Abstract

Patients of chronic diseases, and their informal caregivers, often innovate by developing new solutions to help them cope with their health disorders. This phenomenon has been receiving growing attention from innovation and medical scholars, but little is known about the healthcare factors contributing to the process. Also, peer adoption of the solutions developed by patients or caregivers has not been studied. Given easy access to vast internet resources and peers globally, it is increasingly important to understand what may influence user innovation and its adoption in health, for improving individual well-being and ensuring their safety. In particular, how interactions with peers, with physicians, or search behavior, along with socio-demographics, may influence the decision to develop a solution or adopt one developed by a peer. In this study, we analyze the development and peer-to-peer adoption of user innovations in healthcare and identify individual-level factors associated with these processes. Data was collected via computer-assisted phone survey, from a large, random, and representative sample of adult residents in Portugal (N=6204). We find that in the population considered in this study, estimated 1.3% reported having developed a solution for own use and 3.3% reported to have adopted a solution developed by peers. The three groups (Developers, Adopters, Remaining population) have distinctive characteristics. Gender plays an important role in the solution development, as women are less likely to develop one. Education is positively associated with the development activity, but also with the intentions to adopt a peer-developed solution. Search for health-related information is positively associated with the development, adoption, and the intentions to adopt a solution. Interactions with peers over the internet and rare, but in-person interactions are frequent and have positive association with the dependent variables in all three groups. The results also suggest that the trust in doctors represents an important dimension that shapes the attitudes of the population towards peer-developed solutions.
Development and adoption of innovations developed by patients

Abstract

Patients of chronic diseases, and their informal caregivers, often innovate by developing new solutions to help them cope with their health disorders. This phenomenon has been receiving growing attention from innovation and medical scholars, but little is known about the healthcare factors contributing to the process. Also, peer adoption of the solutions developed by patients or caregivers has not been studied. Given easy access to vast internet resources and peers globally, it is increasingly important to understand what may influence user innovation and its adoption in health, for improving individual well-being and ensuring their safety. In particular, how interactions with peers, with physicians, or search behavior, along with socio-demographics, may influence the decision to develop a solution or adopt one developed by a peer. In this study, we analyze the development and peer-to-peer adoption of user innovations in healthcare and identify individual-level factors associated with these processes.

Data was collected via computer-assisted phone survey, from a large, random, and representative sample of adult residents in Portugal (N=6204). We find that in the population considered in this study, estimated 1.3% reported having developed a solution for own use and 3.3% reported to have adopted a solution developed by peers. The three groups (Developers, Adopters, Remaining population) have distinctive characteristics. Gender plays an important role in the solution development, as women are less likely to develop one. Education is positively associated with the development activity, but also with the intentions to adopt a peer-developed solution. Search for health-related information is positively associated with the development, adoption, and the intentions to adopt a solution. Interactions with peers over the internet and rare, but in-person interactions are frequent and have positive association with the dependent variables in all three groups. The results also suggest that the trust in doctors represents an important dimension that shapes the attitudes of the population towards peer-developed solutions.

This study demonstrates the importance of the peer community, doctor-patient relationship and citizen’s search for information the on innovation and individual attitudes towards peer-to-peer adoption in healthcare. It stresses the need for a reliable online health-related information, and the necessity to deeper understand complex relationships between the need to improve health/fulfill the need and the perception of the health care system.

