Original Paper

Measuring how patients use a web-based personal health record and tools to manage in-vitro fertilization

Annie Y.S. Lau, Amanda Parker, Jane Early, Gavin Sacks, Farshid Anvari, Enrico Coiera

Centre for Health Informatics, Australian Institute of Health Innovation, University of New South Wales, Sydney, Australia

Corresponding Author:

Annie Y.S. Lau
Centre for Health Informatics,
Australian Institute of Health Innovation
University of New South Wales,
UNSW Sydney NSW 2052, Australia
Email: a.lau@unsw.edu.au
Telephone: + 61 2 9385 8891
Fax: + 61 2 9385 8692

(To be submitted as original paper to Journal of Medical Internet Research)

ABSTRACT

Background: The use of a personal health record to integrate one's health data and help consumers manage their own healthcare is highly advocated. However, little is known about how patients actually use web-based personal health systems to manage their health-related tasks.

Objectives: To assess how patients undergoing in-vitro fertilization (IVF) use a web-based personal health record and self-management tools for an eight-week treatment program.

Methods: An online system called *healthy.me* with access to targeted IVF information, a web-based personal health record, and tools such as a schedule manager, was developed at the University of New South Wales. 17 women undergoing an IVF treatment at a major fertility clinic in New South Wales Australia were recruited to use the system for eight-weeks (or until their treatment is completed) from October 2009 to January 2010. Participants were contacted by telephone on a weekly basis for a 10 minute semi-structured interview to elicit their feedback on the system. Online interactions were recorded on computer logs. System usage patterns were reported using descriptive statistics and interview data was coded and examined using qualitative descriptive analysis.

Results: 14 out of 17 participants completed the study. 93% (13/14) participants accessed *healthy.me*, generating 34 user sessions in total. Each session averaged six minutes. Participants accessed the system to update their personal health record and/or to obtain information about the next steps of their treatment program. 43% (6/14) added entries into their personal health record with details of their medication, schedule, test results and health team personnel partially completed. 86% (12/14) accessed all features on the system (i.e. pillbox, test results, schedule, team and journey), with 14% (2/14) regularly accessing the system at each stage of their treatment cycle. The *healthy.me* system alerted 21% (3/14) participants to contact their doctor on critical issues they were not aware of during their treatment program. No major usability issues were reported by participants in their real-life setting. Participants also proposed seven additional features to enhance their experience on *healthy.me*.

Conclusions: Analysis of system usage and interview data reveal high acceptance of *healthy.me*, but with clear variation in usage profiles. Features proposed by participants are shaping the ongoing development of *healthy.me*.

Keywords: healthcare consumer; web-based personal health record; health management; in-vitro fertilization; women

Introduction

Researchers and industry alike have begun to advocate a more decentralised and consumer-driven approach to health IT design and use. The web fundamentally alters the information asymmetry between clinicians and consumers, and its "free market" in information should empower consumers and transform health services [1]. The last five years have seen social computing sites like Facebook and MySpace gain unprecedented community acceptance, and many similar commercial health sites are now in operation. More recently, the convergence of information access via search tools, personal health records, online social networking, and information exchange between consumers and clinicians, is enabling a new class of consumer decision support system [2].

Indeed the rapid emergence of personal health records (PHRs) and the aggressive entry of multinational giants like Microsoft and Google into this market have all the hallmarks of the arrival of a "disruptive technology" [3]. Research in this space is growing rapidly, led by the pivotol discussion presented by Tang and colleagues on PHRs in 2006, clarifying the definitions of integrated and stand-alone PHRs and calling for strategies to increase their adoption [4]. Recently Halamka and colleagues presented three case studies for MyChart at Palo Alto Medical Foundation, PatientSite at Beth Israel Deaconess Medical Center, and Indivo at Children's Hospital Boston, sharing their decade of experiences in implementing integrated PHRs and concluding with a set of new challenges over the next five years [5]. In parallel, researchers have conducted surveys, focus groups and interviews eliciting consumers' attitudes and perspectives on PHRs related to privacy, equality, acceptability, early impacts, policy, and design requirements [6-10]. Others have looked at USB-based PHR devices and their security model [11], conversation dialogues amongst consumers who have access to each other's web-based PHRs [12], designs of data entry methods that increase the accuracy of patient-entered medical information [13], and the role of nursing in PHRs [14].

