

# Teen Use of a Patient Portal: A Qualitative Study of Parent and Teen Attitudes

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## Abstract

We conducted a qualitative study of the attitudes of teens and parents toward the use of a patient portal. We conducted two teen and two parent focus groups, one teen electronic bulletin board, and one parent electronic bulletin board. Videotapes and transcripts from the groups were independently analyzed by two reviewers for significant themes, which were then validated by two other members of the research team. Twenty-eight teens and 23 parents participated in the groups. Significant themes included issues about teens' control of their own healthcare; enthusiasm about the use of a patient portal to access their providers, seek health information, and make appointments; and concerns about confidentiality. In summary, there was considerable support among teens and parents for a patient portal as well as concerns about confidentiality. The teen portal affords an opportunity to negotiate issues of confidentiality.

**Key words:** access to care, patient portal, confidentiality of teen health services

## Introduction

Adolescence is a critical time for delivery of health services. Yet we know that teens often do not get the services they need, such as screening for chronic conditions, immunizations, and health promotion.<sup>1-3</sup> This is particularly true for sensitive services that require confidentiality between the teen and the provider. In fact, concern about confidentiality is one of the major reasons teens forgo needed care.<sup>4</sup> The Internet offers a unique opportunity for confidential and secure communication between the teen and the provider.

Many of the important attributes of teen-provider communication have been shown to be enhanced with the use of a patient portal. Research has shown that patient portals can enhance patient-provider communication, increase overall satisfaction with care, lead to more communication with psychosocial content and increase identification and management of chronic conditions, increase access to health information, and improve disease management for conditions such as diabetes and congestive heart failure.<sup>5-13</sup> There is, however, also concern among patients and providers that a patient portal may compromise physician-patient relations and adversely impact patient confidentiality.<sup>14-16</sup> Some research has also indicated that a significant proportion of patients, when offered the use of a patient portal, do not consistently use it.<sup>17</sup> Clearly the use of a patient portal offers considerable opportunity to improve communication and care for adolescents, particularly in those areas where confidentiality is a concern. However, there has been little research about the attitudes of adolescents and teens toward confidential teen access to a patient portal. An understanding of these attitudes will be crucial to the successful implementation of teen portals. To better assess parents' and teens' attitudes toward the use of a patient portal, we conducted qualitative research using focus groups and electronic bulletin boards to ascertain concerns about and receptivity to confidential teen use of a patient portal.

## **Methods**

### *Study Site*

All subjects were patients of primary care physicians (PCPs) at the Palo Alto Medical Foundation (PAMF), a large, multispecialty group practice. PAMF currently utilizes an electronic medical record system, which is linked to a patient portal where secure messaging, results reporting, and health information are available. Currently, teens cannot access the patient portal.

### *Study Design Overview*

The study was conducted in two phases. First we conducted four focus groups: two with teens and two with parents. We then conducted two online bulletin boards, one for parents and one for teens. Participants were randomly assigned to either an electronic bulletin board group or an in-person focus group. Participants in the bulletin board group were asked to log on at regular intervals and respond to questions and responses from other participants. Participants in the focus groups were asked to attend a two-hour meeting with five to eight other participants. After completion of either the bulletin board group or the focus group, each participant was given a 25 dollar gift certificate in appreciation of his or her participation.

### *Participant Recruitment*

PAMF staff identified potential participants who had been seen in pediatrics or family medicine within the past year. The participants' primary care physicians were asked to consent to having their patients contacted for this research. Letters were sent to parents inviting either the parent or the teen to participate in the study. Where applicable, the teen's willingness to participate was determined. Interested participants were contacted by a research assistant who explained the study and reviewed the informed consent.

Entry criteria included that the family speak English and have Internet access at home. Teens needed to be between 16 and 18 years old, and parents needed to have a teen in the same age range. Parent-teen dyads were not recruited for the study. For the teen groups, consent was obtained from teens who were 18 years old, and assent was obtained for younger teens. Parent consent was obtained for parent groups.

### *Conduct of Focus Groups*

Four 90-minute in-person focus groups were conducted, two with teens and two with parents. All the focus groups were facilitated by a professional qualitative researcher. The key issues outlined in the discussion guide are presented in Table 1. All focus group participants viewed a demonstration of the PAMF patient portal. All four focus groups were videotaped for further analysis.

### *Conduct of Online Bulletin Board Groups*

Two online groups (one for teens and one for parents) were facilitated by a professional qualitative researcher. Participants were asked to view an demonstration of the PAMF patient portal and then log on to a secure Web site once or twice a day for 15 minutes to respond to a series of questions and have a discussion with the other respondents. The study protocol for both the focus groups and the online bulletin board groups was approved by the Institutional Review Boards of PAMF and Stanford University, as well as the HIPAA security officer of PAMF.

### *Analysis*

Videotapes of the focus groups and transcripts from the bulletin board groups were independently analyzed by one of the investigators (D.B.) and the focus group/bulletin board facilitator to identify themes and develop conclusions. Discrepant results between the reviewers were resolved through in-person discussion and consultation with the other two investigators (N.B. and S.W.). The analysis was intended to identify key themes in the study. If there were significant differences of opinions articulated in the groups, these were reflected in the identified themes. Because the qualitative methodology

encouraged free-flowing discussion, the degree of agreement among the subjects for the identified themes was not formally assessed.