1. Introduction

User innovators are individuals who have developed new or modified an existing good or service for own use; they differ from producer innovators for whom profit is the dominant motivation to innovate [1]. Patient innovators are patients, or their non-professional caregivers (e.g., parents, family members), who modify or develop a treatment, a technical aid product, or a medical device to help them cope with a health condition [2, 3]. Innovation scholars have demonstrated the existence of this empirical phenomenon in numerous industries, including healthcare [2, 3]. Survey evidence from measurement studies of user innovation at a national level estimated that up to 0.5 % of citizens in the US, Japan, Finland, and the UK modify or create new products and services for personal healthcare-related use [8, 9, 10]. Besides developing, they may also share or adopt solutions developed by other peers, organize in communities, individually and jointly solve problems, and even
do limited trials with solutions they develop [4, 5, 6, 7]. A study conducted in a population of rare disease patients and their non-professional caregivers showed that the frequency of user innovation might be higher among those afflicted with rare diseases than in the general population. The authors reported that 8% of interviewed survey-respondents had developed a solution that was to the medical practice [4]. When the value of patient developed solutions are considered, there is evidence of patients reporting significant improvements in the quality of life after using their self-developed solutions [4]. Furthermore, Oliveira and Canhão [11] identified successful cases of novel patient-developed solutions that made a significant impact on medical practice. Health benefits and social value of innovations can only be achieved when innovations diffuse – when they are adopted and used by other people. In national-level surveys, the fraction of diffused user innovations observed varied from 5% to 17%, with the most common diffusion pathway being peer-to-peer exchange [8,10, 12]. In the rare disease study, 32% of solutions reported by the patients and caregivers were shared with others – almost double the highest diffusion incidence observed in the general population – but only 5% shared the information with their doctor [4]. The existing evidence strongly suggests that the innovation and diffusion activity by patient innovators is significant, but mostly hidden from the traditional health care system. The adoption side of the peer-to-peer innovations in health, to the best of our knowledge, has received little or no attention from the academia.

Innovation and adoption activity by patients and caregivers in healthcare may be strongly influenced by healthcare-related and socio-technological contextual factors. However, no prior work systematically explored such relationships. For example, we know that people invest significant efforts to search for health-related information (online and offline) [16] and may have well-developed strategies for evaluating the credibility of the information [17]. But we do not know the relationship of such a search with the innovation or peer-to-peer adoption activity. Other socio-technical and healthcare contextual factors of interest may also include characteristics of the peer networks among patients [14, 15], doctor-patient relationships [28, 15, 22], personal responsibility for health, or the trust in the availability of scientific breakthroughs for their health disorder. This work is, to the best of our knowledge, the first to systematically explore the relationships between these contextual factors and health-related peer-to-peer innovation and adoption activity among citizens.

2. Data and Methods
The data used in this study are survey responses from a random and representative sample of adult residents in Portugal (N=6204), collected via computer-assisted phone survey conducted by NOVA Medical School. Professional interviewers were additionally trained by a psychologist to communicate the innovation questions, and two of the authors trained them to fill-in the survey responses in a computer program during the conversation. The innovation section of the survey, which is the focus of this paper, was integrated into a larger project, the second wave of a longitudinal, prospective, observational, population-based epidemiological study (EpiDoC study) (Figure 1) [29]. The first wave, entitled EpiReumaPt (EpiDoC 1), was rigorously designed to gather a representative random sample of residents in Portugal. In this phase, data were collected by face-to-face interviews to 10,661 individuals in the period from 2011 to 2013 [30]. Inclusion criteria
were: Portuguese speaking individuals, 18 years of age or older, non-institutionalized (excluding hospital or nursing homes, military barracks, prisons), for whom cognitive and physical impairments did not prevent completion of the survey, and who were living in a private household in the country.

Participants were selected through a process of multistage random sampling. The sample was stratified according to the Portuguese statistic regions in the 2001 Census and the size of the population (less than 2,000; 2,000-9,999; 10,000-19,999; 20,000-99,999; and ≥100,000 inhabitants). The number of participants of each stratum was proportional to the actual distribution of the population. In Madeira and the Azores, the sample size was increased (oversampling) to allow separate analyses in these regions. Candidate households were selected through a random route process; sampling points were randomly selected on the maps of each locality, where the interviewer began a systematic step count (defined for each locality according to its size), granting each household and everyone an equal probability of being chosen [30].

