



## HOW PATIENTS WANT TO ENGAGE WITH THEIR PERSONAL HEALTH RECORD: A QUALITATIVE STUDY

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# HOW PATIENTS WANT TO ENGAGE WITH THEIR PERSONAL HEALTH RECORD: A QUALITATIVE STUDY

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## ARTICLE SUMMARY

### Article Focus:

What are necessary elements for patient engagement in advanced interactive personal health records (IPHRs)?

### Key Messages:

Engagement in an IPHR is related to integration into current care and the patient-clinician relationship.

Trust in the accuracy, security, and privacy of IPHR information is also linked to the patient-clinician relationship.

Models of technology success and acceptance may warrant modification when applied to primary care use of IPHRs.

### Strengths/Weaknesses:

An advanced IPHR shown to increase use of preventive services was employed for the study.

The sample was drawn from northern Virginia, USA. Other locales may have different IPHR needs and require different strategies to engage patients in IPHR use.

Most participants had ongoing established relationships with their clinician.

## ABSTRACT

**Objective:** To assess factors related to use and non-use of a sophisticated interactive preventive health record (IPHR) designed to promote uptake of 18 recommended clinical preventive services. Personal health records (PHRs) with more advanced functionality may better engage patients and improve health outcomes. However, little is known about how patients want to use or be engaged by such advanced information tools.

**Design:** Descriptive and interpretive qualitative analysis of transcripts and field notes from focus groups of IPHR users and of patients who were invited but did not use the IPHR (non-users).

**Setting:** Primary care patients in eight practices of the Virginia Ambulatory Care Outcomes Research Network (ACORN).

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3 Participants: Three focus groups involved a total of 14 IPHR users and 2 groups of non-users totaled 14  
4 participants.  
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6 Outcomes/Results: For themes identified (relevance, trust, and functionality) participants indicated that  
7 endorsement and use of the IPHR by their personal clinician was vital. In particular, participants'  
8 comments linked IPHR use and the patient-clinician relationship to: 1) integrating the IPHR into current  
9 care, 2) promoting effective patient-clinician encounters and communication, and 3) their confidence in  
10 the accuracy, security and privacy of the information.  
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13 Conclusion: In addition to patients' stated desires for advanced functionality and information accuracy  
14 and privacy, successful adoption of IPHRs by primary care patients depends on such technology's  
15 relevance, and on its promotion via integration with primary care practices' processes and the patient-  
16 clinician relationship. Accordingly, models of technological success and adoption, when applied to  
17 primary care, may need to include the patient-clinician relationship and practice workflow. These  
18 findings are important for health care providers, the information technology industry, and policymakers  
19 who share an interest in encouraging patients to use PHRs.  
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21 Trial Registration Clinicaltrials.gov identifier: NCT00589173  
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24  
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26 HS17046-01).  
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29 **Key words:** health promotion; information management; informatics; patient-centered care;  
30 physician-patient relations  
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34 This study was approved by the Institutional Review Board of Virginia Commonwealth University,  
35 Richmond, Virginia, USA.  
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## 37 38 **BACKGROUND**

39  
40 The concept of patient-centered care is not new to medicine.<sup>1,2</sup> Decades ago, research  
41 demonstrated that engaging patients in their care improves patient satisfaction, quality of care,  
42 and clinical outcomes.<sup>3,4</sup> Recently, national movements aimed at transforming healthcare have  
43 formally defined, incentivized, and institutionalized patient-centered care. The goals of the  
44 Patient-Centered Medical Home espouse these principles.<sup>5,6</sup> State and national legislation  
45 combined with payer initiatives now encourage and support practices to provide patient-  
46 centered care.<sup>7,8</sup> The national *Meaningful Use Roadmap* defines patient and family  
47 engagement from a patient perspective as "actions we must take over time to obtain the  
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3 greatest benefit from the health care services available to us”, further stating that engagement  
4 is both desirable and necessary for health information systems.<sup>5,9,10</sup>  
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9 Personal health records (PHRs) are an important resource to help practices provide patient-  
10 centered care. Currently, the most common functions performed by PHRs include record  
11 keeping, secure messaging, appointment scheduling, and bill payment.<sup>11</sup> Yet, other PHR  
12 features could help facilitate patient engagement in their medical care, including use of plain  
13 English depictions of clinical data, motivational messages to seek needed care, educational  
14 resources, decision aids, and resources and tools to support and guide care.<sup>12,13</sup>  
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21 While electronic PHRs have been available for more than a decade, they are used by only a  
22 fraction of Americans, and practices struggle to promote patient adoption.<sup>11-21</sup> One possible  
23 reason for poor PHR uptake is that many systems are designed solely for use by patients,  
24 lacking integration into the care delivery system.<sup>13,15,19</sup> Tang and Lee suggest that patients may  
25 prefer PHRs that integrate with the electronic medical records (EMRs) of the patients’  
26 clinicians, thus providing better access to laboratory and other data, as well as communication  
27 with the clinician. This, they posit, will facilitate “the type of physician-patient relationship that  
28 will improve health.”<sup>17</sup>  
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39 Whereas Wen and associates concluded (from national survey data) that optimal PHR  
40 promotion should include further study of cultural issues and the doctor-patient relationship,<sup>20</sup>  
41 PHR adoption literature is frequently viewed from physician<sup>21,22</sup> or technology-driven<sup>22,23</sup>  
42 perspectives, e.g. that increasing the number of EMRs will increase PHR uptake.<sup>21</sup> Similarly,  
43 models such as the Model of Information Systems Success,<sup>24</sup> and the Technology Acceptance  
44 Model (TAM)<sup>25</sup> have, at times, been applied to healthcare with little patient perspective,<sup>26</sup> or in  
45 purposively eschewing “person to person trust” in evaluating such models.<sup>23</sup> However, to our  
46 knowledge, no one has evaluated these models in a patient-centered PHR shown to improve  
47 patient outcomes.  
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In 2007, we created an interactive preventive health record (IPHR) that was designed with greater functionality to engage and activate patients in their preventive care. Details about the design of the IPHR,<sup>27</sup> findings from a randomized controlled trial demonstrating that the IPHR significantly improved preventive care,<sup>28</sup> and a how-to-guide showing practices how they can use their PHRs to better promote preventive care, have been previously published.<sup>29</sup> Briefly, patients use the IPHR to add supplementary information to their EMR record and are then presented with a prioritized snapshot of the clinical preventive services that are recommended, based on their individualized risk profile, by the U.S. Preventive Services Task Force and other reputable guideline panels. The summary is accompanied by personalized explanations of the information, tailored motivational messages, recommendations and reminders for action, and decision aids. The information is shared with both patient and clinician.

While multiple studies have evaluated why patients use PHRs with more basic functionality,<sup>10,14</sup> less is known about their interests in and engagement with PHRs with more advanced functionality as provided by the IPHR. As part of our ongoing trials, we used qualitative methods to capture perspectives from both “users” and patients who were invited to use the IPHR but did not use the system (“non-users”), with a lens towards informing the knowledge gaps and varying viewpoints about PHR adoption noted above. As framed by Kuzel, this inquiry was “driven not by a need to generalize or predict, but rather by a need to create and test... interpretations.”<sup>30</sup>

## METHODS

### Design

We employed descriptive and interpretive analysis of focus group transcripts and field notes, with data reduction via coding and editing for development of major themes and sub-themes. A trained moderator led the focus groups, using broad-based questions to explore patients’ perspectives about the IPHR and PHRs in general. A focus group guide was used to ensure consistency of procedures, questions, and discussion topics. The guide and focus group process

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3 were based on the methods described by McNamara and by Crabtree and Miller.<sup>31,32</sup> At the  
4 beginning of each patient focus group, participants completed a brief printed questionnaire  
5 eliciting demographic characteristics and information about interactions with their clinician.  
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7 The study was approved by the Virginia Commonwealth University Institutional Review Board.  
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## 10 11 **Sample**

12 All participants were patients from one of eight family medicine practices that were located in  
13 northern Virginia and participated in the Virginia Ambulatory Care Outcomes Research Network  
14 (ACORN). In order to address sampling adequacy, a minimum total of 12 participants in both  
15 user and non-user groups was targeted.<sup>33</sup> During the first four months the IPHR was available to  
16 the practices, 229 of the 2,250 patients randomly selected and mailed an invitation used the  
17 tool (completed registration and entered data on the website). All of these patients were  
18 invited via email to participate in focus groups. Of the 44 who expressed interest, 30 selected to  
19 provide a range of ages, genders, and practice locations were asked to participate in three user  
20 focus groups. (The first user group was rescheduled due to inclement weather and 3 of 10  
21 participants ultimately attended. The next two groups had 5 and 6 of 10 invited participants  
22 attend, respectively.) Of the 2021 non-users, a random sample of 150 patients, stratified by  
23 age, gender, and practice location, were mailed focus group invitations. From the 32 patients  
24 who responded to the letter, 20 selected to provide a range of ages, genders, and practice  
25 locations were asked to participate in two non-user focus groups; 14 attended. Each participant  
26 received a \$50 gift card incentive.  
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## 43 **Procedures**

44 Focus groups, each approximately 1.5-2 hours in duration, were held at a location near the  
45 participating practices. Group discussion was guided by semi-structured questions with probes  
46 and prompts to provide follow-up lines of inquiry, clarify topics, and stimulate further  
47 discussion. Both user and non-user groups were shown screen-shots demonstrating how the  
48 IPHR worked at appropriate times during the groups so all participants could comment on IPHR  
49 attributes and uses. Sessions were audio-recorded, and the transcriptions of the recordings  
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were then corrected as necessary via comparison to the original recordings. Field notes were also taken to capture aspects of the group interaction that would not be identified on recordings. This included such observations as participant body language and tone, as well as researcher thoughts and reactions.

Transcripts and field notes underwent descriptive analysis with a provisional categorical structure based on focus group question guides. Data were combined with field notes to explore descriptive similarities and differences within and between the groups. Coding and editing of transcripts and field notes were used to derive higher level themes and explanations, and tentative explanations of findings were based on both our data and relevant literature. A four-member team (JWK, AHK, DRL, AJK) performed each step of the analysis independently. Differences in coding, development of themes, and derivation of tentative explanations were discussed by the team until consensus was reached.

## RESULTS

### Study Population

The patients who used the IPHR during the study period were primarily men (56%), white (85%), and more than 50 years old (68%). Of the 50 patients who agreed to participate in focus groups (30 users and 20 non-users), 28 patients attended the sessions, including 14 PHR users and 14 non-users (Table 1). Focus group participants were predominantly women (64%), white (93%), over 50 years old (86%), and all reported having attended at least some college. Nearly all<sup>o</sup> participants rated their health as good to excellent, stated they had been with their clinician at least 3 years, and rated their clinician highly.

**TABLE 1: FOCUS GROUP PARTICIPANTS**

PARTICIPANT CHARACTERISTICS	3 PHR User Groups (n=14)	2 PHR Non-User Groups (n=14)	P value
Gender	5 male 9 female	5 male 9 female	ns

<sup>o</sup> The following is used for the verbal annotation of participant percentages: All=100%, nearly all=80-99%, most=60-80%, many=40-60%, a majority= >50%, some=25-40%, few=<25%.



Mean age (years)	66 (range 50-77)	59 (range 40-75)	0.07
White (%)	100	86	ns
Participant-reported Education, Number of participants	Some college/associate degree-5 College graduate-2 More than college degree-7	Some college/associate degree-2 College Graduate-3 More than college degree-9	ns
Participant-reported number of years with current clinician	2 participants <1 yr 4 participants 3-5yrs 8 participants >5yrs	0 participants <1 yr 8 participants 3-5yrs 6 participants >5yrs	ns
Mean participant-reported visits per year	3.6	3.4	ns
Mean participant quality rating of current clinician	9.23/10 0=worst doctor possible 10=best doctor possible	9.00/10 0=worst doctor possible 10=best doctor possible	ns
Patient-reported health rating, number of participants	Excellent-4 Very Good-6 Good-3 Fair-0 Poor-1	Excellent-3 Very Good-7 Good-3 Fair-1 Poor-0	ns

All but one focus group participant acknowledged using the Internet daily, and some described “constant” Internet use for job and personal purposes. Although nearly all stated that they did not use the Internet as often for health-related matters as for other needs, they did report using the Internet to garner health information, primarily for themselves and their family.

### Themes

Across all five focus groups,\* three major themes emerged about how participants wanted to be engaged by PHRs: they wanted (1) novel content that was relevant to their immediate and ongoing care, (2) a PHR they could trust for accuracy, security, and privacy, and (3) a highly functional PHR, facilitating care and communication with their clinician, and providing access to comprehensive personalized information shared with the clinician. Although utility was said to

\* Unless otherwise indicated, findings described herein are from both user and non-user groups.

be essential, a major reason why participants said they trusted, used, and sought relevance in the IPHR was that it was offered to them by their personal clinician.

### Relevance

A few participants noted that upcoming appointments with their clinician made IPHR use more compelling, contributed to their registering, and led them to notice the content pertinent to that visit. Most, however, reported that the invitation for the IPHR was received at a time unassociated with an office visit or any specific healthcare needs. Indeed many participants reported that as a result they did not feel a pressing need to immediately register for and use the IPHR (Table 2). A few non-users declared that they just had not gotten around to registering. Many participants in both the non-user and user groups voiced the opinion that they could access similar information on the internet, and that they did not recognize that IPHR content was personalized to their needs. Some users commented that they had already fully addressed their preventive healthcare needs with their clinician.

