Patients as Partner in Healthcare: A User Requirement Gathering Activity for Chronic Pain Self-Management Apps

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ABSTRACT

Chronic pain has been increasingly pervasive in the global population with disruptive influences on individuals' physical and psychological aspects and social engagement. With the surge of mobile technology, applications aiming to support the patients' self-management of chronic conditions have emerged in various platforms. However, the lack of user and healthcare professional (HCP) involvement in the development process has been identified in available commercial apps, causing low awareness of the apps, inappropriate delivery of functionalities and usability problems.

In order to fill the gap between the healthcare service provision of existing apps and user expectations, the present study conducted four stages with patients and HCPs. First, an autoethnography was conducted to evaluate the study protocol for the next stage, which was an ESM study with 5 chronic pain sufferers, to understand the management experiences. Then, semi-structured interviews were conducted with 11 patients (stage 3) and 2 health professionals (stage 4) to explore user expectations on the usability and the functionalities.

The results of the autoethnography and the ESM showed the complex and diverse pain conditions. The treatment manifested a lifestyle change, causing significantly behavioural impact. The results of stage 3 revealed that the present pain self-management was insufficient. Multiple facilitating and impeding factors existed in the motivation to adopt and engage with pain apps. Usability needs clustered around the operation and the interface. Stage 3 and 4 uncovered consistent attitudes but complementing requirements emerged on the five functionalities, with pain-related education rated the most crucial, followed by self-tracking, goal-setting, skill training, and social support.

Additionally, and HCP involvement was regarded as important and irreplaceable.

The design and implementation of apps was likely to facilitate a beneficial collaborative patient-HCP relationship.

1. INTRODUCTION

When people confront major life crisis, they tend to go through transitions in both visible and invisible aspects, which differentiates the impact of the transition on their cognitive mindset and daily behaviours. Disruptive health problems are one of the most critical life crisis and lead to long-term healthcare and self-management. Chronic conditions which cause constant pains or aches to the body are a case in point, resulting from a wide range of diseases.

It is widely-accepted that chronic pain (CP) is intractable in diagnosis because of its complicated nature in terms of its causes and symptoms. The treatment relies heavily on individual conditions. On the other hand, the communication between patients and health professionals (HCPs) is usually insufficient and inaccurate [17] due to the different level of understanding of the subjective pain experience. Patients tend to rely more on themselves rather than HCPs in terms of making medical decisions for themselves. Self-management starts to become a pervasive healthcare strategy.

With the surge of technology in recent years, the mobile smartphone has played an increasingly essential role in delivering public healthcare service. It has stepped into the pain management field with multiple functionalities to support patients' daily healthcare needs. There is an increasing number of pain apps available on mobile stores [39].

The goal of the medical apps targeted chronic pain is to support tailored real-time and comprehensive healthcare through functionalities empowered by mobile technology

and additional wearable devices. However, there are still significant pitfalls in the development and implementation chronic pain management apps, as it is still at the early stage of development.

With the continuous advance in mobile technology, it brings the opportunity to deliver better personal healthcare service. However, there is also a trend that most existing chronic pain management apps solely rely on technology but have little focus on the user experiences of the main stakeholders, people with chronic pain [36]. This is not only problematic but opposed to the initial goal of the design, with respect to the observed low usability and usage.

With notice to the gap between the healthcare services provided by available apps and the user expectations, the current study aimed to identify patients pain management experiences and user requirements of two groups of key stakeholders, chronic pain sufferers and HCPs, and provide design implications in the design and development of chronic pain management apps. The study adopted a qualitative approach comprising autoethnography, Experience Sampling Methods (ESM), and semi-structured in-depth interviews for data collecting and thematic analysis for data analysis.

2. LITERATURE REVIEW

In this section, prior research on the chronic pain self-management and related mobile technology were reviewed. Firstly, an introduction of the increasing pervasion and profound life impact of chronic pain was presented. Then, fear-avoidance approach, as the crucial emotional aspect of chronic pain and treatment principle, was introduced. Following that, popular pain management measures were listed as well as the changing role of patients in self-management. Next, mobile apps and five functionalities provided nowadays were introduced. Lastly, pitfalls in existing pain management apps were articulated.

Chronic pain

Chronic pain is defined as recurrent or persistent pain, lasting at least three or six months and showing little change over time (dilatory progression) [27]. It covers lower back pain, neck pain, arthritis, osteoarthritis, headache, post-surgery pain, psychogenic pain, neurogenic pain and so forth.

According to the latest International Classification of Diseases (ICD) [50], chronic pain can be divided into seven categories regarding their causes: 1) chronic primary pain, occurring in at least one anatomic area; 2) chronic cancer pain, caused by cancer and its treatment; 3) chronic posttraumatic and postsurgical pain, caused by a surgery or a tissue damage; 4) chronic neuropathic pain, caused by injury of the somatosensory nervous system; 5) chronic headache and orofacial pain; 6) chronic visceral pain, resulting from the internal organs; 7) chronic musculoskeletal pain, caused by a disease in bones, joints, muscles, or related soft tissue.

As a result of various causes, chronic pain has a high prevalence. According to the World Health Organisation (WHO) survey [21], 21.5% of the global population suffered from single or multiple chronic pain, with the rates varying from 5% to 33% among countries. 17.5% of the population in the United Kingdom experienced chronic pain conditions [30]. Within this group, the percentages of moderate pain and severe pain were 66% and 34% respectively whereas the percentages of constant pain and intermittent pain were 46% and 54% respectively [10].

In addition to the prevalent occurrence in global population, chronic pain conditions are one of the most challenging life transitions in terms of their physical, psychological and social impact.

People with chronic pain need to deal with the physical limitations in their functional capabilities, due to the debilitating process [24]. Specifically, patients face reduced flexibility, body strength and stamina, and even a possibility to transform into disability [15].

On the other hand, psychological factors play an important role in chronic pain experiences. Fear-avoidance (FA) belief is the most influential one, especially in the case of chronic musculoskeletal pain [54]. Fear of the potent pain is the central mental motivation causing the maladaptive behaviour when encountering chronic pain conditions. Based on the prior work on the association between fear and pain [28,53], the FA model of chronic pain has been refined and elaborated [14]. The key to the model is the interpretation of the pain experience. If the pain experience is interpreted as noxious and a threat to the body, then pain-related fear is likely to grow, causing the withdrawal of the faced stimulus or events due to the instinctive self-protection [2]. According to the conditioning learning theory, this fear-related avoidance will further contribute to catastrophizing [48], anxiety, depression, sleep disturbance [10], low self-efficacy and low self-esteems [32].

Because of the restriction of movement and the psychological vulnerabilities, patients experience a lowered life quality [35], with their social engagement with families and friends impeded as well [24]. Besides, a close relationship between the physical and psychological factors is discovered, such as self-efficacy [15] and disability.

Furthermore, chronic pain has a significantly detrimental influence on the quality of sufferers' daily working and study [45,46]. It is reported that 61% of people in the chronic pain community were not able to work in offices but just home. 19% of them became jobless while 13% changed their jobs due to their chronic pain [10]. The under-employment and also the cost of treatment bring huge social implications. As chronic pain ranked the first reason to seek medical help [44], it lays a huge economic burden on society [25].

Chronic pain is a pervasive disruptive health conditions that causes a detrimental impact on personal physical and psychological health, as well on the society.

Chronic Pain Management

Given the complexity residing in the accounts, symptoms, and intensity of chronic conditions, it is challenging for individuals to manage chronic pain in general. Normally, chronic pain patients require long-term and frequent clinical care and medical services in the process of obtaining a consistent and precise diagnosis and the treatment afterward [20]. In addition, the treatment of chronic conditions also addresses a lifestyle change in terms of the persistent medication and non-medication therapies [31].

So far, great effort has been made for chronic pain treatment. Rather than to cure completely, the aim of the treatment and management is to relieve pain and enhance patients' body function. Currently, medication treatments and non-medication approaches adopted by patients are equally popular. In terms of medication, non-prescription analgesics is the most common one to alleviate the pain for most cases. Nonsteroidal anti-inflammatory drugs (NSAIDs) are of the highest demand as prescribed medicine, followed by weak opioids, paracetamol, COX-2 inhibitors and strong opioids. As for non-medication treatment, patients went for massages, physical therapy, and acupuncture [10].

One pertinent barrier in practical diagnosis and treatment. Apart from the diverse nature of chronic pain, the difficulty of the treatment and management also lies in the relationship between patients and the HCPs. In order to obtain an accurate diagnosis and find the best treatment for a patient, it is necessary for the HCPs to understand the pain history of the patient, including the body condition and pain variables. Although doctors can receive an accurate report of the individual's body condition with the help of medical equipment, the feeling of pain is considered personal and subjective. This feeling is delivered through patients' narratives on the intensity, the sensation, the location and the timing of the pain. The lack or failure of the communication and interaction between HCPs and patients will hinder the decision-making process to achieve the best-fit treatment approach [20]. However, with the emergence and development of internet and mobile technology, the relationship between clinicians and patients faces a new change.

Even though there is a great progress in the effectiveness of pain treatment and measurement [20], insufficient management has still been reported. In fact, one-third of people with chronic pain did not seek or receive any medical treatment. It is estimated that 40% didn't have the adequate management of the chronic pain. Only 2% receive a treatment from specialists in chronic pain [10].

Self-management approaches are effective when compared to the lack of healthcare intervention. For example, patients with low back pain and osteoarthritis benefited from those programmes in not only improved symptoms but also reduced mental distress [34]. In a comparative programme targeted back pain, self-management approach appeared to be more effective than diagnostic treatments [55].

Collaborative relationship between patients and HCPs

Although clinicians or HCPs play an important role in the treatment decision, it is patients' responsibility to be proactive and decisive in the management process.

Studies [17] in shared medical decision (SMD) making in the management of chronic pain reveals that there are inevitable differences between the belief and the attitude of patients and the HCPs. The patients strive to be considered as individuals and emphasize their own concerns on pains and life quality whereas the doctors or specialists concentrate on figuring out the diagnosis and treatment rather than patients' personal issues.

Hence, a new patient-professional relationship has been formed, addressing a more proactive role of the patient. Under this context, a new chronic paradigm was proposed to include three elements, the patient-professional partnership, involving collaborative care and self-management education [7]. Generally speaking, patients tend to play a dominant role in healthcare a collaborative partner in healthcare decisions, and active learner in problem-solving skill with the support of clinicians as health consultants [23].

Technically, self-management refers to the ability to manage the symptoms, treatment, physical and psychological consequences and life-style changes inherent in living with a chronic condition [4].

UK government has promoted self-management as the key to primary public health and social care, which emphasises joint problem-solving and shared decision-making process between public patients and their GPs, rather than strict obedience to medical instructions [49]. However, the successful implementation depends on personal capacity and preference [47]. Some areas in the UK even push self-management further to self-test and self-dose involved in the oral anticoagulation therapy for treating diabetes [16].

mHealth and chronic pain management apps

Smartphone and other PDA technology are becoming increasingly ubiquitous, with a growing number of apps (mobile applications) that can be downloaded from online app stores to fulfil thousands of functions, penetrating into every aspect of human activity [26]. The ongoing development of technology makes them more flexible and simple to use, as well as more affordable for a wider range of the population. Hence, it is more likely that clinical data can be collected from individual users when they engage in their regular daily activities, which can be further applied to their healthcare [3].

mHealth, a short form of mobile health, is defined as "*handheld [or wearable] transmitting device[s] with multi-functional capabilities [that can be] used to store, transmit and receive health information and has user control over the access to the health information*" [37]. In other words, it describes the utilisation of mobile communication technologies in healthcare [52], including smartphones and multiple wearable devices.

With the growing attention and effort into the field, the number of pain management apps targeted at patient users on commercial online platforms has risen rapidly over the past few years. In 2011, 111 general pain apps were identified across mobile platforms including iPhone, Android, Windows Mobile, Nokia/Symbian and Blackberry [39]. The number increased to 279 in the following paper using similar inclusion criteria for apps as the previous study [27]. These patient-ordinated apps are the main body of pain-related apps available, with five times available compared to those serving for healthcare professionals [52].

The existing apps concentrate on managing a wide range of pain types and pain implications. According to a review on current pain management apps in the market, the majority of them targets general pain conditions [52]. Besides, apps on managing back pain, headache and arthritis share the same popularity. Still, there are apps designed to target other specific pains and aches.

