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Increasing Patient Engagement in the African American Community through Personal Health Record Use

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Abstract

Personal Health records have many potential benefits to patients, caregivers and institutions. In order to meet meaningful use standards EHR systems must allow patients to be able to access and easily download their healthcare records and images for their own use. Previous studies have shown that African Americans are less likely to enroll in a personal health record than other ethnic populations. This study was done to research and identify possible barriers the have limited the utilization of personal health record use in the African American community. A preliminary survey and focus group were convened to discuss issues affecting PHR utilization.

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Chapter 1- Introduction

Statement of the Problem

Introduction

As we move into Meaningful Use stage 2 one of the significant changes includes a greater focus on patient engagement. In order to meet meaningful use standards EHR systems must allow patients to be able to access and easily download their healthcare records and images for their own utilization. While Personal Health records have many potential benefits to patients, caregivers and institutions, the supporting evidence of specific benefits and the business case for PHR adoption are limited. An individual’s PHR can only be useful if the person understands the importance of maintaining and coordinating health related documentation and activities with health care providers. I will be studying the barriers that affect utilization of Personal health records in the African American community.

Background

Meaningful Use is the set of standards defined by the Centers for Medicare & Medicaid Services (CMS) Incentive Programs that governs the use of electronic health records and allows eligible providers and hospitals to earn incentive payments by meeting specific criteria. Stage 2 of the EHR incentive program which begins in 2014 includes new objectives to improve patient care through better clinical decision support, care coordination, and patient engagement. Patient engagement is a prominent goal of the EHR Incentive Program. Bringing patient engagement to the forefront aims to improve patients’ understanding of their health and related conditions so they take a more active role in their health care. Studies show that patients who are well informed of their medical condition are more likely to comply with their provider’s recommended regimen, thus having better outcomes and patient experiences which lead to having lower healthcare costs associated with certain illnesses. According to a survey published in the Journal of the American Medical Informatics Association, African Americans are less likely to enroll in a personal health record than other ethnic populations. The study also found that differences in education, income, and Internet access did not account for the disparities in PHR registration by race. This focus group will hopefully answer the question of why and how can we turn this around.

Purpose of Study

The purpose of this study is to pinpoint barriers that have inhibited personal health record use aside from education, income, and internet access in the African American community. This study will also be used to create an educational plan that will be used to increase patient engagement and empower the African American Community.

Significance of Study

Previous studies have shown that significant disparities exist not only in access to care but in the type and quality of care accessed by minority populations. Personal health records (PHRs) have the potential to improve patient access and improve health outcomes by allowing people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it (Akerman, 2010). PHRS allow patients to take a more active role in healthcare. However, according to a study published in the Journal of the American Medical Informatics Association titled Disparities in Use of a Personal Health Record in a Managed Care Organization, Minority populations are less likely to take advantage of a Personal Health Record. Factors such as the digital divide, low literacy levels, and low income are all contributing factors to the lack of use in minority populations. The key item discussed in this research was that even when these factors were adjusted the differences in PHR adoption were significantly different and did not account for the disparity. More research must be done to investigate the cultural differences that affect PHR utilization in the African American community.

Conceptual Frame of Reference

This study is based on the work of a study conducted for the Robert Wood Johnson Foundation. This issue brief describes the role that PHRs can play in reducing health disparities, the barriers to PHR adoption for underserved individuals, the reactions of focus group participants to the PHR concept and the implications of the study for reducing health disparities through more widespread use of PHRs.

Bagchi, A., Moreno, L., & Ursin, R. (2007). Considerations in designing personal health records for underserved populations. Retrieved from www.mathematica-mpr.com/publications/pdfs/hlthcaredisparib1.pdf

Definition of Terms

Digital divide- the way in which technology and Internet utilization patterns differ by race/ethnicity and socioeconomic lines

Disparities-differences in treatment between racial, ethnic or other demographic groups that are not directly attributable to variation in clinical needs or patient preferences and persist even after adjustment for socioeconomic factors

Health information Technology (HIT)- refers to a conglomeration of technologies such as electronic health records (EHRs),which include computerized provider order entry (CPOE), electronic clinical decision support tools, and clinical documentation such as physician notes and discharge summaries; personal health records (PHRs)

Meaningful use- The set of standards defined by the Centers for Medicare & Medicaid Services (CMS) Incentive Programs that governs the use of electronic health records and allows eligible providers and hospitals to earn incentive payments by meeting specific criteria.