However, few studies describe the actual experiences of patients using a personal health record to manage their health condition. This paper reports user experiences of 14 women using a web-based personal health management system called *healthy.me* to inform and manage their eight-week IVF treatment program in a real-life setting.

Features of *healthy.me*

healthy.me is a web-based personal health management system developed at the Centre for Health Informatics, University of New South Wales, that allows consumers to store their personal health information, share it with those they have given consent. *healthy.me* has the following features [15] (Figure 1):

1. Personal Record: Allows for self-recording of medical test results and health measurements.

2. Pillbox: Allows for self-recording of current medications and medication adherence.
3. Schedule, to-do list and reminders: An online schedule that allows one to keep track of health-related appointments, displays to-do items, and sends email reminders as well as advice on what to expect and how to prepare for the appointments.
4. Team: A feature that allows the self-recording of clinical and non-clinical personnel looking after one's health.
5. Journeys: A feature that describes the different stages in the management of health conditions that can be used to personalize other sections of the system.
6. Social features including: (i) a profile for each member to store and customise their personal information, (ii) the ability to send and receive messages with other members on *healthy.me*, (iii) access controls on editing and viewing different features by different people, and (iv) blogs, online discussion forum and collaborative authoring of content in wiki style.

Figure 1. Features in *healthy.me* (© University of New South Wales, 2009 -2010)

Example in in-vitro fertilization

In-vitro fertilization (IVF) is a treatment process that involves a complex series of medications and test procedures, as well as risks of both physical and psychological side-effects [16]. To address the information and organisational needs of patients undergoing IVF, one of the modules in *healthy.me* was iteratively developed in consultation with clinical staff at a major fertility clinic in New South Wales Australia.

The IVF module supports patients undergoing an eight-week IVF treatment program through an intensive sequence of blood tests, ultrasound screenings, day surgery procedures (egg collection and embryo transfer), clinical appointments and medication tasks (including self-administered nasal sprays and intramuscular injections). Two usability testing sessions in a controlled university setting with six women of different ages and familiarity with computers were conducted to ensure all known usability issues were resolved before recruiting patients undergoing IVF treatment to participate in a real-life setting.

Methods

Participant recruitment

Posters to recruit patients about to undergo an eight-week agonist (Long Down Regulation) IVF treatment program were placed at four metropolitan branches of a major fertility service provider in New South Wales Australia from October 2009 to January 2010. Nursing staff at these branches assisted in poster distribution. Patients were recruited by a research team member face-to-face or by the telephone. They were given access to a non-mandatory online tutorial describing the features of *healthy.me*. Ethics approval from the Human Research Ethics Advisory Panel at UNSW was obtained for this study.

Procedures

Participants were asked to use *healthy.me* for eight-weeks (or until their IVF treatment is over). At the time of recruitment, they undertook a 10 minute semi-structured interview, eliciting their demographic details and resources that helped them decide on undertaking IVF. During the study, participants were contacted by the telephone each week to undergo a 10 minute semi-structured interview to elicit their feedback on *healthy.me*, their issues of concern, and sources of support they received or sought over the past week. Their online interactions with the *healthy.me* system were recorded on computer logs unobtrusively.

Data Analysis

Descriptive statistics were applied on computer logs capturing participants' usage of the system over the eight-week period. Qualitative descriptive analysis was used to code the weekly interview transcripts, exploring participants' experience of using *healthy.me* and their feedback during the study. All interview data were formatted as narrative text and coded independently by AL and AP. Coding scheme was guided by interview questions designed by AL and EC with flexibility allowing for emergence of new codes.

Results

Participants

17 women were recruited to take part in an eight-week study lasting the duration of one agonist (Long Down Regulation) IVF treatment at a major fertility clinic in New South Wales Australia from October 2009 to January 2010. All but 2 women were undertaking IVF for the first time. Three women later withdrew from the study due to discontinuation of treatment or other reasons, leaving 14 participants completing the study. The majority of participants reported prior use of the Internet for health purposes a few times a month. Eight out of 14 participants reported using a computer, PDA or a mobile phone to keep track of their appointments and medications related to their IVF treatment.