## **Results**

### *Participants*

Nineteen parents and 17 teens participated in the focus groups, and 15 parents and 18 teens participated in the online bulletin boards. Females accounted for 58 percent of teen participants and 98 percent of parent participants. Almost all the participants in the focus group were white (98 percent), and all had commercial insurance. Ninety-five percent of the teen participants were in 11th or 12th grade.

### *Key Issues*

#### *Attitudes toward a teen portal*

In general, both parents and teens were very enthusiastic about the use of a teen patient portal and saw it as an important means for teens to take better control of their own healthcare. Given teen and parent concerns about confidentiality, it is not surprising that both groups had many conflicting feelings about whether or not parents should have access to teen health information, and, if they do have access, what information should be shared with parents and what should be kept confidential.

*Teen: "Putting teen healthcare online will bring teens one step closer to taking control themselves."*

*Teen: "I am concerned that doctors will not keep this information confidential from parents."*

*Parent: "This kind of access will help my teen become much more interested in her healthcare and also motivate her to take control. And that will be great."*

When looking at the specific features of the teen patient portal, both parents and teens were very positive about using the portal to help search for health information. Both groups liked the idea of being able to access information from a trusted source.

*Parent: "My teen would be likely to use the portal because it looked user friendly, it is easy to search, and it seemed very comprehensive."*

*Teen: "I like to be able to get information from a reputable source [not just from friends who may not have the facts]."*

With respect to making appointments online and receiving e-mail appointment reminders, teens felt that dealing with appointments online was less intimidating than making a phone call.

*Parent: "Making an appointment online and checking out lab results will seem 'cool' to kids."*

*Teen: "I like the convenience online appointment making offers."*

Some parents, however, were concerned that teens would be making medical appointments without their knowledge.

Secure messaging with their provider was felt to be a valuable feature by teens. Teens in general felt more comfortable using an e-mail format to ask their provider questions than they did asking questions in person. This was particularly true when it concerned sensitive issues around sexual health. Teens, however, were concerned that their e-mail conversations would be shared with their parents.

*Teen: "This creates a relaxed mood, which makes the doctor more approachable."*

*Teen: "I am concerned that doctors will not keep this information confidential and will mention it to parents."*

Indeed, some parents wanted to be informed about important issues raised during e-mail transactions.

*Parent: "I still want to be informed about serious issues and issues related to my teen's sexual health."*

Being able to check their laboratory or other test results online was appealing to both parents and teens. However, both groups expressed concerns about whether or not teens would be able to understand and appropriately interpret test results.

*Parent: "Teens couldn't process this information alone."*

*Teen: "I might not understand what the results meant and would need to ask my doctor to explain the significance of the results."*

### Implementation of the Teen Portal

Both teens and parents had specific recommendations concerning the use of the teen portal. Both teens and parents wanted to learn about confidentiality and the use of the portal from their provider. Teens wanted to be invited to sign up for the portal and be able to choose the features that they want to use. Teens in general felt that it was their decision whether or not to sign up for the portal and they should not need their parents' approval. Not surprisingly, parents felt they should have to provide consent for their teens to use the teen patient portal.

*Teen: "Parents should not have to give consent for teens to use PAMF Online."*

*Teen: "All of [the] PAMF Online features should be available for teens to choose what they want to use."*

*Parent: "Parents should give permission for each feature [of PAMF Online] that teens want to use."*

Interestingly, both groups were aware of this potential conflict around teen choice and confidentiality. Some of the parents and some of the teens suggested that, for a teen patient portal to work, there would have to be ground rules around confidentiality and disclosure of important health issues that would have to be negotiated by each family.

*Teen: "Parents are the 'enemy' when it comes to our private lives. We need to feel that we have control of our lives."*

*Teen: "Ultimately, what stays confidential should be up to the teen."*

*Parent: "I couldn't trust my daughter to tell me what I might need to know because she may not understand what I should know."*

Another concern discussed by both parents and teens was the potential inappropriate use of the patient portal. This concern was raised around issues of using the portal for urgent or emergent care or for mental or behavioral health problems that could be best addressed elsewhere in the system. Both groups suggested that there be a list of inappropriate conditions posted on the Web site and advice to call 911 in case of an emergency. Parents recommended that there be a required orientation session before teens use the site. Teens also suggested that there be a list of frequently asked questions available on the site.

*Teen: "Post a list of conditions that are inappropriate to discuss on PAMF Online."*

*Teen: "Notify teens not to expect a response within 24 hours so they will know it is not intended for emergency care."*

*Parent: "Post a list of inappropriate problems on the site."*

*Parent: "Educate teens during their orientation [on] how to best use the site."*

Both parents and teens expressed concerns about billing for confidential services that might arise from use of the site. Some parents felt they had a right to know what they were paying for, while other parents were content with paying an annual fee or being billed without details of charges for confidential services.

