Model Techniques for Consumer-Driven Research

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INTRODUCTION

This paper chronicles the Wireless RERC's user research efforts from 2001-2011 and offers lessons learned through these efforts. The authors hope that this model will be of value to other research organizations for including people with disabilities in development of technologies that are truly assistive and supportive.

BEGINNING WITH CONSUMERS

In 2001 the US Department of Education established a priority for a Rehabilitation Engineering Research Center (RERC) to:
• Promote equitable access to and use of wireless technologies by people with disabilities, and,
• Encourage adoption of universal design in future generations of wireless devices & applications

In developing its successful proposal, staff of Georgia Institute of Technology and the Shepherd Center, a private, not-for-profit rehabilitation hospital in Atlanta, GA, believed that understanding why and how people with disabilities use (and why some don't use) wireless technologies was a prerequisite to fulfilling these missions. Shepherd and Georgia Tech staff reviewed US Census reports and other resources, but found little pertinent data. This led to commitment to a research project to answer these questions and apply the answers to guide the RERC's research, development, and training projects.

The cornerstone project of the RERC's proposal was called "Facilitating User Centered Research". The inaugural effort of this research project was development of a Survey of User Needs (SUN). The goal was to gather at least 1200 responses from a cross-section of Americans with disabilities. Along with gathering demographic information and user experience data, the SUN invited respondents to join a Consumer Advisory Network (CAN) to provide additional consumer guidance to R&D projects of the RERC.

CAN members have generously served in focus groups, testing of wireless technologies, and outreach and dissemination activities of the RERC. The Wireless RERC plans to begin its third 5-year cycle in October 2011. As in its previous 10 years, direct consumer participation will be the cornerstone of the RERC's efforts from 2011-2016.

ASKING THE RIGHT QUESTIONS

Upon the launch of the Wireless RERC in October 2001, RERC staff set out to develop an effective tool for understanding the issues of usefulness and usability of wireless technologies by people with disabilities. The American Community Survey (ACS), Census 2000, International Classification of Disabilities and Handicaps (ICIDH), National Health Interview Survey (NHIS), Survey of Income and Program Participation (SIPP), and US Census Bureau Current Population Reports (CPR) were among the statistical resources studied to establish demographic benchmarks for congruent sampling and analysis and to identify existing data pertinent to wireless use and usability.

A draft Survey of User Needs was created and reviewed by a cross-section of researchers, industry contacts, and consumers with disabilities. The draft was then revised and tested among RERC staff and colleagues with disabilities in print, online, and telephone interview formats, with particular attention to accessibility. Additional revisions were made, primarily to balance reasonable time and effort in taking the survey with the breadth of issues to be explored. The revised SUN was reviewed and approved by the Institutional Review Boards of both Georgia Tech and the Shepherd Center.

ENGAGING THE COMMUNITY

RERC staff then set out to encourage the broadest possible participation in the SUN, beginning with current and past patients of Shepherd Center. Outreach also extended throughout Shepherd Center's contacts among local and national organizations trusted and respected by the disability community. This included a mailing to approximately 2200 organizations and leaders with disabilities and postings on disability listservs, with a link to the online survey.

By January 2004 the SUN had received 625 responses, about evenly balanced between paper and online respondents; 423 of these respondents had volunteered to join the Consumer Advisory Network. Minor revisions to the online survey were made in response to comments received regarding accessibility of the survey to some screenreader technologies. Demographics of the 625 respondents were analyzed. Outreach efforts were revised to encourage participation by under-represented groups, including elders, persons of Hispanic origin, and persons of lower income and/or education.

EVOLVING THE SURVEY INSTRUMENT

Late in 2006 SUN participation had exceeded the initial goal of 1200, and CAN membership had reached about 800. RERC staff determined that the time had come to incorporate a number of issues emerging in wireless technology development and among wireless customers with disabilities (especially those with cognitive limitations).

With input from industry partners and consumers, a revised SUN was released in 2007 and again widely promoted with the help of partner disability organizations, internet sites, community, local, and national events, and radio stations. The survey was also released in Spanish, including the capacity to conduct the SUN by phone in Spanish.

