

# Comparative usage of a web-based personally controlled health management system and normal support: a case study in IVF

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## Abstract

**Background:** Research into the impact of personal health record-enabled consumer systems is still in its infancy. Little is known about effective designs of web-based personally controlled health management system (PCHMS), how people use these systems in their real-life settings, nor how usage relates to concurrent support from other sources.

**Objective:** To inform PCHMS design and feature development by assessing how patients undergoing in-vitro fertilization (IVF) use a web-based PCHMS in their real-life setting, and how their usage compares to concurrent support from other sources.

**Methods:** An in-depth formative evaluation study was conducted with 17 women undergoing IVF, who were invited to use a web-based PCHMS called Healthy.me, providing targeted IVF program information over an eight-week treatment. Online interactions were recorded on computer logs. Participants were interviewed weekly by telephone throughout their cycle, and were specifically questioned about their feedback of PCHMS and concurrent sources of support beyond that provided by the system. Interview data was coded and analysed using two-way repeated ANOVA.

**Results:** 62 interviews were collected from 14 participants who completed the study. Twelve of 14 participants accessed all features in Healthy.me, which included i) accessing information about the next steps of their treatment (i.e. journey), and ii) viewing or updating details in their pillbox, schedule, test results and team members during their IVF treatment. Healthy.me alerted 21% (3/14) participants to seek advice from clinic staff on issues that could affect treatment outcome of which they were previously unaware (e.g. sexual practices, frequency and order of ultrasound screenings after a sequence of blood tests). Patients additionally sought support from people, informational resource and organisational tools outside Healthy.me to help decide IVF and manage different stages of their treatment. There was a significant interaction between IVF stage and sources of support ( $F(10,50)=2.54$ ,  $p=.015$ ,  $\eta_p^2=.34$ ). Suggestions are presented on ways to tailor support at different stages of the IVF cycle using a PCHMS.

**Conclusions:** IVF patients seek support from the web-based PCHMS, and concurrently do so with other sources of support. More research is needed to inform PCHMS design that effectively tailors support for patients at different stages of their health journey.

**Keywords:** IVF; personal health record; Internet; women; self-management; health service

## 1 Introduction

Researchers and industry alike now 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” information should empower consumers and transform health services [1]. The last five years have seen social computing sites like Facebook and Twitter gain unprecedented community acceptance, and many similar commercial health sites are now in operation (e.g. [www.patientslikeme.com](http://www.patientslikeme.com)). More recently, the convergence of information access via search tools, personal health records (PHRs), online social networking, and information exchange between consumers and clinicians is enabling a new class of consumer decision support system[2].

Consumer informatics research is growing rapidly, led by the pivotal 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 [3]. Recently, Halamka, Mandl and Tang presented three case studies for PatientSite at Beth Israel Deaconess Medical Center, Indivo at Children’s Hospital Boston, and MyChart at Palo Alto Medical Foundation, sharing a decade of experiences in implementing integrated PHRs [4]. In parallel, researchers have conducted surveys, focus groups and interviews eliciting consumers’ attitudes and perspectives on PHRs, on issues such as privacy, equality, acceptability, early impacts, policy, and design requirements [5-9]. Others have looked at USB-based PHR devices and their security model [10], online conversations among consumers with access to each other’s web-based PHRs [11], data entry methods that increase the accuracy of patient-entered medical information [12], and the role of nursing in PHRs [13].

However, few studies describe the actual experiences of patients using a PHR to manage their health condition, and the implications on the design of PHR. This paper reports a formative evaluation study. It presents a quantitative analysis of how patients undergoing in-vitro fertilization (IVF) used a web-based personally controlled health management system (PCHMS), concurrently with traditional sources of support, over an eight-week IVF treatment program.

## 2 Methods

### 2.1 Intervention

Patients in this study were provided access to a web-based secured PCHMS called *Healthy.me*, which is de-

veloped at the Centre for Health Informatics, University of New South Wales. The PCHMS not only contains a PHR that allows patients and consumers to keep track of their personal health information, they can also i) access consumer-friendly information (‘journeys’) to support their engagement with health service providers, and ii) utilise web-based tools to assist with making decisions, organising tasks, and managing different areas of their health (not only restricted to IVF). Over the study, *Healthy.me* offered the following features [14] (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 to keep track of health-related appointments, to-do items, and sends email reminders.
4. Team: Allows for self-recording of clinical and non-clinical personnel looking after one’s health.
5. IVF journey: A lay description of the different stages a patient will undergo in their IVF treatment, including advice on what to expect and how to prepare for each stage, prepared by the health service provider.
6. Social features for this study included: i) a profile for each member to store and customise their personal information, and ii) the ability to send and receive messages with other members on *Healthy.me*.

