

## **Parent Perspectives on the Design of a Personal Online Pediatric Immunization Record**

Ken Kitayama, Melissa S. Stockwell, David K. Vawdrey, Oscar Peña and Marina Catalozzi

*CLIN PEDIATR* 2014 53: 238 originally published online 17 October 2013

DOI: 10.1177/0009922813506608

The online version of this article can be found at:

<http://cpj.sagepub.com/content/53/3/238>

---

Published by:



<http://www.sagepublications.com>

**Additional services and information for *Clinical Pediatrics* can be found at:**

**Email Alerts:** <http://cpj.sagepub.com/cgi/alerts>

**Subscriptions:** <http://cpj.sagepub.com/subscriptions>

**Reprints:** <http://www.sagepub.com/journalsReprints.nav>

**Permissions:** <http://www.sagepub.com/journalsPermissions.nav>

>> [Version of Record](#) - Feb 12, 2014

[OnlineFirst Version of Record](#) - Oct 17, 2013

[What is This?](#)

# Parent Perspectives on the Design of a Personal Online Pediatric Immunization Record

Clinical Pediatrics  
2014, Vol. 53(3) 238–242  
© The Author(s) 2013  
Reprints and permissions:  
sagepub.com/journalsPermissions.nav  
DOI: 10.1177/0009922813506608  
cpj.sagepub.com  


Ken Kitayama<sup>1</sup>, Melissa S. Stockwell, MD, MPH<sup>1,2,3</sup>, David K. Vawdrey, PhD<sup>3,4</sup>, Oscar Peña<sup>3</sup>, and Marina Catalozzi, MD, MSCE<sup>1,2,3</sup>

## Abstract

**Objective.** To examine desired characteristics of an online immunization record for parents from a predominantly Latino, low-income population. **Methods.** Four focus groups were conducted with parents (n = 29) from an urban, primarily Latino, low-income population in New York. The data were collected and analyzed during winter 2008–2009. **Results.** Participants expressed interest in using an online immunization record that has the ability to show a child's immunization status and to access consumer health information related to vaccinations. Participants suggested that the online record be translated into multiple languages and provide user-friendly interfaces. Participants were enthusiastic about the benefits offered by the online immunization record, highlighting having an electronic copy of their child's immunization record available. Concerns over disclosing personal information were raised, and safeguards to protect confidentiality were requested. **Conclusions.** If concerns about privacy are adequately addressed, parents of low-income, urban children are likely to use and benefit from an online immunization record.

## Keywords

immunization, vaccine, personal health

## Introduction

Childhood immunization is one of the most beneficial and cost-effective public health programs.<sup>1</sup> Immunizations protect not only the children who receive them but also the health of the community in which they live. Despite great scientific advances in creating effective vaccines, many children do not receive the immunizations recommended for them. In 2010, only 74.9% ± 1.2% of US toddlers received the recommended early childhood vaccination series, short of the Healthy People 2010 goal of 80% coverage.<sup>2</sup> Children from low-income families and those belonging to some racial-ethnic minorities are disproportionately underimmunized.<sup>2,3</sup> In addition to underimmunization, thousands of children are overimmunized because of duplicate vaccine administration.<sup>4</sup>

Poor management of immunization information is a major reason for under- and overimmunization.<sup>5</sup> Approximately 25% of US children see more than one immunization provider in their first 3 years of life, leading to fragmented and incomplete vaccination records.<sup>4,6</sup> This is particularly true for Latino children, who have been found to be more likely to have immunization records scattered among multiple providers than non-Latino white children.<sup>5,7,8</sup> Children of parents who maintain

vaccination cards generally have higher vaccination coverage levels than children whose parents have no record available.<sup>9,10</sup> Even so, paper records are suboptimal because parents may have records from multiple providers, or they may forget to bring the records to a care provider visit.

Storing immunization data in an online personal health record (PHR) may improve immunization rates and reduce overimmunization by allowing parents to share a child's complete vaccination history with all providers participating in the child's care. Although a recent study explored the benefits of PHRs for minority, low-income families, there is little information regarding what characteristics would be useful in an

<sup>1</sup>Department of Pediatrics, Columbia University, New York, NY, USA

<sup>2</sup>Heilbrunn Department Population and Family Health, Columbia University, New York, NY, USA

<sup>3</sup>New York-Presbyterian Hospital, New York, NY, USA

<sup>4</sup>Department of Biomedical Informatics, Columbia University, New York, NY, USA

### Corresponding Author:

Marina Catalozzi, Division of Child and Adolescent Health, Columbia University, 622 West 168th Street, VC 402, New York, NY 10032, USA.

