

# Expanding Opportunities and Emerging Experience for Patient Engagement Using Technology

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First, I'd like to acknowledge my colleagues, Dr. Sue Bakken is my mentor and is the PI of one of the major projects I'll be talking about today.

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And here you can also see our funding sources.

## Introduction

### ■ Technology creates patient education and engagement opportunities by:

- Supporting comprehension
- Providing access to high-quality patient education materials
- Promoting communication with clinician

### ■ Two case studies

- WICER :: Tailored visualizations of personal health data
- MIAP :: Online maternity education platform

### ■ Conclusions



Today I'm going to talk about some of the opportunities that technology creates for engaging patients, things that would not be possible, or as straightforward, or easy without technology. I am going to do that in the form of two case studies, the first talking about tailored visualization, that is infographics and types of graphical formats. And then I'm going to talk about MAIP, which is an online maternity platform.

## Case Study: Tailored Visualizations of Personal Health Data

# WICER

Washington Heights/Inwood Informatics Infrastructure for  
Community-Centered Comparative Effectiveness Research



So first, WICER, which is the Washington Heights/Inwood Informatics Infrastructure for Community-Centered Comparative Effectiveness Research.

## WICER

- **Goal: to advance comparative effectiveness research designed to improve hypertension care delivery and population outcomes by building on an existing institution-focused data infrastructure to create a robust community-focused data infrastructure.**
  
- **~5,800 community members in northern Manhattan**
  - Blood pressure
  - Height and weight
  - Waist circumference
  - Fruit servings
  - Vegetable servings
  - Physical activity
  - Smoking
  - Alcohol use
  - Oral health
  - Medication adherence
  - Depression and anxiety
  - Chronic stress
  - Energy
  - Sleep quality
  - Health literacy



WICER was a large AHRQ-funded project that had lots of moving parts. It's focus is on hypertension, and the purpose of this project is really to understand and enhance the health of the community, which is Washington Heights and Inwood – the neighborhood where Columbia University Medical Center is located. This is the community we serve. It's where I live as well. It's largely a Dominican neighborhood. So most of the people are Spanish-speaking, and some also speak English. We sent community health workers into the ambulatory care clinics, a community health center, and into people's homes. We surveyed about 5,800 people and gathered research-quality blood pressures, height, weight, waist circumference, and a whole slew of patient-reported outcomes, including measures of mental health, nutrition, physical activity, et cetera. Most of the people gave the consent to have their survey data linked to their clinical data at New York Presbyterian Hospital, so that's a really rich data source available. And many of them agreed to be contacted for future research. So we now have this wonderful research cohort. Some of them have given swabs for genomic studies, et cetera.

## Returning Data to Participants

- Ethical obligation to communicate with participants and community in a way that is:
  - Accessible
  - Easily comprehended
  - Tailored
  - Actionable
- Comprehension of health information is necessary (but not sufficient) for effective health self-management.
- Low health literacy can be a barrier to comprehension for many Americans.<sup>1</sup>
- Visualizations can support comprehension.<sup>2</sup>
- Existing visualization work is focused on risk communication.<sup>3</sup>

1. Paasche-Orlow MK, Parker RM, Gazmararian JA, et al. The prevalence of limited health literacy. *J Gen Intern Med.* 2005 Feb;20(2):175-184. PMID: 15836552.
2. Garcia-Retamero R, Okan Y, Cokely ET. Using visual aids to improve communication risks about health: a review. *Sci World J* 2012 May;2012:562637. DOI: 10.1100/2012/562637. PMID: 22629146.
3. Ancker JS, Senathirajah Y, Kukafka R, et al. Design features of graphs in health risk communication: a systematic review. *J Am Med Inform Assoc.* 2006 Nov-Dec;13(6):608-18. PMID: 16929039.



