Symbiosis

www.symbiosisonline.org
www.symbiosisonlinepublishing.com

Research article | Journal of Computer Science Applications and Information Technology | Open Access

Personal Health Records in Maternity care "a process evaluation"

Carola JM Groenen[1]*, Noortje TL van Duijnhoven[1], Frank PHA Vandenbussche[1], Marjo J van Hoogstraaten[3], Marjan J Faber[2], Jan AM Kremer[2]

[1]Radboud university medical center, Department of Obstetrics and Gynaecology, Nijmegen, The Netherlands
[2]Radboud university medical center, Radboud Institute for Health Sciences, Nijmegen, The Netherlands
[3]Verloskundige praktijk, Beuningen, The Netherlands

Received: January 03, 2017; Accepted: January 10, 2017; Published: January 20, 2017

***Corresponding author:** Carola JM Groenen, Radboud university medical center, Department of Obstetrics and Gynaecology, P.O. Box 9101, 6500 HB Nijmegen, The Netherlands, Tel: +31643832565; E-mail: carola.groenen@radboudumc.nl*

Abstract

Background: Personal Health Records [PHR, a private, secure, online environment for patients] have been reported to empower patients, to achieve better collaboration between health care professionals and to improve outcome. This process evaluation study explores the feasibility of the introduction of PHR in Dutch maternity care and possibilities for sustainable implementation.

Methods: A process evaluation study was carried out alongside the entire period of the effect study. Quantitative and qualitative methods were used and described reach, dose delivered en dose received of the intervention.

Results: 88% of the target population was reached, while 4% started a PHR [dose delivered] and 83% [out of 4%] used the PHR as intended [dose received].

It took more time for the professionals to integrate this new intervention into their care process than expected before. Pregnant women did not start a PHR when they favoured an alternative way to communicate with the health care professional or when they felt the PHR lacked additional value. Active involvement of the professional in the patients PHR is explicitly mentioned as desirable by pregnant women.

Conclusions: The introduction of a PHR in maternity care is feasible, requiring the following steps: a dialogue between patients and professionals about expectations and wishes, sufficient time for the implementation, using early adopters as part of the implementation and integration of the PHR in standard care.

Introduction

Personal Health Records [PHR] are introduced in health care to support patient centered care [1]. PHRs have variable designs and features, but they all share being an online application through which individuals can access, manage and share their health information in a private, secure, and confidential environment. Furthermore, PHR facilitates the communication among the network of health care professionals surrounding the patient [2, 3]. PHR have been reported to empower patients, to achieve better collaboration between health care professionals and to improve health outcome [2, 4-6]. These intended benefits of a PHR are welcome in any setting of health care, in order to achieve higher standards of care.

Professionals in maternity care in the Netherlands face challenges in optimizing care for mother and child. Active involvement of the pregnant woman and better collaboration between health care professionals are two explicitly mentioned requirements in the new Dutch Guideline Integrated Maternity care [7]. Given the documented positive effects of a PHR, the introduction of PHRs in maternity care might be a possibility to achieve higher standards of maternity care. However, the introduction of a complex intervention as a PHR should not be underestimated. Earlier studies have confirmed that implementation uptake is often the largest challenge of any E-Health project, for patients as well as health care professionals [8, 9]. Previous studies also identified multiple barriers that should be taken into account when designing an implementation strategy. Main barriers identified by patients were no experienced personal value and technical and usability problems with the tool [10, 11]. Main barriers identified by health care professionals were resistance to change, lack of payment, added work, lack of management support and no patient demand [12].