### 2.2 The in-vitro fertilization setting

In-vitro fertilization (IVF) is one of the most common forms of fertility treatment. In Australia, fertility treatment is usually available from private health service providers, where the fertility specialist will individualise the patient’s treatment and recommend one of several treatment cycles, depending on the patient’s circumstances. Two of the most common treatment cycles are an Long Down Regulation Treatment Cycle (which takes 6–8 weeks) [15], or an Antagonist Treatment Cycle (which is usually shorter in length) [15].

An IVF treatment cycle involves undertaking a complex sequence of medications and test procedures, and carries risks of both physical and psychological side-effects [16]. Surveys have shown infertile couples from all socioeconomic levels use the Internet to understand

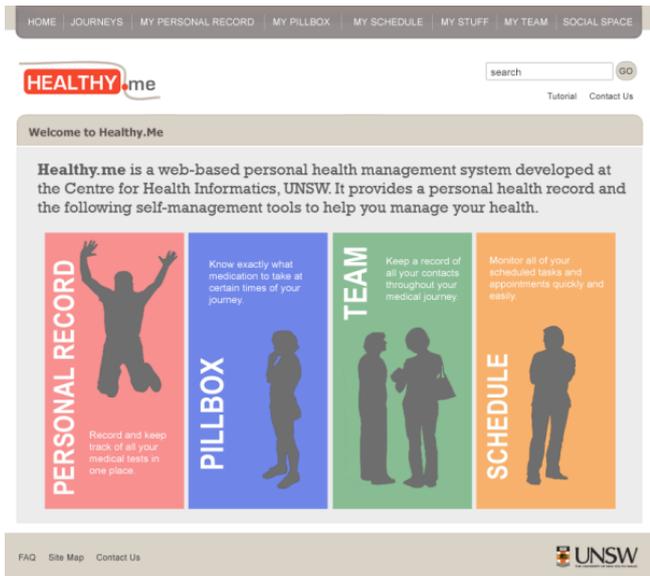


Figure 1: Features in *Healthy.me* (© University of New South Wales, 2009–2012)

their fertility-related problems [17, 18], and most are interested in using web-based applications to assist with their fertility care, such as obtain online access to their personal medical information and results of diagnostic tests [17]. To our knowledge, there are few if any web-based applications in Australia that facilitate a health service provider to help its patients manage the tasks involved in managing their health condition in conjunction with the service provider.

To address the informational and organisational needs of patients undergoing IVF, one of the journeys in *Healthy.me* was iteratively developed in consultation with clinical staff at a major fertility clinic in New South Wales, Australia, using patient material developed by the clinic and established practices and protocols to manage patients for IVF treatment. This IVF journey on *Healthy.me* supports patients undergoing a long down regulation (agonist) IVF treatment program [15], which includes an intensive sequence of blood tests, ultrasound screenings, day surgery procedures (egg collection and embryo transfer), and involves multiple clinical appointments and medication tasks (including self-administered nasal sprays and intramuscular injections) over a six to eight week period.

The six major stages of a long down regulation (agonist) IVF treatment program were:

1. **Decision:** Patients learnt about the process and made the decision with their fertility specialist to undertake IVF treatment.
2. **Nasal Spray:** Patients commenced their IVF treatment by taking GnRH analogue medication either

in a self-administered nasal spray (Synarel) or injection form (Lucrin).

3. **Injections:** Once hormones were “down regulated”, patients commenced follicle stimulating hormone (FSH) treatment by self-administering intramuscular injection. Patients were required to attend the clinic every few days, where nurses closely monitored with blood tests and ultrasounds until attaining an optimum number and size of developed follicles for the human chorionic gonadotropin (hCG) trigger.
4. **Egg collection:** Egg collection was undertaken in a day surgery/hospital under a light general anesthetic.
5. **Embryo transfer:** A few days after egg collection embryos were transferred back into the uterus.
6. **Pregnancy test:** Patients were advised to continue with progesterone medication until pregnancy test. The two-week period in-between the embryo transfer and the pregnancy test could be an emotionally difficult period [14].