We really believe that we have an ethical obligation to return the data to the participants and to the community that supported this project, but it's not enough to say, "Here's a 60-page report, enjoy." You really do need to give people information in a way that they can find usable and actionable. We know from preliminary data that levels of health literacy are quite varying throughout the community but fairly low on average. We've seen that visualizations can support comprehension, but a lot of the work has been done with risk communication, but unfortunately when we looked at the types of data that we wanted to convey, we really didn't see much in the literature that would give us any guidance as to what is the best way to present this information, because most of it really was about risk communication. So we engaged in a whole visualization development process, and here you see an overview.

## Overview of WICER Visualization Process



The first part involved iterative development of prototypes, followed by focus group testing. The modules for ENTICE are almost done -- that is the system that automatically generates and tailors the graphics. Comprehension testing is coming soon.

## Visualization Development

- **Multidisciplinary team: Columbia University School of Nursing, Department of Biomedical Informatics, and Mailman School of Public Health**
- **Collaborative, consensus-based process:**
  1. **Identification of variable types**
  2. **Matching of data types to standard graphical formats**
  3. **Addition of innovative analogy-based formats**
  4. **Iterative prototyping; hallway tests; group feedback**
  5. **Ranking of cognitive tasks in order of increasing complexity**
  6. **Selection of prototypes for each cognitive task**

Arcia A. Bales ME, Brown W, et al. Method for the development of data visualizations for community members with varying levels of health literacy. AMIA Annu Symp Proc. 2013 Nov;2013:51-60. PMID: 24551322.



First, we assembled the visualization working group, which included people from nursing, biomedical informatics, medicine, and public health. We looked first at the kinds of variables we had and asked what we needed to visualize, and then we matched those variables to some standard graphical formats, the kinds you see today, like for example the formats available in Excel. But we also added our own innovative, novel formats, analogy-based formats that you'll see in the upcoming slides. We engaged in iterative prototyping until we felt like we had a few options for each type of data that we wanted to convey. Our main goal was to promote comprehension, and what we had to do was answer the question, "What are the cognitive tasks that somebody needs to complete in order to understand this information? And we started to group our infographics according to those tasks.



## Focus Group Testing

### Sample

- 21 groups: 5 English-speaking, 16 Spanish-speaking
- 102 participants
- Aged 19-91 years
- 85% female; 95% Hispanic

### Procedure

- Printed prototypes, simulated data
- Preliminary comprehension check
- Preference elicitation
- Iterations based on feedback

Arcia A, Suero-Tejeda N, Bales ME, et al. Sometimes more is more: iterative participatory design of infographics for engagement of community members with varying levels of health literacy. *J Am Med Inform Assoc.* 2015 Jul 13 [Epub ahead of print]. DOI: 10.1093/jamia/ocv079. PMID: 26174865.



We conducted 21 groups, with more than 100 participants. Most of the groups were in Spanish. We gave our participants a stack of cardstock with one graphic on each piece of paper. We assimilated data so that everybody was looking at the exact same graphic, and we asked people, "What do you think we're trying to tell you?" The way we framed the exercise was, "If it's not clear, that's our fault that we haven't represented it well. So tell us what you think we're trying to say. How do you interpret this information? What do you like? What do you not like?" We would have multiple versions, different prototypes for a particular type of information. "Of these three, which one do you like the best? How would you improve it?" Et cetera.

## Key Findings

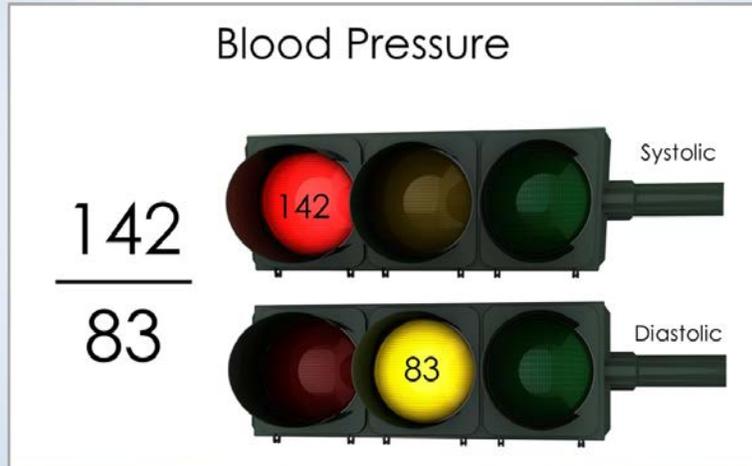
- **Elements of Successful Designs**
  - Information-rich: i.e., sometimes more is more
  - Supported comparison
  - Provided context
  - Employed familiar analogies
- **Literal Interpretation and Iconography**
  - Challenging to depict the right level of abstraction
  - Icon interpretation is dependent on cultural “training”
  - Repeated icons not a familiar graphical convention
- **Motivation and Engagement**