**TABLE 2: REPRESENTATIVE PARTICIPANT COMMENTS ON RELEVANCE**

Sub-themes	Representative Quotations
<b>Lacking Urgency</b>	<i>It was procrastination. It wasn't that I wasn't going to do it.</i>  <i>I said, "Boy, this would be -- this is interesting, I should try it." Stuck it in a pile and forgot about it.</i>
<b>Lacking Novelty</b>	<i>Particularly when it concerns a medical something, I usually look it up, you know, any of the various websites that you can go to.</i>  <i>I am the health related expert in the house. And I have to know what everything is. So yes I go to the Cleveland Clinic and the Mayo Clinic and Johns Hopkins.</i>  <i>United Healthcare has a preventive section to it. You know it's got your records, and then there's hey if you've got a problem, you go to this section and it seemed to cover more.</i>
<b>Redundant to current care</b>	<i>It was not, in my case not new information since my doctor and I had talked about it so much...</i>  <i>She knows what I do for exercise, and she asks me questions when I go in, you know. But, if I didn't have that kind of relationship, then I think I would -- I mean, right now, I don't see, for me, that I need this.</i>

### Trust

Nearly all participants vigorously discussed three components of trust necessary for them to use a PHR: security (protecting their health information), privacy (not sharing their health information with others), and accuracy (ensuring that the clinical content and health

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recommendations proffered by the system were correct and appropriate for them) (Table 3). Most participants reported trusting the IPHR because it was recommended and used by their clinician's practice. A few participants in the non-user groups indicated discomfort with having any of their personal health information on the Internet. However, most participants in all groups expressed the view that clinician endorsement of the IPHR was an indication that their personal health data were secure. Most participants also expressed strong opposition to PHRs developed by commercial entities and to sharing their health information with their insurance company due to the risk of future denial of coverage.

**TABLE 3: REPRESENTATIVE PARTICIPANT COMMENTS ON TRUST**

Sub-themes	Representative Quotations
<b>Security</b>	<p><i>It came through our own doctor; I didn't have any problem with it. If it had just been out of the blue I might have.</i></p> <p><i>At first I was curious as to what is this, but then I guess I trusted it because it was [clinician's office] which I trusted.</i></p> <p><i>I've come to trust him to keep my information in his laptop...you have to trust the doctor.</i></p>
<b>Privacy</b>	<p><i>I think personally I would only trust what I was affiliated with. What should be familiar with me. I mean, Google certainly doesn't know me...</i></p> <p><i>Another Participant: Oh, Yes they do.</i></p> <p><i>The information you have on the system, passing data maybe to insurance companies and then turn around later and say no we're not going to insure you...</i></p> <p><i>I got scared...because I got the impression that I was going to discuss things of my personal nature with my doctor on the website and I didn't like that, and so I discarded it because I'd rather talk about my health face to face with my doctor.</i></p>
<b>Accuracy</b>	<p><i>There's so many sites out there that you wonder how valid. I felt good that [the clinician's office was] endorsing or leading me to a particular site that they must feel confident in the information and the content..</i></p> <p><i>One reason I don't do (Internet health information) a whole lot is because you get conflicting views and I don't know who to believe and who not to believe. So I...ask my doctor.</i></p> <p><i>I was getting emotionally distraught over those things that I was reading (on the Internet) and then, come to find out, I didn't even have to be concerned about it. But... I got to leave those kinds of things to the doctor because that's what he's trained for.</i></p>

Nearly all participants reported having had difficulties distinguishing between accurate and inaccurate health information on the internet (Table 3). A few participants gave examples of

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erroneous health information that caused anxiety or led to poor personal health choices. Most participants stated that they asked their clinician to verify information they found on the web. Nearly all participants reported that they would trust the accuracy of the content and recommendations made by the IPHR because it was endorsed and used by their clinician, and identified their clinician as their primary authority on the accuracy and application of healthcare information.

### Functionality

Functions that the participants identified as important involved two subthemes: enhanced patient-clinician communication and patient-centered utility (Table 4).

**TABLE 4: REPRESENTATIVE PARTICIPANT COMMENTS ON FUCTIONALITY**

#### Enhanced Patient-Clinician Communication

Sub-themes	Representative Quotations
<b>Interactive</b>	<p><i>Direct communications between the doctor and the patient that you can access via the Internet just like medical records, you should be able to access that.</i></p> <p><i>The nurse called me up and said we haven't seen you in so long, you know, and she starts going through this (prevention) stuff...I said well I've been going to my heart doctor...and she said, you should come back you know.</i></p> <p><i>Not dictating, but cooperating, supportive, and provide me the source of the information, let me go there and look at the thing before, you know we make a decision.</i></p>
<b>Focus Discussion</b>	<p><i>I have 15 minutes to talk to him. And this gives me the ability to list everything that's wrong with me...This is what you need to talk to the doctor about in your physical.</i></p> <p><i>I would think anything that would focus my discussion would hopefully focus his as well.</i></p> <p><i>When I go in to the primary care physician, I don't want to just listen to him. I do want to hear what he has to say, but I want to be able to ask what I think are intelligent questions. I'll go do research on that. And then I feel like I can have a better, more productive discussion with the physician.</i></p>
<b>Broaden Discussion</b>	<p><i>What if your doctor disagrees somewhat with the United States Preventive Services Task Force?...It becomes a discussion point.</i></p> <p><i>I think it (conversation with clinician) might be a little bit broader. You go and say, "Here's what I'm seeing or here's what going on with my family."</i></p>
<b>Efficiency Pros and Cons</b>	<p><i>There might be an opportunity to take some of the minor issues off the table, so when you go to the doctor it would shorten the amount of things that you would like to talk to him about because you've answered some of that already.</i></p> <p><i>That email to the doctor, I think, could create a problem. It's very time consuming. You spend all day on the internet answering mail, the doctor will never get paid...SECOND PARTICIPANT: You'd never</i></p>

	<p><i>get your tetanus shot. FIRST PARTICIPANT: ..You'd never get anything else.</i></p> <p><i>So what is this doing for the physician? I mean, we're keeping healthier, but it means a lot more work for him in a way.</i></p>
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**PATIENT-CENTERED UTILITY**

Subthemes	Representative Quotations
<b>Expand Access To Personal Clinical Information</b>	<p><i>It's not just security, but also access. My access to my personal information. I want to have that, and electronic medical records, Internet-based systems can provide me with that.. I trust my physician here because I've developed a relationship with him, but anybody else, I would want to have absolute access to my information.</i></p>
<b>Align Patient-Clinician Information</b>	<p><i>Knowing that all the information is correct to the best of your knowledge, and in one place where it can be accessed by the doctor and by you, it makes me feel very secure.</i></p> <p><i>This information is shared with your physician -- as you update things your provider is going to be made aware of this you know-We need to be on the same page.</i></p>
<b>Provide Personalized Information</b>	<p><i>I think with that information available, I think it will actually help him a great deal to change my lifestyle. I think that's what all this preventive medicine is all about is how you change your lifestyle.</i></p> <p><i>It also gave me some thoughts about the preventive things I should need to know or that I should be thinking about. So it made me think about, gosh I'll have to ask her. For example, something about an aspirin a day, is it something that's appropriate for me?</i></p> <p><i>There was lots of information there but it was not, in my case not new information since my doctor and I had talked about it so much...</i></p>
<b>Comprehensively Address Patient Needs</b>	<p><i>I'm surprised that this isn't something for medications. One doctor says you got to take calcium and another one says you got to take multivitamin and another one says you got to take an aspirin, and people may be taking allergy medicines that they get over the counter...</i></p> <p><i>Some general thing about menopause or some of the women's issues would have been helpful. Age specific things might be helpful, children, you know, developmental or something like that just as a good reference for parents.</i></p> <p><i>Say you had in your history that you had a history of stroke or cancer, would it also give patient education stuff, like here's a link to the American Cancer Society? Or here's a thing for support group information? I'm a surviving cancer patient...</i></p> <p><i>Here's what we want: we're living here but we want to occasionally go somewhere else. Anyone in the country should be able to open and keep track of it accurately...realistically and securely.</i></p>

Many participants stated that they wanted PHRs to enhance communication with their clinician. Several liked being contacted about preventive care after they used the IPHR. Participants described how the IPHR could focus discussions during office visits, making their visits more productive. Conversely, several also mentioned that the IPHR could appropriately

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3 broaden discussions for some topics, such as identifying preventive screening choices that they  
4 or their clinician viewed as warranting dialogue, or starting conversations about lifestyle  
5 changes. However, some participants expressed concern that more time would be required for  
6 busy clinicians and patients to use the IPHR or similar tools. Participants worried about  
7 increased fees for either patients or practices to use similar PHRs in the future.  
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12 Many participants said that a critically important feature of the IPHR was the ability for patients  
13 to access their personal health information. They explained that this access was important so  
14 that they could be “on the same page” as their clinician. They also commented that shared  
15 access to information would contribute to improved accuracy of records and more productive  
16 interactions.  
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21 Many participants identified the personalized advice offered by the IPHR, its prompts to discuss  
22 its recommendations with the clinician (e.g. whether to take aspirin), and its ability to prioritize  
23 recommendations and thereby highlight critical or information to act on, as very important.  
24 Also of interest to many was adding features for comprehensive medication reconciliation, in-  
25 depth information for the whole family for prevention as well as for specific diseases, and links  
26 to local resources that provide support and information for lifestyle changes, preventive care  
27 needs, and chronic diseases. Moreover, several participants stated that PHRs, such as the IPHR,  
28 should be shared seamlessly across all healthcare providers and settings.  
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## 43 **DISCUSSION**

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45 Given the national investment of \$27 billion to promote the adoption, implementation, and  
46 meaningful use of health information technology,<sup>34-36</sup> it is essential to understand how to better  
47 engage patients in using technology if it is to achieve its full potential. Many Americans have  
48 not embraced the use of PHRs,<sup>37</sup> but our findings underscore the general interest of patients in  
49 using such tools if certain attributes are offered. Specifically, users and non-users alike  
50 suggested that engagement was more likely if the PHR seemed relevant to their care, if they  
51 could trust the system, and if it offered functions that could help them manage their health.  
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5 Relevance may seem obvious and implied to clinicians and PHR developers, but this may be less  
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7 apparent to busy patients who view themselves as already capable of finding healthcare  
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9 information and managing their healthcare. When PHR use is integrated into care so that it  
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11 improves the efficiency and quality of their care (e.g. timely use related to clinician visits), its  
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13 relevance becomes more transparent. The PHR becomes a welcome extension of interactions  
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15 with the clinician and the related healthcare team.  
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18 Users also identified trust as an important prerequisite to using a PHR. National surveys have  
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20 clearly documented a level of public concern about personal health information existing on the  
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22 web and about employers, insurers, or even commercial entities being able to access or misuse  
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24 such information.<sup>37</sup> Although such fears may ease over time as more private information  
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26 migrates into the cyber-environment, this reticence may have contributed to the failure of  
27  
28 some commercial PHRs to gain wide acceptance by the general public.<sup>38</sup> Our study participants  
29  
30 also identified the need to trust the accuracy of the information in the PHR. Unfortunately, the  
31  
32 data in many health information systems are commonly incorrect or outdated, often focused  
33  
34 more on billing for service delivery than on conveying useful information to patients,  
35  
36 particularly if the information is obtained from insurance claims databases or hospital  
37  
38 systems.<sup>39,40</sup>  
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40  
41 The addition of certain PHR features that seem popular with patients, such as displaying test  
42  
43 results or supporting asynchronous communication via secure messaging, has generated only  
44  
45 modest increases in actual PHR utilization.<sup>15,19</sup> One explanation is that patients who are  
46  
47 accustomed to more powerful information tools in other aspects of life may expect greater  
48  
49 functionality than merely seeing their information.<sup>41,42</sup> Indeed, participants in this study wanted  
50  
51 much more – including links to personalized recommendations, and resources and tools to help  
52  
53 make information actionable to improve health. As discussed elsewhere, the ability to use  
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55 health information technology to take action is an important requirement to making technology  
56  
57 truly patient-centered.<sup>12,13</sup>  
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5 Across both users and non-users, nearly all participants reported being more likely to perceive a  
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7 PHR as relevant, trustworthy, and functional if it was offered to them by their personal clinician.  
8  
9 We conclude that a key element of engaging patients to use a PHR extends beyond the tool's  
10  
11 design and includes how it is presented to patients and integrated into their care experience.  
12  
13 These concepts are depicted in Figure 1. Overcoming the hurdles for engaging patients begins  
14  
15 with making PHR use routine and related to current needs. Clinician endorsement can generate  
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17 patient trust to begin using the PHR. Ultimately, effective PHR use can lead to engaged and  
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19 motivated patients, more efficient healthcare delivery, even improved healthcare  
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21 outcomes,<sup>27,29</sup> e.g. as already demonstrated by this IPHR.<sup>28</sup>  
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FIGURE 1: PERSONAL HEALTH RECORD (PHR) FEATURES NEEDED TO ENGAGE PATIENTS

