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User Driven Design: First Step in Involving Healthcare Consumers and Clinicians in Developing a Collaborative Platform to Prevent Cardiovascular Diseases

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Abstract

To prevent cardiovascular diseases, eHealth solutions may be used as tools, involving health care consumers in the set-up of their prevention plan, a fundamental condition for improving their long-term adherence to the plan. This paper presents the first step in a web platform design aiming to support the co-elaboration by health care consumers and clinicians of personalized prevention plans. Applying a user driven innovation approach, first, a questionnaire and semi-structured interviews were combined to identify clinicians' needs. Then, three focus group sessions with consumers and clinicians were organized to identify their needs, creating the system workflows, its graphical user interface, and its navigation paths, with the best ideas shaped by paper mockups. An interactive mockup was designed including 30 screens (ex. user dashboards, desk for co-elaborating plan). This user driven approach enabled to design not only the technology and its graphical user interface, but also a prevention plan design process.

Keywords:

Ergonomics; Research Design; Primary Prevention

Introduction

The number of deaths related to preventable risk factors keeps on increasing. High blood pressure is at the top of the list of preventable risks, contributing to more than 10 million deaths worldwide [1]. Tobacco ranks second before obesity and diabetes. When combined, these risk factors are responsible for cardiovascular diseases (CVD), leading to death. Thereby, health prevention actions against those risk factors are essential.

Despite many initiatives, setting up a prevention plan is not easy for health care consumers and clinicians [2]. Prevention is the active and empowered management by a person of his or her health capital. Clinicians mostly initiate prevention actions and require the active involvement of the person. However, from a clinician's perspective, initiating prevention actions is time-consuming while the consultation time is limited, and available tools are unhelpful to support this task [3,4]. As for the health care consumers, they must be highly motivated to be involved in prevention actions [2]. Besides, while healthy people are the main target of prevention actions, prevention is not their priority.

eHealth solutions may be used as tools to modernize prevention practices and get healthcare consumers involved in their prevention plan. Connected devices and web platforms, such as forums and/or social networks, may help health care consumers join health programs (e.g. weight loss or smoking cessation in

groups). Nonetheless, so far, the impact of those solutions is limited [5-7]. To be adopted by health care consumers and be used efficiently, those solutions must be well-integrated into clinicians' work environment and must not increase their workload [8]. Behavior change techniques must be embedded in those solutions to help health care consumers get involved in their prevention plan [10]. Finally, the solutions must appropriately support the codesign of a personalized prevention plan by health care consumers and their clinicians [10,11] to increase the likelihood that health care consumers adhere to their prevention plan: finding a consensus between a consumer's preferences, abilities and habits, and his or her clinician's recommendations is essential. [12,13]

This paper presents the PEPS project that aims to design a collaborative clinician-health care consumer web solution for cardiovascular diseases prevention. The project is ambitious in terms of involving end users (i.e. health care consumers, clinicians) into a codesign approach to ensure that the future solution (i) is usable and (ii) encourages and supports the co-elaboration of personalized prevention plans (PPP) by the clinician and the consumer. A user-driven innovation approach was adopted to tap users' explicit and tacit knowledge and develop innovative solutions. The process systematically and actively involved users to get a sound understanding of their actual needs and practices [14:]. With this goal in mind, in addition to researchers in ergonomics and decision support systems and to electronic health record companies, the project board also included the French College of General Medicine (FCGM) and an association of patient associations (Inter-Associative Collective on Health). The FCGM and the association ensured the involvement of primary care clinicians (general practitioners (GPs) - and nurses) and of persons at risk of CVD at all stages of the design and evaluation process. In this paper, we present the first step in the design process, i.e. the application of codesign proven methods to analyze end users' needs and to get mockups and design specifications codesigned by health care consumers and clinicians.

Methods

The methodology proceeded in three steps.

Preliminary Questionnaire and Interviews

An on-line questionnaire was developed to identify current needs of the GPs. It identified: the technology currently used to prevent CVD, appreciated and criticized features, GPs' expectations, and the behavior change techniques they use to prevent CVD. The questionnaire was sent electronically to members of the FCGM.

Semi-structured interviews were performed to get deeper qualitative insights into the results of the questionnaire. They addressed the same questions plus clinicians' CVD prevention practices, their difficulties, their ideas and proposals to improve their practices, and the perceived pros and cons of PPP. Respondents to the questionnaire who were interested were contacted. The FCGM completed the recruitment with some of their members and nurses.

Focus Groups

Three sessions of focus groups were organized successively. They aimed (i) to validate nurses and GP's needs identified through the questionnaire and interviews, (ii) to support the ideation about how the PEPS solution should work with its graphical user interface and its navigation paths, and (iii) to shape the best ideas with paper mockups.