Two usability testing sessions were conducted in a controlled setting with six women of different ages and familiarity with computers. Substantive usability issues were resolved before recruiting patients undergoing IVF treatment to participate in their real-life setting.

### 2.3 Participant recruitment

Posters to recruit patients about to undergo an IVF treatment program were distributed by nurses at four metropolitan branches of a major fertility provider in New South Wales Australia from October 2009 to January 2010. Patients were recruited in-person or using the telephone by a research team member. They were provided with a 5-minute mandatory online tutorial describing features of *Healthy.me*. The system was only available to patients during the study. Clinicians were not recruited to participate in the study but participating patients were allowed to contact and interact with their clinicians during the study. The inclusion criterion was that participants needed to be patients of the long down regulation (agonist) IVF treatment program at the fertility clinic. Participants were excluded if they did not have access to the Internet at home. Ethics approval from the Human Research Ethics Advisory Panel at UNSW was obtained for this study.

## 2.4 Procedures

Participants were asked to use *Healthy.me* for eight weeks (or until their IVF treatment was over). On-line interactions on *Healthy.me* were recorded on computer logs. At recruitment, participants undertook a 10 minute semi-structured interview (in-person or telephone), eliciting demographic details and various sources that helped them decide undertaking IVF (i.e. decision stage). Participants were then contacted by telephone each week until their treatment was complete for a 10 minute semi-structured interview to elicit their feedback on *Healthy.me* and to identify other sources of support used over the past week, including at the last week of their treatment cycle.

## 2.5 Data coding and analysis

Data from the structured interview questions were coded to analyse use of additional sources of help (non-*Healthy.me*) sought during the study. Qualitative feedback on *Healthy.me* is not presented in this paper. Interview transcripts were audio-recorded, transcribed and coded for informational, practical and emotional support, sought from various sources when deciding and managing IVF. Code categories for sources of support were i) *people* (e.g. clinicians, healthcare providers, partners, family, friends or acquaintances who have experienced or aware of others who have undertaken IVF treatment); ii) *resource* (e.g. books, patient educational pamphlets, websites, DVD, or informational material provided by clinic); and iii) *tools*, e.g. calendars and reminder alarms (paper, mobile phone or computer), timeline of IVF treatment, menstrual cycle chart, or personal diaries). Mentions of using *Healthy.me* were excluded from analysis of these additional sources of support.

The coding process was conducted by AP; AL independently reviewed 10% of data randomly selected in each code category to ensure consistency. Two-way repeated measures analysis of variance (ANOVA) was conducted using PASW Statistics 18 to determine differences between sources of support over different stages of deciding and managing an IVF treatment program. Contrasts were applied to identify specific differences where significance was found. Descriptive statistics were applied to computer log data.

## 3 Results

### 3.1 Participants

Seventeen women were recruited, aged from 27 to 43. All of which but two were undertaking IVF for the first

time. Three withdrew from the study due to discontinuation of treatment or other personal reasons. Sixty-two interviews from 14 participants were collected during the study. The majority (12/14) reported prior use of the Internet for health purposes at least few times a month. Eight of 14 participants reported using a computer or a mobile phone to keep track of appointments and medications related to their IVF treatment.

### 3.2 Usage of *Healthy.me*

Utilisation rate of *Healthy.me* during the study is described in [14]. Twelve of 14 participants accessed all features in *Healthy.me*, which included i) accessing information about the next steps of their treatment (i.e. journey), and ii) viewing or updating details in their pillbox, schedule, test results and team members during their IVF treatment (Table 1). Access to each feature reduced after the first visit to *Healthy.me*, with the IVF journey having the least reduction (Table 1). Sixty-four percent (9/14) participants accessed all features at their first visit to *Healthy.me*. Only 14% (2/14) accessed the system at all stages of their IVF treatment, with the remaining participants accessing a subset of features, mainly journey, schedule and pillbox at different stages of their treatment.