System usage

Thirteen out of 14 participants accessed *healthy.me* during the study, generating 34 sessions in total, with each participant accessing the system six minutes on average at different times of the day over an eight-week IVF treatment program (Figure 2). Three sessions were excluded in the average duration calculation because each of these sessions consisted of more than 30 minute idle activity. All participants reported using *healthy.me* by themselves except for two participants who used the system once with their partners. No major usability problems were reported during the study, except that some participants reported uncertainty while updating their person health record because they forgot the names of nurses looking after them, unsure whether they were allowed to add and/or update entries, or how much or what was relevant to add into their personal health records (e.g. non IVF-related medications).
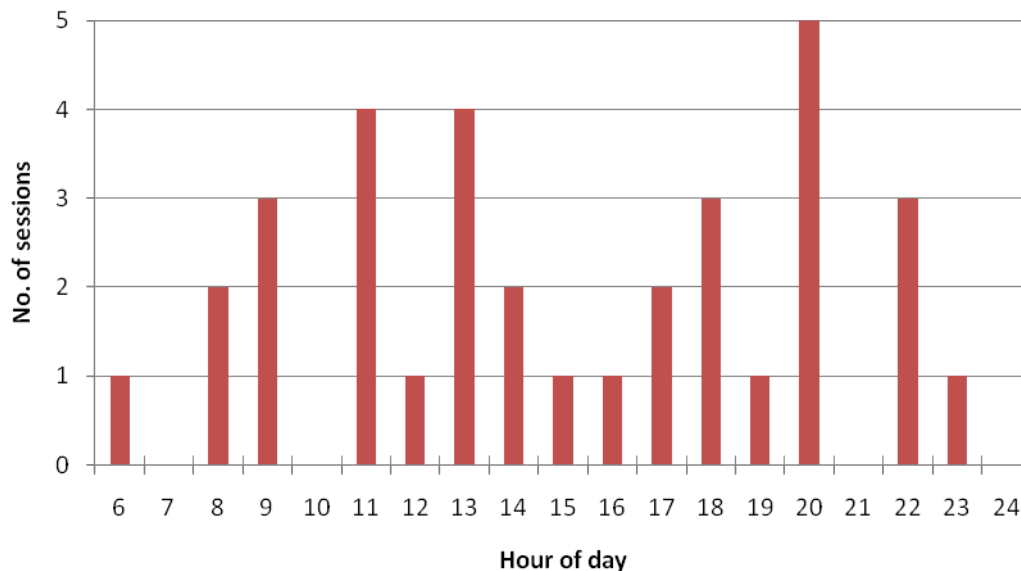

Figure 2. Participants' access to *healthy.me* by hour of day (n=34 sessions)

Participants accessed *healthy.me* between zero and nine times with 50% (7/14) accessing it only once and 43% (6/14) more than once during the study (Table 1). Two participants

accessed *healthy.me* regularly during their IVF treatment, with one participant continuously updating her schedule on *healthy.me* as she progressed through each stage in the treatment program.

Table 1. Frequency of participants accessing *healthy.me* (n=14 participants)

No. of sessions	Participants, No. (%)
0	1 (7%)
1	7 (50%)
2	2 (14%)
3	2 (14%)
More than 3	2 (14%)