Patient empowerment- enabling patients to take a more active role in their health and in the health of their families for example enabling patients to receive electronic copies of their medical records and share their health information securely over the Internet with their families

Personal Health records (PHR)- The PHR is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who

Limitations

The limitation of this focus group is that the small sample size means the group might not be a good representation of the larger population. This focus group should be replicated several times in order to ensure reliability.

Chapter 2- Review of Literature

Introduction:

According to the American Health Information Management Foundation the Personal Health Record (PHR) is a tool that can be used to collect, track and share past and current information about your health or the health of someone in your care. This information can save money and inconvenience of repeating routine medical tests. Even when routine procedures do need to be repeated Personal Health Records can give medical care providers more insight into an individual's personal health story. Surveys show that consumers who use personal health records know more about their health, ask more questions, feel more connected to their physicians and take steps to improve their health (Akerman, 2010). As we move into stage 2 of Meaningful Use one of the significant changes includes a greater focus on patient engagement. To meet Meaningful Use standards EHR systems must allow patients to be able to access and easily download their healthcare records and images for their own use. Studies have shown that PHR use is unequal by race/ethnicity. Studies have also shown that the differences in education, income and internet access does not account for the PHR registration by race. This literature review will examine data on PHR utilization in the African American community.

Methods

An extensive search of literature using the PubMed and JAIMA databases was performed. The search was initially specific to articles or literature published after 2000 and included subjects associated with keywords such as PHR utilization and PHR use in underserved communities. After finding studies that would vaguely mention PHR utilization in the African American community, the search was narrowed to articles that specifically addressed PHR utilization in the African American community by using the keywords PHR and African Americans.

All literature that described the keyword and addresses the topics regardless of study design was retrieved. Research papers, journal articles and editorials were examined. After the initial search, examination of the titles and abstracts of the article retrieved to determine whether the articles were relevant for my analysis. For the purpose of this analysis, only data specific to potential PHR benefits and PHR utilization by African Americans was extracted.

Of the two articles chosen to review one conducts a comprehensive literature review that looks at the impact of personal health record. The other article conducted a 2-year cohort study that assessed the differences in rates of registration within the personal health record portion of the Kaiser Permanente electronic health record.

Results

Over 45 studies retrieved in the initial screening, 15 of the article titles and abstracts had some aspect of the related criteria. The articles were reviewed in-depth. 13 of the articles were excluded because they were did not specifically address the rates of PHR adoption by race or either did not give a clear benefit for using a PHR. Both studies were quite different in their study design, participants, and findings. One of the studies did an extensive literature of the value of PHRs and the other was a 2-year cohort study that assessed the differences in rates of PHR registration by race .

The first study is titled The Value of Personal Health Record Systems. This study was published by Pub Med and details the research done by Dr. David Kaelber and Dr. Eric C Pan. As Personal Health Record use begins to gain more attention and the potential benefits to having a more engaged and informed patient population are becoming revealed there has been a lack of research done in the area of analyzing the quantifiable value of different PHR types (Kaelber, Pan, 2008). The goal of this extensive research project was to present a value analysis of the potential value of Personal Health Record to the United States. The researchers followed the four-step value assessment methodology system to break down the information found into various sections in order to analyze all pertinent information. The important design features of this study include the development of a computer model that integrated all of the costs and benefits evidence and extrapolated this information to the national level. The authors of this study completed a comprehensive literature review that looked at the impact of personal health records. The results of this analysis showed that during the review 493 references were pulled. Those references were further reduced to 265 by limiting to only peer reviewed references in English over the last 10 years. From this 265 the number was further reduced to 137 based on relevance of the abstracts. After the literature review the personal health record taxonomy and evidence framework was created to organize the PHR value analysis. The two most important ideas gained from this article was that it costs billions of dollars to implement and maintain a personal health record, however, with even a small set of functions available could provide significant net benefit to the US Healthcare system through the billions of dollars in potential cost saving. The benefits include improved convenience, quality of care, safety, communication and record keeping. (Kaelber, Pan,2008).

