original paper

User Experience in CONNECARE: Results and Lessons Learnt in Lleida

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OPEN ACCESS

Citation: Vargiu E, Dorado A, Massip M, Gómez-Martínez M, Torres G, de Batlle J, Miralles M (2019) User Experience in CONNECARE: Results and Lessons Learnt in Lleida. XPA & Health Com. 2

Editor: Joan Escarrabill, Hospital Clínic, Barcelona, España.

Recived: 17 de Noviembre de 2019

Accepted: 30 de Noviembre de 2019

Published: 23 de Diciembre de 2019

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Funding: CONNECARE – "Personalised Connected Care for Complex Chronic Patients" is a HORIZON 2020 Research and Innovation Project funded under Call: H2020-PHC-2015 – Topic: PHC-25-2015. Jordi de Batlle acknowledges receiving financial support from the Catalan Health Departament (Pla Estratègic de Recerca i Innovació en Salut (PERIS) 2016: SLT002/16/00364)) and Instituto de Salud Carlos III (ISCIII; Miguel Servet 2019: CP19/00108), co-funded by European Regional Development Fund (ERDF)/European Social Fund (ESF), "Investing in your future".

Acknowledgements: Special thanks to all the clinicians that participated in the co-design process; the technicians that developed, tested, and deployed the system; the volunteers that tested the system; the patients that participated in the studies; as well as all the CONNECARE consortium.

Abstract

In this paper, we focus on the implementation studies performed in the Lleida region under the umbrella of the H2020 EU project CONNECARE. In particular, we refer the overall experience of the users (patients and carers) of the SMS, a self-management system that allows monitoring patients and provides engagement, rewards, and warnings. It monitors: physical activity, health status, self-reported questionnaires, rehabilitation tasks, sleeping pattern, and drugs intake. First, we present the underlying context regarding the implementation studies performed in Lleida. Subsequently, we focus on the strategies of UX (User Experience) that have been performed in two different moments of the project and with different actors. Results are then presented for each of the approaches. A discussion focused on the lessons learnt ends the paper.

Keywords: integrated Health Care Systems, self-management, patient monitoring.

Resum

Experiència d'usuari en CONNECARE: Resultats i Lliçons Apreses a Lleida. En aquest article, ens centrem en els estudis d'implementació realitzats a la regió de Lleida en el marc del projecte H2020 EU CONNECARE. En particular, ens referim a l'experiència general dels usuaris (pacients i cuidadors) del SMS (*system-management system*), un sistema d'autogestió que permet monitorar als pacients i proporciona compromís, recompenses i avisos. Monitora: l'activitat física, l'estat de salut, els qüestionaris de autoinforme, les tasques de rehabilitació, el patró de somni i la presa de medicaments. Primer, presentem el context subjacent respecte als estudis d'implementació realitzats a Lleida. Posteriorment, ens enfoquem en les estratègies d'experiència de l'usuari que s'han realitzat en dos moments diferents del projecte i amb diferents actors. Després es presenten els resultats per a cadascun dels enfocaments. Concloem amb una discussió centrada en les lliçons apreses.

Paraules clau: experiència de pacient, ecosistema digital, *design thinking*

Resumen

Experiencia de Usuario en CONNECARE: Resultados y Lecciones Aprendidas en Lleida. En este artículo, nos centramos en los estudios de implementación realizados en la región de Lleida en el marco del proyecto H2020 EU CONNECARE. En particular, nos referimos a la experiencia general de los usuarios (pacientes y cuidadores) del SMS (*system-management system*), un sistema de autogestión que permite monitorear a los pacientes y proporciona compromiso, recompensas y avisos. Monitorea: la actividad física, el estado de salud, los cuestionarios de autoinforme, las tareas de rehabilitación, el patrón de sueño y la toma de medicamentos.