Arcia A, Suero-Tejeda N, Bales ME, et al. Sometimes more is more: iterative participatory design of infographics for engagement of community members with varying levels of health literacy. *J Am Med Inform Assoc.* 2015 Jul 13 [Epub ahead of print]. DOI: 10.1093/jamia/ocv079. PMID: 26174865.



And here are our findings. One thing that I thought was really interesting was that our participants told us over and over again that “more is more.” They reminded us that just because someone has lower health literacy does not mean they have less desire for information. We just need to find a way to present it in a way that's going to be useful. So oftentimes, when given the choice between different graphics, they wanted the one that had more information. I also know from the research that what people prefer isn't necessarily what supports comprehension the most, so that's why we are doing formal comprehension testing. But the process of the focus groups did help us to do a preliminary comprehension check based on how people were interpreting the graphics. So we feel confident that although the graphics won't all perform equally well when we do comprehension testing, we do have some confidence that people are getting where we're going with these.

## Low Information Graphic: Employs an Analogy

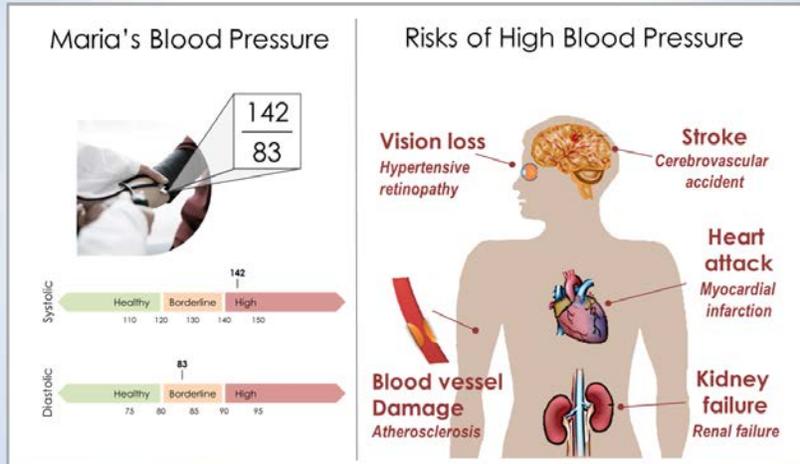


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Here is an example of a low-information graphic. Most people understood this without any problem. It's employing a familiar analogy. We're using these stoplight colors to indicate the reference ranges. But people generally tended not to prefer this because it really does not have very much information.

## Information-Rich Graphic: Employs Analogy, Provides Context



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Compare it to this graphic, our most popular graphic. People really liked this. It still uses the spotlight analogy with the colors and the double number lines, but it provides a lot more information with the reference ranges. You can see, "Oh, my systolic is 142 but I'm only two points away from the next category over, and maybe I can nudge that." And it also provides important context. So you have there the picture of where the blood-- "Oh, this is how the blood pressure is taken. That's what they were doing. This is where that number comes from," and some risks of high blood pressure. I asked people, "Do you want to see this information? What if your blood pressure is normal?" They said, "No, we still want to see it. This is really valuable." I had participants take these home. This is not their blood pressure information, but they said, "I'm going to put this on my fridge," because they really valued what they saw there.