The second article is titled Disparities in Use of a Personal Health record in Managed Care Organizations. This study was published in the Journal of American Medical Informatics Association. The goal of this study was to demonstrate the differences in PHR registration by race. As previously stated the authors assessed the differences in rates of PHR registration. At baseline, 1,777 25-59 year old Kaiser Permanente Georgia enrollees, who had not registered with KP.org, responded to a mixed mode (written or Internet) survey. KP.org registration by race from 10/1/05 (with censoring for disenrollment from Kaiser Permanente) was adjusted for baseline education, comorbidity, patient activation, and completion of the baseline survey online vs. by paper using Cox proportional hazards. Of 1,777, 34.7% (616) registered with KP.org between Oct 2005 and Nov 2007. Median time to registering a KP.org account was 409 days. Among African Americans, 30.1% registered, compared with 41.7% of whites ($p < 0.01$). In the hazards model, African Americans were again less likely to register than whites (hazard ratio [HR] = 0.652, 95% CI: 0.549-0.776) despite adjustment. Those with baseline Internet access were more likely to register (HR = 1.629, 95% CI: 1.294-2.050), and a significant educational gradient was also observed (more likely registration with higher educational levels). This study found that differences in education, income, and Internet access did not account for the disparities in PHR registration by race. In the short-term, attempts to improve patient access to health care with PHRs may not ameliorate prevailing disparities between African Americans and whites.

Discussions

The goal of this review was to present extensive literature results from detailing the significance of personal health records while showing that there is a legitimate concern about the differences in PHR use by race. As the studies have concluded PHRs do have the potential to provide significant benefits to the US Healthcare system; however, in order not to exacerbate prevailing disparities within the African Americans community research must be done to determine the cause in the lack of PHR use in the African American population aside from education, income and internet access.

Chapter 3-Methodology

Methodology –This chapter will provide an analysis of the research design, collection procedure along with profile of subject population.

Research Design

A 15 participant focus group of African American Adults ages 30-70 will be assembled to attempt to pinpoint barriers that have inhibited personal health record aside from education, income, and internet access.

Population and Sample Design

The population sample includes African American Adults ranging in age from 30-70

Data Collection Procedures

A Survey Consent Disclosure form will be given prior to participation in the survey and focus group. A preliminary survey will be given to capture demographic information such as gender, age range, and level of education. All data will remain confidential. After the survey is completed a focus group will convene at an urban African American Church. The focus group will last from 45-60 minutes. It will be an open discussion.

The Topics to be discussed include the following:

What is a Personal Health Record?

How do you currently keep track of your health information?

What do you feel is your role in maintaining your personal health information?

What do you feel is the physician’s role in maintaining your personal health information?

What would be some desirable qualities of a PHR?

Can you think of anyways a PHR could have a positive impact on you or your family? Any negative impacts?

Does anyone have anything else they would like to add?

Statistical Analysis Techniques

The Scissor and Sort analysis technique which is sometimes called the cut-and-paste method will be used to analyze the focus group responses. The first step in applying the technique will be to go through the notes and identify those sections of it that are relevant to the research question. Color-coded brackets will be used to mark different topics within the notes with colors. Each piece of coded material will be cut out and sorted so that all material relevant to a particular topic is placed together. Each topic is treated in turn with a brief introduction. The various pieces of coded notes will be used as supporting materials and incorporated within an interpretative analysis.

Chapter 4-Results

This chapter will discuss the response rate and profile of the focus group along with the results of the focus group questions.

Response Rate of Population: I had 8 people attend the focus group.

Snapshot of Focus Group Respondents:

Age Range of Respondents	
25-34	2
35-44	3
45-54	2
55-64	1
65 or Older	0

Level of Education	
Some high school	1
High school grad	0
Associate Degree	0
Bachelors Degree	4
Graduate Degree	3