Based on lessons learned from earlier studies we designed a study to introduce a PHR in Dutch maternity care, named MyPregn@ncy, using a stepped-wedge design for the evaluation. Stepped-wedge trials are often used for the evaluation of service delivery interventions [13]. In essence, a stepped-wedge cluster randomised controlled trial is a one-way crossover cluster trial in which all study groups will receive the intervention, but the time when they receive this, is randomly ordered [14]. Effects of the introduction of the PHR in our study were measured at levels of health care outcomes, quality of care and collaboration between health care professionals. The results regarding the effects will be published in a future/prospective article. According to the principles of process evaluation [15, 16], the effectiveness of the introduction of MyPregn@ncy will be evaluated after this process evaluation. To complement the findings on effect measures, we

closely monitored the introduction of the PHR systematically. Such a process evaluation is essential to gain insight into the various interacting components of complex interventions in a trial context [15-17]. The aim of this paper is to present the process evaluation of the introduction of MyPregn@ncy in maternity care. By doing so, we explore the feasibility of this intervention and possibilities for sustainable implementation.

Methods

The current process evaluation was carried out alongside the stepped-wedge cluster randomised controlled trial studying the effectiveness of introducing a PHR in maternity care. Details on the study design have been described in the study protocol [18].

Ethical approval

The medical ethical committee of the Radboud university medical center has awarded full ethical approval for this project [CMO No. 2011/381]. The study has been registered at the Dutch Trial Register [NTR4063].

Setting and study population

The study was performed in Nijmegen, a single regional collaborative area in the Netherlands with an average of 4.500 births a year and over 220 health care professionals involved in maternity care. Maternity care was offered by community-based midwives working in 11 independent practices, and by hospital-based midwives and obstetricians [in training], working in two different hospitals [one providing secondary care and one providing secondary and tertiary care]. All health care professionals agreed to participate.

The Intervention

The intervention in this study was the introduction of a PHR to individual pregnant women, independent of gestational age and care setting, *i.e.* she was offered the possibility to start her PHR [MyPregn@ncy]. After registering on a secured website, she decided who was granted access to her PHR and therefore became a member of her personal care team. Functionalities of MyPregn@ncy included: communication with care team members, a diary [blogging feature], a library [storage of important documents], and interactive [medical] modules specifically developed for pregnant women. All team members in one PHR could access all fields in the PHR and could add, act or react. All activities were logged, so the owner had full insight in all delivered input.

Implementation strategy

To successfully implement the PHR, it was initially important that all health care professionals informed the pregnant woman about MyPregn@ncy. Therefore, the professionals must understand the use and possibilities of MyPregn@ncy to explain it correctly to pregnant women. They were all provided with a professional profile, so the pregnant women could invite and add them in their care team and the professionals could actively participate in their PHR. To achieve optimal preparation and propagation of the tool, we created various information leaflets and an informational and supporting website: www.mijnzwangerschap.org. Furthermore, we visited each participating midwife practice and obstetric clinic to explain MyPregn@ncy and the study design. In addition to the face-to-face information by their health care professionals, pregnant women were reached by local newspapers and by a short movie on digital information screens in the practices and clinics. During the study, researchers were available for questions and clarification for both pregnant women and health care professionals. Finally, involved health care professionals received regularly information letters on the progress of the study.

Process measures and data collection

We developed a framework describing evaluation components, based on elements of frameworks provided by Saunders et al. [19] and Hulscher et al. [17]. Quantitative and qualitative data were collected during the entire study period, using various techniques.

Table 1 presents an overview of the used process measures, the data collection methods, the process variables and accompanying research methods.

Our framework was composed of the following the three elements:

Reach: proportion of the target population [all pregnant women during the study period] that received the intervention [offering a PHR]. Quantitatively, reach was registered by the midwives and obstetricians. Quantitatively, reasons if not received were collected by questionnaires of professionals in each midwife practice or hospital.

Dose delivered**:** proportion of the reached pregnant women who actually started her PHR. Quantitatively, dose delivered was based on the number of PHRs in a community-based midwife practice or hospital during the study period. Qualitatively, it was based on barriers and facilitators to start a PHR, derived from 263 questionnaires completed by pregnant women and one focus group of nine professionals.