By December 2007 the revised SUN had received 1208 responses[1]. Owing to assistance from its many community partners, representation across demographic categories of income, education, and employment had measurably improved. By December 2008 a total of 1556 SUN responses had been received[2]. Data analysis revealed significant changes in use patterns, along with significant technological developments, prompting RERC staff to revise the SUN again in 2010. By December 2010, respondents to this most recent version numbered 402. To maintain the SUN's momentum into the next 5-year cycle, the RERC will continue the survey through its current term.

ASSESSING THE DATA

In each version of the SUN, demographic questions have been designed to facilitate comparison with large-scale resources on disability issues:
- American Community Survey (ACS)
- Census 2000
- International Classification of Disabilities and Handicaps (ICIDH)
- National Health Interview Survey (NHIS)
- Survey of Income and Program Participation (SIPP)
- US Census Bureau Current Population Reports (CPR)

In the interest of representing as faithfully as possible the national population of Americans with disabilities, RERC staff regularly assess demographic representation of SUN respondents. Outreach efforts are tuned accordingly. At the same time, the RERC acknowledges that SUN data are based on a non-randomized population sample. The survey is promoted as broadly as possible through convenience sampling techniques, with special effort toward reaching under-represented groups.

Sampling errors are corrected by weighting the response data by family income according to American Community Survey (ACS) microdata on demographics of the U.S. population of people with disabilities. This helps to mitigate potential biases introduced by the convenience sampling approach. The data are weighted by total household income, which is strongly correlated with education level in the ACS sample.

SHARING FINDINGS

The RERC initially planned to release comprehensive reports of SUN findings at major intervals, e.g., annually. However, opportunities to share specific consumer data to inform regulatory action and technology development have encouraged the RERC to communicate results more frequently. The RERC now releases reports on featured topics through monthly "SUNspots"[3], in addition to fulfilling requests for customized reports from industry, regulatory contacts, and publishers[4].

Sharing SUN findings has proven an effective way to continue to grow the RERC's outreach efforts: individual consumers and disability organizations witness the impact of their participation in the RERC's user research, while industry and government managers apply SUN data to stimulate and direct action.

ENGAGING CONSUMERS

Focus Groups

Beginning in 2002, focus groups have been regularly conducted among CAN members to lend additional insight to the data gathered through the SUN. To maximize the usefulness of these events, topical discussions are carefully scripted and introduced with presentation of specific SUN findings.

Composition of these groups is also carefully planned. Some groups include a variety of disabilities, e.g., elder groups, while other groups are more homogeneous, e.g., low-vision/blind and deaf/hard of hearing. Other focus groups consist of clinicians working with specific disability groups, such as those working at Side by Side Clubhouse in Atlanta, which provides support to survivors of traumatic brain injuries in returning to community participation.

Findings of focus groups are analyzed using a "grounded theory" approach[5]. This approach derives central themes from the patterns and common threads of the focus group discussion. Grounded theory analysis of early focus group discussions have enabled RERC staff to uncover issues to be explored in future iterations of the SUN. This analytical technique has also been instrumental in development of "personas", which have become effective vehicles for summarizing quantitative and qualitative findings of the RERC's user research activities[6]. Wireless user personas have been incorporated extensively in the RERC's dissemination and training efforts, especially among its industry partners.

Field Testing

As SUN and focus group findings continue to be gathered and analyzed, specific usability issues among existing technologies emerge. This encourages RERC staff, as well as industry partners, to further explore these issues through user testing. Beginning in 2004, with technical support from industry partners AT&T, Nokia, Research in Motion, and Verizon, RERC staff embarked on a series of field tests of "live" devices among groups of CAN members. Though less controllable than laboratory protocols, field testing is a critical tool for assessing the impact of ambient conditions and real-life situations (e.g., noise, glare, interruptions) on usability of mobile wireless technologies for people with (and without) disabilities.

Targeted User Studies

The RERC responds to emerging wireless issues by enlisting consumer input to help guide industry and regulatory action. The first of these efforts was a study of the experiences of hearing aid users in finding and using compatible wireless phones. Begun in 2006, this study continues today and offers invaluable insight to the impact of regulatory and industry effort to improve wireless access for people with hearing limitations. Users have also been engaged in the development of consumer resources such as "Your Guide to Choosing a Cell Phone" in 2004[7], and "Online Wireless Accessibility Information Resources" in 2010[8]. The Wireless RERC also is conducting a study of the use of social media in emergency situations. The results of this study are intended to guide proposed government rule-making to guide the development of Next-Generation 911 services.