Race of Respondents	
Black/African American	8

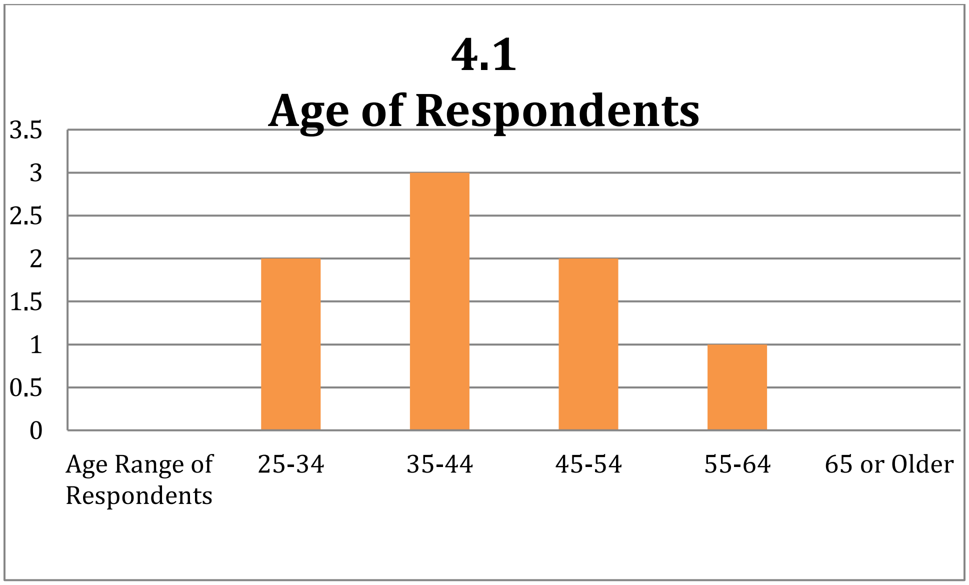
Ability to access the internet consistently	
Yes	8

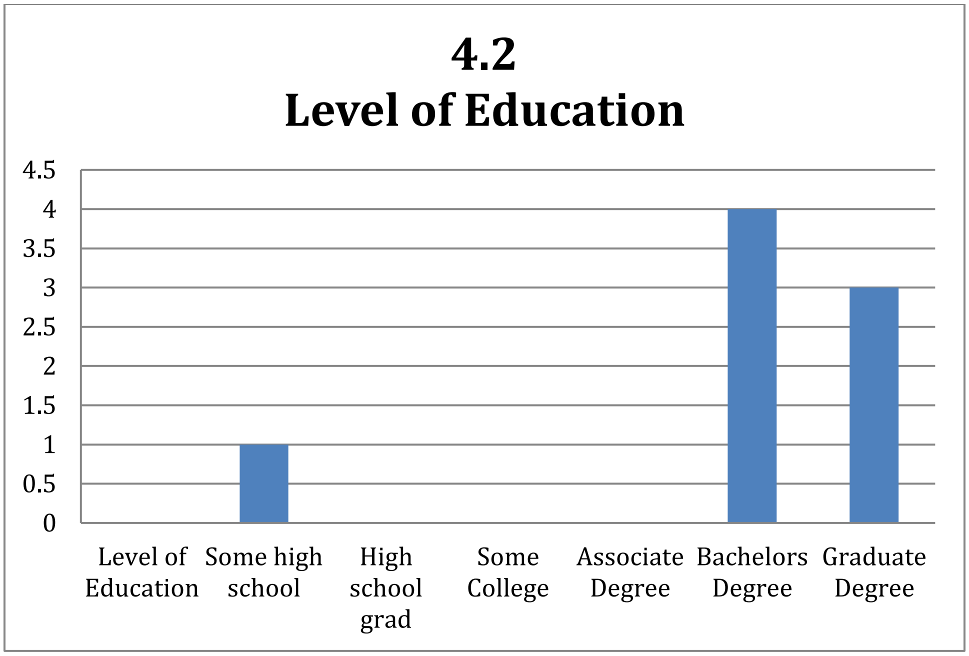
Does your Physicians Office use an EHR?	
Yes	7
No	1

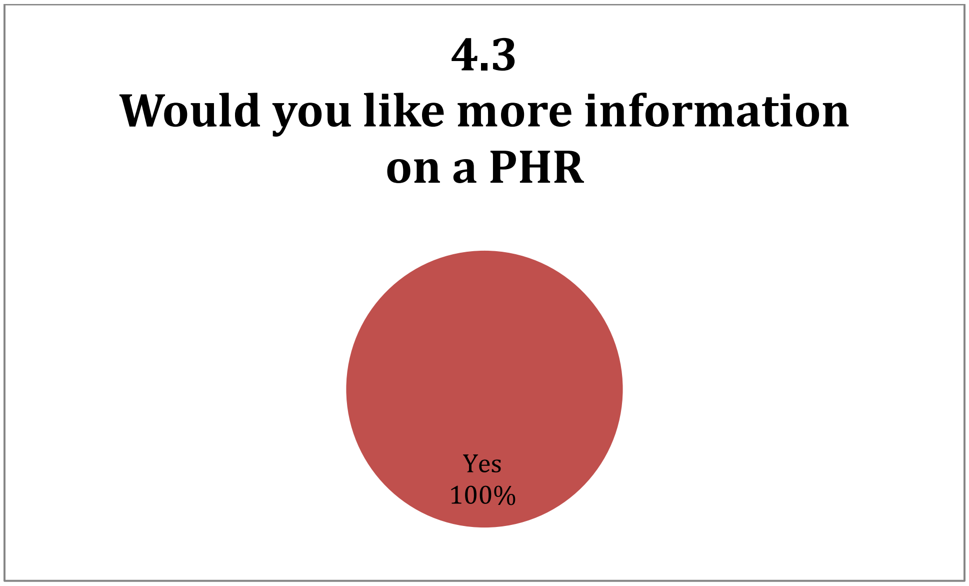
Have you ever accessed a PHR or a Patient Portal?	
Yes	3
No	5

