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MYTHS AND REALITY ABOUT PERSONAL HEALTH RECORDS

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INTRODUCTION

Despite recognized perceived benefits of PHRs for healthcare, their adoption rates remain low. A significant body of research has revealed a number of obstacles to PHR adoption. Among them are patient confidence and trust in the system, ease of access to technology determined by economic and environmental factors, satisfaction with the use of technology determined by level of education and/or self-efficacy, and attitudes to technology determined by its ease of use and usefulness.

METHOD

We did a selective literature review of 18 studies on topics of patient attitudes towards PHRs and obstacles to PHRs adoption was conducted. Relevant studies resulted from searches performed in SciVerseScopus database (1999-January 2012).

FINDINGS

Literature review demonstrated inconsistency in the evidence regarding the barriers to PHR adoption and use.

CONCLUSION

Some long-known facts about barriers to PHRs adoption and use might not always be valid and thus result in misconceptions about the actual reasons for low rates of PHRs adoption and use. We hope that bringing attention to a variety of existing evidence regarding this matter would help research, business, and patient communities to better understand the actual situation with PHRs and exploit their full potential.

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Myth

Patients are not willing to use PHRs due to the fear of jeopardizing the privacy of their health information stored online.

Reality

Despite the fact that patients express concerns about security and privacy of their personal health information used and stored online,[1] in reality very few are actually going to take any actions towards improving privacy and security of their health information.[2]

Suggestions

Increase patient awareness of potential risks to privacy and security of their personal health information if stored online and educate them about precautious measures to be observed. Additionally, continue incorporating security features in PHR design, e.g., automatic log out, verification of user identity, restoring an account via a mobile phone.

Myth

Patients are not willing to share their personal health information. Hence, there is no need for PHRs to be interoperable.

Reality

Patients view the process of health information exchange as beneficial, especially when a patient has several health care providers.[3] Additionally, patients who have serious health problems express willingness to share their health information from a PHR.[2]

Suggestions

Explain to patients the benefits of sharing personal health information with reliable institutions in credible ways; allow such functionality in PHRs; give patients a choice to decide whether to share this information or not. Additionally, establish more trust between a provider and a patient: physicians should learn to trust information entered by patients; patients should develop more responsibility for managing their own health information.

Myth

Including in a PHR as many features as possible will make patients want to use them. System developers know better what features to include in a PHR.

Reality

When compared with the list of PHR features suggested by the American Medical Association's College of Medical Informatics,[4] major inconsistencies are revealed. This means that needs of the end-user remain unmet due to very little involvement of patients in PHR development.[5]

Suggestions

Involve end-users in the process of PHR development and listen to what they have to say about their preferences for certain features and functionality. Emphasize universal design of PHRs with easy to use features for customization and conduct regular needs assessment with the current and prospective PHR users before the official launch of PHRs.

Myth

Patients being the primary beneficiaries of healthcare services should be paying for PHRs but are reluctant to do so. Unless PHRs are free, patients will not use them.

Reality

It has been found that the favorable amount to pay for a PHR among patients with no particular motivation to maintain they system is between US $1.97 - $4.94 per month.[6] Patients with a higher level of motivation including people with serious and chronic illnesses expressed willingness to pay more. Additionally, patients had a perception that a company offering a PHR on a free basis would not provide enough security for the data.[7]

Suggestions

Patients should have a choice between free and paid versions of PHRs depending on the frequency of the PHR use, its criticality for health management, and the need for PHR features required for health management.

Myth

PHRs are easy to use and do not require special skills, knowledge or training on the part of patients.

Reality

Thirty-four millions of American adults consider themselves having a disability or chronic disease.[8] This group of people represent target users of PHRs as they consider PHRs to be a tool for more efficient management of chronic health conditions and diseases and adopt PHRs at a higher rate compared to healthy counterparts.[9] The fact that a lot of PHR users are individuals with certain health problems, sometimes physical, sometimes cognitive, sometimes both, raises a concern about sufficient level of their abilities and skills to use a PHR. Even patients that consider themselves healthy and having necessary skills would like more help with learning how to use PHRs or how to interpret information contained in PHRs.[10]

Suggestions

Increase information and computer literacy among patients. Conduct usability evaluations of PHRs with patient involvement during the early stages of PHR design and development.[7]