The three focus groups sessions complemented each other: they addressed different parts of the PEPS solution (see Figure 1).

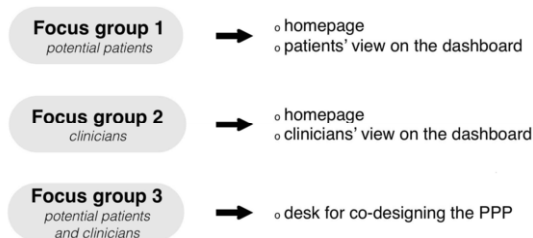


Figure 1– Schematic Representation of the Aims of Each Focus Group Session.

The “studio design” method [15] was the inspiration for the design of the focus groups. This method is a creative problem-solving process to quickly generate ideas and to compare them and achieve a consensus on an agreed-upon solution. It consists in asking participants to sketch mockups in response to a problem. Mockups must be minimal and must enable one to understand the screen's arrangement and content. Several steps of sketching, first individual, then collective, stimulate the creativity and the codesign of a consensual solution that may satisfy the needs of all participants.

Two experts in ergonomics organized and hosted each focus group session.

Focus Group One: Health Care Consumers

This session aimed to get insights regarding the PEPS homepage (accessible without login) and the PEPS prevention dashboard as it appears once logged in with a consumer's account. Participants at risk of CVD (according to their results to the French Federation of Cardiology questionnaire¹) and healthy participants were recruited.

First, the PEPS project, its aims, and the basics of CVD prevention and of prototyping were introduced. Then, participants were confronted with the following problem: how to engage consumers in CVD prevention? To answer it, participants were divided up into two mixed groups, including both at risk and healthy participants. They had to go through four steps:

1. Brainstorming: they were asked to list techniques and information that may be useful to prevent CVD.

2. Individual prototyping: each participant was asked to sketch how those techniques and information could be displayed and arranged on the PEPS solution.
3. Group prototyping: participants had to explain their own mockup to their group and how their solution answered the initial problem. Then, the group had to combine the best ideas and design elements to create the group's mockup.
4. Inter-groups consensus: then, groups were gathered together. They had to present their own mockup before deciding by consensus on the best ideas and combining them into one new mockup.

At the end of the session, participants had to present their mockup to the experts in ergonomics and to explain how it answered the initial problem.

Focus Group Two: Nurses and GPs

This session aimed to get insights regarding the PEPS homepage and the PEPS prevention dashboard as it appears once logged in with a clinician's account. GPs and nurses were recruited by the FCGM. The problem asked was: how a web solution could help prevent CVD?

This focus group was structured like focus group one except on the first step. After an introduction to the PEPS project, instead of brainstorming, participants had to read the list of needs identified through the questionnaire and interviews and the description of four personas of consumers (see Figure 2). A persona is a fictional character created to represent a person that may use a solution [16]. Then participants were divided in two groups including both nurses and physicians and steps two, three and four occurred like in focus group one. At the end of the session, participants had to present their mockup to the experts in ergonomics.

Focus Group Three: Health Care Consumers, Nurses and GPs

This session aimed to describe precisely the PPP co-elaboration process involving health care consumers and clinicians and to create the screens and the arrangement of information that may support it efficiently. Consumers at risk for CVD, nurses, and GPs who did not take part in the first sessions were recruited. After the introduction to the PEPS project and to the goals of the focus group, participants were split into three mixed groups.

Participants had to answer the following problem: how a website could make easier the co-elaboration of a PPP for CVD? This session proceeded in two steps:

1. Group prototyping: paper cards illustrating the features and the information that may support the PPP elaboration identified through the questionnaire, and the interviews were distributed to both groups. Participants could create new cards if needed. At this step, participants were asked to arrange the cards to follow the PPP design process and to create mockups of the related screens. At the end, the groups were gathered together.
2. Inter-group consensus: each group had to present its process and associated screens' mockups. Together, participants had to decide on the best ideas and to combine them into one new mockup of the solution.

Participants had to present their mockup to the experts in ergonomics and to explain how it answered the initial problem.

¹ Questionnaire available on jaimemoncoeur.fr



Figure 2 – Instance of Persona Used to Support the Discussion.

Ergonomics Specifications for the Solution

The experts reworked on the paper mockup of the solution with Sketch® to turn it interactive. Then, the computerized mockup was put online with InVision®. To ensure the final mockup was true to the results of the focus groups and met end users' needs, the link to the mockup was sent to 46 former participants/respondents to the three focus groups and to the questionnaire and interviews. This step enabled to get feedback on the designed mockup. Participants could either make comments through the mockup's link or send their comments by email.