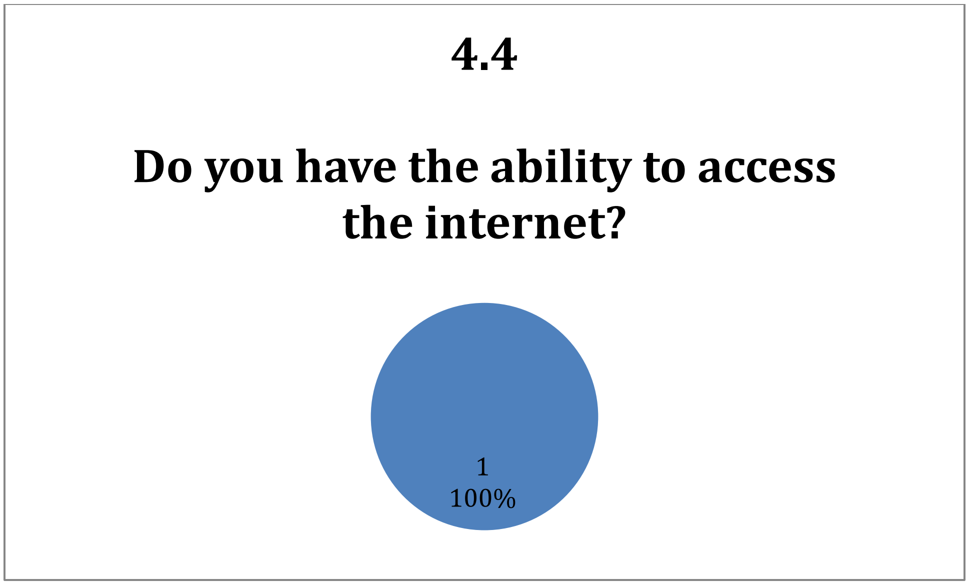
Would you like more information on a PHR?	
Yes	8

Tables


4.1
Age of Respondents
3.5
3
2.5
2
1.5
1
0.5
0
Age Range of Respondents
25-34
35-44
45-54
55-64
65 or Older

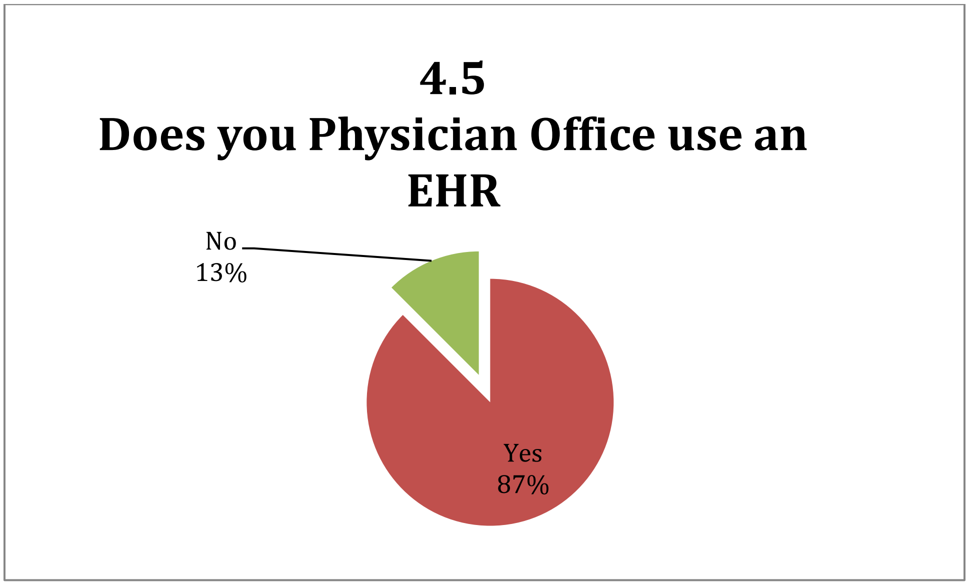

4.2
Level of Education
4.5
4
3.5
3
2.5
2
1.5
1
0.5
0
Level of Education
Some high school
High school grad
Some College
Associate Degree
Bachelors Degree
Graduate Degree


