




Preserving Legacy: A Guide to Message Banking


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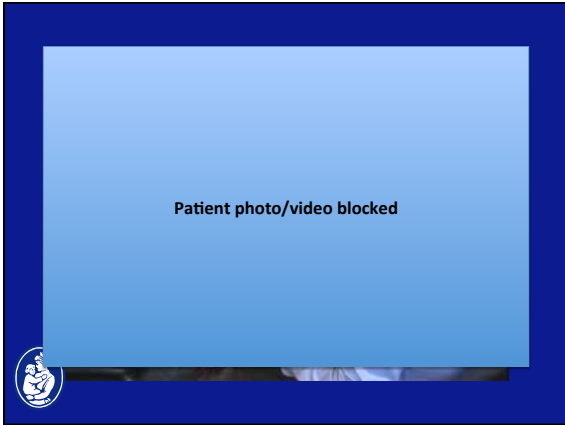
 www.childrenshospital.org/acp

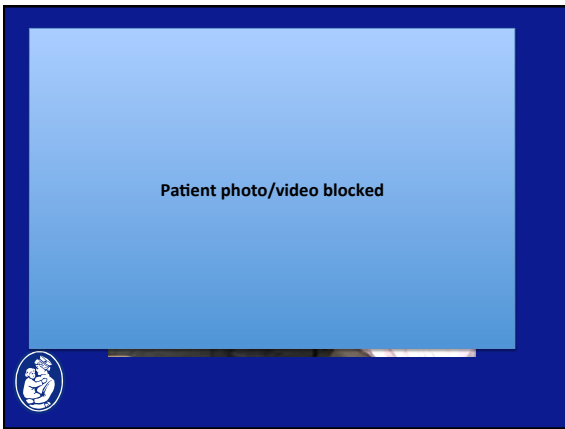
Begin with
THANK YOU
to many extraordinary
people with ALS




Patient photo/video blocked












**Notice the term
'Message banking'
NOT
'Voice Banking'**




**Children's Hospital Boston
History of 'Voice' Banking**



1994: CHB founded a model of AAC service delivery in the ICU including preoperative 'voice banking'.



Patient photo/video blocked



Parent perspective on hearing daughter's voice

Patient photo/video blocked

1998 Incorporated 'Voice' banking to support children living with life limiting illness/at end of life

Patient photo/video blocked

General model for 'voice banking'

- Patient directed focus
- Patients are asked to imagine nonspeaking condition or reflect on previous experience
***many had previous experience
- Patient and family members 'free flow' selection

12

2006

CHB Augmentative Communication Program asked by local ALS provider to see PALS.

2009

- Pilot program launched under grant for fast-forwarding SGD assessments
- Through fast-forward, Initial PALS referrals for high-tech SGD candidates seen by J. Gosnell
- Referrals diversified to head/neck cancer patients post-op
- Suggested our pediatric pre-op model could be applied.



Sidebar:

Let's examine terminology



The term 'voice banking' has continued to be used since we introduced it in the early 90's

BUT

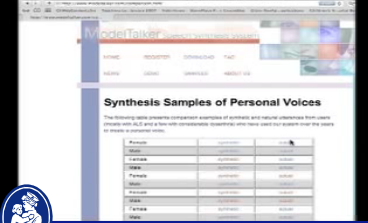
technology has changed!

With research and advanced technology, the term Voice Banking is now used to define a more sophisticated strategy.




ModelTalker
<http://www.modeltalker.com/>

The ModelTalker System was developed by the Nemours Speech Research Laboratory located at the Alfred I. duPont Hospital for Children with funding from the National Institute for Disability and Rehabilitation Research, the National Institutes of Health, and Nemours Biomedical Research.



<http://www.modeltalker.com/comparison.html>





AssistiveWare Video July 2012

ALS forum: post dated 10.06 retrieved: Nov 6, 2011
 "So I finally finished recording the inventory of phrases.
 There are about 1600 phrases and I would think you would need to dedicate a good 2 weeks of 1 or 2 hours a day.
 But it is worth it. From those recorded phrases the Speech Research Laboratory A.I. DuPont Hospital for Children and the University of Delaware synthesized a voice based on my recorded phrases - and it sounds amazing. Far better than I expected. It still sounds a bit electronic - but it sounds better than any other voice synthesizer I've heard such as the one Stephen Heywood had - and best of all it sounds like ME!
 So now I can write anything (even if the words were not in my recorded vocabulary) - and it will be converted into speech using my voice.
 I was almost in tears when I first heard it and I can't express what it means to know that, whatever happens to me, I will be able to communicate with my own voice.
 The whole process and software are FREE and just requires some time commitment on your part.
 I am forever indebted to everyone at the Speech Research Laboratory A.I. duPont Hospital for Children and the University of Delaware
 I would urge all PALS to do this now before it is too late."
<http://www.mandelstam.com/rgarthur.html>

