldn’t do with this. And if I was talking to another parent, even if it was someone who is really into technology, I would be like: ‘You need to physically read this, put it in your hands.’ But again, I mean, it’s useful.”

## Results: Year 2 - Remaining challenges

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- EMR interface
- Medication list/calendars/reminders
- Treatment roadmaps

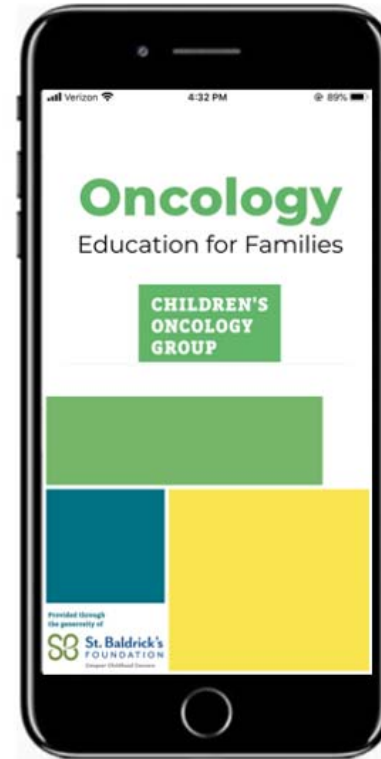


## Conclusions

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- App can make educational materials more accessible for many (but not all) families
- May help in making critical information more readily available to parents
- Features beyond educational content necessary to engage users over long-term
- Not all desired features could be incorporated
- More research needed to determine optimal use of smartphone app in educational process for newly diagnosed families

# Coming Soon: COG KidsCare App



The world's childhood cancer experts

*Through the generous support  
of the St. Baldrick's Foundation*

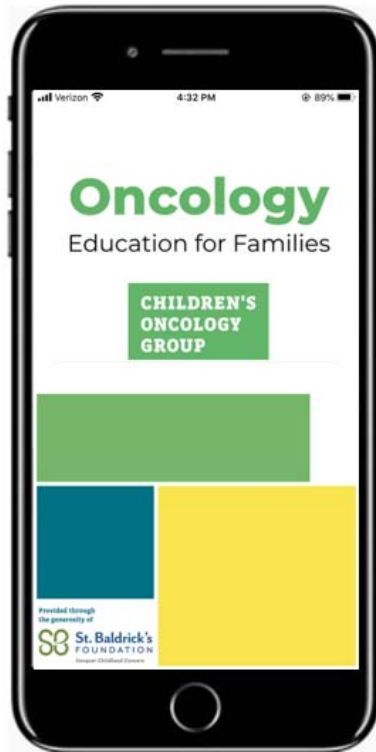
**CHILDREN'S ONCOLOGY GROUP** The world's childhood cancer experts