*Parent: "If teens see lab results, parents should see them too. As long as we are paying the bills and insurance, we [parents] should know what's going on."*

*Parent: "If I was confident the doctor was doing the best thing for my daughter I could pay the bills without knowing the details."*

Teens, however, felt strongly that they wanted their parents to see only general billing information without specific details about services received.

## Discussion

We found that both teens and parents were enthusiastic about the use of a teen portal but had important concerns about confidentiality and the concern that parents would be left out of the loop. These findings are consistent with previous research, which has demonstrated teen interest in using the Internet for health issues and particularly for health issues related to sexuality and substance abuse.<sup>18</sup> Prior research has also shown that both providers and patients view the patient portal in the healthcare system as an important means to enhance provider-patient communication.<sup>19, 20</sup> Finally the use of a Web-based patient portal has the added advantage of providing a better venue for teen self-disclosure of important but sensitive healthcare issues.<sup>21</sup>

With respect to specific features of the teen portal, both teens and parents most valued the possibility of easy access to reliable healthcare information. This finding echoes previous research that has shown that seeking health information is the most used feature of patient portals and of the Internet in general.<sup>22-</sup><sup>25</sup> The use of secure messaging and results reporting raised some concerns on the part of both parents and teens. A significant proportion of parents wanted to know about communication between their teen and a healthcare provider when it involved important healthcare issues. Teens, on the other hand, were skeptical that secure messaging with their provider would remain confidential. Both parents and teens expressed concerns that they may not know how to accurately interpret clinical results or take appropriate actions, leading to poor decision making or resulting in teens' not taking the appropriate action or ignoring the need to seek care.<sup>26</sup> Both parents and teens were positive about using the teen portal for appointment making and appointment reminders. This, again, is consistent with previous research that has demonstrated the popularity of this feature of patient portals.<sup>27</sup> Some parents, however, expressed concern that this capability meant they would not know about clinical appointments of their teens that concerned important healthcare problems.

Our findings suggest an interesting way to use the teen portal to enhance communication between parents and teens in the important area of teen confidentiality. Of interest is the suggestion by some teens and parents that the best solution to these differences would be negotiation between parents and teens as to what information should remain confidential between provider and teen and what information should be shared with parents. Several investigators have shown that parents can have a positive influence on decreasing teen adoption of high-risk behaviors and that the explicit expression of parental concerns can

have a positive impact on teen behavior.<sup>28-33</sup> Our results also show that both parents and teens felt that it was most appropriate for the primary care provider to bring up the issue of the teen portal with the parents and the teen. These findings suggest that the discussion of the teen portal with teens and parents by the provider could provide an important venue for discussion and negotiation of confidential health issues. Enlisting parents and teens in active discussion and negotiation offers an attractive alternative to mandating parental notification—a strategy that has been shown to discourage teens from using health services for sensitive issues.<sup>34, 35</sup> Any negotiation, however, would have to take place in the context of existing legislation protecting teen confidentiality and would have to consider the impact of the power asymmetry between parents and teens in the negotiating process.

## **Limitations**

This study has several important limitations. Because of the limited sample size, care must be taken in generalizing our results to a larger or more diverse population. In addition, our study sample was restricted to older teens and their parents and is almost certainly not directly generalizable to younger teens and their parents. The study also took place in a “social” environment (focus group or electronic bulletin board), which may have biased the results. The restriction of the study sample to teens and parents who had expressed at least some interest in the topic of a teen patient portal may have also biased the generalizability of the results. Finally, it is important to note that, while qualitative research is useful in generating hypotheses for teen use of a patient portal, assessment of the impact of a patient portal on access to care will require controlled intervention trials with measurement of use of the portal, access to care, and health outcomes.

## **Conclusions**

In this study we have found that parents and teens have mixed feelings about teens’ taking more control of their healthcare. Teens are concerned about issues of confidentiality, and parents are worried about being left out of the loop. Both parents and teens felt the teen portal could increase access to care, improve communication with primary care providers, and be used to schedule medical visits. A significant portion of both teens and parents also had concerns about teen portal use. Teens were concerned that their communications would not remain confidential. Parents, on the other hand, were worried about not being informed about significant health issues with their teens. Both groups also felt that the primary care physician should play an important role in introducing the confidentiality policies associated with the use of a teen portal to the teen and family and potentially in helping them negotiate about what issues should remain confidential and where parents can be helpful and supportive. The potential of a teen portal to increase access to care and improve healthcare outcomes for teens and to facilitate discussions of confidentiality and health will be an important direction for future research.

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## Notes

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## **Table 1**

### Key Topics from Discussion Guide

- Attitude toward teens' managing their own healthcare
- How teens get medical information
- What teens' involvement in making appointments should be
- Teen communication with parents about medical information
- Teen attitudes about confidentiality
- Reaction to patient portal
  - Overall reaction
  - Secure messaging with physician
  - Making appointments
  - Receiving test results
- Recommendations of implementation of teen portal
  - Sign-up
  - Decisions about confidentiality
  - Billing for patient portal
  - Most difficult issues