'DANGERS OF MODEL TALKER':
 Don't get me wrong - I think Modeltalker is one of the most amazing programs out there. It is such a comfort knowing that even after I've lost the ability to speak I will still be able to talk using a synthetic version of my voice. All for free. I owe the developers of Modeltalker a huge debt of gratitude.
 As it becomes more and more difficult for me to speak, I've started practicing with the program - and I've uncovered an insidious side to Modeltalker.
 Now every time I have a disagreement with my wife - she takes the computer, types in the response she wants to hear, presses "speak " - and with a "click" I'm agreeing with her.
 "Of course dear, I'd much rather watch taped episodes of Oprah instead of the Superbowl!"
 "By all means, go right ahead and re-decorate the house in pink"
 "You're quite right dear, Angelina Jolie is looking haggard"
 And the problem is I'm usually swayed by such an eloquent and knowledgeable sounding voice.
 But I have to find some way to password protect the program after I caught my nephew typing in: "I look like a monkey and smell like one too"
 Accessed 11.6.11 @ <http://www.alsforums.com/forum/comedy-humour-jokes/14949-dangers-modeltalker.html>


Custom voice created by Scottish company 'Cereproc'
<http://www.cereproc.com/en/home>




Proposed Definitions:


Voice Banking

Message Banking



Voice Banking is a process of recording a large inventory of your speech that is then used to create a synthetic voice that approximates your natural voice.

Done successfully, this would allow one to spell and create unique messages and then speak them through a synthesizer that approximates one's natural speech. The science behind this process continues to be in development with beta-versions of available software. The ModelTalker is one such project from the University of Delaware Speech Research Lab. The website is:
www.asel.udel.edu/speech/ModelTalker.html



The science behind this process continues to be in development. The ModelTalker is one such project from the University of Delaware Speech Research Lab and their business partner AgoraNet.

The website is:
<http://www.modeltalker.com/>
(AgoraNet is the business partner for the speech research lab ModelTalker project)



Message Banking with your own voice *digitally*

record and store words, phrases, sentences, personally meaningful sounds and/or stories using your natural voice, inflection and intonation.

These messages are catalogued as .wav files and may then be linked to messages in a variety of augmentative communication technologies or sound storage files. This will allow you to 'retrieve' a message and speak it in your own voice but does not allow you to create novel messages by spelling. If you have recorded individual words, you may combine those words to create unique messages, although the output will sound more staccato than your natural speaking.



http://www.speech.com/wave/record.htm

Message Banking by proxy is the election of a proxy voice

to do all recordings because issues of fatigue, pain or intelligibility may make it difficult for an individual to bank all messages. In this case, the patient may still bank 'legacy messages' but the majority will be banked by proxy.



**Message Banking:
historically, typical strategy used**

- Acquire high quality microphone
- Create a list of appropriate message
- Use a recording software on your computer such as sound recorder
- Try to record message that sound as natural as possible




Sherelyn 2008
Panthenokinas Neurodegenerative
Disease

Patient photo/video blocked



Outcomes?


- Patients report is 'hard' to know what to record
- "I can't figure out what I am going to want to say"
- Some prioritize and record specific messages to loved ones (terms of endearment, appreciation to loved ones)
- Is tedious and artificial so is a 'chore' to accomplish
- Informal survey of colleagues nationally reveals banking of 10 – 20 messages on average with some instances of about 100



Message Banking:

We can do better!

My dilemma



Email referral: March 04, 2011
Friday @ 7:10 PM

"John, I want to send a patient to you next week for voice banking - he is a 56 y.o. heading into surgery 3.22 for a likely total glossectomy/total laryngectomy. Surgeon does not know if he needs to take the whole tongue but he likely will. The patient is calling Monday to schedule this. His name is: John XX. Let me know what you need - The MD is faxing a referral to you".



What would make this process easier
and more functional?