Six of 14 participants added entries into their PHR, with four using the IVF journey and two manually entering data into the record. Entries were added in the pillbox, schedule, test results and team sections, and updated during the eight-week period. Examples of additions and updates include i) IVF and non-IVF medications (e.g. name, start date, and personal comments); ii) appointments (e.g. upcoming blood test, location, date, to-do items, and email reminders), iii) details of fertility specialist (e.g. name, role, contact number), and iv) test results (e.g. date and time of blood tests, and number of embryos transferred and frozen).

Some participants (4/14) reported uncertainty while updating their PHR because they i) forgot names of nurses looking after them (1/14), ii) were unsure whether they were allowed to add and/or update entries (2/14), or iii) how much or what was relevant to add into their PHR (e.g. non IVF-related medications) (1/14). Two participants accessed *Healthy.me* at each stage during their IVF treatment. One participant continuously updated her schedule as she progressed through each stage in the program. 21% (3/14) participants reported using *Healthy.me* has alerted them to seek advice from clinic staff on important issues that would affect their treatment outcome, which they were unaware of previously (e.g. sexual practices, frequency and order of ultrasound screenings after a sequence of blood tests).

Feature	First visit (n=13)	Subsequent visit (n=21)	% Difference	Total (n=34)
IVF 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 re-sults	12 (92%)	6 (30%)	62%	18 (55%)
Team	12 (92%)	6 (30%)	62%	18 (55%)

Table 1: Sessions and features accessed (n=34 sessions)

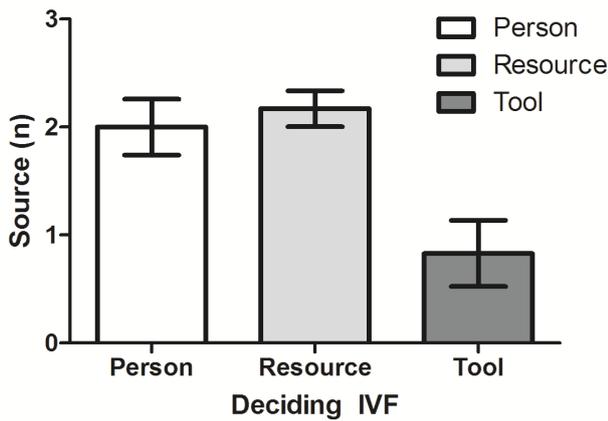


Figure 2: Sources of help participants sought or received deciding on IVF (mean±SEM)

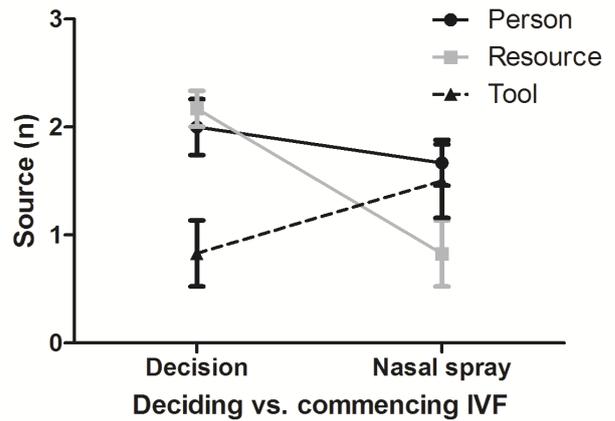


Figure 3: Comparison of sources of help participants sought or received from deciding on IVF to commencing IVF (mean±SEM)

### 3.3 Concurrent sources of help

Patients were interviewed about concurrent sources of support, coded into three categories: i) *people* (e.g. clinicians, partners, other patients); ii) *resource* (e.g. pamphlets, websites, material provided by the clinic); and iii) *tools* (e.g. mobile phone alarms, menstrual cycle chart, personal diaries). Table 2 shows significant differences in the rates these concurrent sources of support were used ( $F(2,10)=9.65, p=.005, \eta_p^2=.66$ ). The frequency of consulting a person was significantly higher than for using informational resource ( $F(1,5)=54.20, p=.001, \eta_p^2=.92$ ).

There was a significant interaction between the IVF stage of a patient and sources of support used ( $F(10,50)=2.54, p=.015, \eta_p^2=.34$ ), when deciding on IVF (Figure 2), and transitioning to commence IVF (Figure 3). When deciding on IVF, participants consulted more people ( $F(1,5)=7.35, p=.04, \eta_p^2=.60$ ) and accessed more informational resource ( $F(1,5)=15.00, p=.01, \eta_p^2=.75$ ) (both relative to number of tools used) than when commencing IVF (i.e. nasal spray) (Figure 3).