Most of the EpiDoc wave participants (10,153) also agreed to integrate into a prospective cohort and be contacted in the next round of surveying – the CoReumaPt (EpiDoC 2) wave (2013-2015). The Portuguese National Commission for Data Protection and the NOVA Medical School Ethics Committee have approved both EpiReumaPt and CoReumaPt [30]. The participants provided informed consent to participate in all phases of the study, and the study was conducted in accordance with the Declaration of Helsinki. Professional interviewers conducted all the interviews. In EpiDoC 2, the follow-up phase, 7,591 (out of 10,153) individuals completed a computer-assisted telephone survey. Of these, 6,204 individuals were asked for and answered the innovation activity part of the survey. The questions about innovation activity were introduced two months after the launch of the follow-up study, which explains the difference in the number of respondents for this study. To guarantee the representativeness of the sample in relation to the Portuguese population (Mainland and Madeira and Azores islands), extrapolation weights were computed and used in statistical analysis. The weights were obtained by calibrating the extrapolation weights originally designed for the EpiDoC 1 (EpiReumaPt) sample. Participants and non-participants of the EpiDoC 2 study were compared regarding their sociodemographic, socioeconomic, and health status characteristics. Weights were then adjusted based on this comparison and the stratification by statistical regions in Portugal, sex, and age groups.

Survey and three groups of the respondents
The first group of questions in the innovation section of the survey measured contextual factors, self-responsibility for health management, search for health information, the frequency of online and face-to-face interactions with peers, trust in medical doctors and medical science. Next, respondents answered a question that split the sample into three groups: i) the developers of solutions to cope with their health disorders; ii) adopters of health-related solutions developed by other patients or caregivers; and iii) the remaining population. The question asked if an individual had developed or adopted a health-related solution developed by other patients. In the case of an affirmative response, the survey continued with sections that focused on the details about solution development or adoption, dividing the population into the developer or adopter groups. The third group, those who neither innovated nor adopted a solution, were asked whether they have ideas about potential
solutions for health-related problems they so far encountered. Those who neither developed nor adopted a patient-developed solution were also asked about their intentions to adopt a patient-developed solution. For all the respondents, the survey started with socio-demographic questions and ended with life habits, functional, and quality of life questionnaires.

**Creative activity: solution development or adoption of a patient-developed solution**

Questions regarding user innovation were built upon a questionnaire used in user innovation measurement surveys [9], adapting it to the health care context. As the conversation was phone-based, the calling party explicitly introduced the purpose of the innovation-related questions. The interviewers asked the respondents if they had, in their free time, done anything that would help them or someone close to them to cope with their health disorders. To ease the interpretation, we provided mental cues of what the potential solutions may be. The cues suggested to the respondents were: medical aid instrument, medical dispositive, behavioral strategy (e.g. a diet, or an exercise plan), tools for everyday life at home or work, solutions related to one's appearance, medication or a combination or drugs, and natural products.

The question about creative activity is formulated to ask about newly developed or modified solutions, and about the adoption of a patient-developed solution for personal use or for someone close to the respondent. From the survey responses on this question, two dependent (binary) variables were created, a solution development variable (Developer) and a solution adoption variable (Adopter). Furthermore, the origin of the advice for the adopter was asked for, to ensure that the source of the solution is a patient/caregiver. The objective was to identify the characteristics of those who had engaged in creative activity, regardless of the artifact's quality that is developed or adopted.

Large share of the population is likely to be neither solution developers nor adopters of peer-developed solutions, as not everyone has a need for a solution to cope with health-related issues. For this group, and to study the drivers of the attitude towards peer-developed solutions in a general population, a theory of planned behavior [31] is used. According to the theory, intentions are a relatively good proxy of future behavior. The behavioral intentions to adopt a patient-developed solution in this study are measured using a two-item scale (see Table 1). Note that due to the survey complexity the groups are exclusive, which means that the developers were not asked if they had also adopted or about their intentions to adopt a solution. Also, the adopters were not asked about their intentions to adopt a solution.