Twelve participants accessed all features on *healthy.me*. Participants accessed *healthy.me* to obtain information about the next steps of their IVF treatment, as well as to view and/ or update details of their pillbox, schedule, test results and team features on *healthy.me* (Figure 3). Access to each feature reduced after the first visit, with *journey* displaying the least reduction (Table 2). 64% (9/14) participants accessed all features on *healthy.me* at their first visit. Only 14% (2/14) participants accessed all features at subsequent visits; the remaining participants accessed a subset of features, mainly journey, schedule and pillbox.
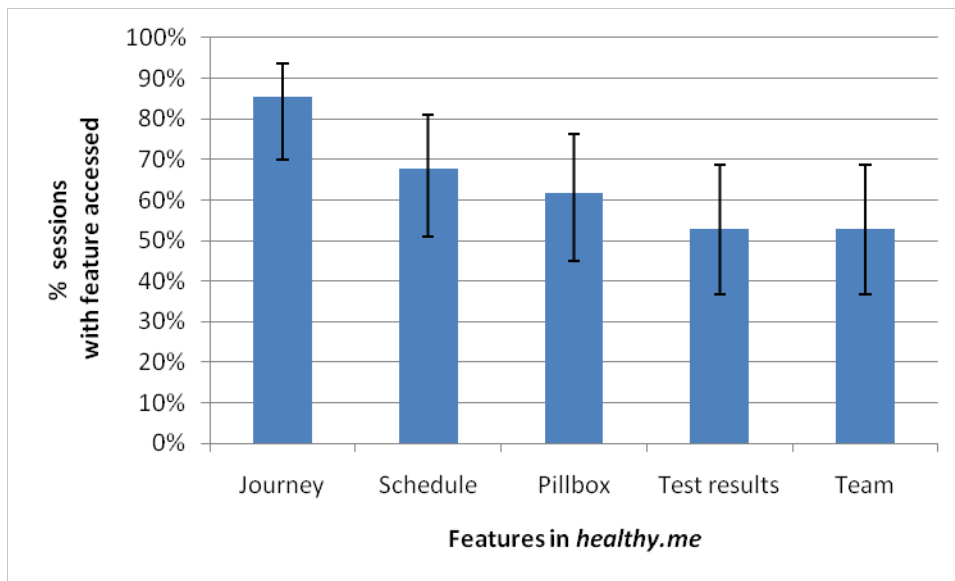

Figure 3. Participants' access to *healthy.me* by feature (n=34 sessions)

Table 2. Sessions and features accessed (n=34 sessions)

Feature	First visit (n=13)	Subsequent visit (n=21)	% Difference (first – subsequent)	Total (n=34)

Journey	12 (92%)	17 (81%)	11%	29 (85%)
Schedule	13 (100%)	10 (50%)	50%	23 (70%)
Pillbox	11 (85%)	10 (50%)	35%	21(64%)
Test results	12 (92%)	6 (30%)	62%	18 (55%)
Team	12 (92%)	6 (30%)	62%	18 (55%)

Six out of 14 participants added entries into their personal health record (Table 3), with four using the IVF module and two using manual methods to add entries, such as adding medications, appointments or contact details of their fertility specialist. Entries of their pillbox, schedule, test results and team were partially completed (Table 3), and updated sparingly during the eight-week period (Table 4). Examples of entries updated during the eight-week period include: entering frequency, start date and/or personal comments against a medication entry; entering location, date, time and to-do items, and/or setting email reminders for upcoming appointments; updating role of clinic staff and their contact telephone number; recording date and time of blood tests; and recording number of embryos transferred and frozen after embryo transfer procedure.

Table 3. Participants adding entries in their personal health record (n= 14 participants)

Feature	No. of entries added	No. of participants	Average (range) per participant	Example of entries added
Pillbox	15	5	3 (1–5)	insert new medication
Schedule	42	6	7 (1–12)	insert new appointments
My Team	10	5	2 (1–3)	insert details of their fertility specialist
Test results				
- Blood test	16	4	4 (4–4)	
- Imaging test	4	4	1 (1–1)	
- Other results	12	4	3 (3–3)	

Table 4. Participants updating entries in their personal health record (n= 14 participants)

Feature	No. of entries updated	No. of participants	Average (range) per participant	Example of updated entries
Pillbox	5	3	1.7 (1–3)	Update frequency, start date and/or entered personal comments against a medication entry
Schedule	11	4	2.8 (1–8)	Update location, date, time, to-do items, and/or set email reminder for upcoming appointments

My Team	5	3	1.7 (1–3)	Update role of clinic staff and their contact telephone number
Test results				
- Blood test	2	1	Not applicable	Update the date and time of blood tests
- Imaging test	0	0	Not applicable	
- Other results	1	1	Not applicable	Update the date, time and number of embryos transferred and frozen

Reasons and self-reported usefulness

Table 5 summarises the reasons participants reported for using or not using *healthy.me* during their eight-week IVF treatment. Some participants reported using *healthy.me* as a central place to store their personal health data, update their next appointment and test results, obtain information about the next steps of their treatment, or to clarify the "little things" one tends to forget or wants to know at each stage of their IVF treatment. Some participants reported not using *healthy.me* at the time they were interviewed because they were intentionally avoiding material related to IVF, their daily routine did not involve access to computers, or that they did not have time or information needs to access *healthy.me*.