Furthermore, the available commercial apps perform as tools to manage the variety of pain condition in the form of either a pain diary or a pain scale [36]. The difference resides in the information input manner of pain episodes. The former allows users to record in detail with words like a journal while the latter provides users with visual analogue scales for pain variables, such as severity, frequency, and location. *Figure 1* shows one example for each, with the left in the form of journal and the right in the form of scales. It is also common in some cases that visual scales are integrated into the pain diary apps.

A review analysed and divided the functionalities incorporated in available pain management apps into five areas showed below [27], with accordance to those elements borrowed from previous pain self-management programmes [32,45].

1) Pain self-monitoring, to track pain through regular entry of pain variables;
2) Goal-setting, to stimulate adherence to tasks for lifestyle change in a descending order of popularity;
3) Pain-related education, to provide various information;
4) Pain self-care skill, to support acquirement of correct posture and muscle relaxation techniques;
5) Social support, to connect users through social media outlets or built-in communities.

The present study will gather user requirements based on these five functionalities and provide future design implications.
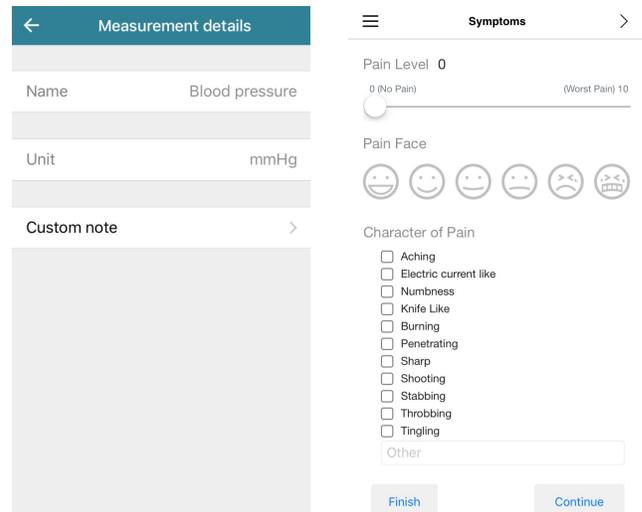

Figure 1. Screenshots of MyTherapy (left) and My Pain Logs (right). Both apps are available in Apple Store and were taken on an iPhone 6s.

Pitfalls in available chronic pain management apps

Chronic pain management apps are still in the early stage of development. They have promising future to be well-

designed and fully-implemented to benefit a greater user group in health self-management. However, there tend to be growing concerns regarding some pitfalls in available chronic pain management apps at present, which are discussed in this section.

Most apps fail to have any form of user involvement [36]. As known in the field of HCI, it is detrimental to not follow a user-centred approach in the design and development process for an interactive product [42]. First of all, it causes low usability for the apps to deliver health service and support pain self-management. Even the most popular reviewed pain management apps on market have flaws in factors such as interface design [36] information sharing, functionality and information delivery. It is the case that those researcher-led pain management apps have more exploration and implication in the usability of functionalities [40]. But this still remains rare and most of these promising apps are still under scientific testing stage unavailable to the public at the moment. All of these brings about the lack of awareness of those pain management apps among the targeted user group. Hence, it is strongly recommended in the field of health care device development that end users should engage in the earlier process of development, so that initial user desires and requirements can be effectively gathered to instruct more usable design solution regarding the contents and interfaces quality [41].

Additionally, the available apps for self-care are lacking in scientific support from HCP or empirical studies [52], which is vital in the development of medical devices [22]. Less than 35% of general medical apps engaged HCPs

during the design and development process [22]. In a recent review of 279 apps available across various mobile platforms aiming at allowing patients to manage chronic pain conditions out of clinical context, not a single app mentioned their underpinning medical rationale or theoretical reference that supported app design, neither any type of scientific evaluation was conducted [27]. All the pain-related apps available in mobile app stores have no evidence basis on any chronic management publications that can be searched on scientific databases such as PubMed or Google Scholar [52]. This gives rise to the concern regarding the quality and validity of the content provided in the apps. Besides, information update when novel scientific findings are made is also essential for information provision pain-related apps, which requires continuous technical maintenance.

Furthermore, the lack of regulations for those medical-related apps remains controversial issues, which cause safety concerns in the domain. There is a lack of guidance on both development procedure and assessment criteria in terms of user involvement, medical support, and user confidentiality. It is the deficient supervision on the app quality that harms the development of pain-related medical apps [11]. There is no consistent agreement on the assessment criteria or evaluation methodology [39]. Under the current situation, the inconsistent quality of apps resulted in low awareness and preference of the apps. Regulations should be applied in the process of engaging users and HCPs to ensure the user experience with accredited usability and functionality.

Due to profit-orientated nature, the absence of consideration in the validity of the description of the apps causes exaggeration or distortion in the promoted effectiveness of functionalities, without sufficient scientific support or empirical evidence in most cases [33]. Although this is common for commercial apps to make such marketing claims in their advertising scheme, it sparks off great concerns for individual health products.

Aims

The above pitfalls suggested a lack of empirical research on both patient users and HCPs to underpin the design and development process of the chronic pain management apps. This may cause the consequent difference between the user requirements and the mobile healthcare services provided. The current study endeavoured to conduct a user research to fill the gap between the user needs and the available products, so as to further inform the design and development of the novel apps that support self-management of general chronic pain. The main research questions are as follow:

1. How do chronic pain patients manage their chronic pain conditions and what they think about the management?

2. What is user experience of current management apps?

3. What do users expect from a chronic pain management apps?

3. METHODS

The study followed the methodology of a qualitative approach. It comprised four stages with multiple data collection methods to explore the user experiences and needs for pain apps.

The first three stages aimed at patients with chronic pain. Firstly, an autoethnography was carried out by the author to evaluate and reflect the diary questions and ensure the validity of stage two.

Secondly, an Experience Sampling Methods (ESM) was employed to identify day-to-day user experiences on their current chronic pain management strategies. It was organised in four topics, including treatment, pain experience, life impact and pain-related information needs. The understanding of user experiences and needs gained from the thematic analysis was to further shed light on the possibility and the difficulty for the self-management apps to provide thorough healthcare.

Driven by that, a semi-structured interview was performed to understand their expectations and concerns on the novel chronic pain management apps in terms of the functionalities, usability, health professional involvement at stage three.

The last stage targeted health professionals. A semi-structured interview was conducted to understand expert views on the introduction of chronic pain apps in patients' self-management, mainly covering topics on the role of health professionals, the needed contents and the functionality of chronic pain apps.

With completing the four stages, the study aimed to construct a comprehensive understanding of the present situation of patients and the user requirements from both stakeholders, to inform the design and development of chronic pain management apps.

Ethics

The research was approved by UCLIC Research Ethics Committee and gained ethical clearance under Professor Ann Blandford's Non-invasive Research on Healthy Adults.

Stage 1: Autoethnography

Participants

The study was conducted in the form of a diary study with the author. The author was diagnosed with rheumatoid arthritis two years ago, and was experiencing chronic pain recurrently.

Apparatus and materials

The autoethnographic diary was filled out on a Microsoft Excel form. The initial questions were shown in *Table 1*.

Initial questions	Refined questions
1. What is your medication need for your chronic condition today?	1. Could you describe your treatment today?
2. How much has the pain influenced you today, and explain it?	2. Could you give a brief description on your pain experience today?
3. What is your information need for your chronic condition today?	3. How does it influence your behaviour today?
	4. Is there anything you would like to know to help manage your pain today?

Table 1. initial (right column) and refined (left column) questions in ESM

Procedure and analysis

Autoethnography requires the researcher to change their role into a participant to get insight on the topic [12].

In the study, the author took the diary for three weeks. After the first week of data entry, the questions in the diary were

assessed to enhance the credibility and effectiveness, and refined to be better-directed and elaborated (see *Table 1*). The refined questions were then applied to stage two. Besides, the autoethnography provided the author with a scope of a pain sufferer and a preliminary understanding of the user needs.

Stage 2: ESM

Participants

5 participants (2 males and 3 females) were hired for the study, aged from 23 to 28. The detailed demographic and pain-related information was shown in *Table 5* (D1 to D5). All of them were master students in the UK but from different countries and background. All the participants also took part in stage three (describe below).

The recruiting criteria used included 1) Are experiencing recurrent and chronic pain from any part of the body for more than three months, with or without a biological cause; 2) Are familiar with the smart phone and mobile applications.

The participants were approached through indirect contact, mainly on the social media Facebook (recruit advertisement see Appendix 1). Participants were contacted to make sure they were eligible for the study. This implied the adopted convenience sampling and purposive sampling [6]. Participants received £20 as compensation.

Apparatus and materials

The ESM comprised a pre-study brief interview, a 21-day diary, a debriefing interview.

The diary form with four questions from autoethnography was released to participants as a google form every day through Facebook Messenger, which was opted by all the participants. They received a reminder text every day with a link to the google form, https://goo.gl/forms/Hc7BRCKmW8Byghyr2.

All the interviews took place in the pre-booked study rooms in Science Library of UCL to offer participants a comfortable and mentally secure environment. The conversations were recorded by a smartphone and the audios were kept safe. The scripts for the pre-study brief and the debriefing interview were printed out in advance.

Procedure

Participants were presented with an information sheet and a consent form (see Appendix 2,3). A pre-study brief was conducted to gain participants' demographic information, pain conditions, and also self-management experiences in brief. Then, participants were asked at their preferred time and communication platform for the reminder text every day.

During the diary study, the researcher sent the reminder to each participant at the confirmed time. The data of all participants from the first week were reviewed and assessed in terms of the quality and the validity of the entries.

After the three-week period, debriefing interviews were settled with each participant. Diary-related questions were asked first. The rest were consistent with the questions in stage three (describe below, see Appendix 4).

Analysis

Thematic analysis was used for the text data and incremental analysis procedure was combined. The data for each participant were first analysed according to each question, so as to summarise the pattern across time. Then, the data for each participant were analysed with *day* as a unit, to seek out the underneath relationship among different questions in one day. This helped to discover the pattern of participants' pain self-management strategies and information needs.

Stage 3: Semi-structured interview with users having chronic pain experiences

Participants

11 participants (4 males and 7 females) were recruited. 5 participants completed the ESM study and were interviewed for the purpose of this study afterward. Nine of them were master students in the UK, with one Ph.D student and one lecturer in university with a bachelor's degree. The participants were from different countries and background (see detail in *Table 5*).

The sampling and approaching methods were the same with the ESM study, except for the inclusion criteria, where potential participants here could have chronic pain

experience either at the moment or in the past. participants got a compensation of £10.

Apparatus and materials

Nine of the interviews took place in the study rooms in Science Library of UCL which were booked in advance. Two of the interviews were conducted through video chat function powered by Facebook because they were oversea participants. Audios were recorded through the smartphone for face-to-face conversation and the QuickTime Player for online.

The interview script was printed out ahead to jot down the key information emerged in the interview and to help control the flow without omitting questions after digging deeper into a small focus. The interview questions were related to topics on demography, pain condition, self-management experiences, prior experiences with pain management apps, user needs and other issues (see Appendix 5).

Procedure

For face-to-face interviews, participants were asked to sign the consent form. Following a short oral description and explanation of the interview, the audio recording started with the permission of participants. After the interview, they were given the incentive and asked to sign the receipt sheet.

For online interviews, participants were asked to stay in a quiet and safe place. And then they were sent the information sheet and the consent form, and were asked to send back the electronic signed consent form. They were informed that only their voice would be recorded before it started. After the interview, incentives were transferred to them. The interviews last from 30 minutes to 60 minutes.

A pilot study with two participants was conducted to evaluate the interview protocol and to practice the researcher's interview ability in probing emerging topics.

For the five participants from the ESM, questions related to pain condition were asked in the briefing and the questions on pain management experiences and expectations on apps were asked in the debriefing interview after a three-week interval.

Analysis

Thematic analysis [9] was used to analyse the qualitative data. An inductive approach was used in the early stage of analysis. The audios were verbatim transcribed by the author to familiarize with the data and generating initial codes. After iterative coding, themes started to emerge and were eventually reviewed for consistency with the original data, a top-down processing was adopted to make sense with the research questions. The process of analysis and data collection was interleaved. All the transcribing, coding, theme emerging were conducted via the qualitative study

tool, NVivo for Mac (11.4.1). Besides, affinity diagram was used to figure out the relationship among themes.