Results

Questionnaire and Interviews

A total of 145 GPs replied to the questionnaire; six GPs and three nurses were interviewed. Five main themes arose. First, clinicians need synthesized, unambiguous, updated information, and advice on the prevention of CVD (e.g. under the form of practical memo) along with a synthesized overview of the PPP. The advice must be adapted to the profile of their patient. In addition, clinicians need information about religious and cultural elements they should consider when designing the PPP (e.g. specific diet).

Second, clinicians highlighted a need for interaction through the PEPS website. They need to share the PPP with their patients, and their experiences with colleagues. They need multimedia supports (e.g. video, comics) along with translated supports to communicate with patients who do not understand French fluently. They also need to set the prevention goals and to modify them if needed. Notifications about patients who did not log on for a long time would also be useful.

Third, clinicians insisted on the ergonomics characteristics of the PEPS website: entering and managing data must be easy and quick. The information displayed must always be easy to understand and reusable to save time. Fourth, the PPP should be integrated into their patient electronic record. In this case, the website could be fully interoperable with this record to avoid duplicate data entries. Fifth, clinicians insisted that their patients must be enabled to communicate together (e.g. through social network) to share their experiences and their tricks to

achieve prevention goals. Patient must also access an address book of experts.

Focus Groups

Focus Group One: Health Care Consumers

A total of 8 consumers took part to the first focus group: 5 at risk and 3 healthy. Participants expressed that prevention information must be easily accessible through the homepage without being connected nor creating an account. Synthesized medical information on CVD, links to related social network, adapted balanced recipes etc. must be easy to find.

Concerning their account, participants highlighted that it must include “a zone displaying a summary of the statistics on calorie burn and food intake, defined prevention goals, and a way to enter daily those data thanks to a slider, for instance (...) I would need also a calendar to enter the number of cigarettes smoked per day and notes about breathlessness during exercise etc. There would be a kind of side menu displaying my profile, my action plan with its main milestones, my progress, and, if goals were not achieved, a way to change them (...) The GP must also have access to the information”.

Finally, health care consumers insisted that the data and the advice must be reliable.

Focus Group Two: Nurses and GPs

Three GPs and four nurses took part in the second focus group.

Clinicians expressed that they should not access the same information as consumers. Once connected, clinicians should see which patients are in a prevention program and, for each patient, charts with statistics to rapidly identify each patient's room for improvement. The website must not be a copy of the patient's electronic record: to avoid double data entry, the website must automatically update data from the patient's electronic record (e.g. automatic retrieval of new lab results). Furthermore, clinicians must be able to access prevention programs and tools and be able to network with colleagues to ask them questions regarding their patients.

As for the health care consumers' accounts, clinicians think that “one should find: the solution must display the PPP with the patient's objective and the level of achievement per week (e.g. under the form of percentage) for each objective (e.g. exercise, level of cholesterol, food intake). The patient must also find

features to enter data such as weight, intakes, amount of exercise, contact details, along with links to recipes and social networks.”

Finally, clinicians insisted on the credibility of the information displayed: “sources and scientific references must be displayed”.

Focus Group Three: Health Care Consumers, Nurses, and GPs

Two GPs, two nurses, and three consumers took part in the third focus group.

The co-elaboration of the PPP must start with the patients completing a questionnaire about their lifestyle, their medical history, their current risks, and data, such as weight, size etc. Then, each GP will “complete those data with other clinical data gathered during an appointment in such a way as to make a diagnosis”. Based on the data entered in the PEPS solution and / or retrieved automatically from the patient electronic record, the solution must propose prevention objectives and associated deadlines. The GP and the healthcare consumer will discuss together the proposed objectives, the ways to achieve them (e.g. exercise, monitoring of intakes) and their implementation into daily life.

To advise consumers and help them make informed decisions, GPs need a toolbox gathering persuasive information (e.g. patient’s gain if an objective is achieved). The information must be proposed clearly and be easy to understand. As for the consumers, they must access rapidly a summary of their objectives and actions to take. They should be able to change the objectives if they are too high.

When entering the PPP agreed-upon in the PEPS website, each GP must be able to order tests to check regularly the progress of their patients. Finally, “once the actions to achieve the goals have been chosen with the patients and entered, one must get a summary of the actions decided, and an appointment must be arranged to check how the PPP is followed.”

Ergonomics Specifications for the Solution

An interactive mockup of the proposed PEPS solution was designed including 30 screens (e.g. homepage, dashboard for consumers, dashboard for clinicians, desk for the codesign of the PPP, see Figure 3). Navigation paths were represented using flowcharts.

Five former participants provided feedback on the mockup. Overall, respondents appreciated the mockup. Their main concerns were:

- The phrasing of the initial questionnaire: some questions require explanations or should be gender-specific. Scientific references should be added to improve the credibility of the questionnaire.
- Despite its usefulness, the “practical information” screen is too cumbersome. The information density should be reduced.
- Links to other relevant websites should be added.