4.3
Would you like more information on a PHR
Yes
100%

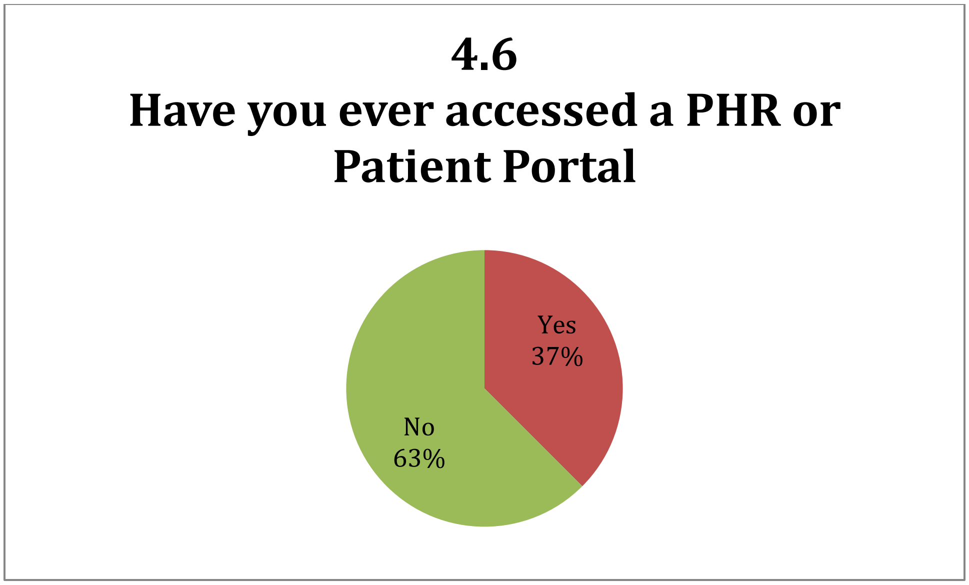


4.4

Do you have the ability to access the internet?



4.5
Does you Physician Office use an EHR



4.6
Have you ever accessed a PHR or Patient Portal

Perspectives from the Focus Group

- Before the discussion began no participant could give a definition of a personal health record.
- Nearly all participants responded that the way they keep track of their personal health information is through their own memory.
- Participants had varying ideas of what their role was in maintaining their own personal health information. Most agreed there main role was to provide the physician with accurate information.
- Nearly all participants agreed that the physician’s role in maintaining their health information was to keep complete and accurate records.
- When participants were asked about what would be some desirable qualities of a PHR the responses were varied most seem to want something easy to access that provides a complete list of information including drug interactions and allergy information.
- When asked about whether they felt PHRs could have a positive impact on their healthcare all agreed that PHRs could potentially have a positive impact, most liked the idea that their loved ones could access the system and be better prepared in the event of an emergency.
- When asked about the negative effects most were concerned about the information falling into the wrong hands or people finding about diseases that they don’t want anyone to know about such as HIV status.

Summary of Chapter

This chapter discussed the results of the preliminary survey given to the focus group in addition to the key points brought up during the discussion.

Chapter 5- Conclusions and Recommendations

This chapter will cover the key points addressed during the focus group as well as major implications resulting from the focus.

Summary of Findings

The results of the preliminary survey showed that overall African Americans need more education and information before they will be able to appropriately use a personal health record. Based on the results there is no central place that the average African American will go and find out about the importance of PHRs. Most had no idea they even exist. It will take some organization taking a planned effort to effectively engage the African American Community. Much like radio personality Tom Joyner organized the “Take a loved one to the Doctor Day” campaign to raise awareness of getting annual check-ups in the African American community. I feel that something such as What’s in your Medical Record Day should be used to increase awareness of personal health record utilization in the African American community. None of the participants which were made up of all African American women initially knew the definition of a personal health record. According to the survey the group of African Americans that chose to participate were well educated with 7 out of 8 having a bachelor’s degree or higher. Differences in education, income or internet access would not have an impact on these particular participants. 87% of participants reported that they use physician practices that use Electronic Health Records. This shows that the majority of respondents use a physician practice that should have access to a patient portal or a personal health record. All participants were African American woman this coincides with previous studies that show women as the leader among personal health record use. All participants stated that they would like more information on PHRs. This shows that the women in this group were interested in reading more about PHRs and that they are eager to learn how to have better healthcare outcomes.