Email: mc2840@columbia.edu

online immunization record, and what barriers to use exist in this community.<sup>11</sup>

The objective of this qualitative study was to bridge the gap in knowledge that exists in determining the desired characteristics of PHR tools for underserved populations—specifically, an online immunization record for pediatric patients. The study was designed to establish whether parents in an underserved, largely Latino, community were interested in using an online immunization record, as well as to identify desirable functions and characteristics of such a system. Potential barriers to use were also elicited, along with parent suggestions for developing and implementing the system.

## Methods

Focus groups were conducted from December 2008 to February 2009. Participants were all parents recruited from Northern Manhattan in a primarily Latino, low-income population. Recruitment was achieved by posting flyers at 4 pediatric community practices and 5 public elementary schools participating in a federally funded school-based health initiative. All recruitment sites were affiliated with an academic medical center or one of its programs. The study was approved by the Columbia University Institutional Review Board.

All participants gave written informed consent prior to the start of the focus group session. Trained focus group moderators used a bilingual semistructured guide, and all discussions were recorded and professionally transcribed. The focus group guide covered topics that included type of immunization information that should be included in a PHR, when and where to access immunization information, participants' general comfort with using online resources, and any anxieties or concerns they would have in using this PHR tool. At the end of the discussion, participants were given visual materials representing a prototype of the PHR immunization record tool to elicit feedback to further its development. Participants received breakfast or lunch and a \$25 gift card as incentives for attending the focus group.

Focus group transcripts were analyzed by 2 authors (MC and KK) using thematic analysis.<sup>12</sup> After discussion, categories were generated inductively based on participants' comments, and a codebook was created. The 2 authors then independently coded the transcripts, resulting in an intercoder agreement rate of 98%. Coding disagreements were discussed and resolved. Dominant themes were identified using an iterative process in which codes were reviewed for relevance and impact.

## Results

Twenty-nine parents participated in 4 focus groups, where 2 groups were led in English and 2 in Spanish. All participants were women and the majority were Latina. The code categories that were developed inductively and iteratively based on the transcripts included Immunization Information (Immunization Schedule, Reactions, Illness Protection), General Health Information (Child Growth Information, Medical Information), When to Access Immunization Records, Comfort with Technology, Feedback on the Proposed PHR System, and Overall Impressions. These categories were condensed into 3 overarching themes outlined below, which were common across all focus groups.

### *Desired Characteristics of an Online Immunization Record*

Parents responded favorably to using an electronic personal immunization record for their children. All groups expressed an interest in being provided with general immunization information, including immunization name, number of doses, administration site and route, and whether certain immunizations are mandatory for school enrollment or other programs.

The ability to identify whether or not their child's immunizations were up-to-date was also highlighted.

If they are missing any vaccinations, how many they've had.

Always is it up to date because usually they need booster shots or whatever or they're missing a vaccination.

Additionally, most parents desired information on what illnesses the different immunizations protect against.

For example, illnesses come along, and you have to vaccinate for them, so that's one of the things that I'd like to see there, so you can know about it, which ones.

And why they gave each immunization, what it's for, you know, if they give you a shot, what the function of it is.

Importantly, participants requested that the online application be available in multiple (and appropriate) languages presented in a user-friendly format free of medical jargon.

It should be in all languages, not just English.

A simple way that we could understand and use, there are things that doctors use that maybe we wouldn't be able to use . . . for example, you . . . wonder, "What is this word?" So it should be easy to use.

Across all focus groups, participants emphasized the importance of holding face-to-face training sessions as well as having an ongoing resource to provide support in using the application.

Training would be fantastic, it would be very helpful. Yes.

An information guide on how to arrive at the point . . .”

### **Advantages to Using an Online Immunization Record**

Participants expressed that the main advantage of a personal online application was the relative ease, speed, and convenience with which they could access their child's updated immunization record for school forms and other paperwork.

It's good because, if you need a copy, you just go there, get one and print it out instead of having to call the doctor's office, wait in line and paying four dollars for a trip there . . . and with a child that you can't leave at home, I think it's good.

You can do a lot of things automatically. It saves a lot of time.

Many participants also highlighted the ability to print out hard copies of their child's online immunization record in case they misplaced their immunization card. They suggested potentially using this hard copy as a reminder for upcoming immunizations or to bring to their next medical appointment, again highlighting the convenience of this PHR tool.

If we have it in the computer, we could print it out . . . And we could put it, if we need a reminder about a vaccination or something like that, we could put it on the refrigerator . . .

Yes, because sometimes . . . when they ask you, “You need to bring the information for the vaccinations.” And then maybe you don't have the book, you lose the book.