Table 5. Participants' self-reported reasons for using or not using *healthy.me*

Using *healthy.me*	Not using *healthy.me*
Reason 1: Study participation	**Reason 1: Intentional avoidance**
• Curiosity / being part of the study	• Not wanting to think about IVF (e.g. worried about pregnancy outcome so intentionally stayed away from IVF material)
	• Information overload from initial research and managing IVF
Reason 2: Preferred information source	**Reason 2: Resources not available / using computers is not part of daily routine**
• Source of good information on medications and procedures	• Lack of time / too busy
• Good visual layout with flexible access to information via hyperlinks	• Work routine did not involve access to computers and the Internet
	• Could not find login details
Reason 3: Met information needs	**Reason 3: No new information needs / information needs being met already**

• Obtained overview and next steps of treatment program	• Not needing new information
• Provided reassurance with information before or after a procedure (e.g. embryo transfer)	• Information needs were already addressed by regular contact with the nurses

Table 6 outlines participants' self-reported usefulness of *healthy.me* during their eight-week IVF treatment. Two participants commented that *healthy.me* alerted them to seek advice from their doctors on critical issues they were not aware of during their treatment program (e.g. sexual practices and the order of ultrasound screenings after a sequence of blood tests). Other participants reported *healthy.me* would be useful for those who needed reassurance during their treatment program, allowing participants to check if they had the right information at each stage, as well as providing assistance with organizing their timetable and medication management:

> *Just I think it's a really good idea, you go through this and there are so many*
> *things going on and then it's really great to have one place to go where you can*
> *go and check information about everything from drugs to when your next*
> *appointment will be, what will happen in the next stage and it's quick to use, I*
> *actually think it's a really good concept.*

Some participants recommended *healthy.me* for those undergoing IVF the first time, as well as those contemplating the decision to undertake IVF treatment:

> *I'd say with IVF, as things change during the cycle you become ready for more*
> *information. So I would say I needed a lot of information up front before I*
> *made the decision to do it and then I didn't need any information for a while*
> *until I actually started the cycle and it was good to get information as the*
> *phases of the cycle were done.*

Some participants commented that *healthy.me* would have been more useful if the clinic updated their personal health record, or that the schedule feature integrated with their personal calendar software application. Some participants commented that providing additional informational support would have been useful, such as providing others' stories and experiences, dynamically updating journey content at each stage of the treatment program, or presenting information in different visual formats.

Table 6. Participants' self-reported usefulness of *healthy.me*

Useful / exceeded expectations	Not useful / did not meet expectations

Category 1: Alerted participants to events they were unaware of during treatment program	Category 1: PHRs not updated by clinic
• Alerted two participants to seek advice from their doctors on critical issues before egg collection.	• Expected clinic staff to update PHRs with test results, appointment details and instructions, given patient's permission.
• Alerted participant on the first ultrasound screening after a sequence of blood test procedures.	
Category 2: Central place of information	**Category 2: Not integrated with participant's calendar**
• Central place for storing and obtaining personal health data and treatment information.	• Online schedule not integrated with patient's personal calendar software application.
Category 3: Providing information reminders	**Category 3: Additional information needs**
• Provided handy reminders on when and how to take medications.	• Expected personally tailored information, access to others' stories and experiences, or information dynamically updated across different stages of the treatment program.

Desirable features for managing IVF treatment

Participants recommended seven additional features for *healthy.me* to manage their IVF treatment:

Feature 1: A personal health record which is preloaded by the clinic with the patient's medical history and names of personnel looking after the patient, maintained and accessible by the patient, which can be updated continuously by clinic staff with test results and subsequent appointment details during the treatment program given patient's consent:

> *… it would be great if it came up on your profile who your primary nurse is and your physicians contact details so you don't have to enter them all manually yourself… and then if your results became available, I mean they make an appointment for you,* [and] *you* [your] *subsequent appointments so if that all appeared on there that would be like a really easy tool to use, it would probably be a lot more useful.*

Feature 2: A schedule summarizing a list of "to-do" items on a daily basis, with a visual progress bar displaying the patient's status relative to a timeline on a patient's journey.