Primero, presentamos el contexto subyacente con respecto a los estudios de implementación realizados en Lleida. Posteriormente, nos enfocamos en las estrategias de experiencia del usuario que se han realizado en dos momentos diferentes del proyecto y con diferentes actores. Luego se presentan los resultados para cada uno de los enfoques. Concluimos con una discusión centrada en las lecciones aprendidas.

Palabras clave: Sistemas integrados de salud, autogestión, monitoreo de pacientes.

Introduction

Nowadays, patients' health care is still fragmented: primary healthcare professionals are responsible when the patient is in the community, whilst hospital care staff take the lead during hospitalization[1]. The EU H2020 project CONNECARE is a technological-oriented initiative aiming at exploring digital tools to support integrated care for complex chronic patients (CCP). CONNECARE provides solutions for two key requirements of integrated care services for chronic patients, namely: (i) Smart adaptive case management (SACM); and, (ii) Collaborative work among the various stakeholders, including patients and their families or carers, and all actors across the different health and social care tiers[2].

The CONNECARE model consists of two major components: an organizational model for integrated care and a technological platform to support the integrated care organizational processes.

The CONNECARE organizational model is based on a 5-step strategy[3]: Case Identification, to select patients eligible for entering the program; Case Evaluation, to stratify patients based on multilevel risk assessment (clinical, environmental and social); Workplan definition, to plan proactive and preventive interventions based on personal circumstances of the patient; Workplan execution, to continuously monitor the evolution of the personalized therapeutical action plan (through questionnaires, measurements with medical devices, educative material, etc. in a patient self-management App), and Discharge, to evaluate the overall intervention. All professionals, both from primary care (PC) and hospital, social workers included, may interact with each other by leaving notes on a

virtual wall to agree upon the Workplan, keeping the continuum of care before hospital discharge. Hospital staff may provide support to PC professionals beyond hospital discharge, and all of them may help and accompany the patient through direct communication tools. In any moment, professionals in charge of a case can have a schematic summary organized in 3 parts: the health status of the patient, with the results of the most relevant taken measures and calculated metrics; the diagnosis through a graphical representation of the human body with the status of her organ under revision; and self-care skills and socio-environmental conditions through a list of barriers.

The technological platform is composed of a Self-Management System (SMS), installed on patients' smartphones (or tablets), and the Smart Adaptive Case Management system (SACM), accessible via Web[4]. The SMS allows monitoring patients and provides engagement, rewards, and warnings[5]. It monitors: physical activity, health status, self-reported questionnaires, rehabilitation tasks, sleeping pattern, and drugs intake. Physical activity and sleeping patterns are monitored through an activity tracker by Fitbit, whereas health status through medical devices by Nokia/Withings. The professionals may also share advices in form of text or videos. Alerts and notifications are sent in case of anomalies or request to actions by the patient. The SACM has extended functionalities for case management to define a case according to the CONNECARE organizational model[6]. Additionally, the SACM includes a Clinical Decision Support System consisting of a visual support tool for locating the patients and organizing their visits[7]. The SMS and SACM interact each other through the CONNECARE Enterprise Service Bus, which connects both subsystems and orchestrates their communication. All professionals, both from PC and hospital, social workers included, interact with each other using a direct communication tool to coordinate the patient's care plan and its execution, assuring continuity of care between hospital, primary, and social care. Patients continuously check their status and execute their assigned tasks through the SMS. Hospital staff, primary care professionals, and social workers may also help and accompany the patients using a messaging function.

In this paper, we focus on the implementation studies performed in the Lleida region with particular reference to the overall experience of the users (patients and carers) of the SMS. First, we present the underlying context regarding the implementation studies performed in Lleida under the umbrella of the CONNECARE project. Subsequently, we focus on the strategies of UX that have been performed in two different moments of the project and with different actors. Results are then presented for each of the approaches. A discussion focused on the lessons learnt ends the paper.

The Underlying Context

The CONNECARE platform has been deployed in two situations:

- Community-based prevention of unplanned hospital-related events in chronic complex patients with high risk for hospitalization (CS1);
- Preventive patient-centred intervention in complex chronic patients undergoing elective major surgical procedures (CS2).