### **General Comfort and Discomfort With Disclosing Personal Information in Using Online Resources**

Many participants expressed comfort with using the Internet in general, with most reporting that they or someone in their household used the Internet for tasks such as online banking or shopping; however, serious concerns with protecting privacy, especially regarding their children's medical information, surfaced in all 4 focus groups

Well, because anybody could—if somebody who had that information and it didn't belong to that person, or they could use it for something else, that would be not good . . . yeah, because a lot of people . . . are doing stuff that they aren't supposed to, taking information from people, you know.

Parents like their privacy so you have to emphasize that.

Many suggested safeguards to ensuring confidentiality, including password verification and limited access to the online record.

I think that sometimes you have in the computer, you have to have your personal—lock? . . . only you can see it.

Some parents were interested in extending access to their child's school and doctor's office, whereas others were more adamant about exclusive access remaining only with the parent.

No, I'm saying I would recommend something maybe in three different places: school, doctor's office and at home . . . because a lot of parents don't have computers.

I would suggest that . . . I have the primary information . . . because an accident could happen.

Yeah, be able to access it at the school, but not necessarily give them the password—that's up to you.

Parents also wanted assurance of the integrity of the personal information that they might share, as well as very stringent confidentiality, particularly with regard to immigration status.

I have a suggestion. A lot of immigrant parents are scared. It should be noted on here that it will be confidential. That they should not worry about, you know, their status.

## **Discussion**

In the focus groups, parents expressed a strong interest in accessing their children's immunization records online, but at the same time, they expressed serious concerns regarding privacy and confidentiality. Understanding parents' perspectives on their desired characteristics for an online immunization record is important for its success.

In this study, as in others, parents highlighted the importance of presenting the information using a meaningful, patient-centered approach, which may differ from the format of a traditional medical record used by

health care providers.<sup>13</sup> Participants in this study requested features such as information about illnesses the vaccines protect against, immunization up-to-date status reminders, multilingual capabilities, and a simple user interface. These desired characteristics are important to take into account when designing any consumer health technology. Parents also expressed interest in receiving training on use of the online system, which may be overlooked in the implementation of PHRs and other health information technology. This training may be particularly important to overcome disparities resulting from the wide range of technical skills found in populations similar to that of the study population.<sup>14</sup>

In this and other studies, patients clearly wanted to access their medical records.<sup>15</sup> Although patients have a legal right to access their medical records, the manner in which health care delivery organizations supply access is variable. In many cases, patients must visit a medical records department to obtain a paper copy of their chart, a process that imposes a considerable barrier to access.<sup>16</sup> In our focus groups, one reason parents wanted online access to information was to avoid having to wait to receive vaccine records. However, if parents intend to use this vaccine information for official purposes such as school entry, methods may be required for verifying the authenticity and integrity of electronic records. Establishment of data provenance and health information exchange are major themes of the United States President's Council of Advisors on Science and Technology (PCAST) report "Realizing the Full Potential of Health Information Technology to Improve Healthcare For Americans: The Path Forward."<sup>17</sup> In the spirit of the PCAST report, some PHRs provide consumers with the flexibility of sharing their information with specific entities, a model that could allow parents to share required immunization information with schools (eg, for registration and enrollment).<sup>18</sup>

Security was an important concern raised by the focus group participants. In another study, respondents were concerned that if their personal information was not kept secure, they could be at risk for identity theft or fraud, or their information could fall into the hands of marketers.<sup>15</sup> Participants in our study expressed similar anxieties. Additionally, because of the large volume of recent immigrants in the medically underserved community where the study was performed, the apprehensiveness of some focus group participants was further compounded by privacy concerns surrounding immigration status. To address these anxieties, particular emphasis should be placed on ensuring that PHR systems adhere to appropriate privacy practices, and on reassuring parents that no immigration information will be stored in the PHR.

While PHRs may provide underserved populations with a "virtual medical home," it is worth exploring other avenues to bridge the "digital divide" that persists in many settings.<sup>19</sup> Broadband Internet access may have variable penetration among the underserved, but the rising ownership of mobile phones in these populations may provide a solution to this problem. A recent study found that African American cell phone owners were more likely than other groups to use mobile health applications; additionally, it was also found that Latino cell phone users were significantly more likely than other groups to use their phone to look for health information.<sup>20</sup>

Limitations to this study exist. It was an exploratory qualitative study to better understand parent perspectives regarding an online immunization record. Our findings may not be generalizable to other technologies or populations. Yet the qualitative analysis presented here does offer certain insight as to why an online immunization record may be useful for parents, what features they are interested in, and what concerns they may have. Another limitation is that all participants were mothers, thereby excluding the opinions of fathers. Finally, it would also be worth considering the adolescent perspective, assessing whether this particular underserved patient population would benefit from an online immunization record.