The schedule should integrate with the patient's personal calendar software application, visually displaying the upcoming step, with the capability of sending alerts or to-do list to the patient:

> *... something that could send alerts (or the to-do list) to your email without looking into it everyday would probably be quite helpful.*

> *... you know that calendar with the pictures, if it was somehow linked it would be handy and it showed you a progress bar of where you are going through that... having the time line (tailored to you).*

> *... I just do think it needs to be more of an integrated tool. If women use diaries or electronic calendars, if it could integrate with that that would be fabulous because then you could…. That's just the way things work these days. So being able (to use) like a plugin for a Microsoft calendar would be fabulous.*

Feature 3: Being able to engage with similar patients is important, such as those who have undergone IVF at the same clinic, on the same treatment program, or going through a fertility treatment program at the same time. This could take the form of an online chat room, discussion forum, email list or subscription to electronic information. Participants value the ability to ask questions from others who have had similar experience, such as "is this normal?", "what do I do?", "should I call the nurses?":

> *... I think that it would be beneficial to actually speak to someone who's actually been through it themselves. That would be extremely helpful... Even if it was just online or something, have some sort of central point where they meet people you know where you could send them a message and go "is this normal?" or you know should I call the nurses or such and such…*

Participants also value the ability to search for other patients' experiences and situations to find out what to expect, to seek reassurance, to clarify concerns, and to compare with similar others on medication in terms of frequency and dosage. As one participant summarized:

> *I've actually found speaking to a lot of girls on the forums going through the same sort of thing that a lot of the clinics differ in the names of the medications and the frequency that you take them...*

Feature 4: Being able to access a "warm expert" (such as a knowledgeable patient), or a clinician, and being able to seek answers to questions on the "little things" that are not-urgent but require clarification:

> *... an email contact like a focus group time thing where a professional can give you a quick response, that would always be really useful, but otherwise you just mull it over and work it out in the end...*

> *...it's only the little things that you don't listen to properly because you've got so much to take in and you are nervous about things.*

> *I think the thing I've found is that when I do have questions that I would like to ask a nurse I sort of thought 'oh no maybe that's a little silly' so I won't trouble them where as if it's just someone where it's a little less formal and weren't as busy as what the nurses are in there who you could just give a quick call to I think that would maybe help.*

Feature 5: Record one's own feelings, experience and concerns against events and stages on their IVF journey, and being able to reflect on it and share it with others:

> *Even if you could have a box when you're having a blood test where you can put in how you were feeling or if you were having any concerns at that stage. It's good to be able to go back afterwards to see how you were feeling and where you were at certain stages which I think would be beneficial to other people to be able to share that as well.*

Feature 6: A message box, such as email, where patients can contact the clinic staff (e.g. nurses) asynchronously for non-urgent matters. Clinic staff can also leave patients messages if they cannot be contacted (vice versa):

> *...if you had a quick question particularly in relation to a side effect or, my issue was do I need to stop taking one medication and it didn't really need a long time on the phone it could have been done with a quick email. That could have been a really easy way, a message or something like that if it was available.*

Feature 7: More information on different aspects relating to IVF, such as (i) a glossary on medical terms, (ii) detailed information on expectations, side effects, tasks, test results and the rationale for different treatment programs, (iii) age-based statistics on the success rates of treatment programs, (iv) detailed information on the biology, (v) information presented in a visual layout, such as timeline or flowchart, and (vi) journey updated with dynamic content at different stages of the treatment program.

Discussion

Main findings

A study of a web-based personal health management system called *healthy.me*, supporting 14 women over eight weeks needed to complete one in-vitro fertilization (IVF) treatment program, was conducted at participants' real-life setting at a major fertility clinic in New South Wales Australia from October 2009 to January 2010. Thirty-four individual sessions with an average duration of six minutes were recorded at different times of the day. Participants accessed the system to update their personal health record and/or to access information about the next steps of their treatment program. No major usability problems were reported during the study. Analysis of our system usage and interview data reveals high acceptance of the system, but with clear variation in usage profiles, and has also yielded several examples of *healthy.me* alerting participants to contact their doctor on critical issues they were not aware of during treatment.