Stage 4: Semi-structured in interview with HCPs

Participants

Two expert participants took part in the interview. One of them was a phycologist with 15 years of clinical experience in chronic pain, the other was a physical therapist from the USA.

Apparatus and materials

The interviews took place at a quiet and private venue. The conversations were recorded with the researcher's smartphone. The information sheet for this study and the consent form were presented as well. And the corresponding script (see Appendix 6) was printed out.

Procedure and analysis

About 100 minutes audio recordings in total were collected. The procedure and analysis protocol were the same as the interview with chronic pain sufferers.

4. RESULTS FOR ESM

The diary study revealed the longitudinal pain self-management experiences of participants on a daily basis, including the pain condition, self-treatment, impact on their behaviour and their information need each day.

For the five participants recruited for a period of 21 days, none of them dropped out half way. Four of them adhered to the diary every day while one of them had four missing entries. Altogether, 101 data entries were gathered and analysed.

It is evident that the lives of all five participants were adversely affected by their chronic pain. *Table 2* demonstrated the numbers of days where they didn't feel any symptoms, didn't give themselves any medication or physical treatment, and didn't experience any behaviour or life impact of the pain. As can be seen, they experienced pain symptoms almost every day and seek for treatment frequently. Their lives were, hence, largely influenced. Pain killers were taken by D2 and D5 to get rid of their stomachache and headache respectively, with D2 having more reliance on physical treatment. It is worth noting that D5 took painkillers 7 times during the three weeks while D2 took only once. By contrary, D1, D3, and D4 relied solely on physical treatment.

4.1 Pain condition – complex and diverse

It can be concluded that for each individual, the sensation of pain was complex in terms of the variety of the symptoms. On average, participants experienced multiple pain conditions or symptoms every day simultaneously, as seen in the case of D2 who felt unwell in the stomach, upper intestine, and rectum. Moreover, most experienced pain without being aware of the reason, though it is not always the case. For instance, D2's pain was partially

	Pain location	Sympto m-free	Non-treatment	Non-impact
D1	Ankle/knee/ shoulder/eye	2	8	7
D2	Stomach	2	1	2
D3	Lower back	2	11	2
D4	Shoulder	0	10	4
D5	Headache	5	14	10

Table 2. Number of days with no symptoms, treatment or life impact for each diary participant in 21 days

correlated to unhealthy food choice, such as spicy or deep-fried food.

On the other hand, the pain reported varied in symptoms over time among each individual, including pain types and intensity. As shown in the *Table 3*, D2 experienced various symptoms with different intensity caused by her stomachache, ranging from feeling of flatulence, to eructation, heartburn, nausea.

To sum up, the complicated and varied pain conditions were closely related to treatment choice and behavioural impact.

4.2 Treatment – a manifestation of lifestyle change

As stated earlier, physical therapy was the most widely adopted treatment. However, two types of therapy were identified depending on the timing they were needed. The first one is the intentional physical treatment, such as the regular workout or physical exercises deliberately scheduled by the participants (D1, D3 and D4) on regular basis. However, it is sticking to the planned training that is the difficulty residing in daily self-management.

The other therapy is the treatment that interferes with personal life events and activities as participants tended to place immediate attention to their unbearable pain upon its occurrence. Common solutions include simple pain-relieve measures such as self-massage for the muscle

(D4) or the stomach (D2), several stretching (D1, D2 and D4), adjusting body postures (D1, D2, D3 and D4), or close eyes for relaxation (D1). In the case of D1, the knee and ankle pain required constant protection even in walking. Additionally, early and sufficient sleep became a wide-accepted notion among participants as well.

Hence, the treatment approach manifests a lifestyle change. As *Table 4* shows, D1 experienced distraction by the pain frequently during the day. D2 needed to stick to a strict diet regarding the quantity and quality of food choices. As a consequence, the diverse treatment that interleaved in daily life caused burden on personal pain management.

Timestamp	Pain experience
22/07/2017 21:40	"I had *a little burning* tdy and felt *heaviness* after eating unhealthy food like chips xD"
23/07/2017 22:52	"*Short eructation* (afternoon 3pm)"
24/07/2017 22:12	"Probably because I consumed too much nuts, my stomach was *shocked*! In other words, it has led to *difficulties to go to toilet for a long time* ^^ and I felt *uncomfortable and heaviness*"
01/08/2017 00:17	"A *little pain in the upper side of the intestines*. Feelings such as *nausea and burning* after 6pm"
02/08/2017 23:21	"Today I didn't experience an explicit pain, only *gases* were accumulated in my stomach"

Table 3 Examples of pain conditions varies in intensity and symptom for D2

4.3 Behavioural impact – work/study, social, and personal interference

As reported by all the participants, chronic pain can impede their work/study behaviour as extra effort and time were required for pain management, leading to reduced efficiency and productivity, which can be especially detrimental when they were under the additional pressure of deadlines. On the contrary, participants reported to feel easier to concentrate and more productive and inspired in the absence of the pain.

Chronic pain can also lead to reduced social activities, as seen in the cases of D2 and D4. In particular, D2 expressed preference of solitude due to exhaustion and pressure from frequent stomachache, whereas D4 ceased his gym workout routine due to the fear of being embarrassed by the strength difference between his friends and himself, as the participants tried to avoid the notion of the weakness of himself. On the other hand, it was risky for D3 to carry on the class because of the possibility of worsening the shoulder pain.

It is evident from the result that chronic pain had a destructive influence on participants' personal life. Firstly, the intention to ease the pain drove the daily behavioural change. Specifically, they were more aware of their walking (D1) or sitting (D3) postures and intended to correct the postures for bodily pain-relief. D2 were required to pay more attention to the daily diet in order to protect the gastrointestinal system. D3 reported sleeping disorder caused by the lower back pain. Furthermore, participants were frequently stuck in the state of low energy, including losing appetite, being tired and sleepy all the time, and easily getting exhausted. Gradually, negative emotional states were found to be accompanied. Participants used "annoyed", "grumpy", "fidgeting", "upset", "complaining",

	Timestamp	Treatment
D1	19/07/2017 21:46	"Seated after being standing a long time to calm my ankle and knee pains, also did some stretching and breathing exercises for the same"
	20/07/2017 21:48	"For the ankles stretches and massage, also taking off shoes while seated. For the lower back also stretches and some walk arounds. Pauses each hour for the eyes"
	29/07/2017 21:30	"Focalized stretch and careful steps taken, eyes closing for some minutes now and then"
D2	20/07/2017 20:40	Eating dairy products. For my breakfast I had oats, and during the day vitamins (fruits and vegetables) have been eaten. I drink tdy only water (not cold)
	28/07/2017 23:35	A mineral water, sticking to the diet five times a day and doing a massage (in a clockwise direction before going to the bed)
	08/08/2017 23:49	Morning massage to help to get rid of gases. Consuming dairy products: warm milk, oats. Drinking mineral water.

Table 4 Examples of treatment that manifests life interference

"intolerable" to describe the constant emotional consequence with chronic pain.

4.4 Information needs

The study discovered a series of general information needs in the self-care of pain conditions, as listed below, which can be used as the source material to inform the content and functionality development of future chronic pain management apps.

1. Possible causality between the occurrence of the pain and their behaviour or the external environment

2. Correct posture to relax the body and feedback

3. The effectiveness of certain medical treatments or tools

4. Alternative physical therapy and their effectiveness

5. Successful resolutions to relieve symptoms

6. The balance between life activities and pain management

7. Goal-setting and reminders

8. Self-assessment of symptoms or conditions

9. Available HCPs

10. Automatically revealed pain patterns

4.5 Other characteristics

Besides the above findings, some interesting characteristics emerged during the period of pain management, which can help enlighten the design process.

Firstly, it can be concluded that all of the participants were engaged in self-management and self-decision making without visiting doctors or consulting HCPs during the time. In addition, all the participants had experienced insufficient management of their own condition, and lack of a systematic and well-planned recovery approach. Finally, the most common information need among participants was the possible reasons for the pain, indicating that they expected their interest in the causal relationship between behaviour and pain episodes to be satisfied.

5.REDULTS FOR INTERVIEW WITH PEOPLE WITH CHRONIC PAIN
5.1 Overview of pain conditions

Summary of descriptive statistics of all participants with their pain conditions were shown in *Table 5*. Among the eleven participants, D1 and P1 reported multiple chronic conditions simultaneously while the rest reported single pain condition. Altogether, 17 chronic pain conditions were recorded. As seen in *Figure 2*, majority of the participants suffer from musculoskeletal pain conditions, followed by chronic visceral pain, headache and post-surgery pain.

Figure 3 illustrated the frequency that each chronic condition caused pain to the participant. More than a quarter of the pain conditions occurred on a daily basis and 7 of them happened on a weekly basis.

Figure 4 showed that the ratings for life impact clustered from 2 to 8, with the mode of 5 while *Figure 5* demonstrated that the pain magnitude was rated from 3 to 10, with the mode of 6. The modes indicated a moderated life impact and relative high pain magnitude respectively on average.

5.2 Present pain self-management experience

Medications and physical therapy

Majority of the participants (6/11，D2, D4, D5, P1, P2, and P3) took analgesic without prescription, making it the most popular choice. Meanwhile, other individual-specific

medications include eye drops (D1), vitamins (P5), crème and plasters to treat respective symptoms such as eye pain, nerve system protection and musculoskeletal pain.

In general, participants held a relatively cautious and conservative attitude towards taking medicines, as illustrated by P2.

> "I'm very very careful when it comes to pills because I know this kind of things are not healthy and it's not good for our body and." (P2)

Participant number	Gender	Age	Chronic pain condition	Duration (years)	Frequency*	Max pain magnitude (0-10)	Life impact (0-10)
D1	Male	28	Ankle pain	1.5	1	5	7
			Knee pain	10	4	7	8
			Eye pain	2	3	5	6
			Lower back pain	8	1	6	5
			Shoulder pain	2	3	3	4
D2	Female	24	Chronic gastritis (stomachache)	Over 20	3	6	6
D3	Female	23	Back pain	1.5	2	5	4
D4	Male	27	Shoulder pain	3	1	8	8
D5	Female	23	Migraine	10	3	8	5
P1	Female	31	Knee pain	6	4	3	2
			Chemotherapy	10	/	/	/
P2	Female	24	Stomachache	4	1	7	8
			Eye pain	1.5	4	8	8
P3	Female	25	Migraine	8	5	6	4
P4	Male	24	Cracked cartilage	3	3	6	5
P5	Female	28	Back pain	0.2	1	10	5
P6	Male	27	Lower back pain	0.5	3	6	5

Table 5 demographic and pain-related information of participants. *Frequency is used to describe the average number of the pain episodes happened in a period time, and is classified into five options: 1) Daily, 2) More than three times a week, including three times, 3) Once or twice a week, 4) Less than once a week, 5) Less than once a month.

Several reasons that cause the above attitude have been discussed. Firstly, participants were concerned about the harmful side-effect of prolong intakes on the organs, mainly in the case of pain-killers. In addition, fear of addiction based on prior experience from others (D1) was also an important factor. Furthermore, several participants (D1 and D5) also expressed doubtfulness on the effectiveness of medicine as the means of curing their condition. The above findings highlight their needs for confirmed information on the use of medicine.

"[...] I'm not fine with taking pills [...]it would be helpful to know whether those pills have any side effects or whether [...] you become resistant [...] Or is there any condition connected to not being able to take them like liver condition or kidney or something." (D1)

"I don't like taking pills and that includes drops. I have seen a lot of people finally [...] get dependent on that [...] They have no pain tolerance." (D1)

"If the suggested treatment is pills [...] whether those pills will cure me or just alleviate [pain]." (D1)

Due to the above reasons, all participants indicated their preference for physical therapies to medications as their main treatment, although those suffering from chronic visceral pain and headache considered medicine as the quicker solution for pain-relief.