**Oncology**  
Education for Families  
**CHILDREN'S ONCOLOGY GROUP**

Provided through the generosity of  
**St. Baldrick's FOUNDATION**



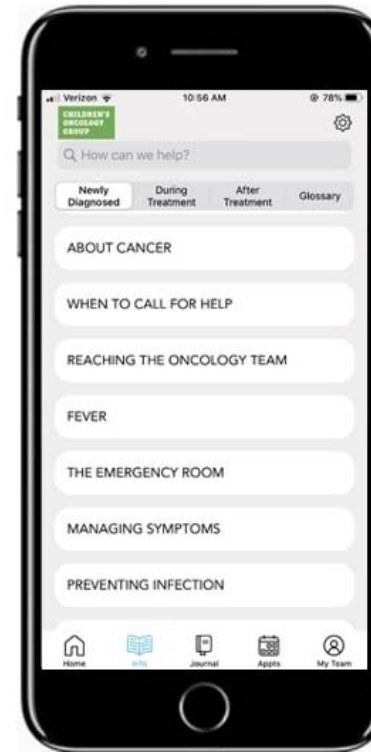
# COG KidsCare App



App ID Screen

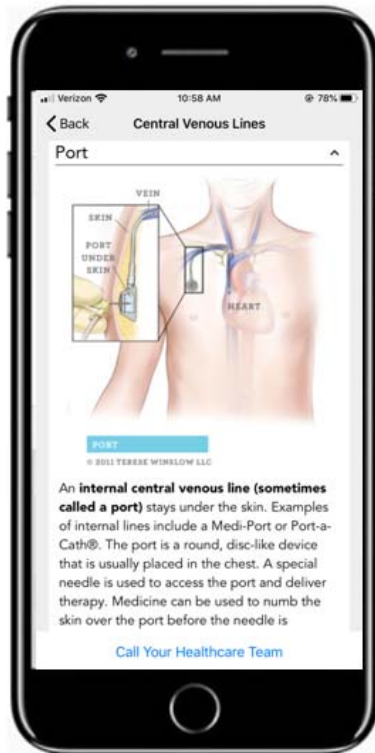


Home Screen



Info Tabs

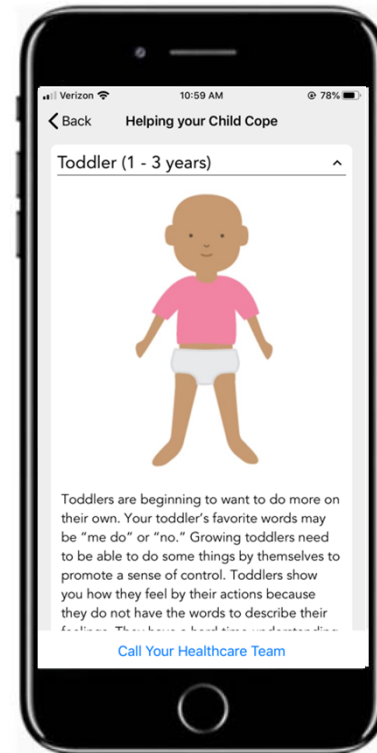
# COG KidsCare App



Info: Port