**Healthcare contextual factors**

Considering the earlier stated goal of this paper, learning about individual creative activity in the health care context, a set of questions was added to the survey. To learn about individual search efforts, the survey measured the depth of search for health information and health-related solutions as the average weekly time spent searching. The As social interactions among patients may influence adoption or intentions to adopt a patient-developed solution, the interviewees were asked about the frequency of their interactions with individuals who are afflicted with the same health disorder or who share interests in the disorder; 5-point Likert scales were used to represent different levels of frequency of interactions.
To measure the perceptions of the scientific frontier, trust in medical doctors, and the attitude towards personal health management, where possible, existing scales were used (reported in Table 1). The medical part of the survey, pertinent to the epidemiological study, included standard measurement instruments that assessed health and quality of life. In this study, the EQ5D score [33] was used, as it is a validated, reliable, and short standard health state instrument that suits the context well. Since we had two measures of EQ5D score, one from EpiReumaPt (2011-2013) and the other from CoReumaPt (2013-2015), a variable that represents the difference between the two EQ5D scores has been generated. Note that this variable is used only in the context of future activities, it is included only in the model that predicts the intentions to adopt a solution. To assess who is afflicted with a health disorder, a binary variable is generated from self-reported data, indicating which individual has a clinically diagnosed chronic non-communicable disease. The list included the following groups of diseases/health disorders: Diabetes, Pulmonary disease, Cardiac disease, Gastrointestinal disease, Neurologic disease, Mental disease, Neoplasic disease, Thyroid and Parathyroid disease, Rheumatic disease. A person is considered ill if there was a report of having at least one disorder from the list.

3. Statistical analysis

Given that measurement instruments were used, the survey was pre-tested on 106 randomly selected interviewees. In this step, exploratory factor analysis is conducted to test whether theoretically constructed four factors could be identified and if there is a sufficient level of internal consistency.

Descriptive statistics are reported for the full sample (N=6204) after applying probability weights to obtain the population estimates [30, 36]. Statistical software, STATA 15, was used to conduct multivariate regression on survey data with the probability weights. The objective of the analysis is to explore the existence of statistically significant associations between the outcomes and independent variables. Three sets of analysis are conducted for the three groups. For the first two groups, developers and adopters, logistic regression is used to study the group differences. For the third group, the ones who neither developed nor adopted a peer-developed solution, the sample is split on one that contains responses from individuals with at least one chronic non-communicable disease, or with none. For both sub-sample, ordinary least square models were used to explore the associations of the independent variables with the intentions to adopt. In all models, the threshold of statistical significance is set to p<0.05.

The scales for self-responsibility for health, trust in doctors, and perceptions of medical science frontiers are included as standardized values, and the interpretation of the coefficients should be in terms of the standard deviations from the population mean.

4. Results

The results of exploratory factor analysis on the initial sample of 106 individuals suggest that the items load well on the four factors, and all the factors have high internal consistency (alpha >= 0.7) [32]. In table 1, factor loadings are reported for the entire sample.
Table 1. Scales, sources, and factor loadings.

<table>
<thead>
<tr>
<th>Construct</th>
<th>Items</th>
<th>Factor loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-responsibility for health</strong> (two items, adapted from a scale by Hibbard, Stockard, Mahoney, &amp; Tusler, [32])</td>
<td>It is me, more than any other person, who is responsible for my health and well-being. (5-point Likert scale: 1-totally disagree; 5-totally agree)</td>
<td>0.9</td>
</tr>
<tr>
<td></td>
<td>The most important factor that influences my well-being and health is my active role and responsibility for my health. (5-point Likert scale: 1-totally disagree; 5-totally agree)</td>
<td>0.9</td>
</tr>
<tr>
<td><strong>Trust in medical doctor</strong> (Reduced scale proposed by Anderson &amp; Dedrick [35])</td>
<td>I trust my doctor so much that I always try to follow his/her advice. (5-point Likert scale: 1-totally disagree; 5-totally agree)</td>
<td>0.9</td>
</tr>
<tr>
<td></td>
<td>If my doctor tells me something is so, then it must be true. (5-point Likert scale: 1-totally disagree; 5-totally agree)</td>
<td>0.9</td>
</tr>
<tr>
<td></td>
<td>I feel my doctor does everything he/she should for my medical care. (5-point Likert scale: 1-totally disagree; 5-totally agree)</td>
<td>0.8</td>
</tr>
<tr>
<td><strong>Perceptions of medical science frontiers</strong> (new)</td>
<td>Do you believe that the medical science can treat your disease? (5-point Likert scale: 1-not at all; 5-completely trust)</td>
<td>0.9</td>
</tr>
<tr>
<td></td>
<td>How likely is it that the medical science can successfully treat you for your disease? (5-point Likert scale: 1-not at all; 5-it certainly can)</td>
<td>0.9</td>
</tr>
<tr>
<td><strong>Intention to adopt a patient developed solution</strong> [33]</td>
<td>How likely is it that you would use a solution developed by another patient to help you cope with your ailment. (5-point Likert scale: 1-very unlikely; 5-I would definitely)</td>
<td>0.9</td>
</tr>
<tr>
<td></td>
<td>Do you intend to use a solution developed by another patient to help you cope with your ailment? (5-point Likert scale: 1-I do not intend to use; 5-I definitely intend to use one)</td>
<td>0.9</td>
</tr>
</tbody>
</table>