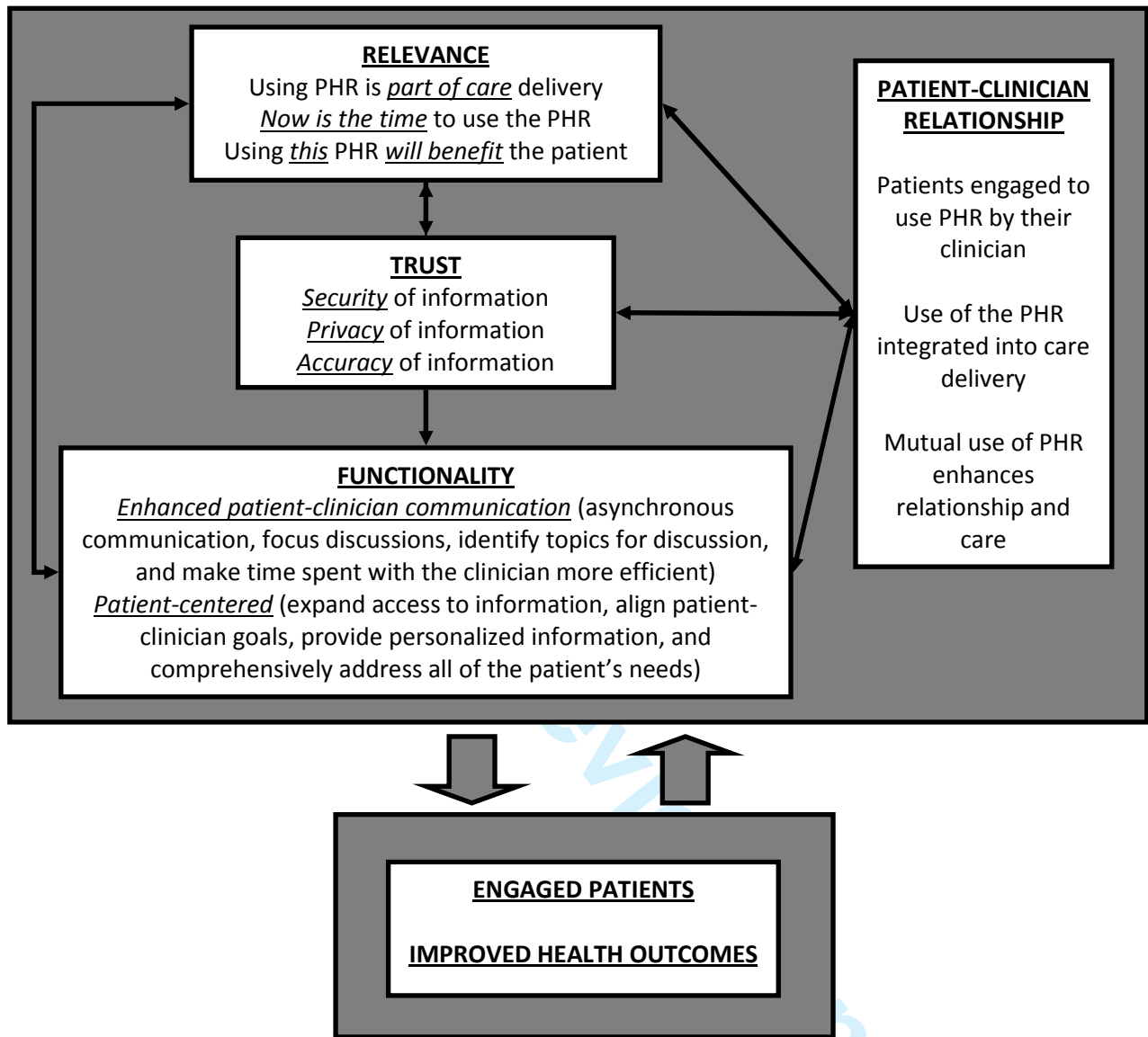
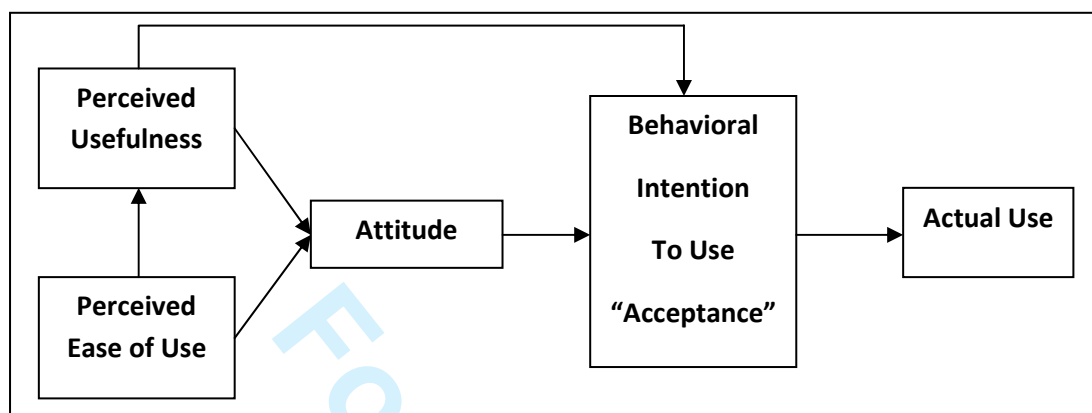


Figure 1 is similar in some regards to the Technology Acceptance Model (TAM), Figure 2.<sup>25</sup> Although many modifications have already been proposed for the TAM,<sup>26,43,44</sup> based on our findings this figure may more accurately portray the relationships needed for patient engagement for primary care IPHRs.

Figure 2: Technology Acceptance Model<sup>25</sup>

Our study has several important limitations. First, while we attempted to assemble focus groups with a representative range of ages and genders, we may have introduced a selection bias in our sample. Participants were older, more likely to be female, mostly white, and more educated than the overall user and non-user populations.<sup>45,46</sup> However, women are more likely than men to use PHRs<sup>47</sup> and to make healthcare decisions for families.<sup>47-49</sup> Other studies indicate that members of different socioeconomic and racial-ethnic groups may have different PHR preferences (e.g. a PHR not based on the Internet) and may require assistance in using a PHR.<sup>50-52</sup> Second, the sample was drawn entirely from eight practices in northern Virginia. Other locales may have different PHR needs requiring different strategies to engage patients in PHR use. Third, all participants were recruited from family medicine offices that already offered a PHR to patients, and most participants had established relationships with their clinician. Accordingly, participants may have emphasized the value of the patient-clinician relationship in PHR use more than populations from other settings. Lastly, whereas the number of participants (28) will not quantitatively generalize to all IPHR users, the nature of qualitative research is often that of looking at specific cases, many times in order to inform the gaps generated by other data, rather than to compete with or duplicate that information.<sup>32</sup>

## CONCLUSION:

To engage primary care patients with an IPHR, this study identifies the importance of relevance, trust and functionality, all integrated with office processes and the patient-clinician relationship. In addition to suggesting possible modifications to established models of technological acceptance, these findings have relevance for healthcare providers, the information technology industry, and policymakers who share an interest in encouraging patients to use personal health records or other information tools. Studies like ours should be expanded and replicated in other settings to more fully understand how to make such technology more useful to patients.

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**Conflicts of interest:** Virginia Commonwealth University holds the intellectual property rights to the interactive preventive care record evaluated in this study. Although the university and developers are entitled to the system's revenue, MyPreventiveCare is a noncommercial product, and no revenues have been generated other than grant funding.

**Contributorship:** J. William Kerns, MD –Design, data acquisition, data analysis/interpretation, drafting/critical revision, and final approval.  
Alex H. Krist MD, MPH-Conceptualization, design, data analysis/interpretation, critical revision, and final approval.  
Daniel R. Longo, ScD.- Design, data analysis, critical revision, and final approval.  
Anton J. Kuzel, MD, MHPE- Design, data acquisition, data analysis/interpretation, critical revision, and final approval.  
Steven H. Woolf, MD, MPH- Conceptualization, data analysis/interpretation, critical revision, and final approval

**Data sharing:** Transcripts for the focus groups in this study are not able to be shared due to requirements of our Institutional Review Board.

**Funding:** Agency for Healthcare Research and Quality

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## HOW PATIENTS WANT TO ENGAGE WITH THEIR PERSONAL HEALTH RECORD: A QUALITATIVE STUDY

Journal:	<i>BMJ Open</i>
Manuscript ID:	bmjopen-2013-002931.R1
Article Type:	Research
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Complete List of Authors:	Kerns, John; Shenandoah Valley Family Practice Residency, ; Virginia Commonwealth University, Family Medicine Krist, Alexander; Virginia Commonwealth University, Family Medicine Longo, Daniel; Virginia Commonwealth University, Family Medicine Kuzel, Anton; Virginia Commonwealth University, Family Medicine Woolf, Steven; Virginia Commonwealth University, Family Medicine
<b>Primary Subject Heading</b>:	Health informatics
Secondary Subject Heading:	General practice / Family practice, Patient-centred medicine, Qualitative research
Keywords:	Health informatics < BIOTECHNOLOGY & BIOINFORMATICS, PRIMARY CARE, PREVENTIVE MEDICINE, QUALITATIVE RESEARCH

SCHOLARONE™  
Manuscripts



**Article Focus:**

What are necessary elements for patient engagement in advanced interactive personal health records (IPHRs)?

**Key Messages:**

Engagement in an IPHR is related to integration into current care and the patient-clinician relationship.

Models of technology success and acceptance may warrant modification when applied to primary care use of IPHRs.

**Strengths/Weaknesses:**

An advanced IPHR shown to increase use of preventive services was employed for the study.

The sample was drawn from northern Virginia, USA. Other locales may have different IPHR needs and require different strategies to engage patients in IPHR use.

Most participants had ongoing established relationships with their clinician.

**ABSTRACT**

**Objective:** To assess factors related to use and non-use of a sophisticated interactive preventive health record (IPHR) designed to promote uptake of 18 recommended clinical preventive services; Little is known about how patients want to use or be engaged by such advanced information tools.

**Design:** Descriptive and interpretive qualitative analysis of transcripts and field notes from focus groups of IPHR users and of patients who were invited but did not use the IPHR (non-users). Grounded theory techniques were then applied via an editing approach for key emergent themes.

**Setting:** Primary care patients in eight practices of the Virginia Ambulatory Care Outcomes Research Network (ACORN).

**Participants:** Three focus groups involved a total of 14 IPHR users and 2 groups of non-users totaled 14 participants.

**Outcomes/Results:** For themes identified (relevance, trust, and functionality) participants indicated that endorsement and use of the IPHR by their personal clinician was vital. In particular, participants' comments linked IPHR use to: 1) integrating the IPHR into current care, 2) promoting effective patient-clinician encounters and communication, and 3) their confidence in the accuracy, security and privacy of the information.

**Conclusion:** In addition to patients' stated desires for advanced functionality and information accuracy and privacy, successful adoption of IPHRs by primary care patients depends on such technology's relevance, and on its promotion via integration with primary care practices' processes and the patient-



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3 clinician relationship. Accordingly, models of technological success and adoption, when applied to  
4 primary care, may need to include the patient-clinician relationship and practice workflow. These  
5 findings are important for health care providers, the information technology industry, and policymakers  
6 who share an interest in encouraging patients to use PHRs.  
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8  
9 Trial Registration Clinicaltrials.gov identifier: NCT00589173  
10

11 Funding support: This work was supported by the Agency for Healthcare Research and Quality (R18  
12 HS17046-01).  
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14  
15 **Key words:** health promotion; information management; informatics; patient-centered care; physician-  
16 patient relations  
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19 This study was approved by the Institutional Review Board of Virginia Commonwealth University,  
20 Richmond, Virginia, USA.  
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## BACKGROUND

1 The concept of patient-centered care is not new to medicine.<sup>1,2</sup> Decades ago, research demonstrated  
2 that engaging patients in their care improves patient satisfaction, quality of care, and clinical  
3 outcomes.<sup>3,4</sup> Recently, national movements aimed at transforming healthcare have formally defined,  
4 incentivized, and institutionalized patient-centered care. The goals of the Patient-Centered Medical  
5 Home espouse these principles.<sup>5,6</sup> State and national legislation combined with payer initiatives now  
6 encourage and support practices to provide patient-centered care.<sup>7,8</sup> The national *Meaningful Use*  
7 *Roadmap* defines patient and family engagement from a patient perspective as “actions we must take  
8 over time to obtain the greatest benefit from the health care services available to us”, further stating  
9 that engagement is both desirable and necessary for health information systems.<sup>5,9,10</sup>

10  
11 Personal health records (PHRs) are an important resource to help practices provide patient-centered  
12 care. Currently, the most common functions performed by PHRs include record keeping, secure  
13 messaging, appointment scheduling, and bill payment.<sup>11</sup> Yet, other PHR features could help facilitate  
14 patient engagement in their medical care, including use of plain English depictions of clinical data,  
15 motivational messages to seek needed care, educational resources, decision aids, and resources and  
16 tools to support and guide care.<sup>12,13</sup>

17  
18 While electronic PHRs have been available for more than a decade and have wide adoption in some  
19 large healthcare organizations,<sup>14,15</sup> they are used by only a fraction of Americans, and practices struggle  
20 to promote patient adoption.<sup>11-13, 16-23</sup> One possible reason for poor PHR uptake is that many systems  
21 lack integration into the care delivery system, including clinicians’ EMRs.<sup>13,17,21</sup> Tang and Lee suggest that  
22 integrated PHRs could provide patients better access to laboratory and other data, as well as  
23 communication with their clinician\*. This, they posit, will facilitate “the type of physician-patient  
24 relationship that will improve health.”<sup>19</sup>

25  
26 To date PHR adoption has typically been approached from clinician<sup>23,24</sup> or technology-driven<sup>24,25</sup>  
27 perspectives, operating under the assumption that increasing the number of clinicians using an EMR will  
28 increase the number of patients who use a PHR.<sup>23</sup> National survey data suggest and others have

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\* (Herein ‘clinician’ means physician, nurse practitioner, or physician assistant.)