Table 1: Process measures, collection methods, process variables and research method

Process Measure	Collection Method	Process Variable	Research Method
Reach	Registration by professionals Questionnaire	Percentage of pregnant women Reasons	Quantitative Qualitative
Dose delivered	Weblog Questionnaires and Focus group	Number of individual PHR Barriers and facilitators	Quantitative Qualitative
Dose received	Weblog Interviews and Field notes	1. Number of sessions 2. Number of relations 3. Discussion threads 4. Downloads of medical modules Experiences	Qualitative Qualitative

Dose received: the extent to which the pregnant women used her PHR as recommended. Quantitatively, dose received was described by [anonymous] log data of the PHR, which were automatically monitored throughout the study period. Outcomes derived from these logs were number of sessions, number of relations, discussion threads and number of downloads of each medical module. Qualitatively, experiences of the PHR by patients and professionals were collected in 65 interviews and field notes. The short interviews with pregnant women were based on a topic list and were performed during three information sessions on pregnancy and birth. Field notes were registered systematically during the entire study period.

Data analysis

Log data were analysed using SPSS [version 20.0 for Windows: SPSS Inc., Chicago, IL, USA]. Interviews and the focus group were transcribed by the interviewer. Two researchers [CG en NvD] read and analysed the transcripts. The principles of thematic content analysis were followed. The transcripts and field notes were coded openly and then organised in subcategories.

Results

Quantitative results are summarized in Figure 1.

Reach

The PHR was offered to 3.925 pregnant woman, this was 88% [range 70 -100%] between practices and clinics of all pregnant women in care. Reasons mentioned by professionals as to why reach was not 100%, achieved were [1] more time was necessary to implement this new tool and incorporate it in standard routine care and [2] there was lack of continuity on peak moments of care in the practice. One site explicitly mentioned that this study started in their hospital at the same time as the transition to a new electronic medical record system. Therefore, there was less attention for this study.

Dose delivered

At the end of the study, 157 pregnant women activated their MyPregn@ncy after being informed by their health care professional [4%]. Large variation was present between sites and over time. One midwife practice revealed 0% pregnant women who activated a PHR, while another midwife practice included 90% of all pregnant women at the end of the study period.

Figure 2 presents an overview over time of the numbers of pregnant women who started MyPregn@ncy.

Patient questionnaires were answered by 263 pregnant women, a response of 90%. Mean reasons for patients not to start a PHR was '*I prefer another way of contact*' [69%], followed by '*I think it has no added value*' [56%]. 16% of the pregnant women expected difficulties with the tool. Another 16% mentioned that a feeling of insecurity was a reason not to start a PHR.

The main barrier mentioned by the professional focus group members was to integrate a new tool in their care program, '*being an additional service and not a necessity*' [95%]. Furthermore, it took more time to completely know all the elements of the PHR tool. During the focus group meeting, the members searched and discussed ways to improve this. This resulted in an underlying barrier, namely the required attitude change in care roles by the professionals [*e.g.* online questions, different professionals/ organisations involved in one PHR]. Professionals shared their concerns regarding time consuming online availability for their patients.

Dose received

Of the users, 27 visited MyPregn@ncy only once [17% non-active users], while the other 130 accomplished at least two log in sessions [83% active-users]. Table 2 presents the log data of the active users. 44% of the users downloaded one of more medical apps.

The app 'birth wishes' was downloaded the most [38,5%], more than two times as much as the app 'depression scale' [16,9%]. The PHR included communication with care team members and the use of medical apps. Log data showed no notable difference between the use of communication aspects or the use of medical apps. However, the interviews showed that the communication part was the most important reason to start a PHR. Almost all pregnant women mentioned that they will start a