Participants recommended seven additional features on *healthy.me* that would enhance the management of their IVF treatment. These include, (i) a personal health record that a patient can access with data preloaded and updated by the clinic (given patient's consent); (ii) schedule summarizing a list of "to-do" items, with a visual progress bar displaying the patient's status relative to the journey timeline, that can synchronize with one's personal calendar software application; (iii) the ability to engage with others who have had or are going through a similar experience; (iv) having access to a "warm expert" who can answer questions about the "little things" that matter in a patient's journey but may seem insignificant to others; (v) record one's feelings, experiences and concerns against events and stages in a journey, and share it with others; (vi) a mechanism to communicate asynchronously with clinic staff and similar others; (vii) more detailed, personally tailored and regularly updated information as one progresses through each stage of the treatment program. Although these features are recommended by participants undergoing IVF treatment, they may also be useful in the management of other healthcare conditions.

Comparison with other studies

Our results confirm with findings reported from Tuil and colleagues, who developed a web-based PHR for couples undergoing fertility treatment [17] and demonstrated in a randomized controlled trial that there are no significant adverse effects on patients using a PHR during their treatment [18]. Our system usage and interview data also iterate with their evaluation results with 51 couples, demonstrating that there are significant differences in website use during different stages of the treatment [19], and that patients need communication and support during the last stages of treatment when there is minimal contact between the patient and the clinic [17].

Our participation rate also aligns with other studies evaluating the use and utility of PHRs for consumers with other health conditions where usage reduces over the duration of the study. Kim and colleagues found that 62% (44/70) participants remained at the end of a 33-month study investigating PHR usage among low-income and/or elderly population

[20]. Other studies on PHR reported a participation rate of 9.3% to 25% among the general population [21-24]. Our average session duration of six minutes also aligns with other studies measuring amount of time participants spent on websites for other healthcare conditions (7 to 9 minutes) [25-26].

Limitations

There are several limitations in this study. First, participants undergoing IVF may not be representative of the general healthcare consumer population, who are often considered to be more self-sufficient, computer-literate, and empowered than consumers with other health conditions. However, when our participants were first presented with *healthy.me*, they expressed uncertainty as one would expect when faced with new technologies, such as being unsure on what kind and how much information to provide when updating their web-based personal health records. Second, participants were interviewed each week, which may have increased their usage of the system; yet, we did not find this trend in our system usage data.

Concluding remarks

Over a decade of research work has gone into developing an evidence-based approach to designing and creating the *content* in consumer decision support systems. However, not much research has examined the strategies needed to facilitate consumers to act on a decision, nor in studying consumers' needs as their health issues progress over time [27]. Web-based personal health records, with connectivity to a health service provider, containing condition specific information and tools that facilitate consumers to act on a decision and manage their condition, hold the prospect that the uptake of health services and the associated health outcomes should improve. However, that prospect at present remains a goal rather than proven certainty. More research is needed to examine how consumers use evolving e-health and personal health record technologies and assess the associated impact on their health outcomes and behaviors.

Conflicts of Interest

The university and researchers involved in this project could in the future benefit from any commercialization of *healthy.me* or its technologies, but no such commercial plans have been developed.

References

1.   Coiera E. Information Economics and the Internet. J Am Med Inform Assoc. 2000 May 1, 2000;7(3):215-21.

2.   Coiera E, Lau AYS, Tsafnat G, Sintchenko V, Magrabi F. The changing nature of clinical decision support systems: a focus on consumers, genomics, public health and decision safety. Yearb Med Inform. 2009;2009(1):84-95.

3.   Mandl KD, Kohane IS. Tectonic Shifts in the Health Information Economy. N Engl J Med. 2008 April 17, 2008;358(16):1732-7.

4.   Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. J Am Med Inform Assoc. 2006 Mar-Apr;13(2):121-6.

5.   Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. J Am Med Inform Assoc. 2008 Jan-Feb;15(1):1-7.

6.   Tulu B, Horan TA. The electronic disability record: purpose, parameters, and model use case. J Am Med Inform Assoc. 2009 Jan-Feb;16(1):7-13.