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3 29 advocated that patient PHR adoption would better increased by designing and promoting more patient-  
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5 30 centered PHRs that consider patients' individual and cultural issues as well as promote the patient-  
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7 31 clinician relationship.<sup>12,22</sup> Similarly, even widely cited models of technology promotion, such as the  
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9 32 Model of Information Systems Success (MISS)<sup>26</sup> and the Technology Acceptance Model,<sup>27</sup> have often  
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11 33 been applied to healthcare with little patient or clinician perspective.<sup>28,29</sup> or in purposively eschewing  
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13 34 "person to person trust" in evaluating such models.<sup>25</sup> To our knowledge, no one has evaluated these  
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15 35 models in a patient-centered PHR shown to improve patient outcomes.  
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17 37 In 2007, we created an interactive preventive health record (IPHR) that was designed with greater  
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19 38 functionality to engage and activate patients in their preventive care. Details about the design of the  
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21 39 IPHR,<sup>30</sup> findings from a randomized controlled trial demonstrating that the IPHR significantly improved  
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23 40 preventive care,<sup>31</sup> and a how-to-guide showing practices how they can use their PHRs to better promote  
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25 41 preventive care, have been previously published.<sup>32</sup> The IPHR was not meant to be a complete PHR or to  
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27 42 replace commercial systems. It did not contain common administrative functions, such as secure  
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29 43 messaging, appointment scheduling, or bill paying. Rather, the IPHR was meant to be patient-centered,  
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31 44 action-oriented, prevention-focused application that functioned within existing PHRs. Briefly, the IPHR  
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33 45 combined a patient's clinical information from his/her clinician's EMR (e.g. history, dates, results) with  
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35 46 patient reported information (e.g. family history, health behaviors). The IPHR robustly applied this  
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37 47 information to national guidelines from the U.S. Preventive Services Task Force and six other guidelines  
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39 48 to provide a very personalized overview of recommended preventive services.<sup>33-40</sup> All recommendations  
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41 49 include personalized explanations of the information in plain language, tailored motivational messages,  
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43 50 links to additional educational resources and decision aids, tools to promote action, and periodic  
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45 51 reminders. The information is shared with both the patient through the IPHR portal and their clinician  
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47 52 via their EHR.  
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46 54 While multiple studies have evaluated why patients use PHRs with more basic functionality,<sup>10,16</sup> less is  
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48 55 known about their interests in and engagement with PHRs with more advanced patient-centered  
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50 56 functionality as provided by the IPHR. As part of our ongoing trials, we used qualitative methods to  
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52 57 capture perspectives from both "users" and patients who were invited to use the IPHR but did not use  
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54 58 the system ("non-users"), with a lens towards informing the knowledge gaps and varying viewpoints  
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3 59 about PHR adoption noted above. As framed by Kuzel, this inquiry was “driven not by a need to  
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5 60 generalize or predict, but rather by a need to create and test... interpretations.”<sup>41</sup>  
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## 8 62 **METHODS**

### 9 10 11 63 **Design**

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14 64 We employed descriptive and interpretive analysis of focus group transcripts and field notes, with data  
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16 65 reduction via coding and editing for development of major themes and sub-themes. We then used a  
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18 66 combination of grounded theory and editing analysis<sup>42</sup> with initial codes derived from key emergent  
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20 67 themes from our interpretive analysis. A trained moderator led the focus groups, using broad-based  
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22 68 questions to explore patients’ perspectives about the IPHR and PHRs in general. A focus group guide was  
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24 69 used to ensure consistency of procedures, questions, and discussion topics. The guide, developed from  
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26 70 ‘discussions with experts familiar with the topic,<sup>42</sup> and focus group process were based on the methods  
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28 71 described by Crabtree and Miller<sup>42</sup> and by McNamara.<sup>43</sup> At the beginning of each patient focus group,  
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30 72 participants completed a brief printed questionnaire eliciting demographic characteristics and  
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32 73 information about interactions with their clinician. The study was approved by the Virginia  
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34 74 Commonwealth University Institutional Review Board.

### 35 36 37 75 **Sample**

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39 76 All participants were patients from one of eight family medicine practices that were located in northern  
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41 77 Virginia and participated in the Virginia Ambulatory Care Outcomes Research Network (ACORN). In  
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43 78 order to address sampling adequacy, a minimum total of 12 participants in both user and non-user  
44  
45 79 groups was targeted.<sup>44</sup> During the first four months the IPHR was available to the practices, 229 of the  
46  
47 80 2,250 patients randomly selected and mailed an invitation used the tool (completed registration and  
48  
49 81 entered data on the website). All of these patients were invited via email to participate in focus groups.  
50  
51 82 Of the 44 who expressed interest, 30 selected to provide a range of ages, genders, and practice locations  
52  
53 83 were asked to participate in three user focus groups. (The first user group was rescheduled due to  
54  
55 84 inclement weather and 3 of 10 participants ultimately attended. The next two groups had 5 and 6 of 10  
56  
57 85 invited participants attend, respectively.) Of the 2021 non-users, a random sample of 150 patients,  
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59 86 stratified by age, gender, and practice location, were mailed focus group invitations. From the 32  
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87 87 patients who responded to the letter, 20 selected to provide a range of ages, genders, and practice

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3 88 locations were asked to participate in two non-user focus groups; 14 attended. Each participant received  
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5 89 a \$50 gift card incentive.  
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## 8 90 **Procedures**

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10 91 Focus groups, each approximately 1.5-2 hours in duration, were held at a location near the participating  
11 92 practices. Group discussion was guided by semi-structured questions with probes and prompts to  
12 93 provide follow-up lines of inquiry, clarify topics, and stimulate further discussion. Both user and non-  
13 94 user groups were shown screen-shots demonstrating how the IPHR worked at appropriate times during  
14 95 the groups so all participants could comment on IPHR attributes and uses. Sessions were audio-  
15 96 recorded, and the transcriptions of the recordings were then corrected as necessary via comparison to  
16 97 the original recordings. Field notes were also taken to capture aspects of the group interaction that  
17 98 would not be identified on recordings. This included such observations as participant body language and  
18 99 tone, as well as researcher thoughts and reactions.  
19

20  
21 100 Transcripts and field notes underwent descriptive analysis with a provisional categorical structure based  
22 101 on focus group question guides. Data were combined with field notes to explore descriptive similarities  
23 102 and differences within and between the groups. Coding and editing of transcripts and field notes were  
24 103 used to derive higher level themes and explanations, and tentative explanations of findings were based  
25 104 on both our data and relevant literature. A four-member team (JWK, AHK, DRL, AJK) performed each  
26 105 step of the analysis independently. Differences in coding, development of themes, and derivation of  
27 106 tentative explanations were discussed by the team until consensus was reached. Model development  
28 107 ensued (AHK, JWK), building on key emergent themes from the interpretive analysis. Initially  
29 108 concentrated on contextual thematic interrelationships (e.g. linked Venn diagrams), resultant thematic  
30 109 modifications resulted in iterations of models which were “based on both process and causal  
31 110 considerations”.<sup>26</sup>  
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## 47 112 **RESULTS**

### 48 113 **Study Population**

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50 114 The patients who used the IPHR during the study period were primarily men (56%), white (85%), and  
51 115 more than 50 years old (68%). Of the 50 patients who agreed to participate in focus groups (30 users  
52 116 and 20 non-users), 28 patients attended the sessions, including 14 PHR users and 14 non-users (Table 1).  
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3 117 Focus group participants were predominantly women (64%), white (93%), over 50 years old (86%), and  
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5 118 all reported having attended at least some college. Nearly all<sup>o</sup> participants rated their health as good to  
6  
7 119 excellent, stated they had been with their clinician at least 3 years, and rated their clinician highly.  
8

9 120 **TABLE 1: FOCUS GROUP PARTICIPANTS**

PARTICIPANT CHARACTERISTICS	3 PHR User Groups (n=14)	2 PHR Non-User Groups (n=14)	P value
Gender	5 male 9 female	5 male 9 female	ns
Mean age (years)	66 (range 50-77)	59 (range 40-75)	0.07
White (%)	100	86	ns
Participant-reported Education, Number of participants	Some college/associate degree-5 College graduate-2 More than college degree-7	Some college/associate degree-2 College Graduate-3 More than college degree-9	ns
Participant-reported number of years with current clinician	2 participants <1 yr 4 participants 3-5yrs 8 participants >5yrs	0 participants <1 yr 8 participants 3-5yrs 6 participants >5yrs	ns
Mean participant-reported visits per year	3.6	3.4	ns
Mean participant quality rating of current clinician	9.23/10 0=worst doctor possible 10=best doctor possible	9.00/10 0=worst doctor possible 10=best doctor possible	ns
Patient-reported health rating, number of participants	Excellent-4 Very Good-6 Good-3 Fair-0 Poor-1	Excellent-3 Very Good-7 Good-3 Fair-1 Poor-0	ns

121  
122 All but one focus group participant acknowledged using the Internet daily, and some described  
123 "constant" Internet use for job and personal purposes. Although nearly all stated that they did not use  
124 the Internet as often for health-related matters as for other needs, they did report using the Internet to  
125 garner health information, primarily for themselves and their family.  
126

### 127 Themes

128 Across all five focus groups,\* three major themes emerged about how participants wanted to be  
129 engaged by PHRs: they wanted (1) novel content that was relevant to their immediate and ongoing care,  
130

<sup>o</sup> The following is used for the verbal annotation of participant percentages: All=100%, nearly all=80-99%, most=60-80%, many=40-60%, a majority= >50%, some=25-40%, few=<25%.

130 (2) a PHR they could trust for accuracy, security, and privacy, and (3) a highly functional PHR, facilitating  
 131 care and communication with their clinician, and providing access to comprehensive personalized  
 132 information shared with the clinician. Although practical usefulness was said to be essential, a major  
 133 reason why participants said they trusted, used, and sought relevance in the IPHR was that it was  
 134 offered to them by their personal clinician.

135 Relevance

136 A few participants noted that upcoming appointments with their clinician made IPHR use more  
 137 compelling, contributed to their registering, and led them to notice the content pertinent to that visit.  
 138 Most, however, reported that the invitation for the IPHR was received at a time unassociated with an  
 139 office visit or any specific healthcare needs. Indeed many participants reported that as a result they did  
 140 not feel a pressing need to immediately register for and use the IPHR (Table 2). A few non-users  
 141 declared that they just had not gotten around to registering. Many participants in both the non-user and  
 142 user groups voiced the opinion that they could access similar information on the internet, and that they  
 143 did not recognize that IPHR content was personalized to their needs. Some users commented that they  
 144 had already fully addressed their preventive healthcare needs with their clinician.

145 **TABLE 2: REPRESENTATIVE PARTICIPANT COMMENTS ON RELEVANCE OF THE IPHR**  
 146 **(WHY THEY DIDN'T FEEL A NEED TO REGISTER)**

Sub-themes	Representative Quotations
<p><b>Lacking Urgency</b></p>	<p><i>It was procrastination. It wasn't that I wasn't going to do it.</i></p> <p><i>I said, "Boy, this would be -- this is interesting, I should try it." Stuck it in a pile and forgot about it.</i></p>
<p><b>Lacking Novelty</b></p>	<p><i>Particularly when it concerns a medical something, I usually look it up, you know, any of the various websites that you can go to.</i></p> <p><i>I am the health related expert in the house. And I have to know what everything is. So yes I go to the Cleveland Clinic and the Mayo Clinic and Johns Hopkins.</i></p>
<p><b>Redundant to current care</b></p>	<p><i>It was not, in my case not new information since my doctor and I had talked about it so much...</i></p> <p><i>She knows what I do for exercise, and she asks me questions when I go in, you know. But, if I didn't have that kind of relationship, then I think I would -- I mean, right now, I don't see, for me, that I need this.</i></p>

147  
 148 Trust

\* Unless otherwise indicated, findings described herein are from both user and non-user groups.



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3 149 Nearly all participants vigorously discussed three components of trust necessary for them to use a PHR:  
4 150 security (protecting their health information), privacy (not sharing their health information with others),  
5 151 and accuracy (ensuring that the clinical content and health recommendations proffered by the system  
6 152 were correct and appropriate for them) (Table 3). Most participants reported trusting the IPHR because  
7 153 it was recommended and used by their clinician's practice. A few participants in the non-user groups  
8 154 indicated discomfort with having any of their personal health information on the Internet. However,  
9 155 most participants in all groups expressed the view that clinician endorsement of the IPHR was an  
10 156 indication that their personal health data were secure. Most participants also expressed strong  
11 157 opposition to PHRs developed by commercial entities and to sharing their health information with their  
12 158 insurance company due to the risk of future denial of coverage.

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21 **TABLE 3: REPRESENTATIVE PARTICIPANT COMMENTS ON TRUST OF AN IPHR**

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Sub-themes	Representative Quotations
<b>Security</b>	<p><i>It (IPHR) came through our own doctor; I didn't have any problem with it. If it had just been out of the blue I might have.</i></p> <p><i>At first I was curious as to what is this (IPHR), but then I guess I trusted it because it was [clinician's office] which I trusted.</i></p> <p><i>I've come to trust him to keep my information in his laptop...you have to trust the doctor.</i></p>
<b>Privacy</b>	<p><i>I think personally I would only trust what I was affiliated with. What should be familiar with me. I mean, Google certainly doesn't know me...</i></p> <p><i>Another Participant: Oh, Yes they do.</i></p> <p><i>The information you have on the system, passing data maybe to insurance companies and then turn around later and say no we're not going to insure you...</i></p> <p><i>I got scared...because I got the impression that I was going to discuss things of my personal nature with my doctor on the website and I didn't like that, and so I discarded it because I'd rather talk about my health face to face with my doctor.</i></p>
<b>Accuracy</b>	<p><i>There's so many sites out there that you wonder how valid. I felt good that [the clinician's office was] endorsing or leading me to a particular site that they must feel confident in the information and the content..</i></p> <p><i>One reason I don't do (Internet health information) a whole lot is because you get conflicting views and I don't know who to believe and who not to believe. So I...ask my doctor.</i></p> <p><i>I was getting emotionally distraught over those things that I was reading (on the Internet) and then, come to find out, I didn't even have to be concerned about it. But... I got to leave those kinds of things to the doctor because that's what he's trained for.</i></p>

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3 161 Nearly all participants reported having had difficulties distinguishing between accurate and inaccurate  
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5 162 health information on the internet (Table 3). A few participants gave examples of erroneous health  
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7 163 information that caused anxiety or led to poor personal health choices. Most participants stated that  
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9 164 they asked their clinician to verify information they found on the web. Nearly all participants reported  
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11 165 that they would trust the accuracy of the content and recommendations made by the IPHR because it  
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13 166 was endorsed and used by their clinician, and identified their clinician as their primary authority on the  
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15 167 accuracy and application of healthcare information.

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17 169 **Functionality**

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19 170 Functions that the participants identified as important involved two subthemes: enhanced patient-  
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21 171 clinician communication and patient-centered utility (Table 4).