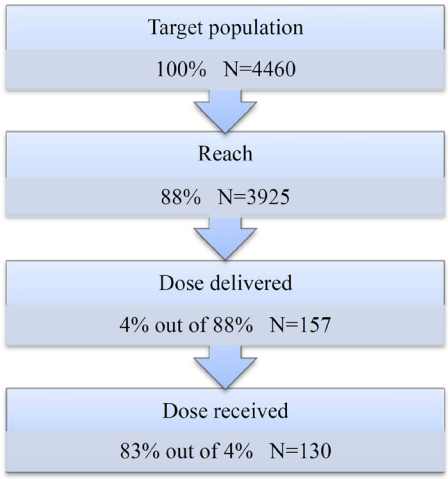

Figure 1: Quantitative results

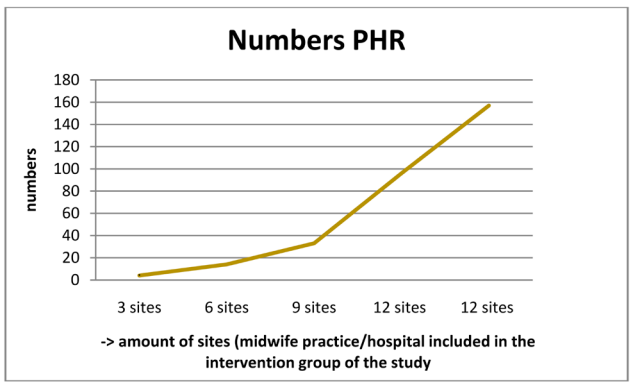

Figure 2: Number of pregnant women who started a PHR over time

Table 2: Pregnant women use PHR (N=130)		
Overall*	**Number of sessions**	**6,5 (5,0)**
Communication*	Number of relations	1,6 (1,0)
	Discussion threads	2,3 (2,0)
Medical Apps**	One of more downloads	57 (44, 0%)
	- Module Birth wishes	50 (38, 5%)
	- Module Baby moves	31 (23, 8%)
	- Module Prenatal visits	29 (22, 3%)
	- Module Depression scale	22 (16.9%)
*Mean (median) **Frequency (percentage)		

PHR when they expect problems in pregnancy or when they want more information or contact with the professionals. Most women mentioned at the same time that everything was going well or that they were satisfied with the current communication with the professionals. Most women with a normal pregnancy and childbirth in history, lacked the need to start a PHR due to these experiences. The information and attitude of the professional was guiding in the decision to start PHR in three out of four pregnant women:

'*When my doctor thinks it is valuable, then I seriously consider to start a PHR'*

'*Because my midwife advised it to me and the practice used this PHR as communication with me, I started*'.

Pregnant women also mentioned that they preferred active communication of the professionals in their PHR:

'*I appreciate it and it would help me if the professional informs me in my PHR, I will not only use this for questions from my side*'.

Problems to start a digital secured PHR with log in were mentioned by 8% of the women. Most women answered that internet based tools or programs are commonly used and therefore expected to be easy in use. 70% of the women mentioned the wish to integrate the PHR with patient portals from the midwife practice or hospital. All women endorsed the value of PHR:

'It is really good that this exists'.

Field notes showed that during the entire study, health care professionals and pregnant women wished for more support for MyPregn@ncy than originally was planned in the implementation activities. This extra support took more time but was provided by the researchers. One midwife practice implemented PHR as part of their standard care. They stressed the importance of a PHR to the pregnant women. By doing so, 90% of their clients started and actively used the PHR. Other professionals got inspired by this midwife practice, but peer support during the study period was only minimal due to the fact that this particular midwife practice started in the last step of the study design.

Discussion

The aim of this study was to evaluate the introduction of, and experiences with MyPregn@ncy, an innovative tool for pregnant women and their professionals.

In our study, the implementation strategy was based on an attempt to tackle the barriers from earlier studies in order to create an optimal implementation strategy. Our results showed that we only partly succeeded. In contrasts to findings of Lau et al. [11], patients did not experience technical and usability barriers. However, no expected value was mentioned as one of the main barriers by pregnant women not to start a PHR, this similar with the findings of Lau et al. [11]. Specifically, pregnant women thought MyPregn@ncy had only added value when there were 'problems' in pregnancy or when they were not satisfied with the current communication with the professionals. Previous studies mainly focused on PHRs used by chronicle ill patients [6, 20]. Because pregnancy and childbirth are life events more than diseases, the value of a PHR may be different for pregnant women.