- Record any time and on the spot
- Have each recording be a .wav file
 - Highest quality so we have flexibility of all platforms at highest quality
- Easily download to a computer and determine communication platform later



On-line search for
'handheld .wav file audio recorder'

- Kept finding 'zoom' products
- Wanted to be certain so called the US distributor:
Samson Technologies Corp.
45 Gilpin Avenue, Hauppauge, NY 11788
- Described my exact mission and was directed to Zoom H1 which I purchased from Amazon and received next day delivery

On-line search of 'handheld .wav file audio recorder'



Zoom H1 Pak Portable Digital Recorder With Accessories Bundle and Headphones
by Zoom (24 customer reviews) | (3)

List Price: ~~\$249.99~~
Price: **\$128.20** Prime
You Save: \$121.79 (49%)
Special Offers Available

In Stock.
Ships from and sold by Amazon.com. Gift-wrap available.
5 new from \$126.95

Demonstration of .wav file creation




- set at 16/44 baud rate
- Must use wind guard
- Hold close to mouth for best quality
- Practice timing of push - speak - push



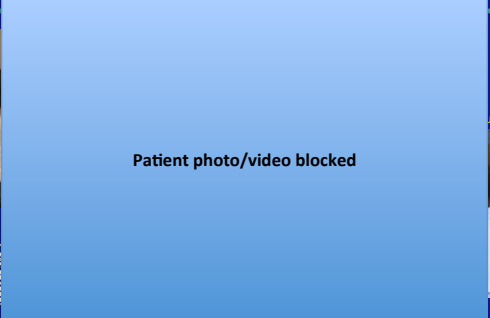
Note:
Going to stay focused on today's topic

Clearly, the broader topic of AAC, alternative access strategies and Feature Matching must be addressed with each patient as early as possible



Charlie, age 42
Diagnosed with ALS at age 41

Patient photo/video blocked




May 2011

Patient photo/video blocked




Need to bank more, body is changing

Patient photo/video blocked

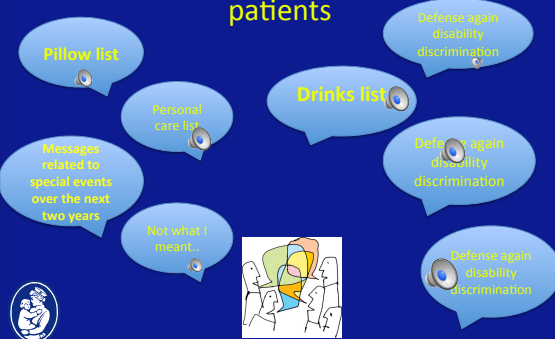


Vocabulary


- Vocal play with children
- Many loving messages to children
- Many messages to wife
- Vacation/quality family time messages
- Anger
- Defending self dignity anticipating severe disability
- Directives to anticipated staff
- Changes in physical state
- Refusal of medical treatment



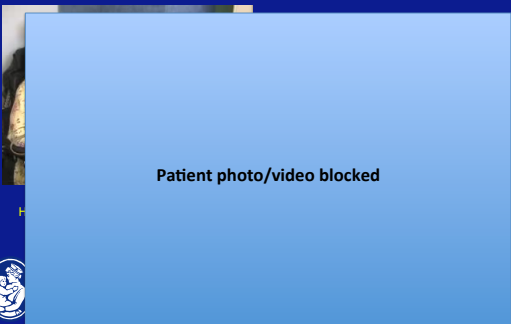
Strategies/categories identified by patients




- Drink list
- Pillow list
- Personal care list
- Messages related to special events over the next two years
- Not what I want
- Defends again disability discrimination
- Defends again disability discrimination
- Defends again disability discrimination