22 172 **TABLE 4: REPRESENTATIVE PARTICIPANT COMMENTS ON FUCTIONALITY**

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24 173 **Enhanced Patient-Clinician Communication From Using an IPHR**

<b>Sub-themes</b>	<b>Representative Quotations</b>
<b>Interactive</b>	<p data-bbox="415 942 1505 1003"><i>Direct communications between the doctor and the patient that you can access via the Internet just like medical records, you should be able to access that.</i></p> <p data-bbox="415 1041 1505 1131"><i>(As a result of using the IPHR) The nurse called me up and said we haven't seen you in so long, you know, and she starts going through this (prevention) stuff...I said well I've been going to my heart doctor...and she said, you should come back you know.</i></p> <p data-bbox="415 1169 1505 1226"><i>Not dictating, but cooperating, supportive, and provide me the source of the information, let me go there and look at the thing (IPHR) before, you know we make a decision.</i></p>
<b>Focus Discussion</b>	<p data-bbox="415 1232 1505 1293"><i>I have 15 minutes to talk to him. And this gives me the ability to list everything that's wrong with me...This is what you need to talk to the doctor about in your physical.</i></p> <p data-bbox="415 1331 1505 1362"><i>I would think anything that would focus my discussion would hopefully focus his as well.</i></p> <p data-bbox="415 1400 1505 1486"><i>When I go in to the primary care physician, I don't want to just listen to him. I do want to hear what he has to say, but I want to be able to ask what I think are intelligent questions. I'll go do research on that. And then I feel like I can have a better, more productive discussion with the physician.</i></p>
<b>Broaden Discussion</b>	<p data-bbox="415 1493 1505 1554"><i>What if your doctor disagrees somewhat with the United States Preventive Services Task Force? (as recommended by the IPHR)...It becomes a discussion point.</i></p> <p data-bbox="415 1591 1505 1650"><i>I think it (conversation with clinician) might be a little bit broader (from using the IPHR). You go and say, "Here's what I'm seeing or here's what going on with my family."</i></p>
<b>Efficiency Pros and Cons</b>	<p data-bbox="415 1656 1505 1747"><i>There might be an opportunity to take some of the minor issues off the table(after using the PHR), so when you go to the doctor it would shorten the amount of things that you would like to talk to him about because you've answered some of that already.</i></p> <p data-bbox="415 1785 1505 1843"><i>That email to the doctor, I think, could create a problem. It's very time consuming. You spend all day on the internet answering mail, the doctor will never get paid...SECOND PARTICIPANT: You'd never</i></p>

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	<p><i>get your tetanus shot. FIRST PARTICIPANT: ..You'd never get anything else.</i></p> <p><i>So what is this doing for the physician? I mean, we're keeping healthier, but it means a lot more work for him in a way.</i></p>
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175 **PATIENT-CENTERED IPHR UTILITY**

Subthemes	Representative Quotations
<b>Expand Access To Personal Clinical Information</b>	<p><i>It's not just security, but also access. My access to my personal information. I want to have that, and electronic medical records, Internet-based systems can provide me with that.. I trust my physician here because I've developed a relationship with him, but anybody else, I would want to have absolute access to my information.</i></p>
<b>Align Patient-Clinician Information</b>	<p><i>Knowing that all the information is correct to the best of your knowledge, and in one place where it can be accessed by the doctor and by you, it makes me feel very secure.</i></p> <p><i>This information is shared with your physician -- as you update things your provider is going to be made aware of this you know-We need to be on the same page.</i></p>
<b>Provide Personalized Information</b>	<p><i>I think with that information available (in the IPHR), I think it will actually help him a great deal to change my lifestyle. I think that's what all this preventive medicine is all about is how you change your lifestyle.</i></p> <p><i>It also gave me some thoughts about the preventive things I should need to know or that I should be thinking about. So it made me think about, gosh I'll have to ask her. For example, something about an aspirin a day, is it something that's appropriate for me?</i></p> <p><i>There was lots of information there but it was not, in my case not new information since my doctor and I had talked about it so much...</i></p>
<b>Comprehensively Address Patient Needs</b>	<p><i>I'm surprised that this isn't something for medications. One doctor says you got to take calcium and another one says you got to take multivitamin and another one says you got to take an aspirin, and people may be taking allergy medicines that they get over the counter...</i></p> <p><i>Some general thing about menopause or some of the women's issues would have been helpful. Age specific things might be helpful, children, you know, developmental or something like that just as a good reference for parents.</i></p> <p><i>Say you had in your history that you had a history of stroke or cancer, would it also give patient education stuff, like here's a link to the American Cancer Society? Or here's a thing for support group information? I'm a surviving cancer patient...</i></p> <p><i>Here's what we want: we're living here but we want to occasionally go somewhere else. Anyone in the country should be able to open and keep track of it accurately...realistically and securely.</i></p>

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177 Many participants stated that they wanted PHRs to enhance communication with their clinician both

178 electronically and in person. Several liked being contacted about preventive care after they used the

179 IPHR. Participants described how the IPHR could focus discussions during office visits, making their visits

180 more productive. Conversely, several also mentioned that the IPHR could appropriately broaden

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3 181 discussions for some topics, such as identifying preventive screening choices that they or their clinician  
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5 182 viewed as warranting dialogue, or starting conversations about lifestyle changes. However, some  
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7 183 participants expressed concern that more time would be required for busy clinicians and patients to use  
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9 184 the IPHR or similar tools. Participants worried about increased fees for either patients or practices to  
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11 185 use similar PHRs in the future.  
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14 187 Many participants said that a critically important feature of the IPHR was the ability for patients to  
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16 188 access their personal health information. They explained that this access was important so that they  
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18 189 could be “on the same page” as their clinician. They also commented that shared access to information  
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20 190 would contribute to improved accuracy of records and more productive interactions.  
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23 192 Many participants identified the personalized advice offered by the IPHR, its prompts to discuss its  
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25 193 recommendations with the clinician (e.g. whether to take aspirin), and its ability to prioritize  
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27 194 recommendations and thereby highlight critical or information to act on, as very important. Also of  
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29 195 interest to many (but not available in this IPHR) were adding features for comprehensive medication  
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31 196 reconciliation, in-depth information for the whole family for prevention as well as for specific diseases,  
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33 197 and links to local resources that provide support and information for lifestyle changes, preventive care  
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35 198 needs, and chronic diseases. Moreover, several participants stated that PHRs, such as the IPHR, should  
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37 199 be shared seamlessly across all healthcare providers and settings.  
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## 201 **DISCUSSION**

202 Given the national investment of \$27 billion to promote the adoption, implementation, and meaningful  
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204 use of health information technology,<sup>45-47</sup> it is essential to understand how to better engage patients in  
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206 using technology if it is to achieve its full potential. Many Americans have not embraced the use of  
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208 PHRs,<sup>48</sup> but our findings underscore the general interest of patients in using such tools if certain  
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210 attributes are offered.  
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208 When PHR use is integrated into care so that it improves the efficiency and quality of patients' care (e.g.  
209 timely use related to clinician visits), its relevance becomes more transparent. The PHR becomes a  
210 welcome extension of interactions with the clinician and the related healthcare team.

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3 212 National surveys have clearly documented a level of public concern about personal health information  
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5 213 existing on the web and about employers, insurers, or even commercial entities being able to access or  
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7 214 misuse such information.<sup>48</sup> Although one could argue that such fears may ease over time as more  
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9 215 private information migrates into the cyber-environment, this reticence may have already contributed  
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11 216 to the failure of some commercial PHRs to gain wide acceptance by the general public.<sup>49</sup>  
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14 218 The addition of certain PHR features that seem popular with patients, such as displaying test results or  
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16 219 supporting asynchronous communication via secure messaging, has generated only modest increases in  
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18 220 actual PHR utilization.<sup>17,21</sup> One explanation is that patients who are accustomed to more powerful  
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20 221 information tools in other aspects of life may expect greater functionality than merely seeing their  
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22 222 information.<sup>50,51</sup> Indeed, participants in this study wanted much more – including links to personalized  
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24 223 recommendations, and resources and tools to help make information actionable to improve health, as  
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26 224 provided by this IPHR.  
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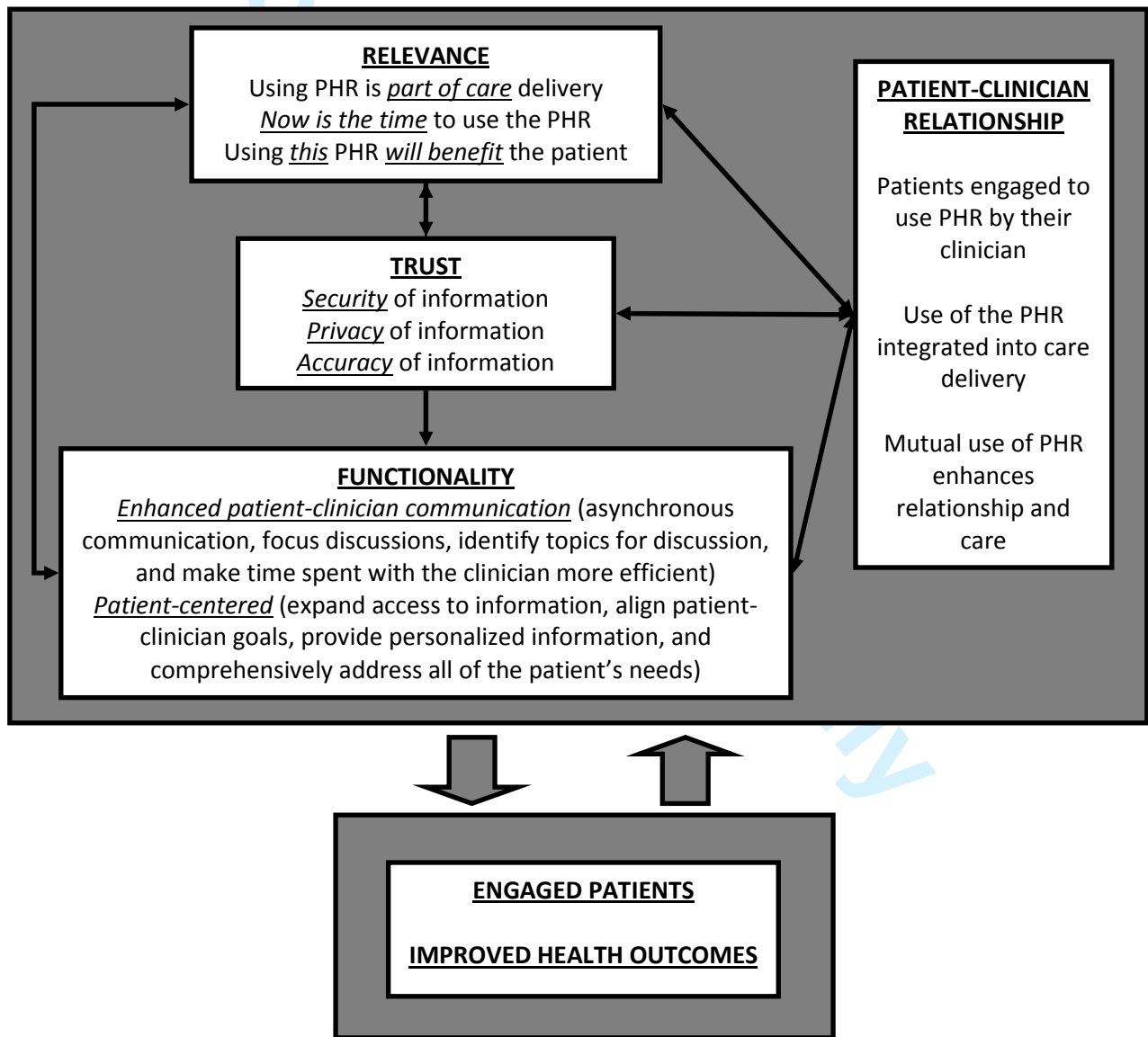
28 225  
29 226 Across both users and non-users, nearly all participants reported being more likely to perceive a PHR as  
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31 227 relevant, trustworthy, and functional if it was offered to them by their personal clinician. We conclude  
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33 228 that a key element of engaging patients to use a PHR extends beyond the tool's design and includes how  
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35 229 it is presented to patients and integrated into their care experience (Figure 1).  
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37 230  
38 231 Although some PHR evaluations seem to show enhanced patient uptake when patients had a *lack* of  
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40 232 trust in their clinician,<sup>52,53</sup> other information seems to indicate that encouragement of PHR uptake by a  
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42 233 patient's clinician has a positive influence on patient use and that patient and clinician PHR use  
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44 234 enhances their relationship.<sup>54</sup> Our findings support Nazi's findings<sup>54</sup> and extend them to show, as in  
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46 235 Figure 1, that the patient-clinician relationship explicitly supports all critical components of patient  
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48 236 engagement in IPHRs.  
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50 237  
51 238 Other models, among them DeLone and McLean's MISS<sup>26</sup> (Figure 2), have been applied to clinical  
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53 239 information systems, including PHRs. Booth states that MISS lacks sensitivities to medical and  
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55 240 relationship-laden milieus of technology (previously described by Sandelowski),<sup>29,55</sup> whereas Figure 1  
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57 241 and our results demonstrate both clinical as well as personal contexts for patients and clinicians.  
58

242 Further, although Archer and colleagues used MISS to categorize aspects of their scoping review of  
 243 PHRs,<sup>23</sup> they only examined selected parts of the model.  
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 245 Differences between Figure 1 and MISS aside, we wish to point out several similarities as well, including  
 246 the previously mentioned use of causal and process elements, and the feedback loop from 'Net Benefits'  
 247 to both 'Use' and 'User Satisfaction'.  
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249 **FIGURE 1: PERSONAL HEALTH RECORD (PHR) FEATURES NEEDED TO ENGAGE**  
 250 **PATIENTS**