## Employs Familiar Analogy, Supports Comparison



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Here's another example of a familiar analogy -- actually, there's two analogies at play here. One is the stoplight colors and the other is the concept of the battery. What I took from this is that we need to employ the images and iconography that people have been trained to use, because, let me tell you, if you don't pay attention to this icon, your phone's going to die. Although I had a few of my eldest ladies who did not understand this, pretty much most people understood it and liked it and found it very useful. So that analogy was very easy to use and people also liked that you could compare it to something else. When we had graphics that had just one piece of information-- for instance, just one battery, people found it actually kind of confusing. They'd ask, "What's the story? What's happening here?" They would invent stuff. When you add comparison, it actually makes it easier for people to make sense of the graphic and it makes it easier for people to use and understand. So that was another important takeaway.

## Employs Familiar Analogy, Supports Comparison

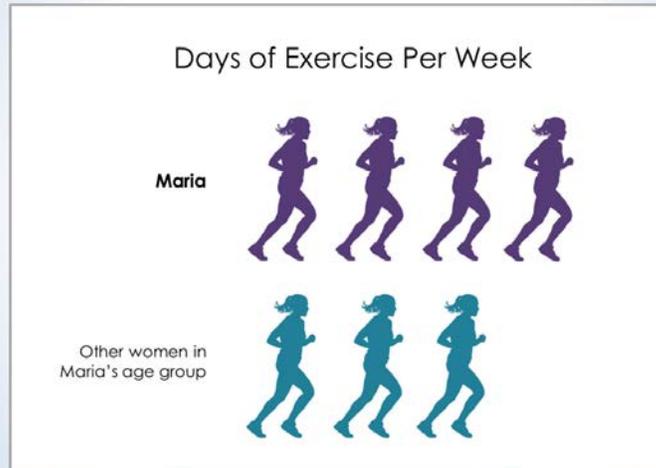


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Here's another example of a familiar analogy. We've been trained by Netflix, Amazon, restaurant ratings and movie ratings. We know how to use this, although I was reminded by a couple of my most elderly ladies that it's not universally understood. I had one of them tell me that the Other Men were in better health because they only had two bad stars and three good stars. It had never occurred to me to interpret the graphic in this way. So it just points out that we do want to capitalize on the kinds of images that people are used to using in their daily lives.