Overall, our focus groups found that parents were interested in using an online immunization record tool. However, while such applications may provide obvious benefits, this study also highlights the importance of eliciting the input of end-users in the development and implementation process. Future studies involving parents and providers will be needed to determine the impact of such a tool on immunization rates and parent-provider communication.

### Acknowledgments

The authors would like to thank Feng Liu and Brandon Hays, MD, for their help with this study as well as the New York-Presbyterian Hospital and its Ambulatory Care Network for its support.

### Authors' Note

The content is solely the responsibility of the authors and does not necessarily represent the official views of the Microsoft Corporation. The funder did not influence the study design or analysis.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was supported by a grant from the Microsoft Be Well Fund. The funder did not influence the study design or analysis.

## References

1. Andre FE, Booy R, Bock HL, et al. Vaccination greatly reduces disease, disability, death and inequity worldwide. *Bull World Health Organ*. 2008;86:140-146.
2. Centers For Disease Control and Prevention. National and state vaccination coverage among children aged 19-35 months—United States, 2010. *MMWR Morb Mortal Wkly Rep*. 2011;60:1157-1163.
3. Klevens RM, Luman ET. U.S. children living in and near poverty: risk of vaccine-preventable diseases. *Am J Prev Med*. 2001;20:41-46.
4. Feikema SM, Klevens RM, Washington ML, Barker L. Extraimmunization among US children. *JAMA*. 2000;283:1311-1317.
5. Stokley S, Rodewald LE, Maes EF. The impact of record scattering on the measurement of immunization coverage. *Pediatrics*. 2001;107:91-96.
6. Yusuf H, Adams M, Rodewald L, et al. Fragmentation of immunization history among providers and parents of children in selected underserved areas. *Am J Prev Med*. 2002;23:106-112.
7. Smith PJ, Stevenson J. Racial/ethnic disparities in vaccination coverage by 19 months of age: an evaluation of the impact of missing data resulting from record scattering. *Stat Med*. 2008;27:4107-4118.
8. Darden PM, Gustafson KK, Nietert PJ, Jacobson RM. Extra-immunization as a clinical indicator for fragmentation of care. *Public Health Rep*. 2011;126:48-59.
9. Rosenthal J, Rodewald L, McCauley M, et al. Immunization coverage levels among 19- to 35-month-old children in 4 diverse, medically underserved areas of the United States. *Pediatrics*. 2004;113:e296-e302.
10. McElligott JT, Darden PM. Are patient-held vaccination records associated with improved vaccination coverage rates? *Pediatrics*. 2010;125:e467-e472.
11. Horan TA, Botts NE, Burkhard RJ. A multidimensional view of personal health systems for underserved populations. *J Med Internet Res*. 2010;12:e32.
12. Boyatzis RE. *Transforming Qualitative Information: Thematic Analysis and Code Development*. Thousand Oaks, CA: Sage; 1998.
13. Winkelman WJ, Leonard KJ, Rossos PG. Patient-perceived usefulness of online electronic medical records: employing grounded theory in the development of information and communication technologies for use by patients living with chronic illness. *J Am Med Inform Assoc*. 2005;12:306-314.
14. Pagliari C, Detmer D, Singleton P. Potential of electronic personal health records. *BMJ*. 2007;335:330-333.
15. Markle Foundation. National survey on electronic personal health records: A survey by Lake Research Partners. [http://www.markle.org/sites/default/files/research\\_doc\\_120706.pdf](http://www.markle.org/sites/default/files/research_doc_120706.pdf). Accessed July 22, 2012.
16. Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. *J Am Med Inform Assoc*. 2008;15:1-7.
17. President's Council of Advisors on Science and Technology. Report to the president realizing the full potential of health information technology to improve healthcare for Americans: the path forward. December 2010. <http://www.whitehouse.gov/sites/default/files/microsites/ostp/pcast-health-it-report.pdf>. Accessed January 10, 2012.
18. Crilly JF, Keefe RH, Volpe F. Use of electronic technologies to promote community and personal health for individuals unconnected to health care systems. *Am J Public Health*. 2011;101:1163-1167.
19. Schoevers MA, van den Muijsenbergh ME, Lagro-Janssen AL. Patient-held records for undocumented immigrants: a blind spot. A systematic review of patient-held records. *Ethn Health*. 2009;14:497-508.
20. Fox S. *Mobile Health 2010*. Washington, DC: Pew Research Center; 2010.