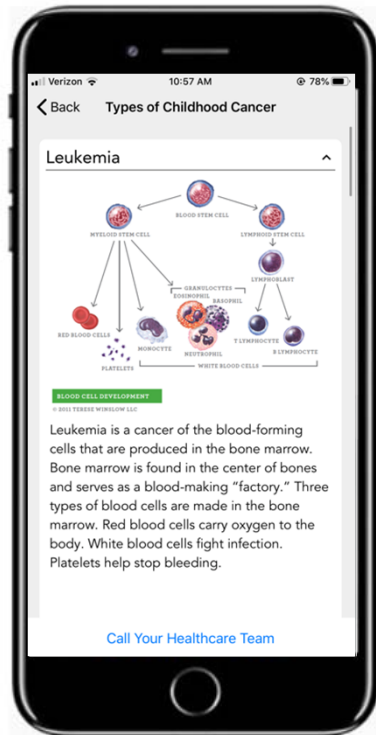


Info: LP

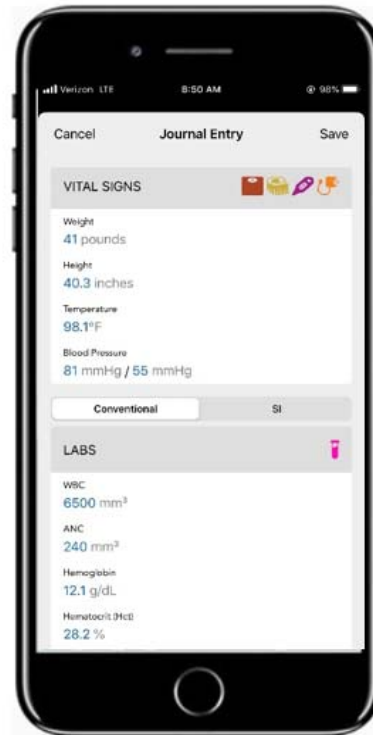


Info: Coping

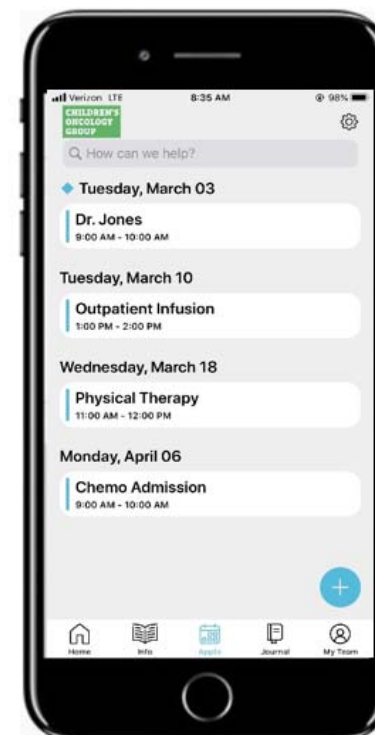
# COG KidsCare App



Info: Cancer Types



Journal

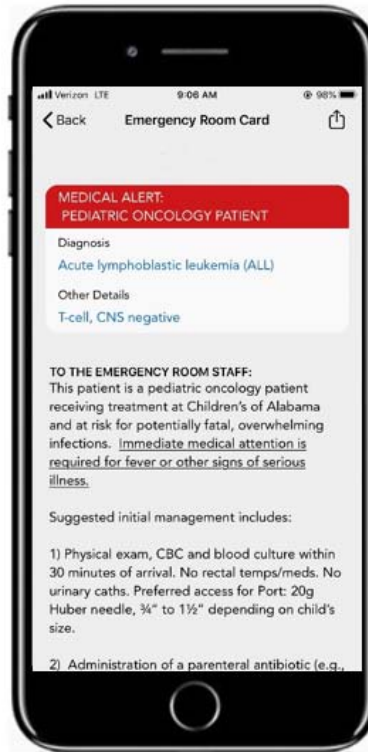


Appointments

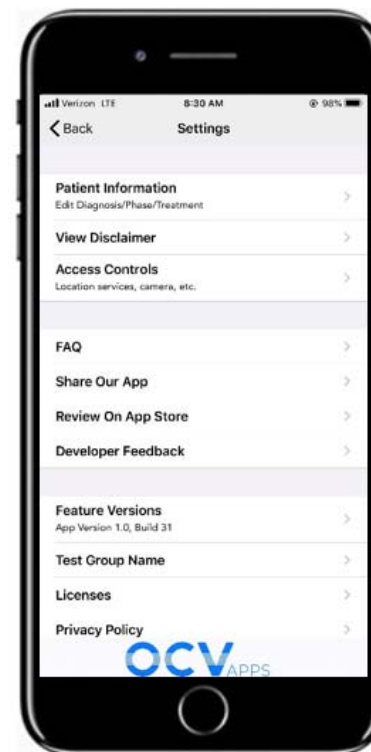
# COG KidsCare App



My Team

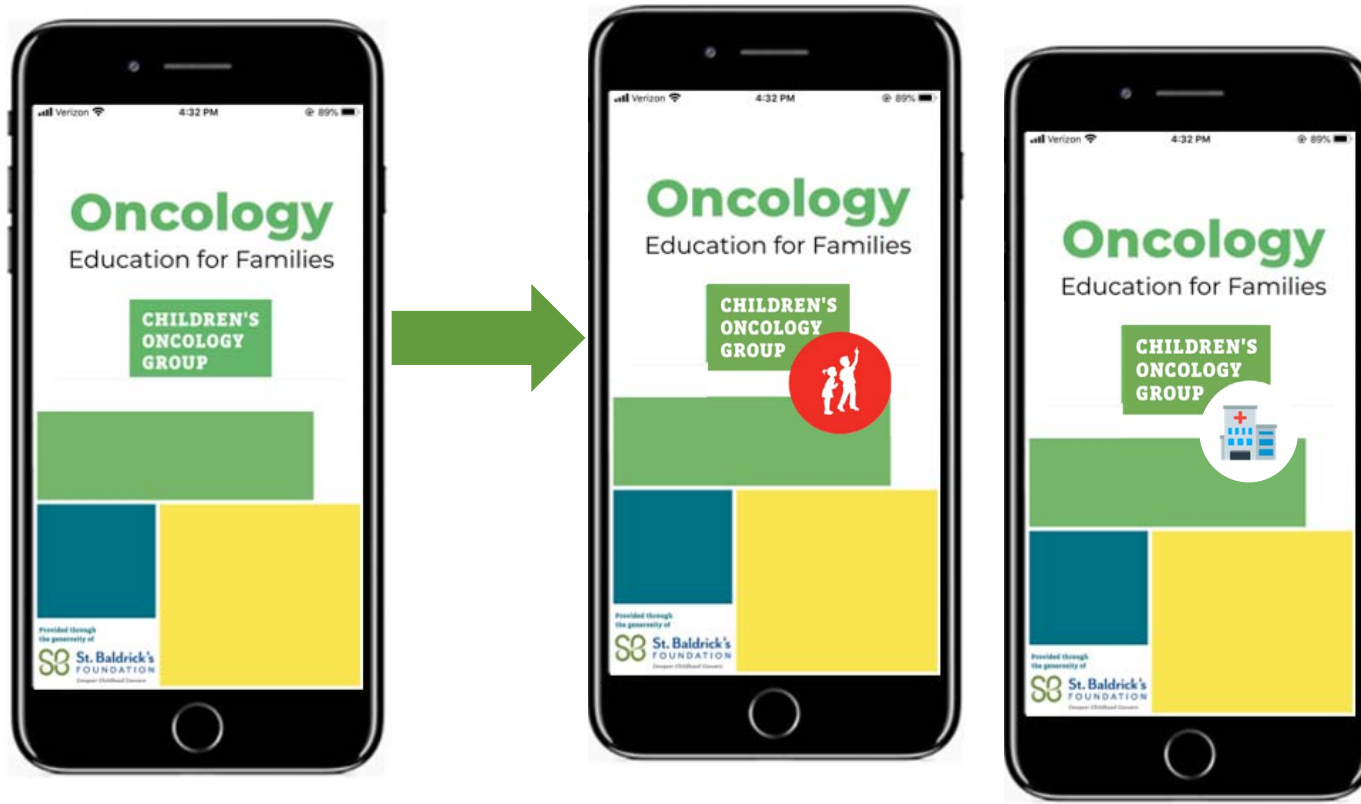


ER Card