7.   Roblin DW, Houston TK, 2nd, Allison JJ, Joski PJ, Becker ER. Disparities in use of a personal health record in a managed care organization. J Am Med Inform Assoc. 2009 Sep-Oct;16(5):683-9.

8.   Weitzman ER, Kaci L, Mandl KD. Acceptability of a personally controlled health record in a community-based setting: implications for policy and design. J Med Internet Res. 2009;11(2):e14.

9.   Hoerbst A, Kohl CD, Knaup P, Ammenwerth E. Attitudes and behaviors related to the introduction of electronic health records among Austrian and German citizens. Int J Med Inform. 2010 Feb;79(2):81-9.

10.   Montelius E, Astrand B, Hovstadius B, Petersson G. Individuals appreciate having their medication record on the web: a survey of attitudes to a national pharmacy register. J Med Internet Res. 2008;10(4):e35.

11.   Wright A, Sittig DF. Encryption characteristics of two USB-based personal health record devices. J Am Med Inform Assoc. 2007 Jul-Aug;14(4):397-9.

12.   Frost JH, Massagli MP. Social uses of personal health information within PatientsLikeMe, an online patient community: what can happen when patients have access to one another's data. J Med Internet Res. 2008;10(3):e15.

13.   Kim MI, Johnson KB. Patient entry of information: evaluation of user interfaces. J Med Internet Res. 2004 May 14;6(2):e13.

14.   Lee M, Delaney C, Moorhead S. Building a personal health record from a nursing perspective. Int J Med Inform. 2007 Oct;76 Suppl 2:S308-16.

15.   Coiera E, Lau AYS. healthy.me: an online research platform to support consumer health management. Health Informatics Conference; 2010; Melbourne Australia: (accepted 09/04/2010).

16.   Verhaak C, Smeenk J, van Minnen A, Kremer J, Kraaimaat F. A longitudinal, prospective study on emotional adjustment before, during and after consecutive fertility treatment cycles. Human Reproduction. 2005;Aug;20(8):2253-60.

17.   Tuil WS, Verhaak CM, De Vries Robbe PF, Kremer JA. IVF patients show three types of online behaviour. Hum Reprod. 2008 Nov;23(11):2501-5.

18.   Tuil WS, Verhaak CM, Braat DD, de Vries Robbe PF, Kremer JA. Empowering patients undergoing in vitro fertilization by providing Internet access to medical data. Fertil Steril. 2007 Aug;88(2):361-8.

19.   Tuil WS, van Selm M, Verhaak CM, de Vries Robbe PF, Kremer JA. Dynamics of Internet usage during the stages of in vitro fertilization. Fertil Steril. 2009 Mar;91(3): 953-6.

20.   Kim E-H, Stolyar A, Lober WB, Herbaugh AL, Shinstrom SE, Zierler BK, et al. Challenges to Using an Electronic Personal Health Record by a Low-Income Elderly Population. J Med Internet Res. 2009;11(4):e44.

21.   Weingart S, Rind D, Tofias Z, Sands D. Who uses the patient internet portal? The PatientSite experience. J Am Med Inform Assoc. 2006;13(1):91-5.

22.   Hsu J, Huang J, Kinsman J, Fireman B, Miller R, Selby J, et al. Use of e-Health services between 1999 and 2002: a growing digital divide. J Am Med Inform Assoc. 2005;12(2):164-71.

23.   Ralston J, Hereford J, Carrell D. Use and satisfaction of a patient Web portal with a shared medical record between patients and providers. AMIA Annu Symp Proc. 2006;1070.

24.   Ralston J, Carrell D, Reid R, Anderson M, Moran M, Hereford J. Patient web services integrated with a shared medical record: patient use and satisfaction. J Am Med Inform Assoc. 2007;14(6):798-806.

25.   Lewis B, Williams D, Dunsiger S, Sciamanna C, Whiteley J, Napolitano M, et al. User attitudes towards physical activity websites in a randomized controlled trial. Prev Med. 2008;47(5):508-13.

26.   Leslie E, Marshall A, Owen N, Bauman A. Engagement and retention of participants in a physical activity website. Prev Med. 2005;40(1):54-9.

27.   O'Connor AM, Stacey D, Rovner D, Holmes-Rovner M, Tetroe J, Llewellyn-Thomas H, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2001(3):CD001431.