Physical therapies were perceived as effective among participants in general. For users with chronic musculoskeletal pain, the common physical therapies mentioned included focalised training, massage, temperature therapy, acupuncture and some novel electronic therapies. Among all, focalised trainings such as

strength training, and cardio exercises (swimming and running) were widely accepted (D1, D3, D4 and P6). For

users with chronic visceral pain and headache, they preferred massage at the pain location, such as on the

stomach for stomachache or around the head for migraine, and regular exercise to stay healthy.
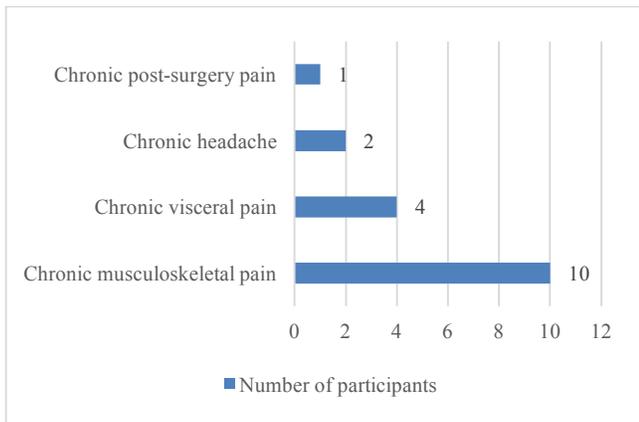
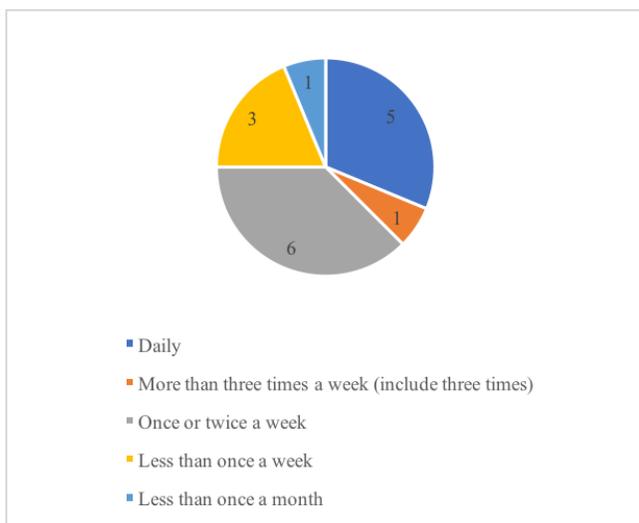**Figure 2 The distribution of pain conditions among participants.**

Figure 3 The distribution of pain episode frequency of all the pain conditions

Figure 4 The distribution of self-reported life impact among participants
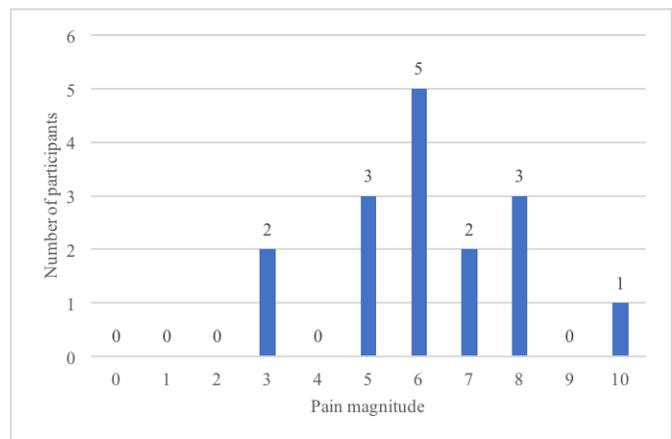
Figure 5 The distribution of self-reported pain magnitude among participants

Information seeking

Another commonly practiced pain self-management experience comprises of information seeking from both technology-related and non-technology sources.

Online search engines, medical websites and online community accounted for the majority of the technology-related sources. Most participants expressed their emphasis on the quality and reliability of the medical content of the websites. Assessing the source websites and learning from

them usually happened simultaneously. P5 and P6 both listed the same website (www.MD.com) as their favourite.

> *"Google is something I really use very often. But it depends on the webpage. I don't believe in every." (P2)*

Besides, online communities such social media were also common mediums of information seeking process among participants (P1 and P5), although communication was confined to reliable connections, such as personal contacts of the participants, or person suffering from similar
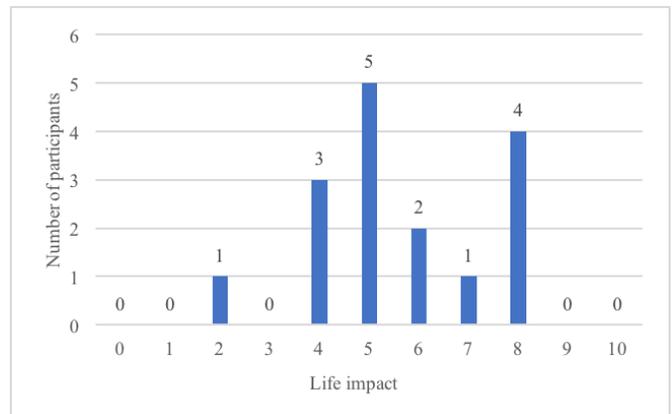
conditions. P1 reported that they joined online community at the first four or five years of the chronic condition. P5 stated that they shared pain experiences and medical treatment with people having same problem on social media, typically Facebook. However, this kind of communication was only restricted to reliable personal connections such as sharing contacts among friends which can be trusted. Additionally, P2 dialled a medical hotline once for pain information.

Non-technology information sources included acquaintance who suffered from a similar situation. Parents were

consulted the most often, especially when the chronic condition started at an early age. Besides, D1 mentioned meeting a friend with the same knee pain, who shared his pain experience and treatment. However, pain condition, as a private issue, was the least choice as an appropriate topic for friends, as P3 suggested. The other non-technology source referred to people surrounded with related expertise in health management. D4 talked about the regular conversations with multiple personal trainers in the gym who underwent special sessions to supervise members on their physical training to avoid pain.

In the process of self-management, participants showed a discrepancy in their attitudes and motivations for seeking information outside the medical environment. While several participants were proactive in seeking information related to their chronic pain to better manage their conditions, most of them stopped at surface research (P3), with only a few participants who are persistent enough to seek further information (P5) but none has had subsequent treatment actions. Some reasons for this include doubtfulness of proposed treatment due to misalign of expectations, as such process often leads to major treatments such as surgery as the recommended method, which was beyond what the participants' expectation of conservative treatments. On the contrary, there were also a few participants who were reluctant to seek information, largely because the information available did not address their distinctive conditions specifically (D2), or they have already grown accustomed to their body conditions (P1).

"Every time they suggest surgery I still refused. I still don't think I am at that point yet, and also because of the research that I did, because what I have been talking to people that experience the same thing, I conclude that surgery is not really necessary," (P5)

"It [searching on Google] is not helpful because people just share their personal opinions. But, you have different types of symptoms and different types of disease, so it is very difficult to find proper information. So when you saw someone eat some things are really helpful but it can opposite for me." (D2)

"Maybe I don't have… deep desire to learn more… Maybe because I was quite young at the time when I got the surgery. So, I just learned how to get used to that kind of situation first." (P1)

5.3 Motivations and attitudes to pain management apps

Participants expressed mixed attitudes upon the idea of utilizing mobile apps to facilitate their pain management experience. Facilitating and impeding factors, were summarised below to understand the core elements that might influence user decision-making and behaviours.

Facilitating factors

Facilitating factors referred to the elements that motivate the adoption and engagement of pain management apps. The most significant factor was related to the satisfaction of user expectation and needs for information and functionality. Personal and social factors were involved as well.

Desires for information provision

D1 stated that it was important to provide valuable information for their pain condition, indicating a guarantee in both quality and spectrum. Particularly, they required concrete, useful and diverse information. This contributed to a profound app engagement.

"[…] so I will get bored if I don't get results in a short term. If I see it's useful, various and diverse according to the range of situations that can happen, then I guess that would motivate me to keep on using it […] It would need to be practical, concrete, useful information […] not an encyclopaedia of knowledge." (D1)

Desires for functionalities

The delivery of the functionalities facilitated the users to start using the apps. They expressed needs to combine their personal healthcare into daily schedule. For back pain sufferers such as D3 and D4, finding a proper time for physical training to fit in their busy daily plan and emotional support to encourage stamina were preferred. For headache and stomachache sufferers such as D3 and D5, keeping a discipline on suitable diet and sleeping pattern was required.

"Its more about schedule […] unhealthy food like fast food, spicy food is prohibited for me. But I really like it […] Sometimes it is like an alarm, you have to eat." (D3)

Personal pain condition

One of the participants mentioned that the need for the apps was related to the severity of their personal condition. Usually, with a higher frequency of the pain occurrence, they felt more eager to interact with the apps.

"If it got very frequent […] I probably would [use it]." (P3)

Increased attention on personal healthcare

P3 stated that one advantage of those pain management apps was that it can draw their attention onto self-healthcare when they live busy lives through functions such as reminders or schedule planner.

"So at least I [the app]t can increase your attention." (P3)

Positive review

Positive reviews from people they trusted were valued in the decision-making process. Most of the participants said that they would use the app if it is recommended by people around.

"If somebody said that existed I would one hundred percent download that immediately." (D4)

Impeding factors/Barriers

Impeding factors were the barriers that prevent participants from interacting with the pain management apps.

Low awareness

None of the participants had used a pain management app for their condition. The main reason was that they were not aware of the existence of this kind of apps. And they didn't expect any medical apps can help manage their chronic pain.

"I don't know this app." (D5)

"It's just not that common thing to have a migraine app." (D5)

Lack of trust

P2 stated that they expected to talk to a real person about their chronic situations more than with an app. They needed emotional feedback and understanding of their situation as an individual.

"But it's not something that is programmed because I'm a human being, I'm not a robot [...] to be able to talk to someone." (P2)

The notion of P2 presented a low belief in the role of mobile technology in health management. They trusted the communication with human beings, such as the face-to-face appointment with a doctor or a specialist, but were reluctant to rely on a programmed app when managed their chronic pain.

"I respect the studies but I don't think that kind of technology is able to control or to make my health better, or to control my health." (P2)

The trust was even lower when it came to conditions such as headache where causes were difficult to locate and analgesic was the only solution.

"I wouldn't have what kind of the questions I should ask them about my headache, because headache is still something you really cannot find any solution, you just have to take pain-killers." (P2)

Management avoidance

When they reached the point after a relatively long period, they felt their conditions as something normal in their life. They intended to avoid over-management on their pain condition. They adjusted their mindset to focus more on their main life tasks rather than their pain. This resulted in a reluctance to seek external assistance on pain management.

"I don't feel any necessary itself that I need to try to deal with it. So I don't feel a strong need about that." (P1)

Sense of guilt

Usually pain management apps required regularly consistent interaction of users. However, participants concerned that they might generate a sense of guilt once the interaction was disrupted, which would further impede them from using the apps. D4 introduced his prior experience with health control apps in which he started with a high expectation but ended up with a mental burden. The sense of guilt was viewed more disruptive to engagement than missing the possible benefits of the apps. This indicated that user engagement should be considered in the design of the apps.

"When I go off track I feel guilty that I've stopped taking care of myself and stop doing it [...] So instead of using it becoming a tool to empower me it then becomes something that makes me feel guilty and stressed [...] All it's doing is asking me to give the information instead of finding a way to encourage me to continue my actions to take care of myself." (D4)

5.4 User needs on specific functionalities

Under this theme, participants' views on five functionalities were concluded, including pain-related education, self-tracking, goal-setting, skill training and social support.

Pain-related education

Among the five functionalities, pain-related education was rated at the top of the list in terms of the importance.

"That's one of the things that I think I would like to know most." (D4)

Treatment-related content

In terms of the content of the pain-related education, it should focus on spreading knowledge on alternative self-treatments targeted certain chronic conditions as stated by most participants. In the case of musculoskeletal pain, D1 and D4 wanted the solutions for their pain while P5 stressed the multiple alternatives supplied that can be tried based on personal preferences.

"More specifically what I can do to fix that." (D4)

"It is not just like one options [...] so I want it to be varied. So you can choose what you want to do with yourself." (P5)

What's more, the treatment discussed here not only involved the medication or physical therapy, but also covered other respects such as the proper diet and the rest schedule, as the example of D2 and D5 illustrated respectively.

"[...] and also about the schedule, because you know five times a day, okay, I wake up at 5 am so I would eat at 6 am. So, when is my next time to eat." (D2)

"Maybe some food that is helpful if I have this problem." (D5)

In the two cases of migraine, P3 and D5 displayed the interest in the cause of the pain as their doctors provided little explicit explanation in the medical approach on account of the limitation of scientific research. P3 stated the need for education on the latest results of medical research on the migraine-related topic which could be beyond the knowledge of doctors who spent most time diagnosing and neglecting the cutting-edge research.