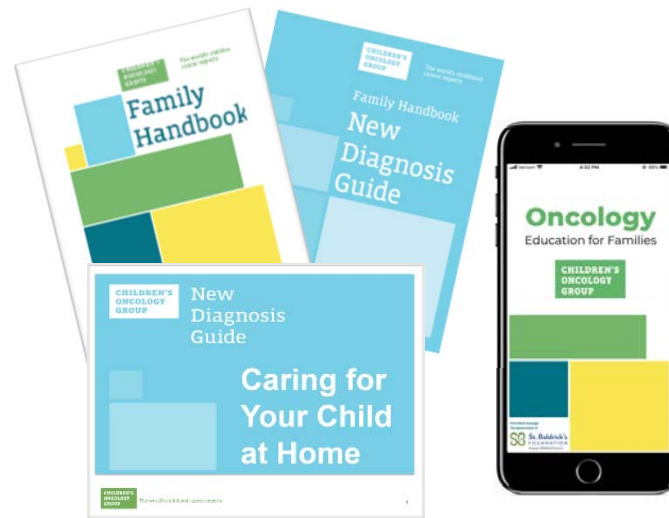
Settings

## Coming Soon - COG KidsCare App: Customizable Content



## COG KidsCare App: Long-Term Goals

- Results of this study set the stage for future testing of the app in a clinical trial within the Children's Oncology Group in order to determine effectiveness of the app in enhancing information access and sustained learning.