Participants also consulted people, accessed infor-

mational resource, and used tools to manage their IVF treatment. However, a different combination of these sources was used when managing the treatment (Figure 4). Once participants commenced IVF, they used more tools (relative to informational resource) at each stage during IVF, compared to when deciding on IVF ( $p<.038$ ). As the IVF treatment progresses, the number of sources used in each category (person, informational resource, and tools) remains consistent and does not differ significantly, both compared to the preceding stage ( $p>.05$ ) or since commencing IVF (i.e. nasal spray) ( $p>.05$ ).

### 3.4 Comparison of *Healthy.me* and concurrent sources of help

Although participant access of *Healthy.me* decreased over the course of IVF treatment, participant use of a concurrent source of support (i.e. people, resource, or tools) remained relatively consistent throughout different stages of treatment (Figure 5). Combining access rates of all 14 participants, the frequency of accessing *Healthy.me* at each stage ranges from 3 to 13 sessions,

Source of help	Stage of IVF <sup>a,b,c</sup>						Stage	F, p, $\eta_p^2$	
	1	2	3	4	5	6		Source	Stage × Source
<b>Person</b>	2.0 (0.6)	1.7 (0.5)	2.2 (1.2)	2.2 (0.8)	1.7 (0.5)	2.2 (1.0)	F(5,25)=.79, p=.57, $\eta_p^2$ =.14	F(2,10)=9.65, p=.005, $\eta_p^2$ =.66	F(10,50)=2.54, p=.015, $\eta_p^2$ =.34
<b>Resource</b>	2.2 (0.4)	0.7 (0.5)	0.7 (0.8)	0.8 (0.4)	0.8 (0.4)	0.8 (1.2)			
<b>Tool</b>	0.8 (0.8)	1.3 (1.0)	1.8 (0.4)	1.7 (0.8)	1.7 (0.8)	1.3 (1.0)			
<i>Healthy.me</i>	N/A	1.0 (0.6)	0.6 (1.0)	0.4 (0.7)	0.2 (0.4)	0.2 (0.4)	N/A		

Table 2: Sources of help participants sought or received at each stage of IVF. <sup>a</sup> Values are means (SD), reported in number of sources of help sought or received; N/A means not applicable. <sup>b</sup> Stage of IVF: 1=Decision; 2=Nasal spray; 3=Injection; 4=Egg collection; 5=Embryo transfer; 6=Pregnancy test. <sup>c</sup> Mauchly's test indicated no violation of assumption of sphericity for main effect stage  $\chi^2(14)=20.07$ ,  $p = .23$  and main effect source,  $\chi^2=2.41$ ,  $p = .30$ .