"If there is a way that they could deliver me information about migraines like the new research [...] So, doctors themselves aren't always going to be like up to date with what's going on." (P3)

13

Best-fit information

P4 stated that the information presented in the apps needed to be best-fit to the personal conditions rather than general knowledge of the chronic pain.

"And if I can find relevant information because it is quite unique condition." (P4)

The precise provision of pain-related education could take advantage of other functionality such as the input pain variables in self-tracking. The combination helped to link pain experience to the best-fit information.

"If you can have the list of all the things, and you can tick what you feel of your experience." (P5)

Besides, D3 suggested the education on emotional adaptation, that could motivate users to stay positive.

"[...] words that can encourage you to fit and to help you to keep positive emotions." (D3)

In terms of the delivery form of the education, D3 stated that they need multi-media to make the education immersive and convincible.

"I think if that app can provide some video, it would be more professional and more persuasive." (D3)

Self-tracking

Ten participants were for the self-tracking function. They expressed their own requirements for improving experience with the function.

Medical records

Five participants (P1, P2, P3, P5 and D5) mentioned its basic contribution as a medical record to show precise pain history. Real-time input of pain episodes as a medical evidence not only reduced the cognitive burden on users' memory for past pain experienced, but also offered standardized symptom information for specialists and doctors to get a conclusion.

"... the doctor needs to know precisely information to get the correct diagnosis." (P5)

Increased awareness

Self-tracking enabled the enhancement of self-awareness of their body condition. P1 reported that living with pain persistently led to neglecting the pain in some cases, which could be detrimental in terms of missing medical implication of the pain.

"[...] to make you aware of your own condition and to make you care more about it." (D5)

Outcome from the input

Despite the acceptation of the function, participants showed dissatisfaction with the basic tracking and requested more.

With the information collected in the apps, they expected to see the patterns of their pain in the past as D1 stated. This provided them with the self-evaluation and self-knowledge of the progress of their pain management.

"I mean it will have to do something with that information... if it deducts something or shows patterns or stuff like that." (D1)

D4 emphasized that the evidence of the progress they achieved encouraged them to carry on their pain management as it was a life-long procedure. The presentation of the progress helped to increase confidence level and self-efficacy.

"It felt like such a slow time to recover. I wish that I was able to see the progress I was making [...] like I've come this far during the recovery." (D4)

Despite the past pattern, participants also anticipated predictors of future pain occurrence. They felt less motivated in continuously self-reporting unless they could figure out the causality between their behaviour and pain input.

"If I know what could help to prevent my pain next time, it will be helpful in this case." (D2)

Furthermore, ensuring the persistent engagement with the apps was also the matter concerned with participant, as D4 stressed. The low engagement could cause negative consequences on participants' self-evaluation. As the emotional outcome, the sense of guilt led to ceasing to use apps.

"I know myself I probably would stop recording because I'm not focused on my pain... I stopped paying attention so I feel guilty so I don't report..." (D4)

Goal-setting

Majority of the participants (9/11) viewed goal-setting as a necessary functionality in their cases. The most important function of goal-setting was to serve as reminders as people tend to neglect their pain management due to their busy schedules and other tasks at hand.

"For example, having more water will help me and it reminds me to drink water every day." (D5)

Due to the priority of other life tasks, users expected the goal-setting function to integrate with their personal habits and daily schedules. Especially for the musculoskeletal pain sufferers, the treatment was contingent on the intensity of daily activities. The apps were expected to empower the users to deal with the conflict between the goal-related tasks and life tasks.

"When I work very carefully, I put all my attention to the study, and I forget to have relaxing." (D3)

However, it still remained difficult on how to deliver the goal and supervise the goal-accomplishment process as

implied by the need of D3. The key requirement was to strike a balance between facilitating self-discipline to follow the plan and avoiding being interruptive and intruding to their daily lives.

"But in some instant, it might be distracting my attention if this app keeps sending me notification to remind me to do what." (D3)

The failure of self-discipline was always caused by the priority given for other life tasks over their pain management tasks. Hence, D4 appealed for a stronger support on the execution of the goal-related tasks to further achieve effective and profound goal of behaviour changes.

"I end up prioritizing other things despite the fact that I have this goal as well." (D4)

"It helps me to plan ahead but it doesn't help me to follow through." (D4)

Two participants regarded the goal-setting function as unnecessary in their cases. With a migraine at low frequency, P3 thought there was no practical goal in the management except taking pain-killers when the pain happened.

"Goal-setting probably not again… because just accepting the truth that there is nothing much I can do." (P3)

Skill-training

Some participants thought skill-training function would be useful because of the deficiency in their own self-treatment skills. D2 wanted to learn other effective treating skills besides the simple massage. D3 was eager to figure out the massage methods with optimal pain-relief effect through acquiring the accurate position of functioning points on human body.

"What I do is like just simple massage in the clockwise direction." (D2)

"If the app could tell me some specific points, and massage those points could help reducing pain." (D3)

As P6 stated that this function could help in finding the most suitable and correct physical therapies for the lower back pain as there were plenty of postures aimed at different body part which cause difficulty in distinguishing by patients.

"So some exercises you do as a sportsman and try to do those, sometimes I feel it's not helpful for my back, but more helpful for my arms and my shoulders… i should have something just special for my lower back." (P6)

Also, D4 thought that the skills taught should cover different pain sensations and empower the users to learn to take specific solutions to each one.

"When that happens, I'll be able to tell myself without having to go to the app… and I should do these things and that would help me manage myself in the moment." (D4)

P3 regarded the skill-training apps as the emergence apps that they could turn to when the pain occurred, so that they could follow the instructions to carry out certain relaxing skills to relieve the pain immediately.

"But if I had it on my phone… which is like emergence apps, and then you just click in… and then it's coming on and then I can do then." (P3)

P5 stressed the beneficial role of multi-media played in the acquirement of pain-related skill. It could not only support better learning outcome but also provide real time feedback for self-examination of posture.

"If the app can not only give me the information and the picture, if it has some actual video or movement that I can see with whether I do it right or wrong. (P5)

Social support

Regarding the social support function, most participants expected to both share and read pain experience with people who have similar conditions through the platform. D3, as well as others, stated that personal treatment-related experience was valued most important to be shared for reference by others, including medication, physical therapies and other strategies.

"If there is some online space that they can meet people who has like the exactly same condition as me […] I tried this medicine or I tried this exercise […] and maybe other people can learn from it." (D3)

P6 viewed the social support function as important considerably especially when some patients were alone and helpless.

"For example, I am staying alone, and nobody is looking after me." (P6)

Moreover, the emotional support in this function was underlined. P6 stated that it was the people with same pain experience that were easier to understand the feelings and the needs of themselves.

"Because sometimes you cannot talk about these things with a lot of strangers, or even sometimes in family, because they give you very [inappropriate advice]." (P6)

Those who could fully understand them were able to comfort each other mentally through sharing emotions, as P5 requested. This helped to deal with the sense of loneliness and helplessness and to grow self-acceptance during the encounter.

"It is more like somebody tell me, encourage me that I can get out of this pain, you are not alone, it is just this

simple support from someone to get you through the pain.” (P5)

Hence, D4 stated they could be motivated through others' positive experiences.

“There have been times where I've felt empowered though… see that they're able to get better and get stronger and take care of themselves… that has motivated me to see that evidence.” (D4)

However, P3 mentioned the engagement with this social support function would only be restricted to the occasions when they were experiencing pain episodes to seek for timely solutions or advice, rather than regular community activities.

“If I can just dip into it when it happens and then not have to go on it, like I wouldn't, be joining like a migraine community or something.” (P3)

Also, P2 hoped the apps could ensure a relatively large scale of user group to provide multiple suggestions and various experiences regarding one pain condition.

“When the app is international globally, for instance, got like ten thousand people when I post something and people could answer that.” (P2)

On the other hands, several participants held a negative point on this function. Although they would prefer to learn from others' experiences, they felt reluctant to share their own feelings and pain-related encounters.

“I don't think it's something I would engage with… I have never wanted to share my experience.” (D4)

D2 expressed their concern on extending individual and personal experience and opinion into their own situation.

“Maybe it will be very helpful for them to take medicine, or do some exercise, but it can be opposite for me.” (D2)

5.5 User needs on usability

This theme concluded the usability-related user requirements on chronic pain management apps.

Customisation

D1 hoped the content and structure of the sections displayed on the apps could be customized according to personal preference and pain condition relevance to a flexible extent. D5 also mentioned that the content or information provided needed to be linked to their own condition through a filter.

“Like I can customize and so the results that I want to see will pop up or show themselves more […].” (D1)

“Effectively read only information on my condition and filter out other information.” (D5)

Simplicity

Participants expressed the desire for simple interface and means of interaction in order to stimulate user engagement. Regarding the input methods, D1 mentioned the employment of multiple choices and visual scale while D5 suggested a smarter input which detected frequently-used words.

“Easier input like tick boxing…” (D1)

“It can detect your most frequent used words and then you can just select it instead of input when you come across it again.” (D5)

The simplicity also referred to the interface of the apps. In order to increase the learnability, D2 hoped to avoid too many buttons while D5 preferred straightforward instructions or symbols.

“It should be simple, and understandable. Don't have a lot of buttons, so I get confused.” (D2)

“I need to know what function in which position on the interface, and those icons stand for what function. You have a glance and you know it.” (D5)

App size

Two participants mentioned that there should be a restriction on the size of the apps resulted from the huge number of apps stored on the phone and the low frequency of utilisation of this kind of app compared with others.

“It shouldn't take a lot of storage in my phone.” (D5)

Operation

Besides, two participants expressed the requirement for the speed of the operation of the apps.

“If it makes the app very slow or having a bug or keeps dropping, then it will be a problem.” (P6)

Privacy

D1 stated that the apps should avoid constraint on synchronisation with social media accounts which should be left optional for users.

“I don't see what the point is on synchronizing things…” (D1)

Ad-free

D5 also mentioned that this kind of apps should be advertisement free to make them more professional and reliable.

“Should not have ads, ads make the application look fake” (D5)

5.6 Involvement of HCPs

When asked the role of the HCPs in the apps, all the participants viewed it positively and indispensably.

Online diagnosis

As P2 stated, the main role the HCPs could play was to review patients' experiences and give direct suggestions. Because patients were lacking in medical knowledge to differentiate the severity of the situation (P1).

"When someone post something really serious that a doctor can say, hey I just read this and [...] that is not normal, it is better if you really see a doctor." (P2)

"That I have some pain but I don't know whether this is because of my own constant pain or what happened there." (P1)

These pain-related diagnoses could work when they provided with answers quickly and straightforward for the possible causes or consequences of the symptoms experienced and posted. These simple diagnoses could avoid subjective speculations of their disease, especially the negative ones.

"For instance, of my headache... is that normal, maybe I have other problems, maybe I have cancer [...] but the doctor could maybe say, when you have this and that, that's definitely, could be this or this illness." (P2)

Video appointment

Besides online diagnoses, P4 also requested the function of real time video consultation with HCPs through the apps.

"30 min consultation or something, you get the video chat." (P4)

P1 expressed that the need for the app diagnoses was out of the fact that specialists or doctors in real life was difficult to reach without a scheduled appointment. And it was not worth the effort for some simple questions.

"I think people will have some questions about their condition... but it is difficult to ask the doctor all the time." (P1)

Face-to-face consultation

Contrast to receiving programmed reply from an app, P2 stated the importance of talking to a real doctor on the pain-related issues. And P2 also recommended that students from medical school could be a trustworthy source of medical support. P4 reported that a reasonable fee could be applied for the service.

"If there are doctors, even students... I could trust them... Because they study there, they want to be a doctor." (P2)

"You might have to pay for it." (P4)

In addition to doctors and specialists, physical trainers and other types of HCPs were needed to provided health suggestions on the apps as well.

"People who like help people exercise, trainer for patients, for that kind of people will be fit for that." (P1)

Reference

Another way of involving the HCPs in the apps was mentioned by D4. Due to the varied body conditions from one to one, it was advised to enable prior professionals to leave a reference or rundown of the matters that needed extra attention regarding the body condition and the treatment of the that individual. This could ease the process of medical service provision when the individual encountered moving from city to city.