The role of the professional endorsing the value of a PHR turned out to be the most important facilitator to start a PHR. For pregnant women, an advice or motivational explanation from the professional was essential in the consideration to start MyPregn@ncy. Furthermore, when using the PHR, active input from the professional was of great value and was mentioned as facilitator.

Professional barriers from earlier studies also emerged from our study. The focus group with professionals, together with field notes results, showed us the two main barriers: difficulties to change and the expected additional work. Professionals had their concerns regarding time consuming online availability for their patients. However, this was not a result from the log data and the experiences of users. A recent study confirms our results, showing that patients refrained from asking too many questions and were cautious in making knowledge claims about their disease in a PHR [20]. Professionals mentioned that they, only during the study, realised this tool is disruptive and it requires new processes of care, leading to other roles and attitudes of, and communication between patients and professionals. Handling and acceptation of these changes by professionals requires a change in norms which they must endorse to embrace the use of a PHR. More extensive discussion about the changing norms could possibly have incorporated higher support of the professionals. The behaviour of patients depending on traditional norms was explored before stating that the expected value of a PHR is hindered by traditional norms about patient-professional interactions [20]. These results call for more commitment to professionals and patients to get used with the possibilities and the method/use? of a PHR. Our findings confirm a difference in patient and professional expectations of the tool. An open dialogue about expectations and wishes between pregnant women and professionals should therefore be part of the implementation process.

Earlier adopters of an innovative tool can play an important role in the process of change and adoption. This was clearly seen in the results of our study. One midwife practice included almost all their pregnant women in the study by making the PHR part

of their standard care. This incorporation method with new results led to serious interest from other professionals. It was therefore unfortunate that this midwife practice only started in the last phase of the study, which made that their influence to other professionals was only minimal in the study period. A strength of this study was participation of all multidisciplinary healthcare professionals in the area, making the option to start a PHR possible for all pregnant women in the area. Also, we deliberately introduced the PHR in standard care rather than in a theoretical study setting, to explore which elements are important for introduction of a PHR in common maternity care. Furthermore, we believe the combination of quantitative and qualitative research methods gave us sufficient insight into the implementation process.

Despite these strengths, this study was not without limitations. First, the total number of active pregnant women of the PHR was small. Second, pregnant women were not actively involved in designing the implementation elements. Finally, we focused on inventory of mainly barriers to start a PHR and minimally on facilitators. Future research should embed these elements.

This study emphasises that the introduction of a PHR requires some essential steps. First a dialogue between patients and professionals about expectations and wishes is needed. Second, enough time and efforts for the implementation elements involving patients and professionals should be provided. Third, early adopters should be recruited as part of the implementation elements. Fourth and finally, the PHR should be embedded in standard care.

All together, the present study was an innovative experience for the professionals how to provide the pregnant woman with a more central role to support patient centered care. The development of PHRs in care widely continues, accompanied by the integration of different patient records. Our study strongly supports this integration of patient records in PHR in order to create additional value for each patient, specifically, pregnant women. In the Netherlands, the government stated a national goal that all patients should have the possibility to create a PHR in 2020 [21]. Lessons learned that disruptive innovations such as PHR need time to go along with new norms and methods. Although the lack of uptake of PHR is a widely known phenomenon [10], the literature on negative findings in this field is still scarce. Researchers should not feel discouraged to publish negative findings because in failure many significant lessons can be learned [11]. The results from this process evaluation contribute to the feasibility of this intervention and possibilities for further implementation.

Acknowledgements

The study is financially supported by ZonMw [The Netherlands Organisation for Health Research and Development, grant number 50-50200-98-057].

We thank all participants of and professionals who provided input for the development and evaluation of the intervention.