CONNECARE followed an implementation research approach, using an intervention study focused on implementing the CONNECARE organizational model and technology in real life clinical setting with an intervention group and a matched control group. Implementation studies were performed in 4 sites: Barcelona and Lleida (Spain), Groningen (Netherland), and Ashdod (Israel). Studies started on July 2018 and ended on September 2019. A total of 288 patients were recruited and completed the programme.

In Lleida, 77 patients (48 CS1 and 29 CS2) were recruited having the following eligibility criteria:

- Being assigned to a Primary care centre of the region of Lleida;
- Age 55 +;
- Living at home (not in a nursing home) and being discharged back to the community;
- Understanding either Catalan or Spanish;
- No Dementia/cognitive impairment (GDS < 5);
- Successfully passing a basic technological competence test (to assess connectivity and adherence to the use of technology of the patient and/ or the carer);
- To sign the informed consent.

Specific criteria for CS1 were:

- Admission to the ER of University Hospital Arnau de Vilanova and University Hospital Santa Maria because of a Respiratory or Cardiovascular cause (COPD exacerbation or heart failure decompensation);
- LACE score >7.

Specific criteria for CS2 were:

- Scheduled elective hip or knee arthroplasty surgery in the University Hospital of Santa Maria.
- Charlson ≥ 3 or having at least one chronic disease as comorbidity.
- Complex pharmacological treatment (≥ 4 pills/day).
- Adjusted Morbidity Group (GMA) ≥ 3.
- American Society of Anesthesiologists (ASA) = II or III.

It is worth noting, that especially in Lleida, due to the age of the patients, several times the SMS has been used by the carers (typically, sons and daughters) instead of the recruited patient.

Materials and Methods

When the overall project reached an advanced stage of design and development and the implementation studies started in all the sites, we started working on the UX and tested the experience of CONNECARE patients using the SMS. First, a UX expert without any previous knowledge of CONNECARE performed a heuristic and usability analysis. In so doing, the expert felt the same reactions and frustrations of a real new user. In fact, the objective of this technique was to analyse and detect the usability problems that cannot be detected trough

the testing activity. At the very end of the project, the expert on UX organized a co-creation session in Lleida aimed at measuring the UX experience of patients and carers that used the CONNECARE SMS during the studies.

UX by the expert

A UX expert who never used the SMS before performed a heuristic analysis and a usability test. The heuristic analysis focused on: general aspects; identity and information; adopted language; used labels; overall structure and organization; layout; provided help; accessibility; and control and feedback. The usability test evaluated all the aspects related to: accessibility; functionalities; adopted colours, graphics and visual consistency; communication and information; and provided help.

UX by patients and carers

Starting from the proposed actions by the UX expert, at the end of the project, a focus group session took place at the Hospital Santa Maria in Lleida performed by a UX expert supported by an expert in technology. In the workshop, those experts had the opportunity to work together with 3 carers of patients with long-term chronic diseases, users of the SMS and 3 clinicians. The objectives of this session, participated by 3 clinicians and 3 carers, were:

- Understand the problems and needs of patients and carers;
- Develop first main ideas with patients and clinicians to understand what should be the main features to be added in future releases and be able to prioritize them;
- Define design challenges according to the needs and problems encountered.

Using the silent brainstorming technique[8], three questions were proposed to all the participants:

- How has the app helped you?
- Which difficulties did you have by using the app?
- Which functionalities should the app have in the future?

Participants had 5 minutes to answer to each question. Answers were collected in forms of post-it that the participants put in the entrance door of the meeting room.

Moreover, to analyse the usability problems that the app could have, we performed a usability test with 5 users, with different profiles, different knowledge, age, and cultural level. The selected users were not patients or carers that used the SMS before and did not participate in the studies.