"I haven't got to see a physio here in London because I just can't be bothered... If an app, that can reference. I'd love for recommendations from professional... of what's going on with me because I'm always fighting with the professionals because they just don't believe..." (D4)

Recommendation

The next function related to HCPs was providing recommendations for the most relevant professionals around the living area of the users, as P2 stated. This would benefit people experiencing the pain in an unfamiliar city.

"you could also have a check-up where I live the same country." (P2)

Content

Last but not least, the content on the apps should be supervised by the HCPs with their expertise in the related field. The quality of information was expected to be guaranteed to be reliable, correct, objective, and latest.

"As long as the information was accurate and like a peer review..." (P3)

"They can at least make the information is objective and latest." (P6)

"Because you want to make sure you can trust the information. because you know online world is not always safe and trustworthy." (P5)

P1 stated that the trust in the content could be built on the provision of the evidence supporting the apps. D3 and D5 both mentioned that being presented with some ridiculous and peculiar treatment made the source unreliable

"But need to have some kind of certification, not just acknowledged by the company." (P1)

"For example, to ask you to eat something wired for the treatment..." (D5)

6.RESULTS FOR INTERVIEW WITH HCPS
6.1 Background of participants

Two participants involved in the study were HCPs with expertise and experiences of dealing with chronic pain patients. H1 was a psychologist with a background of sixteen-year clinical experience in a UK pain management

programme while H2 worked as a qualified personal physical therapist in USA.

Generally, both of the health experts held positive attitudes on the role of mobile technology in supporting self-management of chronic condition.

The themes emerged focused mainly on the topics related to chronic pain self-management from the perspective of HCPs. The first was their perception of the relationship between patients and doctors in chronic pain management. Whereas the rest five clustered as the functionalities empowered by the self-management apps at the prospect.

6.2 Perception of relationship between patients and doctors

Low referral rate

H1 pointed out that the referral rate from general practitioners (GPs) to specialists was considerably low in practice.

"I mean a tiny proportion of people with pain get a pain clinic. Maybe less than one percent of people with chronic pain get referred pain." (H1)

This was resulted from the lack of specific knowledge on pain-centred treatment of GPs, which led to the disregard for the medical needs of patients with chronic pain in a clinical context. As a consequence, they prescribed patients medicine which was adverse for long-term consumption based on their habit of drug usage.

"GPs haven't been taught about pain, they have their own beliefs. Some of them give opioids in far too generously which isn't the answer at all, and some just tell people to go away." (H1)

Nevertheless, H1 explained that there were actually remarkable specialists in the field. The little access to them caused not only under-diagnosis of patients but also a waste of medical resources on the other hand.

"I mean there's excellent people at the national hospital but only a small portion of patients get referred to them for a formal diagnosis of making." (H1)

Irreplaceable

When asked about how the reliance on HCPs would change when patients were provided with increasing information sources and smart tools through the internet and mobile platforms, both H1 and H2 emphasized that the role of HCPs which enabled face-to-face consultation was irreplaceable in the self-management of chronic pain.

H1 referred to an Australian public health campaign to demonstrate that it was difficult to shift the healthcare model from high dependence on clinical services to self-management.

"And there was a much smaller rate of referral to specialists during the times the campaign… But when they stopped doing campaign it went back to the old model of taking longer time off work and having appointments and going for X-ray as most." (H1)

H1 believed that face-to-face consult overweighed other internet-based novel sources and forms of medical services.

Satisfy information needs

First of all, H1 stated that the quality of the information provided and other flaws accounted for little threat from the internet and emergent tools. These flaws would be discussed in detailed in the theme of pain-related education.

"But that [a new type of relationship between patients and doctors] is assuming that the information is all correct and all consistent." (H1)

After all, H1 and H2 both stated that doctors, specialists and other HCPs played a fundamental role in suggesting proper medical assessment and measurement. They were capable to achieve accurate diagnoses through utilizing their expertise in manipulating medical instruments and drawing medical judgement.

"One of the real benefits about delivering pain management face to face is that you can do a proper assessment with people, and then try and make sense of their experience in the light of chronic pain." (H1)

It was their authority in pain knowledge that laid the foundation of trust and high reliance in pain management, which was not comparable with other sources and forms of information. HCPs were able to satisfy the information need of chronic pain patients.

"Internet doesn't substitute for relationship with a doctor who you feel can understand, can diagnose, can tell you if you've got something dangerous. Going on the Internet is not going to tell them whether they've got cancer or not, is not going to convince them they have got cancer. They want a scan and the doctors look at the scan with them and say there is no evidence of cancer, you have no signs of cancer." (H1)

"If you think you've got an undiagnosed disease, you're not going to take any notice of a website." (H1)

Satisfy personalisation needs

Both H1 and H2 reported that users always preferred to receive personalised medical services. General online information was less trusted because they lacked clear evidence of their own body conditions. A thorough diagnosis provided them with the evidence or reference for the direction of their further information seeking behaviour.

"People still find it difficult to personalize themselves […] So, they may feel, that's fine for other people as chronic pain. But I don't have a diagnosis yet so I'm not sure this is for me." (H1)

Their needs for personalisation cannot be satisfied by the general online information or the standardized diagnosis from the apps, until they confirmed their own specific body conditions and personal symptoms with their doctors.

"That's why people like personalized health care, even most of it is carried through with an app, they want at some point the reassurance to be specific to their experience and their body and their problem. (H1)

Also, the delivery of the diagnosis and treatment was patient-centred in a face-to-face meeting, as H2 claimed. This means that when communicated the pain information to patients or clients, they tended to go through the assessment process and explain the situation and solution in a detailed and understandable manner.

"I would tell them what I received, what was happening in the body, point it out and make them feel it, and show it to them, and then tell them what my plan was for going to work on strengthening this, structuring this, changing this, then I would tell them go from the small part right away. this is something you have to be committed to…" (H2)

Satisfy emotional needs

The other advantage of face-to-face consults was its caring for patients' or clients' psychological aspects and emotional needs. H2 stated based on her experience with clients suffering recurrent and persistent pain that they easily lost hope and became demotivated and confused for their treatment especially after several ineffective attempts.

"If this doesn't work, then people are dying to shut it up, especially there is no open minded going into it, because there they have a mindset usually of this, there's nothing I can do." (H2)

HCPs were able to identify the emotional state of the patients and keep encouraging them to try more therapies to stay hopeful. This was obtained through the trust in the decisive and authoritative image of health experts.

"By half of what I did give them the hope of a good fix that. If you already had two back surgeries, but I don't care about your back surgeries but what I care about is the reason you have them. it's because of this this and that and those are all fixable problems." (H2)

"But I can guarantee a reduction in pain." (H2)

The new role of HCPs in self-management apps

Regardless of the indispensable role of HCPs in chronic pain management, H1 mentioned the deficiency of it under the information era. The challenge always remained that only a small portion of patients received treatment while there were a huge number of patients suffering chronic pain still seeking. The opportunity resided in that technology nowadays supported various communication and interaction manners, such as telephone or video appointment. However, HCPs were reluctant to change.

"Healthcare professionals tend to be very stuck in old ways of working. [...] doctors, physios, psychologists, all of them. So, they tend to be used to sort of face to face appointments. Even getting members to do telephone appointments has been hard." (H1)

This is out of the emotional attachment of HCPs on their patients, as chronic patient was used to see their doctors regularly.

"[...] part of the difficulty for people in having confidence in managing themselves is because health care professionals find it so hard to let go of them." (H1)

Even though this reflected responsibility of the HCPs, it hindered the self-management in terms of appointment time consumption and the hustle of commuting.

"And ultimately if we want people to be more self-managing of their disorders and more autonomous, we have to let go of them." (H1)

6.3 Pain-related education

Deficiency in current online information provision

H1 expressed her concern that the online information environment faced by patients was not safe and sometimes problematic in terms of the quality and the usefulness. Firstly, the medical information online lacked consistency and reliability. Users eager for effective treatment were exposed to overwhelming unverified or untested therapies or treatments.

"You can get all sorts of rubbish [on the internet], stuff telling you to buy expensive and completely unproven cures from places [...] magnets to put in your shoes make it put on your head [...] there isn't one consistent evidence-based story on the Internet." (H1)

Secondly, information claimed on commercial sites was used to exaggerating or twisting the effect of their products or services, flooded with misleading or false knowledge, likely causing both momentary lost and health damage on users.

"I often see patients who've tried extraordinary things and spend a lot of money on stuff that's clearly rubbish [...] There is a website saying five-dimensional water cures chronic pain. There is no such thing. People stack stuff like that [...]." (H1)

Thirdly, the presentation and the material on those digital sources focused on pain-related medical terminology so that it was not friendly for the general public. Patients could hardly benefit from it when the professional information was beyond their understanding.

"There aren't any decent model if you look at explanations of pain on the Internet, they mostly show anatomical detail which is not relevant [...]." (H1)

H1 mentioned the existence of useful websites available and recommended some of them. Those reliable and useful sites usually had clinical support from the empirical research.

"The N.H.S. ones. They're not very much easy to find but they're accurate. The so-called pain toolkit which is very good." (H1)

However, these sites were less easy to reach than the commercial ones. Because they were always presented at lower positions on the search result interface and were less likely to be accessed as it was user habit to read from the top articles or links.

"But they're not necessarily going to come up first when people Google chronic pain. And a lot of [...] won't automatically look down the first ten things, oh that's the N.H.S. one that must be good quality information. They often go for the one at the top or the next one and that could be complete rubbish." (H1)

Role of education

Due to the variety in the quality of the information online and lack of medical knowledge themselves, patients were not confident in identify the correct and related information.

"So, they do go looking for more information but it's rarely specific enough for them to have huge confidence in it." (H1)

In line with the difficulty in information behaviour, H1 suggested that general patients should be offered reliable and relevant pain-related education on explanation of the cause and different symptoms in self-management to avoid more self-damage.

"One of the best helpful things is to provide a proper explanation of pain so people understand why it gets worse when they're miserable or stressed and why if they're having a really good time, it doesn't mean the pain is gone away." (H1)

Besides, implementing pain-related education would benefit the communication and interaction between HCPs and patients when they needed to make decision on the assessment and the treatment. The understanding of the accounts resulted in increased trust in medical decision and better clinical outcome.

"I think without understanding pain better, most patients struggle to understand why we recommend the treatments we do." (H1)

The education should throw light on knowledge of the nervous systems as well in order to understand the correlated factors and avoid on their own.

"I think helping people understand pain and how the nervous system changes in response to pain, what amplifies it and all this sort of things [...] but also most doctors don't explain it until they get a pain clinic where

the doctor will explain pain. But I mean a tiny proportion of people with pain get a pain clinic." (H1)

6.4 Tracking

The objective of the self-tracking was to provide personalised analysis of the potent correlation between behavioural variables and pain variables, so as to inform users' future behaviour to prevent or reduce the pain. H2 suggested that real time feedback of user behaviour could be presented in the form of reminder to instruct exercise and rest.

"Habit tracking is very important. Like log in, how long you sat on that day [...] it might be a correlation. (H2)

Habit tracking during the period with pain was viewed as the most valuable variable. Because users' habitual behaviour would closely affect the pain but was paid little attention as it stayed beyond the consciousness of users. HCPs needed to assist them recall the past events to understand the cause and related factors before prescribed any treatment.

"Tracking habits, I think would be really good. Just on days that they have experienced a lot of pain. But also providing pretty full information but that's what happens to look for because people just don't know they generally have no awareness about their body like zero." (H2)

"Initially they'll be like I have no idea but they do know. You just have to help them find it." (H2)

H2 suggested that three aspects of patients should be tracked, habitual movement, diet and mental states, for these three elements were found normally to be the predictors of chronic pain episodes.

"The body can be affected by physical condition, so your movement, your habits, whatever we talked about all that. Your body can be affected by your diet, it's huge. your body can be affected by your mental state and your emotions so that's why chronic pain is so complex because it could be any combination of those three." (H2)

6.5 Goal-setting

Goal-setting function was agreed to be involved in chronic pain self-management apps as well to support continuous self-management. H2 explained that the difficulty in chronic pain treatment was that patients failed to stick to the continuous plan made after the diagnosis, which caused the failure in outcome and the increase of social burden.