## Difficulty With Generalizing

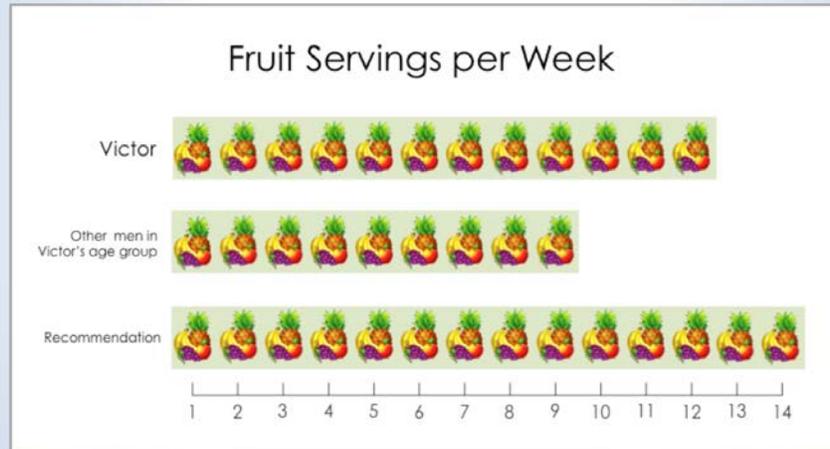


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So here's an example of icons that did not work well. I had focus group attendees tell me that Maria was active. They could tell me she was fast. But they could not tell me how many days per week she exercised, which I found kind of baffling. But the fact is that this is a convention. The graphical convention of using repeated icons to represent repeated instances of a more general class of things was one that I had to conclude was not very familiar to this population. Maybe in Europe, where you see a lot more iconography, people would be comfortable with this, but in our neighborhood this didn't really fly. I mean, a lot of people understood it, but many people did not. So we tried all kinds of things with icons. We thought icons would be great, but they just really, failed. One of the things that I noticed with this is that when people would talk about this graphic, they would talk about running, jogging, walking, but they would never generalize to other forms of exercise, like swimming or soccer. I would ask them, "I want to represent exercise generally. Is this a good example? Is this good image?" And they said yes, but they still would only talk about running, walking, jogging, so I would ask, "Can you think of anything else? Work with me here." Nobody could come up with anything better than this. So one of the things that we found was we had a very difficult time showing things at the right level of abstraction. Exercise, fruits and vegetables were the three main areas where we had problems with this. It was just really, really difficult because also people took things very literally. We had another graphic just like this one but with pairs of tennis shoes, and people would say, "Oh, those are the shoes you have to buy."

## Literal Interpretation



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Here's another example of where we got into literal interpretation. The original version of this graphic had little apple icons, and people would look at this and they would say, "So many apples." "Apples every day. Victor eats lot of apples." Their feedback to me was that I should show a group of fruits so that people would understand that it's not just apples. So I worked on my little graphic, I made my little icons and I come back with this, and the people who saw the apples and then who saw this said, "Oh, this is much better. This is much better because then you can see that it's not just apples, it's a variety of fruits." But the people who saw only this version asked, "Same fruits every day?" I had people very carefully scrutinizing the image, "Pineapple, grapes..." People were really looking at the details of the image. They were really interpreting it very literally. It was a very important message that we had to be very careful about what went into that message. Remember the calendar? We couldn't use the calendar, because for the CDC 30-day measure, for example. "Out of the last 30 days, were you sad, blue or depressed?" if we had a graphic that had five days noted on the calendar, people would say, "Oh yes, it's that time of the month for Maria," or "Oh yes, she was depressed from the first Sunday through the first Thursday of the month." Our data are not that specific, but that's how people interpreted it. So we're actually going forward with a graphic that's not as sexy, it's not as exciting, it's just little blocks, it's a simple icon array, but people understood it and they didn't attach additional significance that we didn't intend.

## Engagement

### ■ Focus groups:

- “This has lots of information that I think everyone would understand perfectly well.”
- “I liked it a lot, too, because it was a very instructive topic and so then you take precautions with your health.”
- “Thank you. Because imagine, in our countries nobody bothers with these things. You suffer from high blood pressure there and you’ll have to deal with it however you can.”

### ■ Comprehension study pilot:

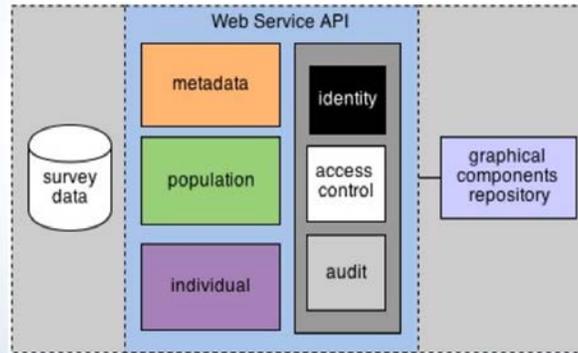
- “I was even surprised at how you put it because it opens one’s mind so that one can make more changes to one’s own health.”
- “...[I]t’s very, very, very useful, that. Very good.”

Arcia A. Suero-Tejeda N, Bales ME, et al. Sometimes more is more: iterative participatory design of infographics for engagement of community members with varying levels of health literacy. *J Am Med Inform Assoc.* 2015 Jul 13 [Epub ahead of print]. DOI: 10.1093/jamia/ocv079. PMID: 26174865.



Here are a few quotes from our focus group participants. Some people would take their entire stacks of graphics home because they thought they were really interesting and useful. I also have run four pilot participants through the comprehension study with graphics that I built by hand, or that I tailored by hand, and I had one who said, "It opens your mind so that you can make changes to your own health," and I nearly started crying at my desk. This is what we've been working for for two years. So I think that we really did see evidence of engagement and people said they found it motivating. Even just the process of being participants in the focus group -- people found educational and engaging.