Descriptive statistics are reported in table 2 for the three groups (developers, adopters, and remaining population). In total, 6,008 responses were included, after removing responses of the individuals who could not answer creative activity related question. For categorical variable, absolute count is provided, together with population estimates percentages in the brackets. For continuous variables, means and standard deviations are population estimates.

The results show that 1.3% of the population reported being developers and 3.3% peer-to-peer adopters. The respondents have on average 9 years of formal education (SD ± 4 years), and 49% reported being diagnosed with at least one of non-communicable chronic disease.

Table 2. Descriptive statistics for the three groups. Percentages Population estimates in

<table>
<thead>
<tr>
<th></th>
<th>Innovator 75 (1.3)</th>
<th>Adopter 210 (3.3)</th>
<th>Remaining population 5,723 (95.4%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>40 (34.0%)</td>
<td>172 (58.4%)</td>
<td>3,146 (47.6%)</td>
</tr>
<tr>
<td>Age (mean ± sd)</td>
<td>44.62 ± 14.40</td>
<td>49.53 ± 17.09</td>
<td>46.41 ± 17.85</td>
</tr>
<tr>
<td>Years of education (mean ± sd)</td>
<td>9.36 ± 3.28</td>
<td>8.33 ± 3.93</td>
<td>8.92 ± 3.81</td>
</tr>
</tbody>
</table>
Perceptions of medical authority

Trust in doctors scale (mean ± sd)

Self

Depth of Search: Search time on health (hours per week) (mean ± sd)

Interaction with other patients / caregivers (face-to-face)

No

Yes

Frequency of interaction with other patients/caregivers (face-to-face)

Quality of life, EQ5D Score – CoReumaPt (mean ± sd)

EQ5D Score difference CoReumaPt-EpiReumaPt (mean ± sd)

Number of chronic diseases (mean ± sd)

Physical exercise at least once/week

Statistical Region in Portugal (NUTS II)

Employed full-time, part-time, domestic worker

Temporally work disabled/Retired

Unemployed

There are notable differences among the three groups along several dimensions. Within the developers’ group, males represent the majority (66%). Also, unemployment or temporal disability/retirement among the developers (54%) is higher than among adopters (39%) or the remaining population (35%). The developers have, on average, one more year of education than the adopters. For all three groups, interacting with peers (patients/caregivers) via the internet is rare, and the remaining population (neither developers nor adopters) are more active in that regard, with 2% more active people than in the other two groups. Majority of the developers and adopters have frequent in-person interactions, 65% and 53%, respectively. The adopters have a higher number of comorbidities, 2.1 compared to 1.9 for developers and 1.5 for the rest of the population, on average. While all three groups have left-skewed self-responsibility for health (4.9 out of 5), developers are more active than others, as 64% exercise regularly compared to around 40% in other two groups. All three groups have high trust in doctors, with a marginally higher value for the remaining population, 4.5 compared to 4.3 out of 5. Perception of medical science frontier is also left-skewed, with average values of 3.5 for the adopters, and 3.8 for the other two groups.
Absolute values of correlations between independent variables (correlation matrix available upon request) were below 0.35, with four exceptions. These exceptions were: age and education \( (r = -0.6) \), age and having at least one chronic disease \( (r = 0.41) \), having at least one chronic disease and the quality of life score \( (r = -0.38) \), and quality of life score and education \( (r = 0.38) \). However, at these values, the correlation listed above are not considered problematic regarding multicollinearity.