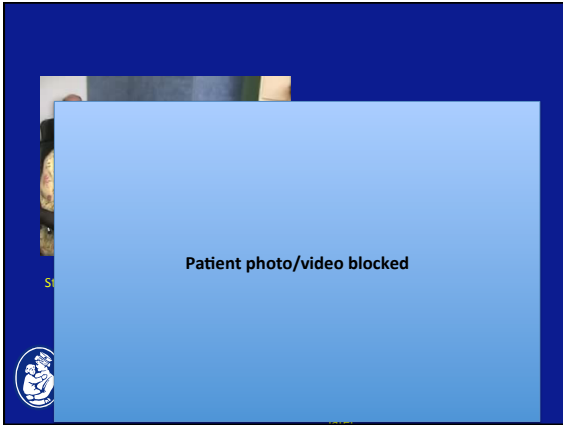


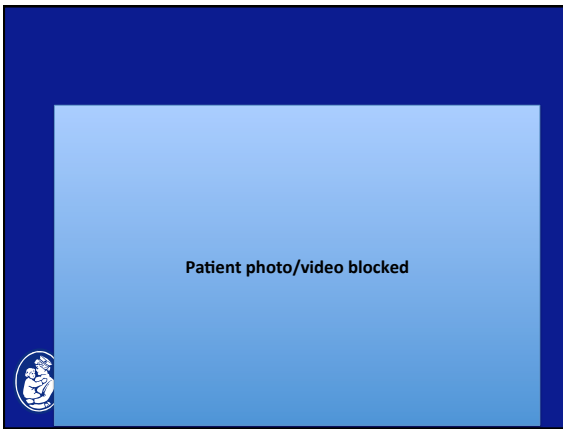
Susan

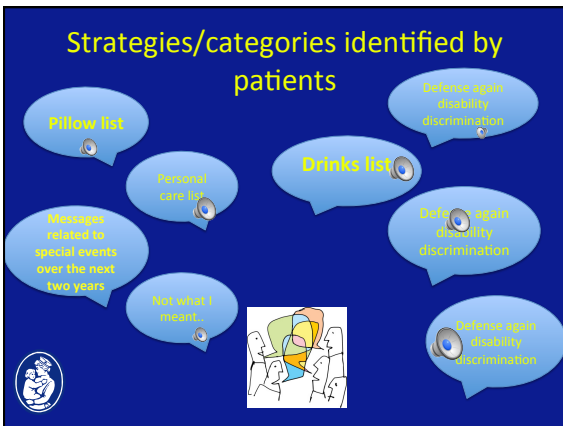


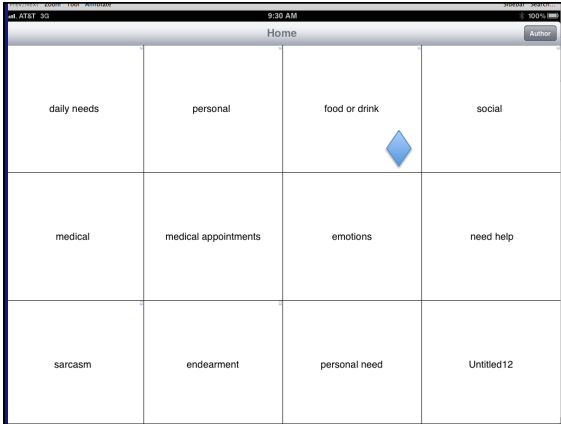
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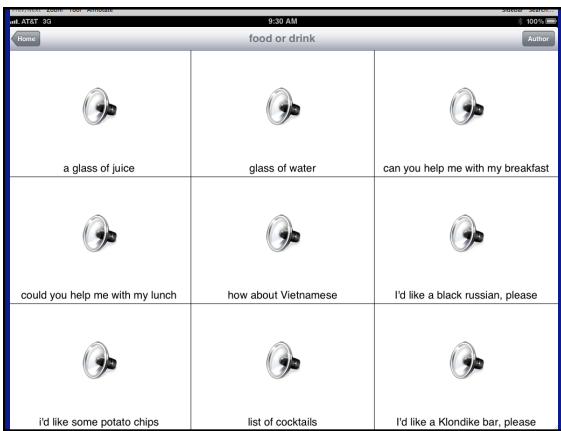












Without patient involvement, having meaningful vocabulary is as likely as finding a...



A photograph showing a thin metal needle stuck through a dense pile of dry, golden-brown straw or hay. The needle is positioned diagonally across the frame, with its tip buried deep within the tangled fibers of the straw.

Legacy Messages:

- ...those messages, often delivered with unique intonation and prosody, that are unique or particular to you.
- It may be a 'trademark' message you say or it may be a trademark *delivery* of a message that many people say.
 - A legacy message does not need to be meaningful to the general population instead, it may have unique and personal meaning to only you and a loved one.
 - Further, a legacy message does not need to be real words to be meaningful. It may be the way you clear your throat in a sarcastic manner to communicate "I told you so" or it might be the invented pet name you have for a loved one delivered with your unique voice, intonation and prosody.
 - Similarly, legacy message may be that stereotypical thing you say after your favorite sports team scores or it may be a unique greeting you deliver to friends. Those close to you may be helpful with identifying these *Legacy Messages* because sometimes they are so naturally part of socially relating with others, you may not even be aware you are 'known' for them.