The test was composed of the following 5 tasks:

1. Imagine that your doctor has prescribed this app and that you want to communicate with him, how would you do to send him a message?
   Try sending a message to your doctor.
2. Your doctor has prescribed a questionnaire through the app.

Answer the questionnaire.

3. Imagine that you have been performing the daily amount of steps that have been prescribed to you, and you want to see the evolution of your daily steps. Check the evolution of your daily steps.
4. Imagine that your doctor has prescribed you to enter your weight. Add your weight in the application.
5. Imagine that your doctor has prescribed that you take the blood pressure, how would you do it? Take the blood pressure through the device.

Results

UX by the expert

The expert performed the heuristic analysis measuring each item in a scale from 1 (the lowest score) to 5 (the maximum score). Results obtained in each category are shown in Table 1.

Category	Number of items	Average score	Total score
General aspects	7	3.57	25
Identity and information	3	2.7	8
Adopted language	4	3	12
Used labels	5	3.6	18
Overall structure and organization	6	3.17	19
Layout	7	2.43	17
Provided help	3	1	3
Accessibility	3	3.34	10
Control and feedback	4	3.75	15
Total score			**144/210**

Table 1: Summary of the results of the heuristic analysis.

How has the app helped you?			
Follow-up	**Communication**	**Positive Impact**	**Education**
Patient follow-up	Quick and easy communication	Increased tranquillity	Health education
Support to the carer to check if is doing well	Communication improvement		Send educational videos
Anomaly detection	Improves bidirectional communication		
Daily information	Direct contact with the doctor		
Priority in the patients			
Higher control			
Better follow-up			
Obtaining clinical variables			

Which difficulties did you encountered by using the app?			
Wearable devices	Login (password)	Robustness	Training
The use of wearable devices is expensive	Not knowing how to recover the password	Slowness	Lack of tutorials and factsheet
Hard synchronization	User lock (complicated access)	Complaints because it hangs	A lot of time to do training
Difficult wearables installation		More functionalities more difficulties	
Bluetooth did not work		The app sometimes fails	
I just put the data manually		Some videos did not open	
		Difficulty in some smartphones due to lack of space	

Table 2: Results of the silent brainstorming (1st and 2nd questions).

Which functionalities do you suggest for the future?		
Medications	Communication	Follow-up
Can prescribe medications	Video calls	Accelerometer drop sensor
Section with updated medication	Direct contact phone with the doctor	
Medication reminders	Being able to talk to the doctor for questions	
	Lack of contact on weekends	
	Be able to send PDF's, videos and images of tests and audios gathered from health devices	

Table 3: Results of the silent brainstorming (3rd question).

The results of the usability test performed by the UX expert allows technicians to gather a feedback and to improve the app, accordingly. The usability test performed by patients and carers (see next section) has been done with the improved version of the app.

As a final remark, the expert suggested to organize three UX sessions with real users (patients, carers, as well as nurses and professionals): a focus group, a usability test, and a bipolar laddering. Due to time constraints and availability of the users, the bipolar laddering was not performed. Results regarding the focus group are given in the following section.

UX by patients and carers

Table 2 shows the answers given to the first two questions performed during the silent brainstorming, organized in categories. Answers to the third question are reported in Table 3.

Regarding the suggestions on the medications, it is worth noting that even if, the drug prescription is available in the SMS, clinicians in Lleida decided to not include it in their studies. Singly, this functionality appears as a requirement dur-

ing the UX session.

By considering the results of the silent brainstorming, the main suggestions by the UX expert were:

- The solution should allow self-management of drugs and medications. It would give them greater independence from their careers.
- Integrating a chatbot could help in stop feeling lonely and solve questions that are usually common in a group of specific patients, solving questions about illness, physical activity, nutrition or emotional state.
- Including a diary in which patients and carers can take note of relevant issues, suggested actions, and also critical questions to be done to the clinicians could help in improving the follow-up, especially for the weekend.
- Being able to make video calls with the doctor or a call would reinforce the patient-doctor and doctor-patient link so that they can dispel any doubts or problems they may have.