Conclusions

The results of this survey and focus group show that in general the African American focus group participants either have not heard of a personal health record or have chosen not to use a personal health record. Based on the results of this focus group many African Americans still continue to keep track of personal health information in their memory. This can lead to miscommunication, omission, or errors when it comes to relaying important health information to a physician or loved one. While the focus group participants mainly used physician practices that used Electronic Health Records those same participants were unaware of the importance keeping track of the personal information in a medium other than their mind. Once the definition and importance of a PHR were discussed all seemed to want more information as it did sound like a great resource to utilize. While the benefits of a PHR did seem to excite participants the fear of personal information falling into the wrong hands or sensitive health information such as HIV status being made public. Previous studies have also pointed to fear of security as a main barrier to PHR utilization (Garvin, Rudman, Stewart, 2009).

Implications of Study

This study shows that once provided the correct information on the importance of PHRs African American participants were eager to find out how to utilize a PHR; however there needs to be some sort of formal campaign used to raise awareness of PHR benefits.

Recommendation

Based on the survey and focus group I would suggest more research be done into finding out about which healthcare provider or outlet is leading the way on educating patients of personal health record utilization. Most participants in my focus group were highly educated; however, they did not initially know the definition of a PHR. Some entity needs to take the lead in getting the information out to the public regarding to PHR uses and its potential benefits.

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Appendix A

Date 09/16/2013

CONSENT DISCLOSURE STATEMENTS FOR SURVEY RESEARCH

Increasing Patient Engagement in the African American Community through Personal Health Record Use

Purpose of the Research Study:

This research is being conducted by Andrea Lynn Perkins, who is a student at the University of Tennessee Health Science Center. The purpose of the research study is to gain insight into barriers that prevent African Americans from engaging in their healthcare via personal health records. This research will also help to provide knowledge on future resources that need to be implemented to increase engagement and empower the African American Community.

Research Procedures

An anonymous survey will be given at the beginning of the session. The survey should take approximately 5 minutes. A focus group will be convened at an urban African American Church. The focus group will last from 45-60 minutes. It will be an open discussion and the group responses will be used to better understand how to increase patient engagement in the African American community through Personal Health record use.

No risk greater than those experienced in ordinary conversation are anticipated. Failure to participate will not adversely affect you in any way. Participation is voluntary.
Individual participants may not benefit by participating in the focus group.
There is no identifying information on the survey form. All data will remain confidential.

Consent is implied by participating in this focus group.
Signature of Investigator

IRB NUMBER: 13-02726-XP IRB APPROVAL DATE: 09/17/2013

Appendix B

Increasing Patient Engagement in the African American Community through Personal Health Record Use

Researcher: Andrea Perkins

Carefully read each question and circle the best answer below:

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1. Gender:
    a. Male
    b. Female

2. Please select the category that includes your age.
    a. 25-34
    b. 35-44
    c. 45-54
    d. 55-64
    e. 65 or older

3. What best describes your level of education
    a. Some high school
    b. High school graduate or equivalent
    c. Some college
    d. Associates degree

   e. Bachelor's degree
   f. Graduate Degree
   g. Prefer not to answer

4. Which one of the following best describes you?
   a. White/Caucasian
   b. Hispanic/Latino
   c. Black/African American
   d. Native American

5. Do you have access to the internet on the regular basis?
   a. Yes
   b. No

6. Do you use a physician's office that has an Electronic Health record?
   a. Yes
   b. No

7. Have you ever accessed a personal health record or patient portal?
   a. Yes
   b. No

8. Would you like more information regarding how to maintain your own personal health record?

   a. Yes
   b. No

Appendix C

Focus Group Topics:

What is a Personal Health Record?

How do you currently keep track of your health information?

What do you feel is your role in maintaining your personal health information?

What do you feel is the physician’s role in maintaining your personal health information?

What would be some desirable qualities of a PHR?

Can you think of anyways a PHR could have a positive impact on you or your family? Any negative impacts?

Does anyone have anything else they would like to add?