## ENTICE<sup>3</sup> Electronic Tailored Infographics for Community Engagement, Education, and Empowerment



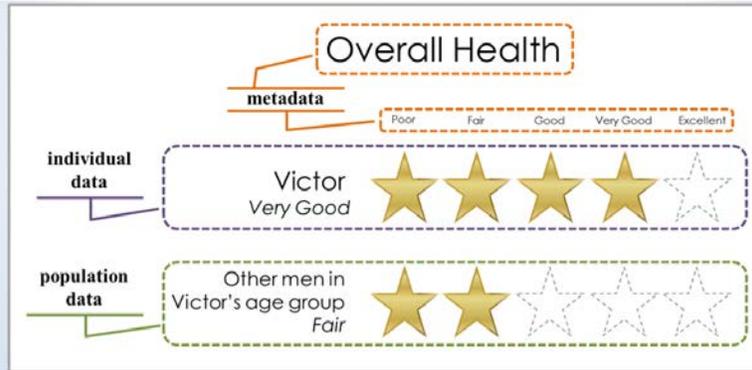
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So this is diagram for ENTICE, Electronic Tailored Infographics for Community Engagement, Education and Empowerment. The blue box in the middle represents the Web application, which is ENTICE. It queries the metadata, the population data, and the individual data that it needs and then goes to the graphical components library where it pulls the different pieces that it needs to assemble the graphic. The gray box on the right represents the security. Here is where the users' identity is verified. It gives them access to the things that they should access and not somebody else's data, and creates an audit trail.

### ENTICE<sup>3</sup>

## Electronic Tailored Infographics for Community Engagement, Education, and Empowerment



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Here is the overall health graphic again. I've annotated it so that you can see the title and response options, or the metadata. And you can see Victor's individual data, and the population-level data.

## Comprehension Testing

- Randomized controlled trial
- Each group serves as the other's control
- N = 144
- Compare visualization to text
- Testing comprehension, ease of comprehension, motivation
- t-Tests of summated scores
- Two-way ANOVA for main and/or interaction effects of age, literacy

Arcia A. Bakken S. Experimental protocol to assess comprehension and perceived ease of comprehension of tailored health infographics compared to text alone. Poster presented at the American Medical Informatics Association Annual Symposium, 2014 Nov 15-19; Washington, DC.



We will start comprehension testing soon. It is a randomized control trial in which each group serves as the other group's control. We will be comparing visualizations to text for comprehension, perceived ease of comprehension, and motivation for some of the items.

## Comprehension Item

Group A, "Maria"	Group B, "Gloria"
<p>Depression Symptoms</p>  <p>Maria Low</p> <p>Other women in Maria's age group Moderate</p>	<p>Depression Symptoms</p> <p>Your level of depression symptoms is very low. The level of depression symptoms for women in your age group is moderate.</p>
<p>Prolonged Stress</p> <p>Your level of prolonged stress is moderate. The level of prolonged stress for women in your age group is very high.</p>	<p>Prolonged Stress</p>  <p>Gloria Low</p> <p>Other women in Gloria's age group Very High</p>

**Visually and conceptually similar paired items**

## Sample Item

Compared to others in  
your age group, was your  
level of depression  
symptoms:

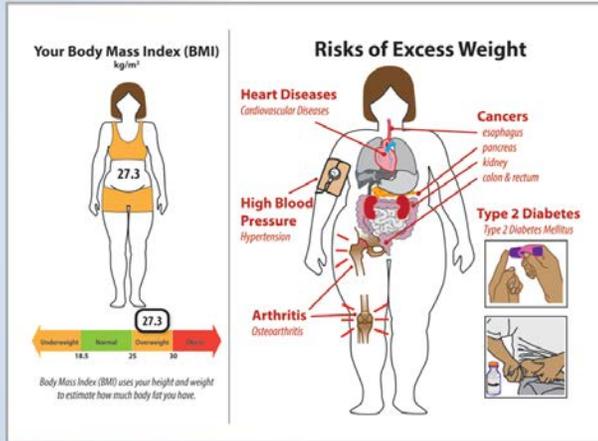
- Lower
- The same
- Higher
- I'm not sure

Arcia A. Bakken S. Experimental protocol to assess comprehension and perceived ease of comprehension of tailored health infographics compared to text alone. Poster presented at the American Medical Informatics Association Annual Symposium, 2014 Nov 15-19; Washington, DC.