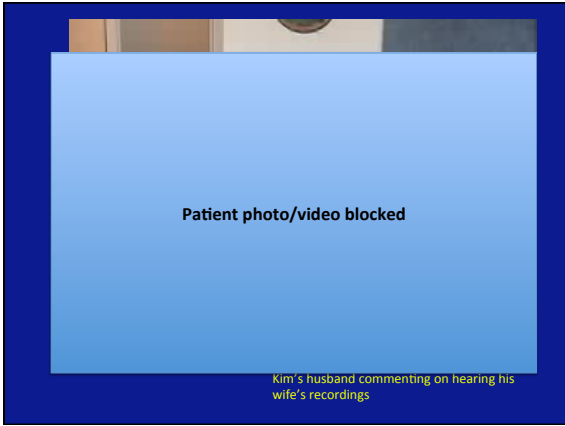
- **Core Vocabulary** refers to messages and words that are frequently used by many individuals across many contexts. This vocabulary typically consists of "functor" words such as "is, was, he, she" and common nouns and primary verbs (e.g. person, like, want). (Beukelman & Mirenda, 1992).
- **Fringe Vocabulary** is vocabulary specific or unique to a person or to one activity or topic (Beukelman & Mirenda, 1998).

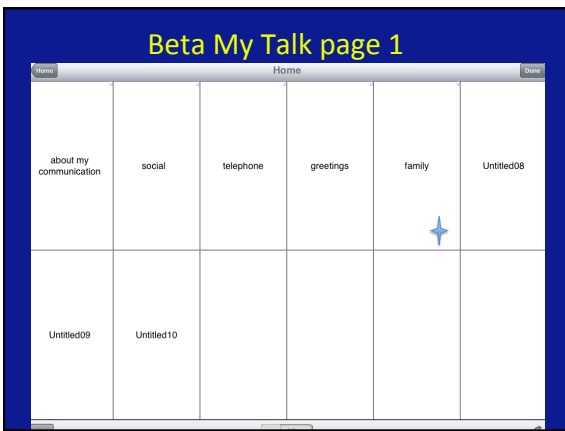


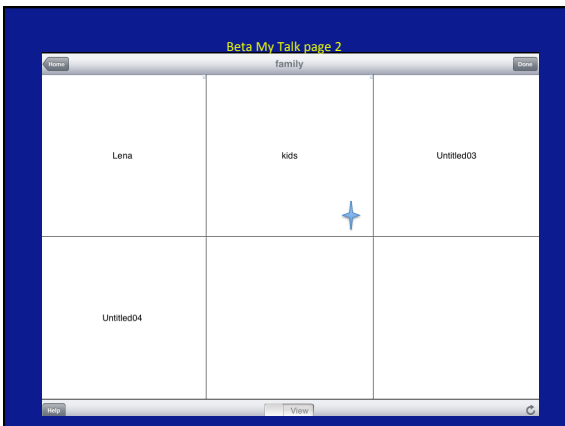
**Categories of messages banked
(initial analysis)**

- Personal messages/noises/sounds that are uniquely meaningful
- Appreciation
- Conversational modifiers
- Family routines
- Initiation of social activity
- Explanation of condition
- Expletives
- Personally relevant locations
- Social – time of day related











Beta My Talk page 3

morning talk to kids	tender moments	discipline	encouragement	pride	goodnight
Untitled007	Untitled003				


Beta My Talk page 4

 Rose, you are just the most beautiful little girl I have ever seen	 goodnight, Joe, I love you son	Untitled003	Untitled004	Untitled005	Untitled006
Untitled007					

Vocabulary selection


**Categories of messages banked
(initial analysis)**

- Sports/cheers
- Conversational starters
- Conversational enders
- Compassion toward others
- Complaints
- Personal info (biographical)
- Personal state




**Categories of messages banked
(initial analysis)**

- Messages to children
 - Daily routine
 - Pride
 - Tender moments
 - Discipline
 - future
- Requesting assistance
- Phone conversation
- References to future
- Humor and Sarcasm
- Social questions




Early referral of PALS

- **Determining goals and motivations**
- **Voice vs Message banking**
- **Bank now, select platform later**
- **Vocabulary and counseling**