**Results of the multivariable analysis**

Results of the multivariable analysis are shown in table 3. Three dependent variables (Developer, Adopter, Intentions to adopt) correspond to the three groups of interest.

**Developer**

Considering the solution development for own use (model 1), the results show that women are less likely to develop a solution for own use (OR: 0.4, CI 95% 0.2-0.81, \( p<0.05 \)). Education is positively associated with the development activity (OR: 1.13, CI 95% 1.03-1.24, \( p<0.05 \)) and the developers are more likely to be unemployed than employed (OR: 6.45, CI 95% 2.4-17.29, \( p<0.01 \)). Considering health care contextual factors, the developers are more likely to have face-to-face interactions with other patients or caregivers (once a month or more) than no interaction (OR:4.9, CI 95% 2.2-11, \( p<0.01 \)). Also, they are more likely to have at least one chronic, non-communicable disease (OR: 2.85, CI 95% 1.40-6.97, \( p<0.01 \)), and to search for health information more intensely than the rest of the population (OR: 1.14, CI 95% 1.04-1.26).

**Adopter**

The population of adopters is significantly different from the population of developers. Adoption (model 2) is weakly positively associated with female gender (OR: 1.54, CI 95% 0.95-2.52, \( p<0.1 \)) and online interactions with other patients (OR: 2.12, CI 95% 0.95-4.47, \( p<0.1 \)). Adopters are, like developers, more likely to invest time to search for health information than the remaining population (OR: 1.11, CI 95% 1.03-1.2, \( p<0.01 \)).

**Remaining population – intentions to adopt**

In models 3 and 4, the dependent variable is the intention to adopt a solution developed by a patient or a non-professional caregiver. Intentions, according to the theory of planned behavior, are a proxy for actual behavior. In this study, they are interpreted as attitudes towards peer-developed solutions.

The results for the sub-sample of individuals with at least one chronic non-communicable disease (model 3) suggest a distinct combination of statistically significant associations. Intentions to adopt are negatively associated with age \( (\beta: -0.01; \text{CI 95% } -0.02- -0.01; \ p<0.01) \), and positive with education \( (\beta: 0.02; \text{CI 95% } 0.00-0.03; \ p<0.05) \). Like developers and adopters, in the remaining population, those with a chronic disease with higher intentions to adopt are more likely to invest their time to search for health-related information \( (\beta: 0.07; \text{CI 95% } 0.02-0.13; \ p<0.05) \), and more likely to have frequent in-person interactions with other patients/caregivers. Unlike the other two groups, developers and adopters, doctor-patient relationship plays an important role; the lower the trust in doctor, the higher is the intention to adopt a peer-developed solution \( (\beta: -0.08; \text{CI 95% } -0.14--0.02; \ p<0.01) \).

Within the remaining population, sub-sample of individuals without a chronic disease is very similar to the sub-sample of those with a chronic disease. Distinctive characteristic of
the former sub-group is a negative association between retirement/temporary work disability and the intentions to adopt a peer-developed solution (\( \beta: -0.2; \ CI \ 95\% \ -0.4 - 0.03; \ p<0.05 \)) (model 4).
Table 3. Multivariable analysis with population estimates