This is sample item. Maria is in Group A. She's going to see the graphic for the depression symptoms but the text for prolonged stress, whereas Gloria, in Group B, will see the text for depression symptoms and the graphic for prolonged stress. We can do this because each graphic has a buddy that's either visually or conceptually very similar. Sometimes they're exactly the same, but the user will know that. And everybody gets the same items. I very carefully built the items so that everyone gets the same items but everybody will have a different answer key. So primarily we're going for just comprehension, not verbatim comprehension.

## Motivation and Ease of Comprehension Items



- Does this information about excess weight motivate you to make changes to how you manage your health?
- Please rate how difficult or easy this information was to understand.

Arcia A. Bakken S. Experimental protocol to assess comprehension and perceived ease of comprehension of tailored health infographics compared to text alone. Poster presented at the American Medical Informatics Association Annual Symposium, 2014 Nov 15-19; Washington, DC.



This is new graphic. No participants have seen this yet. Who knows if they'll understand it? It is modeled after the Risks of High Blood pressure graphic. We are asking for the ones that have a behavioral component, "Does this information motivate you to take changes to how you manage your health?" and, "Please rate how difficult or easy this was to understand." We are asking that for every single item, both text and graphic.

This is why you do pilots...I had a participant who talking aloud, clearly did not understand the graphic and did not understand the information, and then responded to the second question, "it's very easy." So I rearranged the questions so that "How are you interpreting the graphic?" is asked first and the content questions later. We'll see if that helps.

## Future Directions

- **New-York-City Hispanic-dementia-caregiver Research Program (NHiRP)**
  - Aim 3: Web-based family health information system
  - Apply existing visualizations where appropriate
  - Develop new visualizations using established methods
  
- **Applicable to NIH Precision Medicine Initiative**
  - Returning clinical, patient-reported, and genomic results to patients in a health-literate way
  - Visual integration of evidence



I've just been funded to work on a project with Hispanic caregivers of patients with dementia, in which we will be creating and adapting graphics where they can track their health and the health of the person for whom they're caring. We will be getting into different types of visualizations and will be tracking trends over time. We will probably be getting more into line graphs and maybe some animation. There are not a lot of different ways of doing it that are better than that. But we also want to talk about how this is applicable to Obama's Precision Medicine initiative because there's a lot of communication that then happens. What are your genomic results? What does the evidence say about what is going to work for you?

## Case Study: Online Maternity Education Platform



The second case study is one that I'm originating. It is called Maternity Information Access Point, or "My App" in English, or "Mi App" in Spanish. I'm reminded of something that a doula told me that she tells her patients, "You are your own primary care provider. You are the one who makes the day-to-day decisions about how you're going to feed yourself, your hygiene, your activities," et cetera." Pregnant women have to make lots of self-management decisions. They are absorbing information like crazy because intrapartum is not the time for a decision aid. They don't have time to research and deliberate. They have to already know it so that when they need it, they can access it.

## Maternity Information Access Point (MIAP)

Maternity  
Neighborhood



- Care Guide™ by Maternity Neighborhood™
- Mobile-ready, web-based maternity education platform
- Incorporates secure provider/client messaging
- Integrates with electronic health record (EHR)
- Research partnership goal: meet learning needs of and be accessible to Medicaid-enrolled pregnant women
- Context: extant but narrowing digital divide

Maternity Neighborhood logo used with permissions from Maternity Neighborhood, Charlottesville, VA. All rights reserved.