Opportunities for participation in nationwide CAN studies complement focus group and user-testing opportunities, which have historically been conducted in the Atlanta and Washington, DC areas. Diverse opportunities help to grow and nurture the CAN and add to the SUN database, i.e., as consumers learn of an opportunity to participate, they take the SUN and join the CAN. In this way, the Wireless RERC continues to grow user participation in its research efforts. This was most recently demonstrated among some of the 1000 people who have responded to the social media/emergency communications survey mentioned above.

NETWORKING AND COLLABORATION

Commitment to user research is not synonymous with consumer advocacy. Unbiased research collaboration is critical to the effectiveness of organizations such as the Wireless RERC, which naturally works across consumer, government, and industry lines. The RERC values its position within a network of hundreds of direct and indirect contacts among these communities. Some of these generous collaborators are mentioned below. More are welcome.

The RERC employs a variety of channels to share its user research findings, including its own websites (wirelessrerc.org and mywirelessreview.com) and online and print versions of its newsletters to its Consumer Advisory Network and to industry, government, and advocacy partners. However, much of its success in dissemination of user research findings is the result of generous collaboration by key individuals and organizations, including:

Consumer advocacy organizations:
- American Association of People with Disabilities
- American Stroke Association
- Center for Visually Impaired
- Coalition of Organizations for Accessible Technologies
- Hearing Loss Association of America
- National Association of the Deaf
- National Federation of the Blind
- Side-by-Side Clubhouse

- Telecommunications for the Deaf and Hard of Hearing

Publishers CRC Press, McGraw-Hill, and Springer-Verlag, as well as the publishers of:
- Aging Today
- Assistive Technology
- Design For All of India Newsletter
- International Journal of Emergency Management
- Journal of Engineering Design
- Topics in Stroke Rehabilitation
- Universal Design Magazine

Broadcast and online information and news sources:
- Abledata
- ACB Radio Chat
- AbilityHub.com
- Bnet
- DisabilityNation
- Georgia Radio Reading Service
- MCB Horizons
- National Public Radio
- The Washington Post

Professional and industry organizations sponsoring conferences and exhibitions:
- Abilities Expo
- CTIA-The Wireless Association
- G3ict
- Industrial Designers Society of America
- Human Factors and Ergonomics Society
- RESNA
- Wireless Technology Forum

Industry partners offering hardware, software, and technical support to the RERC's user research efforts, as well as opportunities to share findings through in-service training of marketing and technical development staff:
- AT&T
- Alliance for Telecommunications Industry Solutions
- Nokia
- Research in Motion
- Verizon

Educational institutions employing user research findings in universal design student projects:
- Georgia Institute of Technology (GA Tech)

- Virginia Polytechnic Institute and State University (VA Tech)

Rehabilitation research partners:
- Center for Assistive Technology and Environmental Access
- RERC for the Advancement of Cognitive Technologies
- RERC on Communication Enhancement
- RERC on Telecommunications Access
- RERC on Workplace Accommodations

Government agencies utilizing user research findings to inform development of government policy on topics including broadband accessibility, hearing aid compatibility, and emergency communications:
- Access Board
- Federal Communications Commission
- Department of Justice
- Federal Emergency Management Agency

SUMMARY

The authors hope that the efforts described in this paper offer useful lessons to other research organizations for including people with disabilities in consumer-driven research and development of technologies that are truly assistive and supportive. In addition, Wireless RERC staff offer these specific suggestions to future researchers:

- Establish demographic benchmarks for congruent sampling and data analysis
- Engage individuals and organizations trusted and respected by the disability community
- Allocate additional resources for engaging hard-to-reach constituents
- Evolve survey instrument(s) as needed to address technology and/or user developments
- Conduct regular data analysis to tune survey and recruitment efforts
- Be alert to "teachable moments", events, and other opportunities for sharing data
- Encourage ongoing participation among all stakeholders: share progress/results and opportunities for additional participation
- Seek opportunities to involve consumers on local as well as national level

- Engage in web-based networks, discussion groups

Consumer-driven research is critical to ensuring that technologies under development are truly assistive to the current population of people with disabilities, to those millions who will experience disabilities during their lifetimes, and even to those without disabilities. Experience by the Wireless RERC from 2001-2011 illustrates that actionable user research results from paying attention to opportunities for ongoing evolution and effective collaborations across advocacy, government, and industry organizations.

ACKNOWLEDGMENTS

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