<table>
<thead>
<tr>
<th>DEPENDENT VARIABLES</th>
<th>Developer (vs. all the rest)</th>
<th>Adopter (vs. all the rest)</th>
<th>Intentions to adopt (remaining population)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(model 1) Odds Ratio</td>
<td>(model 2) Odds Ratio</td>
<td>With a chronic disease With a chronic disease</td>
</tr>
<tr>
<td>INDEPENDENT VARIABLES</td>
<td></td>
<td></td>
<td>(model 3) (model 4)</td>
</tr>
<tr>
<td>Gender: Female vs. Male</td>
<td>0.40**</td>
<td>1.54*</td>
<td>-0.11** 0.01</td>
</tr>
<tr>
<td>Age (in years)</td>
<td>0.99</td>
<td>1.00</td>
<td>-0.01*** -0.01***</td>
</tr>
<tr>
<td>Education (in years)</td>
<td>1.13**</td>
<td>0.95</td>
<td>0.02** 0.02***</td>
</tr>
<tr>
<td>Employment: Temporarily work disabled /Retired vs. Employed (full- or part-time)</td>
<td>1.41</td>
<td>0.98</td>
<td>-0.01 -0.2**</td>
</tr>
<tr>
<td>Employment: Unemployed vs. Employed (full- or part-time)</td>
<td>6.45***</td>
<td>1.02</td>
<td>0.04 -0.15</td>
</tr>
<tr>
<td>Marital status (Married/union vs. Single/Widow/Divorced)</td>
<td>2.46*</td>
<td>1.20</td>
<td>-0.00 -0.03</td>
</tr>
<tr>
<td>Regular physical exercise</td>
<td>1.87**</td>
<td>0.85</td>
<td>0.03 1.34</td>
</tr>
<tr>
<td>Health state, EQ-5D Score – CoReumaPt</td>
<td>0.63</td>
<td>1.09</td>
<td>0.02 -0.22</td>
</tr>
<tr>
<td>Diff. EQ-5D Score: CoReumaPt-EpiReumaPt</td>
<td>NA</td>
<td>NA</td>
<td>-0.10 -0.03</td>
</tr>
<tr>
<td>F2F Interaction with other patients / caregivers: less than once a month vs. no interactions</td>
<td>0.68</td>
<td>1.24</td>
<td>0.28*** n.a.</td>
</tr>
<tr>
<td>F2F Interaction with other patients / caregivers: once a month or more vs. no interactions</td>
<td>4.82***</td>
<td>1.21</td>
<td>0.28*** n.a.</td>
</tr>
<tr>
<td>Online interactions with other patients</td>
<td>0.62</td>
<td>2.12*</td>
<td>-0.07 n.a.</td>
</tr>
<tr>
<td>Health information search depth (hours per week)</td>
<td>1.15***</td>
<td>1.11***</td>
<td>0.07** -0.00</td>
</tr>
<tr>
<td>Personal responsibility for health (standardized)</td>
<td>1.06</td>
<td>1.14</td>
<td>-0.04* 0.03</td>
</tr>
<tr>
<td>Trust in physician (standardized)</td>
<td>0.92</td>
<td>0.94</td>
<td>-0.08*** -0.14***</td>
</tr>
<tr>
<td>Trust in medical science (standardized)</td>
<td>0.99</td>
<td>0.81</td>
<td>-0.02 -0.02</td>
</tr>
<tr>
<td>With at least one disease vs. no disease</td>
<td>2.85***</td>
<td>1.02</td>
<td>n.a. n.a.</td>
</tr>
<tr>
<td>Region fixed effects</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Constant</td>
<td>0.00**</td>
<td>0.02***</td>
<td>0.54** 0.36</td>
</tr>
<tr>
<td>Observations</td>
<td>5,576</td>
<td>5,494</td>
<td>2,800</td>
</tr>
<tr>
<td>Prob &gt; F</td>
<td>&lt; 0.001</td>
<td>&lt; 0.001</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>R-squared</td>
<td>n.a.</td>
<td>n.a.</td>
<td>0.16</td>
</tr>
</tbody>
</table>

Legend: * p < 0.1; ** p<0.05; *** p<0.01
5. Discussion

The analysis suggests that solution development and adoption of peer-developed solutions are relatively infrequent but significant phenomena, and that the three groups have distinctive characteristics. Population estimates of the share of solution developers, 1.3%, is over two times higher than the estimate of the share of health care related innovation by citizens in the UK [8, 10]. Since there was no restriction on the novelty of the reported solutions, as it could not be established, the reported estimates in this study are regarding solution developers, and not user innovators. In other words, the comparison is not applicable. Regarding the population estimates of the adopters, this is the first such measure.