My tech partner is Maternity Neighborhood. They make an electronic health record that is designed specifically for maternity care, for midwives and birth centers. Their product, Care Guide is an online maternity education platform. The provider can give their patient a login and invite them to access a library of curated, high-quality information. The provider can also upload their own documents and do secure messaging. The tool can be integrated into with the EHR so that the provider can remind patients of upcoming tests, send them corresponding information and provide e-consent.," The entire engagement is documented in the EHR. So my interest in this project is, we meeting the needs, including health literacy, of these women? Are we meeting everybody's needs with this kind of product?

## MIAP Pilot: Feasibility and Acceptability of an Online Maternity Education Platform

- 4 groups by language (English/Spanish) and parity (nulliparous/multiparous)
- 6 to 8 participants per group

### Initial Focus Groups

- Barriers to and facilitators of Internet access
- Internet use, including social networking, for maternity info
- Preferred forms of access to maternity information
- Acceptability and desired attributes of an online platform

### Field Testing

- One month
- Mobile hotspots to ensure connectivity
- Messaging with MIAP staff
- Log files capture user actions

### Follow-up Focus Groups

- Usability and user satisfaction measures
- Experiences with MIAP
- Suggestions for improvement



Arcia A. Bader D, Warner ERA. Feasibility and acceptability of an online maternity education platform. Poster accepted for presentation at American Medical Informatics Association Annual Symposium; 2015 Nov 14-18; San Francisco, CA.



This is a qualitative study to look at the acceptability and the feasibility of this tool for Medicaid-enrolled women. We recently started collecting data. Recruitment is difficult--but we are running four different groups, English and Spanish, of first-time moms and experienced moms. In these initial groups we're looking at barriers and facilitators of Internet access, how women are using the Internet for maternity care information, what sources - Internet and other - they are using, what they are preferring, how they get the information, and what they think about the idea of this platform, whether they think they would use it, and what they would like about it or not. Then we have a field-test of about one month where we will give them a mobile hotspot so that they always have as much data as they need, and we will be messaging them as though we're the provider. We can't give them specific medical information but we can support their education efforts. During the course of their usage, we will be capturing all of the user actions in the system logs that we can later download the log files to analyze what they used, what they looked at, when, how long, and how often they used it. Finally, we'll bring them back a month later and gather standardized metrics of usability and user satisfaction and talk about their experiences, e.g., what did they like, what did they not like, and what can we improve.

## Future Directions

- Pending results of pilot
- Study effect of MIAP implementation on clinical outcomes
- Real-time log file analysis to inform clinical care and patient education



The future directions for that project will really depend on what we learn, where does it make sense to go next, but one possibility is definitely to study the effect of this kind of platform on clinical outcomes. Right now it's just maternity, but I think it has group applicability to all kinds of other conditions, for example, diabetes. If you are newly diagnosed with diabetes, there is a lot of information to learn and process over a long period of time, and this may be the kind of technology tool that could support it.

Also, if we could analyze the log files as people are using the tool, could use their usage patterns to inform clinical care? For example, what resources are they accessing again and again, or what search terms are people using, or maybe we should rewrite our materials to match the search terms that people are using because this is the language that they are using.

## Conclusions

- **Technology expands opportunities for . . .**
  - Large-scale tailoring to support comprehension and engagement
  - Ease of dissemination
  - Client ↔ clinician communication
  - Seamless documentation of patient engagement
  - Contributing to the Learning Health System by analyzing logged user actions
- **Research priorities**
  - Optimal visualization formats for commonly used data types
  - Culture- and language-specific variations to visualization needs



I would like to conclude by mentioning again that technology is what makes some of this large-scale tailoring possible. It certainly eases dissemination when you have something that's Web-based, and it can really support client and clinician communication. Both visualizations and the platform can do that. We have all these data streams that we should be harnessing to promote a learning health system.

Moving forward, the research priorities that I think are important are optimal formats for visualizing different types of data. There is a lot that we might want to visualize that hasn't been tested yet. And, we need to be cognizant that what is going to work in one local environment may not work in another. Our lessons with icons, in particular, really drove home the message that you can't assume that your idea is going to work for everyone. So I encourage you to ask people. Thank you.