"Because they found that people were not accessing their doctor or following their doctor's plans the way they should. And people will end up in a hospital and cost the system, a huge amount." (H2)

H1 pointed out that some digital tools targeted the rehabilitation of musculoskeletal pain available on the market would indeed cause pain and damage to patients. Because the daily training goal was beyond their physical

limitation but the patients were not aware of that ahead. Besides, this would cause negative emotions such as frustration and discouragement and hinder future pain self-management.

> "The problem is most of what's been done has been either very much about just exercise routines, and often pushing too far[...] For most of the time they just feel out competed by who they're playing with and they feel discouraged." (H1)

However, if patients managed to achieve the goal, they would be motivated to continue their training and stay positive.

> "If someone aims to take how many thousand steps a day and it tells you what proportion you've done of that and it might prompt you to do more." (H1)

Thus, it is important to set appropriate goals for patients. Both of the participants thought HCPs should play a crucial role in assisting to set appropriate goals for individual patients. By appropriate, it means not only that the amount of training should within the limitation of patients' body restriction, but also that the goals should follow a systematic approach for steady progress. The goal-setting was to optimize the overall medical outcome as well as the healthy mental state.

> "Then they need help, thinking about how to start to get back to activity, and I think there's a huge role for technology helping people set goals work towards it in systematic way." (H1)

In order to ensure the outcome, supervision on the execution and implementation should be applied. This implied the opportunity to integrate the goal-setting with the tracking function. Thereby, feedback of the accomplishment of the goal could be delivered to the patients and the HCPs to strengthen the treatment outcome trough both mental and physical aspects.

> "Basically, they need to work up on their sitting tolerance and that needs really careful steady progress. And technology can do that much better than people can with pencil and paper." (H1)

6.6 Social support

The psychological aspects played a vital role in self-management decision making. H1 mentioned that patients tended to have more trust and recognition on people with the same pain experience. And they were more willing to accept treatments at the same time.

> "I know a number of patients who've said what a difference it made when patients described similar problems and then they used these methods and that helped them." (H1)

The function of social support was believed to be beneficial in this aspect. H2 stated that the social support should allow people to share the treatments they underwent and the outcome within the group of certain pain condition, as well as the pain-related personal information to provide evidence supporting others' decision making.

> "[...]so you had a particular condition and you just could see all the sort of things people were doing or trying. So at least you didn't feel hopeless like at least [...]" (H2)

The point of sharing treating experiences among the cohort, as H2 stated, was to encourage patients to stay a proactive and hopeful attitude toward their chronic conditions. This further positively affect their life values and mental states for the long run.

> "Even if it's not helping at least they're proactive which means you feel more empowered which I think is a big problem with chronic pain, feel like you're just powerless." (H2)

7. DISCUSSION

The four stages contributed to a comprehensive user research to inform the design and development of mobile apps that aimed to empower the users to self-manage their chronic pain conditions at home. Altogether, 11 chronic pain patients and 2 HCPs were involved in the research. The chronic conditions reported included chronic musculoskeletal pain conditions (10/17), chronic visceral pain (4/17), headache (2/17) and post-surgery pain (1/17).

The combined results of autoethnography and ESM showed a dilemma that the developing of such apps were difficult but urgent. On the one hand, chronic pain self-management was found to be complex and diverse for its recurrent symptoms [10]. Treatment characterised a personalised lifestyle change. Patients expected distinctive and customised functionalities to satisfy the physical and psychological needs in their pain self-management [48]. The development team was hence under the pressure of expanding the products to allow customised services. To be practical, we suggested conducting focused user research to understand the pattern of user needs of a specifically targeted group before developing apps.

On the other hand, the novel digital healthcare service is urgent and necessary as supported by the results that the chronic conditions had considerably impacted patients work/study, social activities and personal lives to a disruptive extent [46]. Moreover, their current self-management was perceived to be insufficient and problematic because of the lack of treatment alternatives and management supervision. In addition, the emotional aspects were neglected, which caused the negative emotions among patients such as low self-efficacy or the lack of confidence in treatment.

Hence, the findings on user experiences contributed to validating the launch of pain management apps. It was promising to develop apps as a novel approach to

healthcare service to improve the current situation of the insufficient management.

7.1 Design implications on functionalities

The interviews conducted in stage 3 and 4 gathered perspectives from the key stakeholders, patients and HCPs. The results demonstrated a holistic understanding of the core elements that needed to be taken into consideration in the early stage of functionality planning and developing.

Among the five functionalities mentioned in the interviews, pain-related education was regarded as the most essential and useful one. Pain education was the second pervasive function (45.9%) in the released apps in mobile stores [27]. The content provided on three main topics (condition/disease information, symptoms and triggers, and treatment) was sufficient to meet user needs. However, both users and HCPs expressed a skeptical attitude on the quality and reliability of the content. There was yet no empirical support on this aspect [27]. We recommended to build closer and constant connections with medical resources and clinical authorities, to get access to reliable contents and empirical evidence.

Self-tracking was reported to be the second necessary and promising functionality. The existing apps focused on condition monitoring, medication and appointment reminder [39]. Participants extended the existing functions to include the provision of the causal relationship between behaviour and pain episodes and the predictors for future pain occurrence. H2, one of the HCPs, suggested monitoring three common predictors of pain, which were habitual behaviour, diet and mental status, to generate the pain-related advice to users.

Goal-setting was viewed as the important function following self-tracking. The difficulty in general goal-setting in pain management was to develop the appropriate goals that matched individuals' body conditions and to supervise the goal accomplishment stage by stage. Only two apps were identified to be able to help users develop and achieve management goals [8]. The current results emphasized that HCPs should assist patients to set appropriate and systematic goals which led to a steady functioning improvement. In order to encourage users to adhere to the goals and engage with the apps, we suggested the developers add more elements related to emotional inspiration but avoid elements that would lead to the sense of guilt, embarrassment, lack of confidence or low self-efficacy [1].

The need for skill training was reported by a limited number of users in the current research, even though it was embedded in the most pain apps (77.4%) [27]. They were mainly desired by chronic musculoskeletal pain patients for exercise training strategies and relaxation in pain episodes. Despite the multi-media provided currently, they required extra real-time feedback on their own postures because of the fear to aggravate their condition.

Social support was considered the lease important feature, though it was considered effective for sharing pain experiences and treatments from peers or people with same conditions by theory [18]. This might result from the participant sample which comprised young adults with mild pain conditions. As students and new employers with an advanced education background, they tended to deprioritise the pain condition and the treatment mentally and struggled to protect the integrity and normality of life with less intention to engage in a pain-specific social group. Only when they were experiencing severe pain episodes, they would use the social feature to seek for effective interventions.

The majority of available apps provided single functionalities from those five [27]. This was not sufficient for the participants who required a comprehensive customised support from the apps. We recommended an integration of the functionalities. For example, the self-tracking and goal-setting were likely to be combined to provide dynamic feedback on the goal accomplishment status and patients pain condition, which was likely to encourage engagement.

The design implications essentially emphasised the involvement of user research and clinical resources, to match the development goal and the user needs for. It was key to ensure the functionalities provided to address the pursuit of the personalised user experience and intuitive engagement.

7.2 User research in mHealth: involvement of users and HCPs

The current user research contributed to identifying the gap between the functionalities in available apps and the end users' expectations. The research outcome implied that user research has an essential role from the start of the development process to the later phases of testing the products [41]. However, 86% of chronic pain management apps had no involvement of HCPs, either as information providers or reviewers [39].

From the perspective of users, they expressed that clinical support was the foundation of trust in the apps. They would refuse the sources that provide false or exaggerated information. From the perspective of HCPs, the support from HCPs or clinics implied an extra responsibility taken by the organisation, while guaranteed a more reliable pain management sources with patient-friendly content for patients.

Moreover, the existing commercial apps faced the lack of the empirical study with patients [57], especially for commercial medical apps [43]. The lack of user involvement led to potential risks in app development and implementation, further threatening the management of users' conditions when using the apps. However, the attempt to involve users might be impeded by several factors, including the lack of time and financial resources

[41] and ethical issues [29]. This needed future study into the development stages to offer effective solutions.

7.3 The collaborative patient-HCP relationship

UK government promoted a shifted medical model in social healthcare section from complete reliance on clinical resources to joint problem-solving and shared decision-making process [49]. A tendency was found to be consistent with the government call. Patients suffering chronic conditions relied more on self-management rather than clinical treatment [10]. Following the initial visit to the clinics when the symptoms first appeared, they sought additional information from other sources to learn about their disease and treatments [19]. With the combined knowledge from HCPs and other sources, they made their daily treatment decisions based on their life priority, daily schedule and personal intentions [4]. As such, their role in personal healthcare was more as a partner than a receiver of medical decisions [56].

This demonstrated a collaborated relationship between the patients and HCPs and an SMD process [17]. The compliance on medical regimes had been weakened and patients were allowed more flexibility and initiative in their own medical choices [38].

The current situation was that insufficient pain management [10,51], reflected through the lack of pain education and the limited clinical resources, hindered the model transformation. The insufficient management was reflected in two regards, the lack of pain education and the limited clinical resources.

Firstly, the lack of pain-related education accounted for the insufficient pain management (H1 stated). Because patients with little pain-related knowledge held a misunderstanding of the pain triggers and body conditions, encountered abuse of drugs, believed in unreliable treatments. All these behaviours would cause further damage to patients' current situation. Even well-educated patients faced difficulties in setting systematic goals or control the emotional consequences, due to the lack of pain-specific knowledge.

The conflict between the limited medical resources and the fixed resources invested into an individual patient increase the difficulty in access to pain specialists in general. The clinical system considered the in-person meeting between patients and specialists as a way of healthcare service delivery. However, such infrequent mode of consultation appeared to be ineffective in dealing with minor questions that arose for self-management in daily practice. Moreover, HCPs' awareness of a collaborative and partner role they involved in was not emphasized in clinical practice. HCPs demonstrate an attitude that they should contribute to a higher involvement and a greater input in medical decisions than patients [5]. In addition, clinical primary care was responsible for insufficient management of chronic pain. GPs tended to keep a low referral rate for patients, and provided inadequate pain-related education to their patients.

To sum up, the access to health care services from specialists were limited with decreasing medical resources provided to general public.

The aforesaid difficulties gave rise to the novel pain management apps and directed the promising future development to stimulate the collaborative partnership between patients and HCPs. They could provide multiple platforms ranging from reliable information provision, text or video pain-related education, and integrative means such as in-app consultation through messages, audio chats, video appointments. The combination of technology and HCPs provided patients with useful medical information sources and holistic support on SMD and self-management [17]. The apps stimulated a more efficient collaborative relationship between patients and HCPs. Moreover, they could provide stronger support in self-management practice with the delivery of the effective functionalities, which serves as the alternatives of clinical recommendations. Patients were exposed to more options and given the freedom to choose the optimal solution based on their perception of body conditions and preferences.

Pain management apps have the potential to empower the patients to self-manage their pain as a partner in healthcare and to maintain the collaborative relationship with the HCPs. We suggested future design and development should focus on this aspect.

7.4 Limitations

The patient participants recruited in the study were well-educated young adults with at least a bachelor's degree. This could result in biased sampling because the education background of users indicated that the user group was relatively familiar with technology and information seeking. Meanwhile, the chronic pain types included were limited with a constraint range of pain variables as well. Those factors could influence their perception of needs for functionalities of mobile apps. More research is needed when extends the current design implications into development.

There are some other interesting individual themes emerged during the interview, but they were excluded from the paper as they were not coherently connected with the themes articulated and the limitation of the paper length. For example, the expert opinion on the lack of regulations of healthcare apps; the user needs on their privacy protected by the apps. As one of the most important issues involved in chronic pain self-management, the emotional aspect was mentioned but not the focus of the research due to the ethical clearance. Further research is expected to conduct on this aspect and provide implications on the design and development of apps.

Besides, the design implications in this paper is limited to general chronic pain management apps. For future apps designed for a specific group of patients, user research is needed to understand the specific pain conditions, body

conditions, user requirements for functionalities and usability. Indeed, more stakeholders can be taken into consideration to attain enhancement in the effectiveness, usability and functionality of apps.

8. CONCLUSION

The study employed a qualitative approach with four stages aiming to address different research questions to complete a comprehensive user research.