## Thank you!

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- ...to the families, nurses, physicians, nurse practitioners, psychosocial team, app developers, and research team members who contributed to this work.



## Resources for Patient/Family Education: APHON

<https://aphon.org/education/patient-family-resources>



### Pediatric Hematology/Oncology Resources for Patients & Families

#### APHON Handbooks for Patients and Families

The following handbooks, produced by APHON, provide an overview for patients and their families on specific hematologic and oncologic diseases. Each handbook is written at the 6th-grade level allowing parents to review it with their children. Select a topic to filter the handbooks and download the resource by clicking on the handbook of your choice. [Additional resources from other organizations](#) are also available.

- SHOW ALL
- ADOLESCENTS AND YOUNG ADULTS
- ONCOLOGY
- HEMATOLOGY

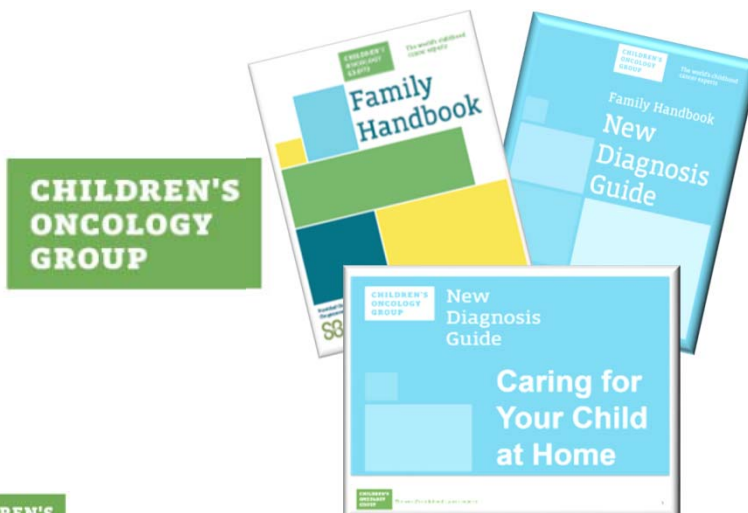




## Resources for Patient/Family Education: COG

<https://childrensoncologygroup.org/index.php/cog-family-handbook>

or  "COG Family Handbook"



CHILDREN'S  
ONCOLOGY  
GROUP

The world's childhood cancer experts

### How to Use the COG Family Handbook: New Diagnosis Guide and Caring for Your Child at Home Slide Set

The *New Diagnosis Guide* and the associated *Caring for Your Child at Home Slide Set* are focused teaching tools for pediatric oncology patients and their families.

#### How do I integrate the *New Diagnosis Guide* and *Slide Set* into practice?

- **Provide** the *New Diagnosis Guide* to patients and families at the time of diagnosis
- **Review** the *New Diagnosis Guide* to promote safe discharge from the hospital or clinic after first cancer directed therapy
- **Use** the *Caring for Your Child at Home Slide Set* as a slide show to teach patients and families about going home for the first time. This is not intended to be self-directed learning that a family reviews on their own. The speaker notes in the slide set serve as a guide for nurses as they teach this important content. The Spanish and French versions include speaker notes in those languages to allow for an RN who natively speaks the language to facilitate the teaching or for use with an interpreter.
- **Designate** appropriate staff at your institution to complete and review the "Treatment Overview" handout in the *New Diagnosis Guide* with patients and families (e.g. physicians leading the diagnosis talk, advanced practice providers, nurses).



## Abbreviations

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FULL TERM	ABBREVIATION
Acute lymphoblastic leukemia	ALL
Association Pediatric Hematology Oncology Nurses	APHON
Children's Oncology Group	COG
Electronic medical record	EMR
Emergency Room	ER
Evidenced based practice	EBP
Nurse practitioner(s)	NP(s)
Registered Nurse(s)	RN(s)
Standard Deviation	SD

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