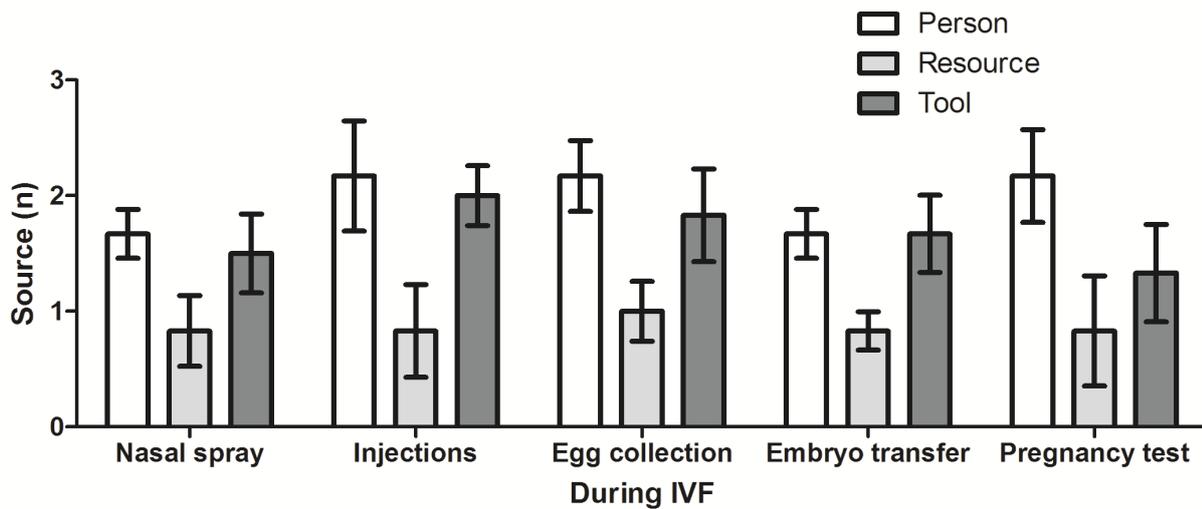


Figure 4: Sources of help participants sought or received at different stages while managing IVF (mean ± SEM)

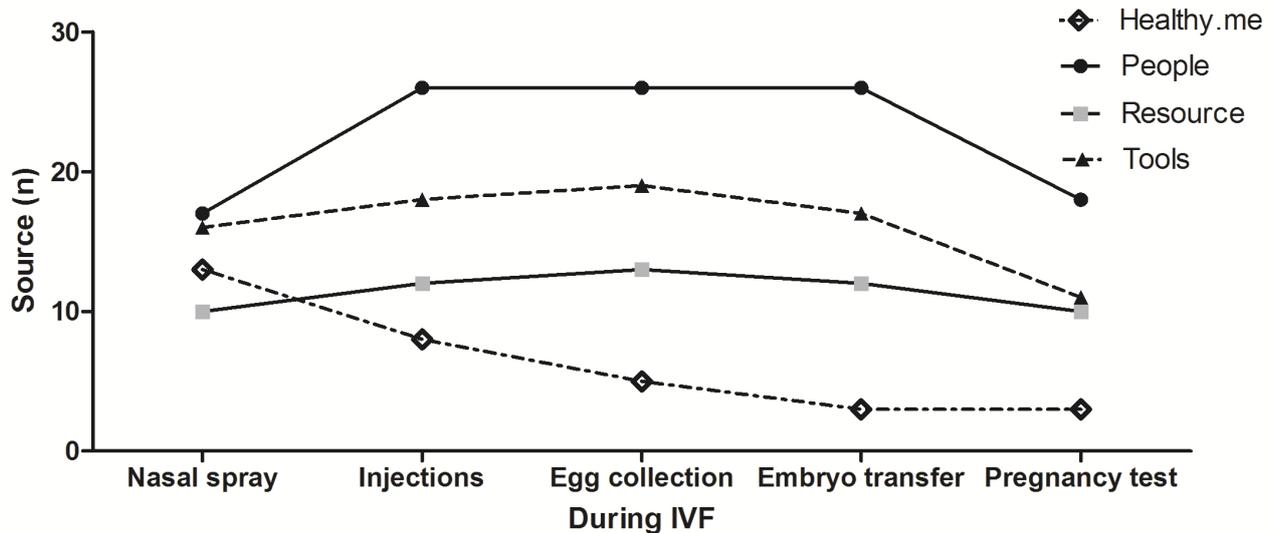


Figure 5: Total frequency of *Healthy.me* access and number of sources of support sought concurrently during IVF treatment for all participants combined

the number of persons whose help was sought at each stage varies from 17 to 28, number of informational resources from 10 to 13, and the number of tools used from 11 to 19 (Figure 5).

## 4 Discussion

### 4.1 Principal Results

Our findings with IVF patients over an eight-week period show that patients not only used a web-based PCHMS, but also concurrent sources of support to help decide IVF and manage their IVF treatment. Although participant access to *Healthy.me* decreased over the course of treatment, the frequency of seeking concurrent sources of help remained consistent throughout the course. In fact, the large number of concurrent sources accessed by participants at each stage of treatment suggests that designs of PCHMS should also facilitate patient access to their *traditional* sources of support (people, resource and tools), at different stages of their health.

The frequency of seeking support from people, informational resource and organisational tools differed significantly overall ( $p=.005$ ) and across stage ( $p=.015$ ). People remain the most frequently accessed source of support regardless of whether patients are deciding or managing IVF treatment. Usage of web-based tools (IVF journey, schedule, pillbox, test results, and team) appeared to enhance the interaction between patients and their care team. Although half the participants only accessed the system once during the study, those who accessed the system more than once reported instances

where the system alerted them to seek advice from clinic staff on important issues that would affect their treatment outcome of which they were unaware of previously (e.g. sexual practices, frequency and order of ultrasound screenings after a sequence of blood tests).