A series of results are aligned with the extant academic literature in user innovation. Regression results suggest that solution developers are more often men, and educated individuals, confirming the findings from the study of user innovations by consumers in the U.K. [8, 10]. Also, active interactions with peers are positively associated with solution development (model 1, table 3), which corroborates the findings of Hienerth and Lettl [25] who studied the influence of peer communities on user innovation. From a public policy perspective, if the goal is to stimulate solution developer by patients and caregivers in healthcare, a meaningful investment could be in the development of communities of peers. An example of successful investment is Enabling the Future community of mostly patients and that caregivers that develop open-source 3D printed hands [5]. Albeit, integrating knowledge and experience of users to improve health care is complex, and the effects often fail short of the expectations [38]. While intuition may suggest internet as a great platform for communities, the results of this study suggest that most of the respondents, developers, adopters, and even ill people from the remaining population who have higher intentions to adopt a peer-developed solution, prefer in-person interactions among peers over contacts through the internet.

From table 3, model 1, one may conclude that the developers are more likely to be unemployed than employed. A plausible explanation may be that they have more time to reflect upon needs and solutions; or, that unemployment is associated to a higher likelihood of suffering from health disorders and to having financial difficulties [35], which implies higher need to solve problems.

Group-mean comparison suggests that the average time spent searching for health-related information by the developers (2 hr/week) is almost twice the time spent by the adopters (1.1 hr/week) and four times higher than for the rest of the population (0.5 hr/week). This result emphasizes the importance of the provision of curated and accurate information. Namely, following an advice of a peer, without consulting a health professional may be quite dangerous. For example, applying a plant extract without understanding side effects or permitted dosages may provoke serious health issues.

Considering adoption of solutions developed by patients or caregivers, the regression results do not suggest any stark characteristic of the group of adopters. But, the application of the intentions to adopt, a concept from the theory of planned behavior, reveals an important association. The attitude of those who did not engage in neither developing a solution nor adopting one, may be influenced by the doctor-patient relationship. In light of the safety concerns regarding the diffusion of (self-made) health solutions in informal communities of patients and caregivers, doctors are a vital element of health care system that helps patients establish safety and efficacy of the available solutions. A negative
association between the intentions to adopt and age (models 3 and 4, table 3) possibly reflects the generational change in the perception of the role of the conventional health care system. Namely, older individuals may be used to the paternalistic doctor-patient relationship, and they may put a higher value on the official source of health-related solutions. Education is positively associated with the intentions to adopt a solution, which is also potentially linked to the paradigm shift in health care from paternalistic to more egalitarian relationships between patients and health professionals.

In this study, data have been collected from a prospective cohort. As we worked with cross-sectional data, only associations may be claimed. Recollection and interpretation bias may be present in the data. Although some people may have developed or adopted a patient-developed solution without being aware of it, the focus of this work was to explore the characteristics of those who are aware and have had chosen to develop or adopt a peer-developed solution. Hence, these biases are likely not to influence the results significantly. A set of preemptive steps were taken before administering the survey to control for item-related (common method) bias, as suggested by Podsakoff et al. [37]. These measures include ease of cognitive load on the individuals and the design of the questions and their order to avoid the item-related bias.

6. Conclusions
This paper is the first exploratory analysis of creative activities in the general population that focuses on health care and takes into consideration health care contextual factors. It demonstrates distinctive characteristics of the patients/caregivers developers of solutions, adopters of peer-developed solutions, and the attitudes of the remaining population. Two actionable takeaways from the study are the importance of supplying reliable health-related information to patients who are searching for solutions for their medical programs, and, at the same time, investing in goof doctor-patient relationship.

Treating patients as equals is becoming the new mantra in organized health care systems [39], and we need to consider carefully what does it mean, regarding their creative work, knowledge contribution, and organization and delivery of medical care.

7. References