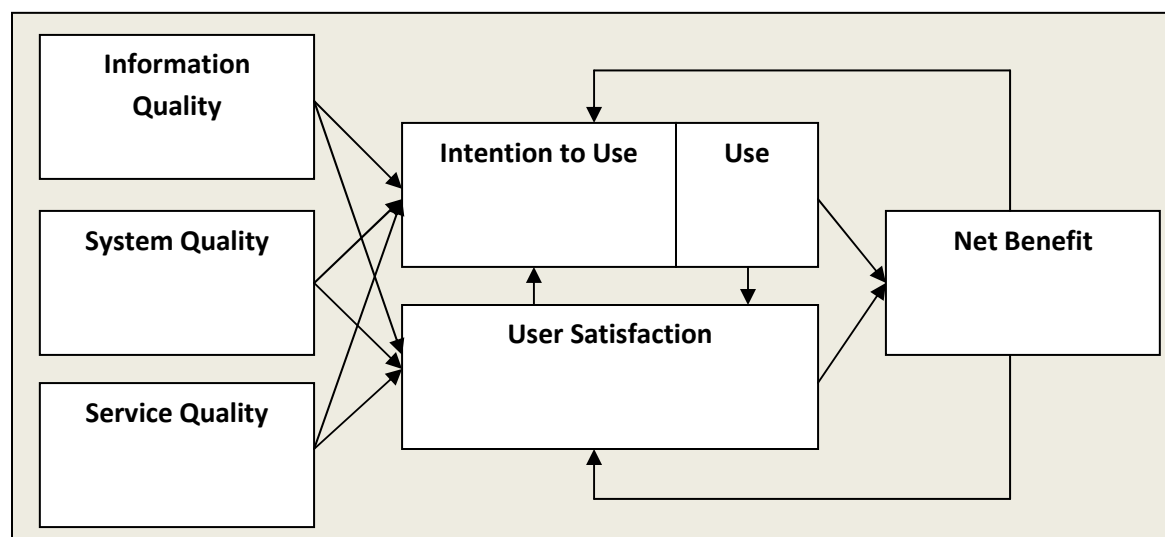
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For peer review only

FIGURE 2: DELONE AND MCLEAN'S MODEL OF INFORMATION SYSTEM SUCCESS<sup>26</sup>



Our study has several important limitations. First, while we attempted to assemble focus groups with a representative range of ages and genders, we may have introduced a selection bias in our sample. Participants were older, more likely to be female, mostly white, and more educated than the overall user and non-user populations.<sup>56,57</sup> However, women are more likely than men to use PHRs<sup>58</sup> and to make healthcare decisions for families.<sup>58-60</sup> Other studies indicate that members of different socioeconomic and racial-ethnic groups may have different PHR preferences (e.g. a PHR not based on the Internet) and may require assistance in using a PHR.<sup>61-63</sup> Second, the sample was drawn entirely from eight practices in northern Virginia. Other locales may have different PHR needs requiring different strategies to engage patients in PHR use. Third, all participants were recruited from family medicine offices that already offered a PHR to patients, and most participants had established relationships with their clinician. Accordingly, participants may have emphasized the value of the patient-clinician relationship in PHR use more than populations from other settings. Lastly, whereas the number of participants (28) will not quantitatively generalize to all IPHR users, the nature of qualitative research is often that of looking at specific cases, many times in order to inform the gaps generated by other data, rather than to compete with or duplicate that information.<sup>42</sup>

## CONCLUSION:



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3 282 To engage primary care patients with an IPHR, this study identifies the importance of relevance, trust  
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5 283 and functionality, all integrated with office processes and the patient-clinician relationship. In addition  
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7 284 to suggesting possible modifications to established models of technological acceptance, these findings  
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9 285 have relevance for healthcare providers, the information technology industry, and policymakers who  
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11 286 share an interest in encouraging patients to use personal health records or other information tools.  
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13 287 Studies like ours should be expanded and replicated in other settings to more fully understand how to  
14  
15 288 make such technology more useful to patients.  
16

289

17 290 **Acknowledgments:** The authors thank the participating study practices: Fairfax Family Practice,  
18 291 Gainesville Family Medicine, Herndon Family Medicine, Lorton Station Family Medicine, Prince William  
19 292 Family Medicine, South Riding Family Medicine, Town Center Family Medicine, and Vienna Family  
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21 294 RN, and in designing the project from Stephen F. Rothemich MD, MS. as well as Kristin Schmidt in  
22 295 project assistance.

23 296 **Conflicts of interest:** Virginia Commonwealth University holds the intellectual property rights to the  
24 297 interactive preventive care record evaluated in this study. Although the university and developers are  
25 298 entitled to the system's revenue, MyPreventiveCare is a noncommercial product, and no revenues have  
26 299 been generated other than grant funding.  
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**Article Focus:**

What are necessary elements for patient engagement in advanced interactive personal health records (IPHRs)?

**Key Messages:**

Engagement in an IPHR is related to integration into current care and the patient-clinician relationship.

Models of technology success and acceptance may warrant modification when applied to primary care use of IPHRs.

**Strengths/Weaknesses:**

An advanced IPHR shown to increase use of preventive services was employed for the study.

The sample was drawn from northern Virginia, USA. Other locales may have different IPHR needs and require different strategies to engage patients in IPHR use.

Most participants had ongoing established relationships with their clinician.

**ABSTRACT**

**Objective:** To assess factors related to use and non-use of a sophisticated interactive preventive health record (IPHR) designed to promote uptake of 18 recommended clinical preventive services; Little is known about how patients want to use or be engaged by such advanced information tools.

**Design:** Descriptive and interpretive qualitative analysis of transcripts and field notes from focus groups of IPHR users and of patients who were invited but did not use the IPHR (non-users). **Grounded theory techniques were then applied via an editing approach for key emergent themes.**

**Setting:** Primary care patients in eight practices of the Virginia Ambulatory Care Outcomes Research Network (ACORN).

**Participants:** Three focus groups involved a total of 14 IPHR users and 2 groups of non-users totaled 14 participants.

**Outcomes/Results:** For themes identified (relevance, trust, and functionality) participants indicated that endorsement and use of the IPHR by their personal clinician was vital. In particular, participants' comments linked IPHR use to: 1) integrating the IPHR into current care, 2) promoting effective patient-clinician encounters and communication, and 3) their confidence in the accuracy, security and privacy of the information.

**Conclusion:** In addition to patients' stated desires for advanced functionality and information accuracy and privacy, successful adoption of IPHRs by primary care patients depends on such technology's relevance, and on its promotion via integration with primary care practices' processes and the patient-

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3 clinician relationship. Accordingly, models of technological success and adoption, when applied to  
4 primary care, may need to include the patient-clinician relationship and practice workflow. These  
5 findings are important for health care providers, the information technology industry, and policymakers  
6 who share an interest in encouraging patients to use PHRs.  
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9 Trial Registration Clinicaltrials.gov identifier: NCT00589173

10  
11 Funding support: This work was supported by the Agency for Healthcare Research and Quality (R18  
12 HS17046-01).  
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14  
15 **Key words:** health promotion; information management; informatics; patient-centered care; physician-  
16 patient relations  
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19 This study was approved by the Institutional Review Board of Virginia Commonwealth University,  
20 Richmond, Virginia, USA.  
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## BACKGROUND

1 The concept of patient-centered care is not new to medicine.<sup>1,2</sup> Decades ago, research demonstrated  
2 that engaging patients in their care improves patient satisfaction, quality of care, and clinical  
3 outcomes.<sup>3,4</sup> Recently, national movements aimed at transforming healthcare have formally defined,  
4 incentivized, and institutionalized patient-centered care. The goals of the Patient-Centered Medical  
5 Home espouse these principles.<sup>5,6</sup> State and national legislation combined with payer initiatives now  
6 encourage and support practices to provide patient-centered care.<sup>7,8</sup> The national *Meaningful Use*  
7 *Roadmap* defines patient and family engagement from a patient perspective as “actions we must take  
8 over time to obtain the greatest benefit from the health care services available to us”, further stating  
9 that engagement is both desirable and necessary for health information systems.<sup>5,9,10</sup>

10  
11 Personal health records (PHRs) are an important resource to help practices provide patient-centered  
12 care. Currently, the most common functions performed by PHRs include record keeping, secure  
13 messaging, appointment scheduling, and bill payment.<sup>11</sup> Yet, other PHR features could help facilitate  
14 patient engagement in their medical care, including use of plain English depictions of clinical data,  
15 motivational messages to seek needed care, educational resources, decision aids, and resources and  
16 tools to support and guide care.<sup>12,13</sup>

17  
18 While electronic PHRs have been available for more than a decade and have wide adoption in some  
19 large healthcare organizations,<sup>14,15</sup> they are used by only a fraction of Americans, and practices struggle  
20 to promote patient adoption.<sup>11-13, 16-23</sup> One possible reason for poor PHR uptake is that many systems  
21 lack integration into the care delivery system, including clinicians’ EMRs.<sup>13,17,21</sup> Tang and Lee suggest that  
22 integrated PHRs could provide patients better access to laboratory and other data, as well as  
23 communication with their clinician\*. This, they posit, will facilitate “the type of physician-patient  
24 relationship that will improve health.”<sup>19</sup>

25  
26 To date PHR adoption has typically been approached from clinician<sup>23,24</sup> or technology-driven<sup>24,25</sup>  
27 perspectives, operating under the assumption that increasing the number of clinicians using an EMR will  
28 increase the number of patients who use a PHR.<sup>23</sup> National survey data suggest and others have

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\* (Herein ‘clinician’ means physician, nurse practitioner, or physician assistant.)



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3 29 advocated that patient PHR adoption would better increased by designing and promoting more patient-  
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5 30 centered PHRs that consider patients' individual and cultural issues as well as promote the patient-  
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7 31 clinician relationship.<sup>12,22</sup> Similarly, even widely cited models of technology promotion, such as the  
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9 32 Model of Information Systems Success (MISS)<sup>26</sup> and the Technology Acceptance Model,<sup>27</sup> have often  
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11 33 been applied to healthcare with little patient or clinician perspective.<sup>28,29</sup> or in purposively eschewing  
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13 34 "person to person trust" in evaluating such models.<sup>25</sup> To our knowledge, no one has evaluated these  
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15 35 models in a patient-centered PHR shown to improve patient outcomes.

16  
17 37 In 2007, we created an interactive preventive health record (IPHR) that was designed with greater  
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19 38 functionality to engage and activate patients in their preventive care. Details about the design of the  
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21 39 IPHR,<sup>30</sup> findings from a randomized controlled trial demonstrating that the IPHR significantly improved  
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23 40 preventive care,<sup>31</sup> and a how-to-guide showing practices how they can use their PHRs to better promote  
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25 41 preventive care, have been previously published.<sup>32</sup> The IPHR was not meant to be a complete PHR or to  
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27 42 replace commercial systems. It did not contain common administrative functions, such as secure  
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29 43 messaging, appointment scheduling, or bill paying. Rather, the IPHR was meant to be patient-centered,  
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31 44 action-oriented, prevention-focused application that functioned within existing PHRs. Briefly, the IPHR  
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33 45 combined a patient's clinical information from his/her clinician's EMR (e.g. history, dates, results) with  
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35 46 patient reported information (e.g. family history, health behaviors). The IPHR robustly applied this  
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37 47 information to national guidelines from the U.S. Preventive Services Task Force and six other guidelines  
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39 48 to provide a very personalized overview of recommended preventive services.<sup>33-40</sup> All recommendations  
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41 49 include personalized explanations of the information in plain language, tailored motivational messages,  
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43 50 links to additional educational resources and decision aids, tools to promote action, and periodic  
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45 51 reminders. The information is shared with both the patient through the IPHR portal and their clinician  
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47 52 via their EHR.

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49 54 While multiple studies have evaluated why patients use PHRs with more basic functionality,<sup>10,16</sup> less is  
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51 55 known about their interests in and engagement with PHRs with more advanced patient-centered  
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53 56 functionality as provided by the IPHR. As part of our ongoing trials, we used qualitative methods to  
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55 57 capture perspectives from both "users" and patients who were invited to use the IPHR but did not use  
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57 58 the system ("non-users"), with a lens towards informing the knowledge gaps and varying viewpoints

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3 59 about PHR adoption noted above. As framed by Kuzel, this inquiry was “driven not by a need to  
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5 60 generalize or predict, but rather by a need to create and test... interpretations.”<sup>41</sup>  
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## 8 62 **METHODS**

### 9 10 11 63 **Design**

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14 64 We employed descriptive and interpretive analysis of focus group transcripts and field notes, with data  
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16 65 reduction via coding and editing for development of major themes and sub-themes. We then used a  
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18 66 combination of grounded theory and editing analysis<sup>42</sup> with initial codes derived from key emergent  
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20 67 themes from our interpretive analysis. A trained moderator led the focus groups, using broad-based  
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22 68 questions to explore patients’ perspectives about the IPHR and PHRs in general. A focus group guide was  
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24 69 used to ensure consistency of procedures, questions, and discussion topics. The guide, developed from  
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26 70 ‘discussions with experts familiar with the topic,’<sup>42</sup> and focus group process were based on the methods  
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28 71 described by Crabtree and Miller<sup>42</sup> and by McNamara.<sup>43</sup> At the beginning of each patient focus group,  
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30 72 participants completed a brief printed questionnaire eliciting demographic characteristics and  
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32 73 information about interactions with their clinician. The study was approved by the Virginia  
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34 74 Commonwealth University Institutional Review Board.

### 35 36 37 75 **Sample**

38  
39 76 All participants were patients from one of eight family medicine practices that were located in northern  
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41 77 Virginia and participated in the Virginia Ambulatory Care Outcomes Research Network (ACORN). In  
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43 78 order to address sampling adequacy, a minimum total of 12 participants in both user and non-user  
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45 79 groups was targeted.<sup>44</sup> During the first four months the IPHR was available to the practices, 229 of the  
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47 80 2,250 patients randomly selected and mailed an invitation used the tool (completed registration and  
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49 81 entered data on the website). All of these patients were invited via email to participate in focus groups.  
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51 82 Of the 44 who expressed interest, 30 selected to provide a range of ages, genders, and practice locations  
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53 83 were asked to participate in three user focus groups. (The first user group was rescheduled due to  
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55 84 inclement weather and 3 of 10 participants ultimately attended. The next two groups had 5 and 6 of 10  
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57 85 invited participants attend, respectively.) Of the 2021 non-users, a random sample of 150 patients,  
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59 86 stratified by age, gender, and practice location, were mailed focus group invitations. From the 32  
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61 87 patients who responded to the letter, 20 selected to provide a range of ages, genders, and practice

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3 88 locations were asked to participate in two non-user focus groups; 14 attended. Each participant received  
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5 89 a \$50 gift card incentive.  
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## 7 90 **Procedures**

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10 91 Focus groups, each approximately 1.5-2 hours in duration, were held at a location near the participating  
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12 92 practices. Group discussion was guided by semi-structured questions with probes and prompts to  
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14 93 provide follow-up lines of inquiry, clarify topics, and stimulate further discussion. Both user and non-  
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16 94 user groups were shown screen-shots demonstrating how the IPHR worked at appropriate times during  
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18 95 the groups so all participants could comment on IPHR attributes and uses. Sessions were audio-  
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20 96 recorded, and the transcriptions of the recordings were then corrected as necessary via comparison to  
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22 97 the original recordings. Field notes were also taken to capture aspects of the group interaction that  
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24 98 would not be identified on recordings. This included such observations as participant body language and  
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26 99 tone, as well as researcher thoughts and reactions.