References

1. Archer N, Fevrier-Thomas U, Lokker C, McKibbon KA, Straus SE. Personal health records: a scoping review. J Am Med Inform Assoc. 2011;18(4):515-522. doi: 10.1136/amiajnl-2011-000105.
2. 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;13(2):121-126.
3. Price M, Bellwood P, Kitson N, Davies I, Weber J, Lau F. Conditions potentially sensitive to a personal health record (PHR) intervention, a systematic review. BMC Med Inform Decis Mak. 2015;15:32. doi: 10.1186/s12911-015-0159-1.
4. Osborn CY, Mayberry LS, Mulvaney SA, Hess R. Patient web portals to improve diabetes outcomes: a systematic review. Curr Diab Rep. 2010;10(6):422-435. doi: 10.1007/s11892-010-0151-1.
5. Silvester BV, Carr SJ. A shared electronic health record: lessons from the coalface. Med J Aust. 2009;190(11 Suppl):S113-6.
6. Tenforde M, Jain A, Hickner J. The value of personal health records for chronic disease management: what do we know? Fam Med. 2011;43(5):351-354.
7. Nederland Z, Zorg CP. Zorgstandaard Integrale Geboortezorg. 2016.
8. Irizarry T, DeVito Dabbs A, Curran CR. Patient Portals and Patient Engagement: A State of the Science Review. J Med Internet Res. 2015;17(6):e148. doi: 10.2196/jmir.4255.
9. Mair FS, May C, O'Donnell C, Finch T, Sullivan F, Murray E. Factors that promote or inhibit the implementation of e-health systems: an explanatory systematic review. Bulletin of the World Health Organization. Bull World Health Organ. 2012;90(5):357-364. doi: 10.2471/BLT.11.099424.
10. Greenhalgh T, Hinder S, Stramer K, Bratan T, Russell J. Adoption, non-adoption, and abandonment of a personal electronic health record: case study of HealthSpace. BMJ. 2010;341:c5814.
11. Lau AY, Arguel A, Dennis S, Liaw ST, Coiera E. "Why Didn't it Work?" Lessons From a Randomized Controlled Trial of a Web-based Personally Controlled Health Management System for Adults with Asthma. J Med Internet Res. 2015;17(12):e283. doi: 10.2196/jmir.4734.
12. Bishop TF, Press MJ, Mendelsohn JL, Casalino LP. Electronic communication improves access, but barriers to its widespread adoption remain. Health Aff (Millwood). 2013;32(8):1361-1367. doi: 10.1377/hlthaff.2012.1151.
13. Hemming K, Haines TP, Chilton PJ, Girling AJ, Lilford RJ. The stepped wedge cluster randomised trial: rationale, design, analysis, and reporting. BMJ. 2015;350:h391. doi: 10.1136/bmj.h391.
14. Brown CA, Lilford RJ. The stepped wedge trial design: a systematic review. BMC Med Res Methodol. 2006;6:54.
15. Moore GF, Audrey S, Barker M, Bond L, Bonell C, Hardeman W, et al. Process evaluation of complex interventions: Medical Research Council guidance. BMJ. 2015;350:h1258. doi: 10.1136/bmj.h1258.
16. Oakley A, Strange V, Bonell C, Allen E, Stephenson J. Process evaluation in randomised controlled trials of complex interventions. BMJ. 2006;332(7538):413-416.
17. Hulscher ME, Laurant MG, Grol RP. Process evaluation on quality improvement interventions. Qual Saf Health Care. 2003;12(1):40-46.
18. Groenen CJ, Faber MJ, Kremer JA, Vandenbussche FP, van Duijnhoven NT. Improving maternity care using a personal health record: study protocol for a stepped-wedge, randomised, controlled trial. Trials. 2016;17(1):202.
19. Saunders RP, Evans MH, Joshi P. Developing a process-evaluation plan for assessing health promotion program implementation: a how-to guide. Health Promot Pract. 2005;6(2):134-147.
20. Visser LM, Bleijenbergh IL, Benschop YW, Van Riel AC, Bloem BR. Do online communities change power processes in healthcare? Using case studies to examine the use of online health communities by patients with Parkinson's disease. BMJ open. 2016;6(11):e012110.
21. Haastert Cv, Steen Jvd. Rapport 'Persoonlijk GezondheidsDossier'. Utrecht: NPCF. 2015.