		User 1		User 2		User 3		User 4		User 5	
Age		61		64		67		30		37	
Gender		Female		Female		Female		Female		Female	
Professional activity		Caregiver and active peasant		Educator and caregiver		Employee and caregiver		Nurse		Nurse	
Skills		Primary education + Commercial skills		Bachelor and Commerce				Nursing graduate		Nursing graduate	
Use of smartphone/tablet (Y/N)		Y		Y		Y		Y		Y	
Use of social nets (Y/N)		Y		Y		N		Y		Y	
First time using a healthcare app (Y/N)		Y		Y		Y		Y		Y	
		Sec	Score	Sec	Score	Sec	Score	Sec	Score	Sec	Score
Task	Send a message	52	1	20	1	90	0	10	1	10	1
	Answer a questionnaire	30	0.5	50	0.5	n/a	-	60	1	210	0.5
	Check steps evolution	120	0	60	1	n/a	-	20	1	165	0
	Add the weight	30	1	20	1	n/a	-	20	1	25	1
	Take the blood pressure	330	0	150	0	n/a	-	100	1	77	1
	Avg.	112.4	0.5	60	0.7	n/a	n/a	42	1	97.4	0.7

Table 4: Results of the usability test. For each performed task, we report the time required to complete it (in seconds) and the score given by the UX expert.

Improve patient confidence with the wearable devices providing a short training.

Regarding the usability test, experts collected information, results of the tasks, and observation in form of individual cards. Profile information and results are summarized in Table 4, names have been omitted for the sake of privacy.

The selected users were potential patients or carers (3) or nurses of the hospital (2). User 3 had clear problems in using the app and, actually, asked to stop the test because she found it very stressful. The rest of the users found the message functionality easy and clear, and had no problem in sending a message. In general, potential patients/carers did not consider intuitive the way to recognize the questionnaire to be answered. They also gave feedback on the adopted blood-pressure monitoring device. Potential patients/carers find it comfortable, but consider the conventional one faster and they are more familiar with it. Moreover, using a different app to measure the blood pressure was not intuitive and appreciate. User 2 also found task 5 hard and she did not think she knew how to do it alone. The 2 nurses considered the app very easy to use and intuitive. In particular, even if User 4 encountered difficulties in some tasks, she completed all of them at good speed. On the other hand, User 5 found some problems in accessing the daily steps evolution.

Discussion

CONNECARE is a technological-oriented project aiming at exploring digital tools to support integrated care services. The ambition of the project, developed with an implementation research approach, was to co-design, develop, deploy, and evaluate a novel smart, adaptive integrated care system for chronic case management. One of the key achievements of the overall project is that the final release of the SMS is a relatively mature digital tool and patients felt they could recommend it.

Lessons learnt after testing of the technological components of the project prompted the proposals aiming at facing the needs for digital support embedded into different service workflows. In particular, further evolution of the SMS and its linkage with GDPR-compliant digital tools supporting collaborative work among stakeholders across healthcare tiers (and providers) constitutes a priority to foster digital transformation of healthcare. Interoperability with health information systems from different providers and/or health information exchange platforms across providers is a must.

Finally, we learnt that, in order to improve satisfaction and engagement, patients need to perceive the app as relevant and give them a clear and simple added value. Probably one solution is to have less features but very clear and effective. On the other side, one of the strength of the proposed approach is that patients are normally more responsive to the use of the app when they know that there is someone on the other side who is monitoring them, receiving and checking the data, and communicating with them. As a final remark, both researchers and healthcare professionals acknowledged the importance of running a methodologically sound user experience analysis when assessing digital tools for integrated care. This has proved useful for improving usability and ease of use of the tools, but also to assess in a quantitative and qualitative manner an important and often overlooked dimension of evaluation, which is

patient experience. When possible, this analysis should happen more than one time during the evaluation process, during the development cycles, to let the collected assessment feedback improve the final patient experience.

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