**–Tools and options to consider
(based on patient’s interest)**

- Simple/low tech
- iDevice options
- Dedicated/integrated SGD




Patient photo/video blocked




Paul, age 52
diagnosis: ALS ten months prior to first visit

Patient photo/video blocked




Introduction to Message Banking:
the process

Patient photo/video blocked



September

Patient photo/video blocked



October and November

Patient photo/video blocked



NOTE: comment on supervision of some

Categories

- Greetings
- Need 'food/drink'
- Need 'medical'
- Need 'personal'
- Advice to boys
- Apologies
- Appointments
- Communication with doctors
- Phone calls to friends
- Car related messages
- Change of location/position in the house
- Social initiation 'do you wanna..'
- Environmental needs/control
- Encouragement to others
- General social
- Gratitude
- To family 'be there for each other'
- Silly intonations
- Statements about medical status
- Special occasions
- Sports
- Thanks and love to others
- Thanks (general)



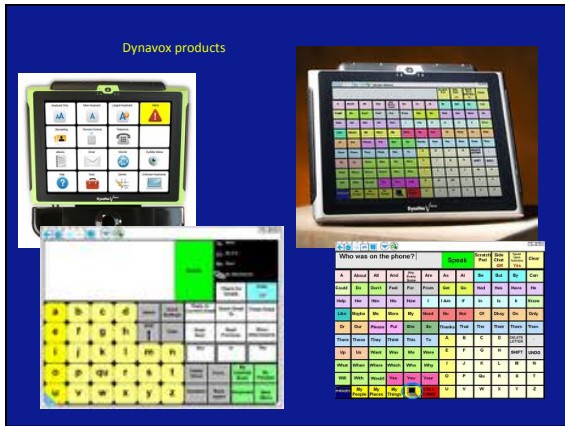
Meaghan, age 11 dx: Juvenile Huntington's Disease Message Bank on iPad

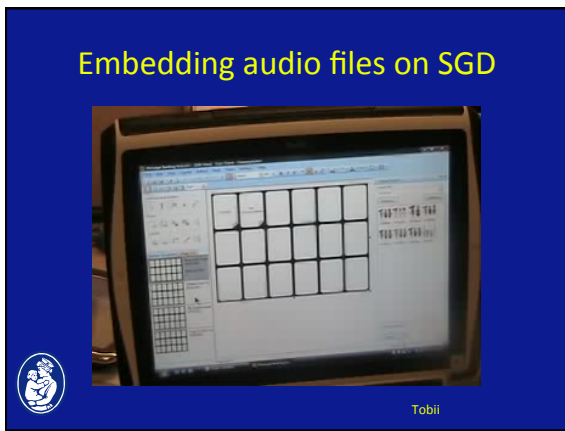
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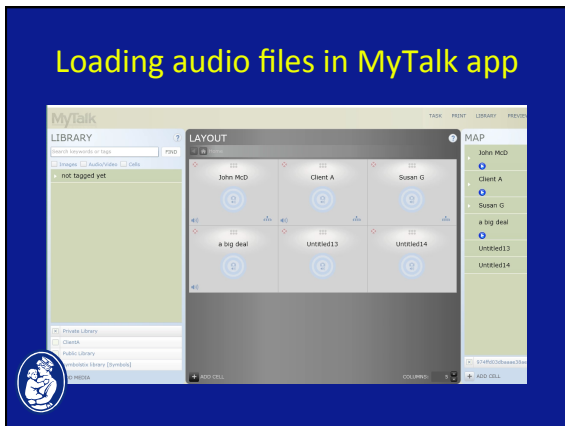


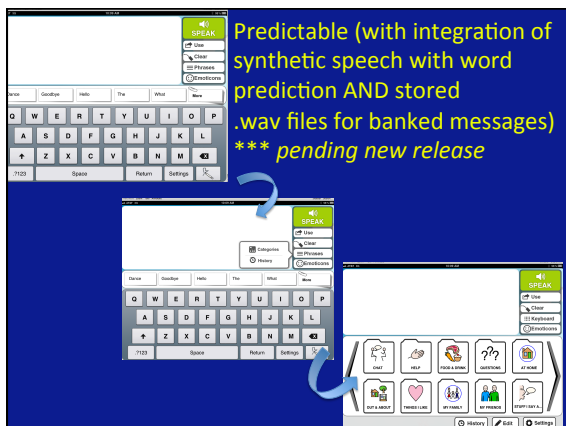
What Platform??

There are MANY but here are a few possibilities









Today:
www.childrenshospital.org/acp
In mid-August:
<http://www.patientprovidercommunication.org>