### 4.2 Comparison with prior work

Our results concur with findings reported by Tuil and colleagues, who developed and studied a web-based PHR for couples undergoing fertility treatment [19-21]. They demonstrated differences in website or information use at different stages of IVF [19], and that patients continued to need communication and support during the last stages of treatment when contact between the patient and the clinic was minimal [21]. This study extends these studies by illustrating a range of traditional sources of support that were used concurrently with a web-based PCHMS, at different stages of deciding and managing IVF treatment. It also concurs with a study that shows patients access a variety of support sources (e.g. people and tools) in addition to online information for IVF treatment [15]. This study also demonstrates that patients' access to human support, informational resource and tools happens in a broader context of interactions, external to a web system. These interactions seem to vary depending upon the stage of fertility treatment, which warrant further investigation to support patients' needs at different stages of their treatment program.

Participant activity reduced during the study, which is in common with other PHR studies. Kim and colleagues found that 62% of participants remained at the end of a

33-month study that investigated PHR usage among low-income and/or elderly population [22]. Other studies reported a PHR participation rate of 9.3% to 25% among the general population [23-26].

#### 4.3 Implications on personally controlled health management system for fertility treatment

Fertility treatment can be an intensive and a deeply emotional experience for women [14], which is possibly one of the reasons for reduced system engagement during the study. Variations in usage of a PCHMS and other concurrent sources of support suggest that a more tailored approach, which incorporates patients' traditional sources of support, as well as new sources of support that lie outside the patients' network, could be of significant benefit to patients at different stages of their health journey. For example:

- During *nasal spray* and *injection*, i) online videos that educate patients on how to administer the medication, and ii) online/mobile phone tools that facilitate the booking of appointments, sending reminders for medication administration, and upcoming appointments, could be helpful.
- During *egg collection* and *embryo transfer*, an asynchronous mode of communication (e.g. an online discussion forum) with healthcare professionals and past/present patients could potentially i) reduce the anxiety one may face with these procedures, and ii) reduce the level of interruption to clinical staff at the health service from traditional mode of synchronous communication (e.g. telephone);
- For patients awaiting the results of their *pregnancy test*, telephone calls from a healthcare professional to deliver news of pregnancy outcome, and to monitor the emotional state of the patient during the wait, would be most appropriate at these sensitive moments.

#### 4.4 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 proactive than patients 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 PHRs. Second, participants were interviewed each week, which may have increased their usage of the system. However, we did not see this trend in our system usage data. Third, generalisability of our findings is limited by a small sample size, conducted on a single IVF treatment protocol at one fertility clinic across four metropolitan branches. Our recruitment rate was affected by the Christmas/New Year holiday season. A typical IVF treatment requires six to eight week and our recruitment commenced in October. Fewer women than usual decided to undertake IVF treatment during this period, and doctors recommended alternative treatment programs that were shorter in length. Although 14 patients remained at the end of the study, 62 interviews were collected during the study, which is substantial to illustrate an overview of IVF patient experiences. Future studies should avoid the holiday season when recruiting IVF patients for research studies.

## 5 Conclusions

Over a decade of research work has gone into developing an evidence-based approach to designing and creating *content* in consumer decision support systems [29]. However, there has been little research into the actual experiences of consumers using a web-based PHR. Further research is needed to inform design of PCHMS that effectively supports consumers and patient to manage different stages of their health. In particular, conducting formative evaluation studies with patients utilising a PCHMS in their real-life study could i) clarify the characteristics of different stages and the various journeys that patients may experience, ii) identify ways of incorporating patients' and consumers' traditional and new sources of support, and iii) understand how best to utilise different delivery medium to support the variety of health management tasks consumers undertake for different health conditions at different health service providers.

Web-based PCHMS, with connectivity to a health service provider, providing access to people, resources and tools, hold the prospect that 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 inform effective PCHMS designs, examine how consumers use emerging e-Health and PHR technologies, and assess the associated impact on their health outcomes and behaviors.

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## Conflicts of interest

The university and researchers involved in this project could in the future benefit from any commercialisation of *Healthy.me* or its technologies. JE is an employee at IVFAustralia.

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