Discussion

The main objective of the PEPS project was to design a usable tool supporting the co-elaboration of PPP for CVD. The design approach adopted in the project relied on a user driven

innovation process to empower end users and give them an active role in the design of the web solution. The “studio design” method involved GPs, nurses, and health care consumers at risk for CVD. As a result, these end users produced mockups of the solution. Even if participants were not used nor trained to graphical user interface techniques, they proved to be able to draw relevant basic mockups, with the information organized within an arrangement. Working on problems they could face during the co-elaboration of PPP helped the participants imagine and design solutions that could help them.

The user driven innovation strategy places the users at the core of the innovation process in a systematic way and facilitates the integration of their knowledge into the increasingly complex design process [17]. Participants’ profiles noticeably impacted the design process and its results. Focus group one involved health care consumers, a very heterogeneous population in terms of technology and health literacy, background, needs etc. They proceeded mostly (i) by listing and accumulating different needed information and features and then (ii) by prioritizing those elements to achieve a consensus on the relevant elements the web solution should include. Clinicians who took part in focus group two proceeded differently. Since they are a quite homogenous group (more than health care consumers even if it represented both GPs and nurses), they expressed similar needs and did not have to reach a consensus on the information and features to display. Consequently, all along the mockups refining process, they questioned in detail how the mockups they produced would actually work *in situ*; they identified blocking elements and found solutions to fix them. Finally, involving both health care consumers and clinicians in focus group three enabled them to discuss the PPP design process and to exchange on their respective needs and constraints. The common thinking participants had on the co-elaboration of the PPP allowed them to go deeper than designing the graphical user interfaces of the web solution. Adopting a user driven design process enabled them to design not only a technology but, to a larger extend, a socio-technical system [18].

Comments we get about the online interactive mockup were considered to improve it; an improved version was presented with related specifications to developers. The PEPS web solution is now under development. Once available, its usefulness and its usability will be evaluated with representative end users other than the ones involved in the design process. Then, the solution will be deployed in pilot sites to evaluate its medium and long-term usage. To ensure the PEPS platform is well-accepted and therefore may support the long term prevention of CVD, attention will be paid to acceptability factors by exploring how well the platform is integrated into daily life, how it contributes to transform clinicians’ and health care consumers’ activities, and to what extent the solution fits end users’ personal and social values. [19]

Conclusions

The PEPS project aims to develop a web solution that supports the co-elaboration of the PPP by health care consumers and clinicians. The applied user driven innovation approach enabled to design an interactive mockup of the proposed PEPS solution including 30 screens. This mockup supports the process of co-elaboration of PPP. Ultimately, it must help increase the likelihood that health care consumers adhere in the long run to PPP for cardiovascular diseases.

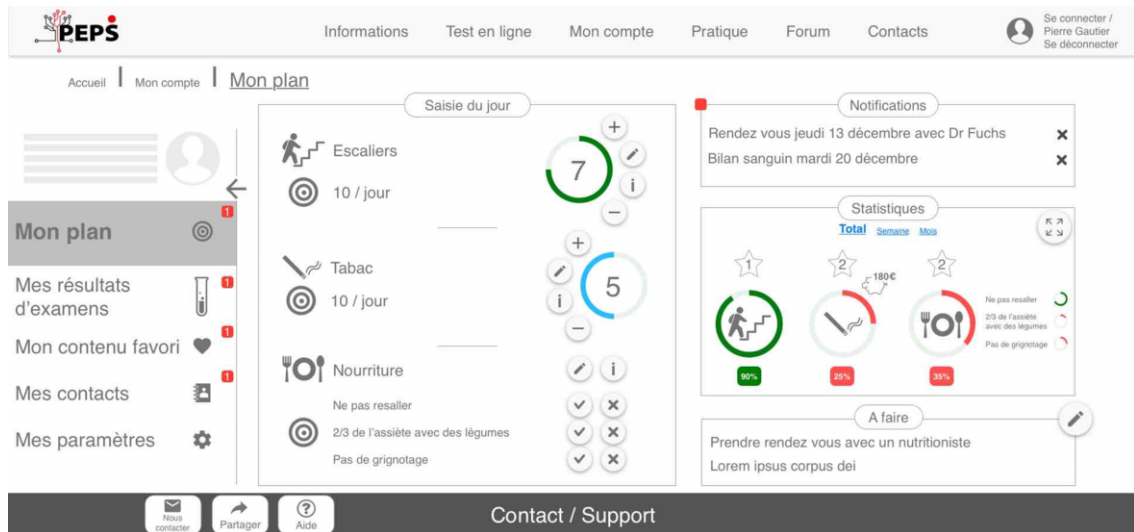


Figure 3— Screens of the Mockup Redesigned by the Experts in Ergonomics - The View the Consumers Have of Their Dashboard

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