27 100 Transcripts and field notes underwent descriptive analysis with a provisional categorical structure based  
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29 101 on focus group question guides. Data were combined with field notes to explore descriptive similarities  
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31 102 and differences within and between the groups. Coding and editing of transcripts and field notes were  
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33 103 used to derive higher level themes and explanations, and tentative explanations of findings were based  
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35 104 on both our data and relevant literature. A four-member team (JWK, AHK, DRL, AJK) performed each  
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37 105 step of the analysis independently. Differences in coding, development of themes, and derivation of  
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39 106 tentative explanations were discussed by the team until consensus was reached. **Model development**  
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41 107 **ensued (AHK, JWK), building on key emergent themes from the interpretive analysis. Initially**  
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43 108 **concentrated on contextual thematic interrelationships (e.g. linked Venn diagrams), resultant thematic**  
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45 109 **modifications resulted in iterations of models which were “based on both process and causal**  
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47 110 **considerations”.**<sup>26</sup>

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## 49 112 **RESULTS**

### 50 113 **Study Population**

51 114 The patients who used the IPHR during the study period were primarily men (56%), white (85%), and  
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53 115 more than 50 years old (68%). Of the 50 patients who agreed to participate in focus groups (30 users  
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55 116 and 20 non-users), 28 patients attended the sessions, including 14 PHR users and 14 non-users (Table 1).

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3 117 Focus group participants were predominantly women (64%), white (93%), over 50 years old (86%), and  
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5 118 all reported having attended at least some college. Nearly all<sup>o</sup> participants rated their health as good to  
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7 119 excellent, stated they had been with their clinician at least 3 years, and rated their clinician highly.  
8

9 120 **TABLE 1: FOCUS GROUP PARTICIPANTS**

PARTICIPANT CHARACTERISTICS	3 PHR User Groups (n=14)	2 PHR Non-User Groups (n=14)	P value
Gender	5 male 9 female	5 male 9 female	ns
Mean age (years)	66 (range 50-77)	59 (range 40-75)	0.07
White (%)	100	86	ns
Participant-reported Education, Number of participants	Some college/associate degree-5 College graduate-2 More than college degree-7	Some college/associate degree-2 College Graduate-3 More than college degree-9	ns
Participant-reported number of years with current clinician	2 participants <1 yr 4 participants 3-5yrs 8 participants >5yrs	0 participants <1 yr 8 participants 3-5yrs 6 participants >5yrs	ns
Mean participant-reported visits per year	3.6	3.4	ns
Mean participant quality rating of current clinician	9.23/10 0=worst doctor possible 10=best doctor possible	9.00/10 0=worst doctor possible 10=best doctor possible	ns
Patient-reported health rating, number of participants	Excellent-4 Very Good-6 Good-3 Fair-0 Poor-1	Excellent-3 Very Good-7 Good-3 Fair-1 Poor-0	ns

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38 121  
39 122 All but one focus group participant acknowledged using the Internet daily, and some described  
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41 123 “constant” Internet use for job and personal purposes. Although nearly all stated that they did not use  
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43 124 the Internet as often for health-related matters as for other needs, they did report using the Internet to  
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45 125 garner health information, primarily for themselves and their family.  
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### 48 127 **Themes**

49 128 Across all five focus groups,\* three major themes emerged about how participants wanted to be  
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51 129 engaged by PHRs: they wanted (1) novel content that was relevant to their immediate and ongoing care,  
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55 <sup>o</sup> The following is used for the verbal annotation of participant percentages: All=100%, nearly all=80-99%, most=60-80%, many=40-60%, a majority= >50%, some=25-40%, few=<25%.  
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130 (2) a PHR they could trust for accuracy, security, and privacy, and (3) a highly functional PHR, facilitating  
 131 care and communication with their clinician, and providing access to comprehensive personalized  
 132 information shared with the clinician. Although practical usefulness was said to be essential, a major  
 133 reason why participants said they trusted, used, and sought relevance in the IPHR was that it was  
 134 offered to them by their personal clinician.

#### 135 Relevance

136 A few participants noted that upcoming appointments with their clinician made IPHR use more  
 137 compelling, contributed to their registering, and led them to notice the content pertinent to that visit.  
 138 Most, however, reported that the invitation for the IPHR was received at a time unassociated with an  
 139 office visit or any specific healthcare needs. Indeed many participants reported that as a result they did  
 140 not feel a pressing need to immediately register for and use the IPHR (Table 2). A few non-users  
 141 declared that they just had not gotten around to registering. Many participants in both the non-user and  
 142 user groups voiced the opinion that they could access similar information on the internet, and that they  
 143 did not recognize that IPHR content was personalized to their needs. Some users commented that they  
 144 had already fully addressed their preventive healthcare needs with their clinician.

145 **TABLE 2: REPRESENTATIVE PARTICIPANT COMMENTS ON RELEVANCE OF THE IPHR**  
 146 **(WHY THEY DIDN'T FEEL A NEED TO REGISTER)**

Sub-themes	Representative Quotations
<b>Lacking Urgency</b>	<p><i>It was procrastination. It wasn't that I wasn't going to do it.</i></p> <p><i>I said, "Boy, this would be -- this is interesting, I should try it." Stuck it in a pile and forgot about it.</i></p>
<b>Lacking Novelty</b>	<p><i>Particularly when it concerns a medical something, I usually look it up, you know, any of the various websites that you can go to.</i></p> <p><i>I am the health related expert in the house. And I have to know what everything is. So yes I go to the Cleveland Clinic and the Mayo Clinic and Johns Hopkins.</i></p>
<b>Redundant to current care</b>	<p><i>It was not, in my case not new information since my doctor and I had talked about it so much...</i></p> <p><i>She knows what I do for exercise, and she asks me questions when I go in, you know. But, if I didn't have that kind of relationship, then I think I would -- I mean, right now, I don't see, for me, that I need this.</i></p>

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 148 Trust

\* Unless otherwise indicated, findings described herein are from both user and non-user groups.

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3 149 Nearly all participants vigorously discussed three components of trust necessary for them to use a PHR:  
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5 150 security (protecting their health information), privacy (not sharing their health information with others),  
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7 151 and accuracy (ensuring that the clinical content and health recommendations proffered by the system  
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9 152 were correct and appropriate for them) (Table 3). Most participants reported trusting the IPHR because  
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11 153 it was recommended and used by their clinician's practice. A few participants in the non-user groups  
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13 154 indicated discomfort with having any of their personal health information on the Internet. However,  
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15 155 most participants in all groups expressed the view that clinician endorsement of the IPHR was an  
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17 156 indication that their personal health data were secure. Most participants also expressed strong  
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19 157 opposition to PHRs developed by commercial entities and to sharing their health information with their  
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21 158 insurance company due to the risk of future denial of coverage.

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TABLE 3: REPRESENTATIVE PARTICIPANT COMMENTS ON TRUST OF AN IPHR

Sub-themes	Representative Quotations
Security	<p><i>It (IPHR) came through our own doctor; I didn't have any problem with it. If it had just been out of the blue I might have.</i></p> <p><i>At first I was curious as to what is this (IPHR), but then I guess I trusted it because it was [clinician's office] which I trusted.</i></p> <p><i>I've come to trust him to keep my information in his laptop...you have to trust the doctor.</i></p>
Privacy	<p><i>I think personally I would only trust what I was affiliated with. What should be familiar with me. I mean, Google certainly doesn't know me...</i></p> <p><i>Another Participant: Oh, Yes they do.</i></p> <p><i>The information you have on the system, passing data maybe to insurance companies and then turn around later and say no we're not going to insure you...</i></p> <p><i>I got scared...because I got the impression that I was going to discuss things of my personal nature with my doctor on the website and I didn't like that, and so I discarded it because I'd rather talk about my health face to face with my doctor.</i></p>
Accuracy	<p><i>There's so many sites out there that you wonder how valid. I felt good that [the clinician's office was] endorsing or leading me to a particular site that they must feel confident in the information and the content..</i></p> <p><i>One reason I don't do (Internet health information) a whole lot is because you get conflicting views and I don't know who to believe and who not to believe. So I...ask my doctor.</i></p> <p><i>I was getting emotionally distraught over those things that I was reading (on the Internet) and then, come to find out, I didn't even have to be concerned about it. But... I got to leave those kinds of things to the doctor because that's what he's trained for.</i></p>



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3 161 Nearly all participants reported having had difficulties distinguishing between accurate and inaccurate  
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5 162 health information on the internet (Table 3). A few participants gave examples of erroneous health  
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7 163 information that caused anxiety or led to poor personal health choices. Most participants stated that  
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9 164 they asked their clinician to verify information they found on the web. Nearly all participants reported  
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11 165 that they would trust the accuracy of the content and recommendations made by the IPHR because it  
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13 166 was endorsed and used by their clinician, and identified their clinician as their primary authority on the  
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15 167 accuracy and application of healthcare information.

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17 169 Functionality

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19 170 Functions that the participants identified as important involved two subthemes: enhanced patient-  
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21 171 clinician communication and patient-centered utility (Table 4).

22 172 **TABLE 4: REPRESENTATIVE PARTICIPANT COMMENTS ON FUNCTIONALITY**

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24 173 **Enhanced Patient-Clinician Communication From Using an IPHR**

Sub-themes	Representative Quotations
<b>Interactive</b>	<p data-bbox="415 938 1492 999"><i>Direct communications between the doctor and the patient that you can access via the Internet just like medical records, you should be able to access that.</i></p> <p data-bbox="415 1035 1474 1129"><i>(As a result of using the IPHR) The nurse called me up and said we haven't seen you in so long, you know, and she starts going through this (prevention) stuff...I said well I've been going to my heart doctor...and she said, you should come back you know.</i></p> <p data-bbox="415 1165 1487 1224"><i>Not dictating, but cooperating, supportive, and provide me the source of the information, let me go there and look at the thing (IPHR) before, you know we make a decision.</i></p>
<b>Focus Discussion</b>	<p data-bbox="415 1230 1463 1291"><i>I have 15 minutes to talk to him. And this gives me the ability to list everything that's wrong with me...This is what you need to talk to the doctor about in your physical.</i></p> <p data-bbox="415 1327 1360 1358"><i>I would think anything that would focus my discussion would hopefully focus his as well.</i></p> <p data-bbox="415 1394 1495 1486"><i>When I go in to the primary care physician, I don't want to just listen to him. I do want to hear what he has to say, but I want to be able to ask what I think are intelligent questions. I'll go do research on that. And then I feel like I can have a better, more productive discussion with the physician.</i></p>
<b>Broaden Discussion</b>	<p data-bbox="415 1493 1487 1554"><i>What if your doctor disagrees somewhat with the United States Preventive Services Task Force? (as recommended by the IPHR)...It becomes a discussion point.</i></p> <p data-bbox="415 1589 1495 1650"><i>I think it (conversation with clinician) might be a little bit broader (from using the IPHR). You go and say, "Here's what I'm seeing or here's what going on with my family."</i></p>
<b>Efficiency Pros and Cons</b>	<p data-bbox="415 1656 1500 1751"><i>There might be an opportunity to take some of the minor issues off the table (after using the PHR), so when you go to the doctor it would shorten the amount of things that you would like to talk to him about because you've answered some of that already.</i></p> <p data-bbox="415 1787 1495 1833"><i>That email to the doctor, I think, could create a problem. It's very time consuming. You spend all day on the internet answering mail, the doctor will never get paid...SECOND PARTICIPANT: You'd never</i></p>

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	<p><i>get your tetanus shot. FIRST PARTICIPANT: ..You'd never get anything else.</i></p> <p><i>So what is this doing for the physician? I mean, we're keeping healthier, but it means a lot more work for him in a way.</i></p>
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175 **PATIENT-CENTERED IPHR UTILITY**

Subthemes	Representative Quotations
<b>Expand Access To Personal Clinical Information</b>	<i>It's not just security, but also access. My access to my personal information. I want to have that, and electronic medical records, Internet-based systems can provide me with that.. I trust my physician here because I've developed a relationship with him, but anybody else, I would want to have absolute access to my information.</i>
<b>Align Patient-Clinician Information</b>	<p><i>Knowing that all the information is correct to the best of your knowledge, and in one place where it can be accessed by the doctor and by you, it makes me feel very secure.</i></p> <p><i>This information is shared with your physician -- as you update things your provider is going to be made aware of this you know-We need to be on the same page.</i></p>
<b>Provide Personalized Information</b>	<p><i>I think with that information available (in the IPHR), I think it will actually help him a great deal to change my lifestyle. I think that's what all this preventive medicine is all about is how you change your lifestyle.</i></p> <p><i>It also gave me some thoughts about the preventive things I should need to know or that I should be thinking about. So it made me think about, gosh I'll have to ask her. For example, something about an aspirin a day, is it something that's appropriate for me?</i></p> <p><i>There was lots of information there but it was not, in my case not new information since my doctor and I had talked about it so much...</i></p>
<b>Comprehensively Address Patient Needs</b>	<p><i>I'm surprised that this isn't something for medications. One doctor says you got to take calcium and another one says you got to take multivitamin and another one says you got to take an aspirin, and people may be taking allergy medicines that they get over the counter...</i></p> <p><i>Some general thing about menopause or some of the women's issues would have been helpful. Age specific things might be helpful, children, you know, developmental or something like that just as a good reference for parents.</i></p> <p><i>Say you had in your history that you had a history of stroke or cancer, would it also give patient education stuff, like here's a link to the American Cancer Society? Or here's a thing for support group information? I'm a surviving cancer patient...</i></p> <p><i>Here's what we want: we're living here but we want to occasionally go somewhere else. Anyone in the country should be able to open and keep track of it accurately...realistically and securely.</i></p>

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177 Many participants stated that they wanted PHRs to enhance communication with their clinician **both**

178 **electronically and in person.** Several liked being contacted about preventive care after they used the

179 IPHR. Participants described how the IPHR could focus discussions during office visits, making their visits

180 more productive. Conversely, several also mentioned that the IPHR could appropriately broaden

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3 181 discussions for some topics, such as identifying preventive screening choices that they or their clinician  
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5 182 viewed as warranting dialogue, or starting conversations about lifestyle changes. However, some  
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7 183 participants expressed concern that more time would be required for busy clinicians and patients to use  
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9 184 the IPHR or similar tools. Participants worried about increased fees for either patients or practices to  
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11 185 use similar PHRs in the future.

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14 187 Many participants said that a critically important feature of the IPHR was the ability for patients to  
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16 188 access their personal health information. They explained that this access was important so that they  
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18 189 could be “on the same page” as their clinician. They also commented that shared access to information  
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20 190 would contribute to improved accuracy of records and more productive interactions.

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22 192 Many participants identified the personalized advice offered by the IPHR, its prompts to discuss its  
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24 193 recommendations with the clinician (e.g. whether to take aspirin), and its ability to prioritize  
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26 194 recommendations and thereby highlight critical or information to act on, as very important. Also of  
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28 195 interest to many (but not available in this IPHR) were adding features for comprehensive medication  
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30 196 reconciliation, in-depth information for the whole family for prevention as well as for specific diseases,  
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32 197 and links to local resources that provide support and information for lifestyle changes, preventive care  
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34 198 needs, and chronic diseases. Moreover, several participants stated that PHRs, such as the IPHR, should  
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36 199 be shared seamlessly across all healthcare providers and settings.

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## 38 201 **DISCUSSION**

39 202 Given the national investment of \$27 billion to promote the adoption, implementation, and meaningful  
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41 203 use of health information technology,<sup>45-47</sup> it is essential to understand how to better engage patients in  
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43 204 using technology if it is to achieve its full potential. Many Americans have not embraced the use of  
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45 205 PHRs,<sup>48</sup> but our findings underscore the general interest of patients in using such tools if certain  
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47 206 attributes are offered.

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50 208 When PHR use is integrated into care so that it improves the efficiency and quality of patients' care (e.g.  
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52 209 timely use related to clinician visits), its relevance becomes more transparent. The PHR becomes a  
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54 210 welcome extension of interactions with the clinician and the related healthcare team.

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3 212 National surveys have clearly documented a level of public concern about personal health information  
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5 213 existing on the web and about employers, insurers, or even commercial entities being able to access or  
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7 214 misuse such information.<sup>48</sup> Although one could argue that such fears may ease over time as more  
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9 215 private information migrates into the cyber-environment, this reticence may have already contributed  
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11 216 to the failure of some commercial PHRs to gain wide acceptance by the general public.<sup>49</sup>  
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14 218 The addition of certain PHR features that seem popular with patients, such as displaying test results or  
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16 219 supporting asynchronous communication via secure messaging, has generated only modest increases in  
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18 220 actual PHR utilization.<sup>17,21</sup> One explanation is that patients who are accustomed to more powerful  
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20 221 information tools in other aspects of life may expect greater functionality than merely seeing their  
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22 222 information.<sup>50,51</sup> Indeed, participants in this study wanted much more – including links to personalized  
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24 223 recommendations, and resources and tools to help make information actionable to improve health, as  
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26 224 provided by this IPHR.  
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28 226 Across both users and non-users, nearly all participants reported being more likely to perceive a PHR as  
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30 227 relevant, trustworthy, and functional if it was offered to them by their personal clinician. We conclude  
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32 228 that a key element of engaging patients to use a PHR extends beyond the tool's design and includes how  
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34 229 it is presented to patients and integrated into their care experience (Figure 1).  
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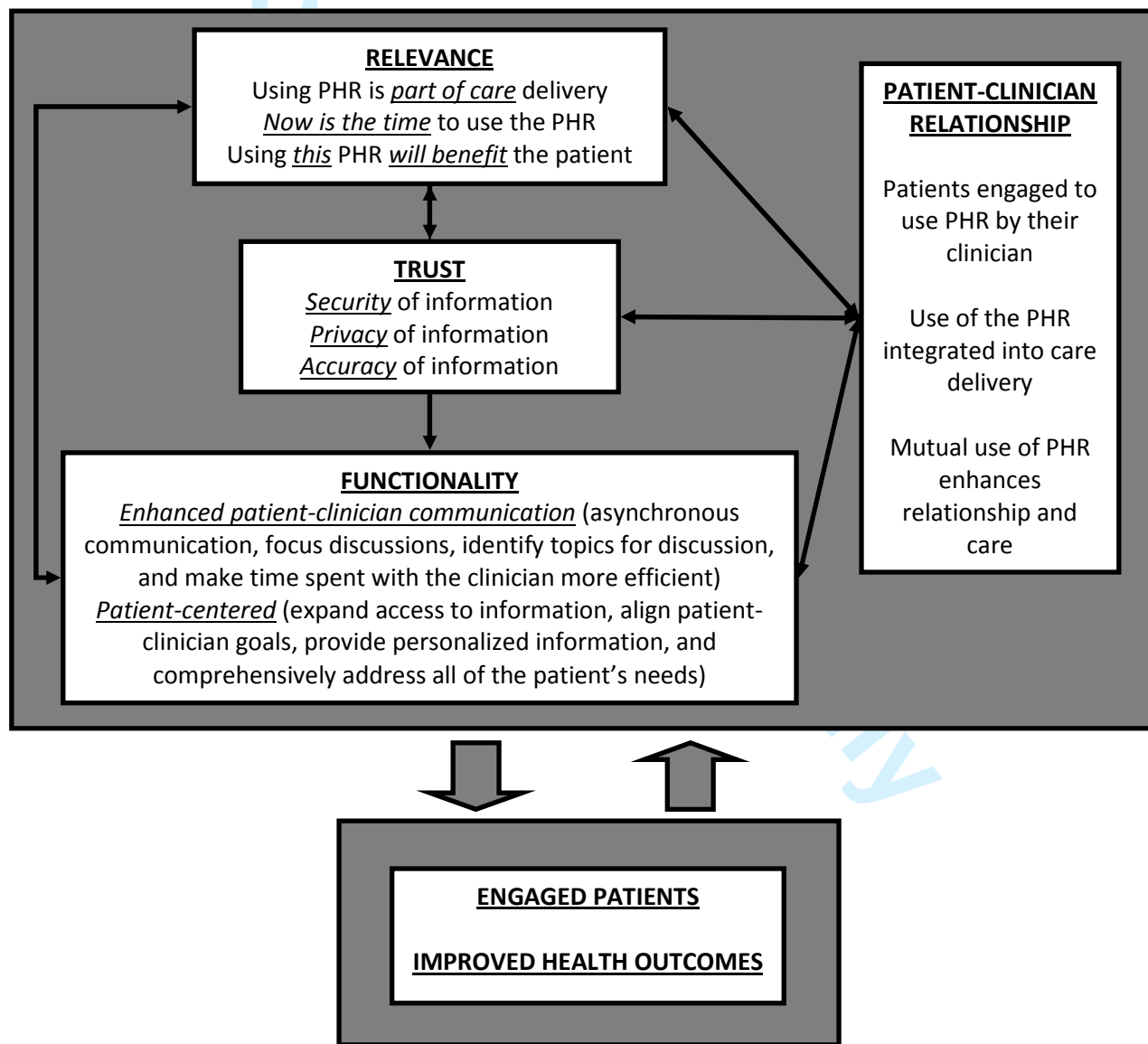
36 231 Although some PHR evaluations seem to show enhanced patient uptake when patients had a *lack* of  
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38 232 trust in their clinician,<sup>52,53</sup> other information seems to indicate that encouragement of PHR uptake by a  
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40 233 patient's clinician has a positive influence on patient use and that patient and clinician PHR use  
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42 234 enhances their relationship.<sup>54</sup> Our findings support Nazi's findings<sup>54</sup> and extend them to show, as in  
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44 235 Figure 1, that the patient-clinician relationship explicitly supports all critical components of patient  
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46 236 engagement in IPHRs.  
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48 238 Other models, among them DeLone and McLean's MISS<sup>26</sup> (Figure 2), have been applied to clinical  
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50 239 information systems, including PHRs. Booth states that MISS lacks sensitivities to medical and  
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52 240 relationship-laden milieus of technology (previously described by Sandelowski),<sup>29,55</sup> whereas Figure 1  
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54 241 and our results demonstrate both clinical as well as personal contexts for patients and clinicians.  
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242 Further, although Archer and colleagues used MISS to categorize aspects of their scoping review of  
 243 PHRs,<sup>23</sup> they only examined selected parts of the model.

244  
 245 Differences between Figure 1 and MISS aside, we wish to point out several similarities as well, including  
 246 the previously mentioned use of causal and process elements, and the feedback loop from 'Net Benefits'  
 247 to both 'Use' and 'User Satisfaction'.

249 **FIGURE 1: PERSONAL HEALTH RECORD (PHR) FEATURES NEEDED TO ENGAGE**  
 250 **PATIENTS**



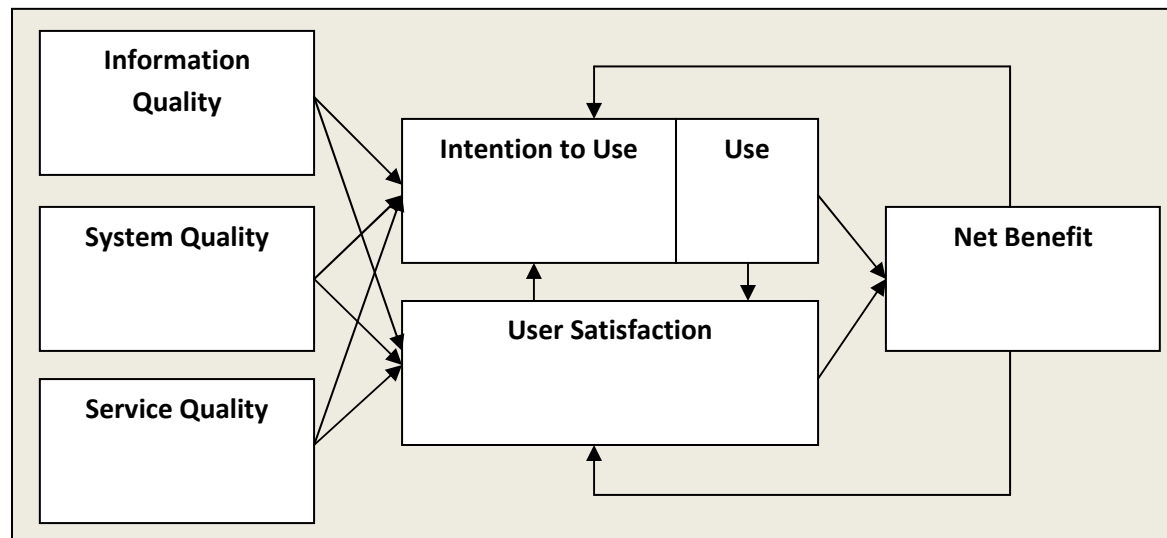
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For peer review only

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FIGURE 2: DELONE AND MCLEAN'S MODEL OF INFORMATION SYSTEM SUCCESS<sup>26</sup>



Our study has several important limitations. First, while we attempted to assemble focus groups with a representative range of ages and genders, we may have introduced a selection bias in our sample. Participants were older, more likely to be female, mostly white, and more educated than the overall user and non-user populations.<sup>56,57</sup> However, women are more likely than men to use PHRs<sup>58</sup> and to make healthcare decisions for families.<sup>58-60</sup> Other studies indicate that members of different socioeconomic and racial-ethnic groups may have different PHR preferences (e.g. a PHR not based on the Internet) and may require assistance in using a PHR.<sup>61-63</sup> Second, the sample was drawn entirely from eight practices in northern Virginia. Other locales may have different PHR needs requiring different strategies to engage patients in PHR use. Third, all participants were recruited from family medicine offices that already offered a PHR to patients, and most participants had established relationships with their clinician. Accordingly, participants may have emphasized the value of the patient-clinician relationship in PHR use more than populations from other settings. Lastly, whereas the number of participants (28) will not quantitatively generalize to all IPHR users, the nature of qualitative research is often that of looking at specific cases, many times in order to inform the gaps generated by other data, rather than to compete with or duplicate that information.<sup>42</sup>

## CONCLUSION:

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3 282 To engage primary care patients with an IPHR, this study identifies the importance of relevance, trust  
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5 283 and functionality, all integrated with office processes and the patient-clinician relationship. In addition  
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7 284 to suggesting possible modifications to established models of technological acceptance, these findings  
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9 285 have relevance for healthcare providers, the information technology industry, and policymakers who  
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11 286 share an interest in encouraging patients to use personal health records or other information tools.  
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13 287 Studies like ours should be expanded and replicated in other settings to more fully understand how to  
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15 288 make such technology more useful to patients.  
16

289

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18  
19 291 Gainesville Family Medicine, Herndon Family Medicine, Lorton Station Family Medicine, Prince William  
20  
21 292 Family Medicine, South Riding Family Medicine, Town Center Family Medicine, and Vienna Family  
22  
23 293 Medicine. We received invaluable advice and assistance with the focus groups from Christine C. Kerns,  
24  
25 294 RN, and in designing the project from Stephen F. Rothemich MD, MS. as well as Kristin Schmidt in  
26  
27 295 project assistance.

28 **Conflicts of interest:** Virginia Commonwealth University holds the intellectual property rights to the  
29  
30 296 interactive preventive care record evaluated in this study. Although the university and developers are  
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32 297 entitled to the system's revenue, MyPreventiveCare is a noncommercial product, and no revenues have  
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34 298 been generated other than grant funding.  
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