The ESM study was conducted after the refinement based on the practice of autoethnography to understand users' chronic pain management experiences. The difficulty in the daily self-manage resided in the complicated and diverse nature of chronic conditions and the personalised treatment which manifested a lifestyle change in patients. Together with the destructive impact on their work/study, social and personal life, it suggested the urgent and promising role that mobile apps could play in supporting patients' current situation of insufficient self-management.

To further explore the user requirements on the design and development of pain management apps, semi-structured interviews with both key stakeholders, patients and HCPs, were analysed on the motivation of utilising the apps, expected functionalities and usability and integrated into design implications.

To facilitate the initial adoption and engagement, we suggest design and development teams to make use of the facilitating factors, such as the desires for information provision, appropriate functionalities, and positive reviews while avoiding or working on the impeding factors, such as lack of trust, low awareness of the apps and negative emotions encountered.

Among the identified five functionalities, pain-related education was viewed as the most necessary one, followed by self-tracking, goal-setting, skill training and social support. There were available commercial apps providing such functionalities, but all faced with deficiency in the quality and contents of the delivered services. The most essential solution made was to reflect HCP involvement in the functionalities as developer or reviewer, or enable direct communication through multiple media within the apps. HCP involvement not only builds the trust on the apps among patients, but also supports the transformation of self-management model from the compliance on the clinical decision to a SMD model, which indicates a novel collaborative patient-HCP relationship.

Future work should focus on the involvement of user research on specific chronic pain user groups and other stakeholders to gain design and development requirements for a particular app, so as to increase the awareness and satisfaction in the domain.

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APPENDIX 1: ADVERTISEMENT OF ESM

Experience sampling method

Study Advertisement

Participants needed

The study looks into how technology can enhance current chronic pain management, aiming to inspire the development of new pain management apps.

Participants needed in the current study

- Are experiencing constant and chronic pain from any part of the body for more than three months, with or without a biological cause. The pain can originate from either tissue damage or is neuropathic. (For example, lower back pain, neck pain, arthritis pain, headache, post-surgery pain, psychogenic pain, neurogenic pain and so forth.)
- Are familiar with smart phone and mobile applications

Tasks

In the study, you are requested to do a diary study for three weeks, which need you to answer several questions related to your pain condition during the day and takes about 10 to 15 minutes every time. And a short debriefing interview will be carried out before the end of the study.

You will get a 20£ as reward after your final completion of the diary study.

If you are interested, send a message to Yvonne at 07729099204, or email with your name and your intention to participate. The experiment starts on 16 July.

It will be greatly appreciated if you are qualified and willing to attend the study! Welcome on board to the ship of the chronic pain communities to earn a chance for a better life! Many thanks!

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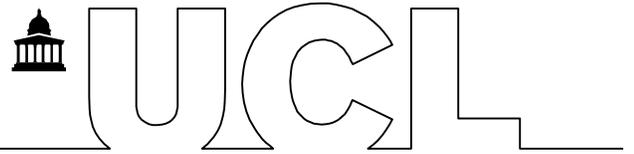
Information Sheet for Participants in Research Studies

You will be given a copy of this information sheet.

Title of Project: **Re-finding Normal in life transition: user-centred design innovations for chronic pain management apps**

This study has been approved by UCLIC Research Department's Ethics Chair

[Project ID No]: UCLIC/1213/015

Name, Address and Contact Details of Investigators:

Principal investigator:

Professor   Ann   Blandford
UCL   Gower   Street
London   WC1E   6BT
United Kingdom

+44 (0)20 3108 7049

We would like to invite you to participate in this MSc dissertation project overseen by researchers at UCL. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

We are aiming to design or evaluate a tool that would help you to manage health and wellbeing related information about yourself. We are interested in what information you keep track of or would like to keep track of (e.g., medication, pain management experience, information needs); when and how you would like to record it; when and how you would like to access it; and how you would like it to be presented to you. You will not be asked personally sensitive information, and can refuse to answer any questions that you don't wish to.

All data will be handled according to the Data Protection Act 1998 and will be kept anonymous. Only students taking the UCL MSc module "Human Factors for Digital Health" and the module leader, Professor Ann Blandford, will have access to your anonymised data. With your permission, anonymised quotations from your interview may be used in reports about the study.

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

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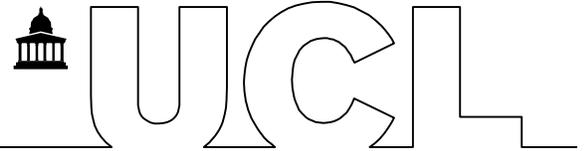
Informed Consent Form for Participants in Research Studies

(This form is to be completed independently by the participant after reading the Information Sheet and/or having listened to an explanation about the research.)

Title of Project: **Re-finding Normal in life transition: user-centred design innovations for chronic pain management apps**

This study has been approved by UCLIC Research Department's Ethics Chair

 [Project ID No]: UCLIC/1213/015

Participant's Statement

I ………………………………………….......................................

agree that I have

- read the information sheet;
- had the opportunity to ask questions and discuss the study;
- received satisfactory answers to all my questions or have been advised of an individual to contact for answers to pertinent questions about the research and my rights as a participant and whom to contact if I have any concerns.
- I understand that my participation will be audio recorded and I am aware of and consent to the analysis of the recordings.

I understand that I am free to withdraw from the study without penalty if I so wish. I understand that I consent to the processing of my personal information for the purposes of this study only. I understand that any such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Signed: Date:

Investigator's Statement

I …………………………………………………………………..

confirm that I have carefully explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits (where applicable).

Signed: Date:

APPENDIX 4: INTERVIEW SCRIPT OF DEBRIEFING

<div align="center">Debriefing interview script (Diary participants)</div>

Introduction

Hi, first of all, thank you very much for doing the diary study. As stated before the start of the diary study, we still need to conduct a post-diary interview for me to understand your thought on the diary study, and some additional questions on the topic.

Just as a remind, my study is about how technology can help people better manage their chronic pain. By 'manage', it not only means the medical or physical treatment you have, but also includes other coping methods, for example, keeping a diary of your pain condition, tracking your pain intensity and frequency, getting information from multiple sources. All of these pain related experiences are involved. In this interview, I want to know about your own pain management experience and how mobile applications can help you cope with your chronic condition. I am sorry that some of the topics we have already come across a bit last time, but we will discuss in detail this time.

 Can I start to record the conversation now?

Topic Guide and questions related

- **Supplement questions based on the review of last interview individually**
    - How do you feel about the diary study?
    - Can you conclude your information need from your diary??
- **Management experience**
    - How useful do you think your daily management are?
    - What do you think is the difficult part when you manage your chronic condition?
    - Could you describe the impact of your chronic condition on your daily life?
    - How do you deal with this impact?
- **Prior experience with pain management apps**
    - Have you ever heard about this kind of apps?
    - Is anyone around you using these apps?
    - Why you don't use this kind of apps?
    - Would you like to use some apps to help you manage your pain?
- **User needs**
- Expected functions and contents
    - If there is such app that can help you manage your chronic condition, what do you expect from it?
    - What kind of functions you want?
    - How useful do you think the following functions for you?
    - What content would you need from each function?
        1. Pain tracking/self monitoring (not enough)
        2. Goal-setting function
        3. Pain-related education
        4. Skill training – specific
        5. Social support
- Other issues:
    - To what extent, would you share your personal information and experience on those apps?
    - Who would you like to share?

How do you want the health professionals to be involved?

APPENDIX 5: INTERVIEW SCRIPT FOR NON-DIARY PARTICIPANTS

Semi-structured interview script (non-diary participants)

Introduction

Hi, thanks for agreeing to take part in this interview. As stated in the consent form you have just signed, you are free to stop the interview at any point without a reason. And your information and the conversation will be kept safe and confidential. The interview will last about an hour, and you'll be given 10 pounds for your participation.

My study is about how technology can help people better manage their chronic pain. By 'manage', it not only means the medical or physical treatment you have, but also includes other coping methods, for example, keeping a diary of your pain condition, tracking your pain intensity and frequency, getting information from multiple sources. All of these pain related experiences are involved. Meanwhile, mobile technology is more and more popular today. This is true in pain management field as well. In this interview, I want to know about your own pain management experience and how mobile applications can help you cope with your chronic condition. Can I start to record the conversation now?

Please speak in slower speed so that it is easier for me to transcribe.

Topic Guide and questions related

- **Demography**
    - May I know your age?
    - May I know your education background?
    - May I know your occupation?
    - May I know your residence country?
- **Pain condition**
    - What kind of chronic condition do you have? (pain type)
    - Where do you have the pain? (location)
    - Could you describe the sensation of the pain? (sensation)
    - How long have you had it? (duration)
    - How often do you have the pain? Has it changed along time? (frequency)
    - On a scale from 0 to 10, 0 means not at all, 10 means extremely painful, how would you describe your pain magnitude?
    - On a scale from 0 to 10, 0 means not at all, 10 means extremely great, how would you describe how much the chronic condition has impacted your life?
- **Management experience**
    - Could you describe your treatment history in brief? (start of the pain, symptoms, frequency of seeing doctor, medication, etc.)
    - How do you think about the treatment?
    - How do you learn about your pain and your own condition outside the clinical environment? (sources of intervention, advice and information, technology and non-technology)
    - Who would you consult? / Do you know people share same condition as you? (peers)
    - How do you think about these sources?
    - How do you manage your pain normally, besides the medication you already mentioned?
    - How useful do you think these management are?
    - What do you think is the difficult part when you manage your chronic condition?
    - Could you describe the impact of your chronic condition on your daily life? (examples)
    - How do you deal with this impact?
- **Prior experience with pain management apps**
    - Do you have any prior experience with pain management apps?
    If yes,
    - Could you describe your experience in detail? (what app, function, frequency, duration)
    - How do you evaluate those apps?
    - What do you think can be improved for those apps?
    If no,
    - Have you ever heard about this kind of apps?
    - Is anyone around you using these apps?

- Why you don't use this kind of apps?
- Would you like to use some apps to help you manage your pain?
- **User needs**
- Expected functions and contents
    - If there is such app that can help you manage your chronic condition, what do you expect from it?
    - What kind of functions you want?
    - What is your concern of those kind of apps?

    - How useful do you think the following functions for you?
    - What content would you need from each function?
        6. Pain tracking/self monitoring
        7. Goal-setting function
        8. Pain-related education
        9. Skill training – specific
        10. Social support
- Other issues:
    - To what extent, would you share your personal information and experience on those apps?
    - Who would you like to share?
    - How do you want the health professionals to be involved?

In-depth semi-structured interview – health professionals

Interview Guide

Introduction

Hi, thanks for agreeing to take part in this interview.

My study is about how technology can help people better manage their chronic pain. By 'manage', it not only means the medical or physical treatment people have, but also includes other coping methods that support for physical and mental wellbeing, for example, keeping a diary of pain condition, tracking pain intensity and frequency, getting information from multiple sources and others, gain social support. In this interview, I am interested in mobile phone applications that can help self-management of chronic pain and conditions. So basically, this study is a user requirement gathering research before the design of such apps. And the topic of the this interview is what kind of role can health professionals play in patients self-management?

This conversation will be recorded and transcribed for analysis. It will be helpful if you could louder and slower so that it is easier for me to transcribe.

Structure

1. Background
   - Could you tell me your expertise and your experience with treating people with chronic pain?
   - How often do you see one patient with chronic pain? (underlying that heavy self-reliance is the pervasive management style, i.e., less reliance on clinician; In the case of the experimenter, I see doctor every 6 weeks, leaving myself deal with the pain and mental adaptation most of the time)
2. Because of the nature of chronic condition, that people experience them recurrently and for a really long time, and because of the development of internet as well, people can easily get information and make healthcare decision by them own. This means self-management of chronic condition is more common now.
   - How do think about the relationship between health professionals and patients?
   - How can patients better self-manage their pain outside of the hospital in general?
     (divided into different stages, different degrees and types of pain)
   - As a phycologist, how to better provide emotional support?
     /How you suggest the patients deal with the negative emotional feelings throughout the everlasting treatment?
   - How do you think mobile technology can help them to self-manage their pain?
   - In which way?
3. For the sake of patients, what do you think health professionals can play the role in this kind of apps?
   - What kind of information should be involved in those apps?
   - What kind of function could be involved?
4. Their view on the existing chronic pain management apps in terms of the reliability of the contents and the technology
   - Are you aware there are mobile applications available on smart phones, which target at pain users and claim to help their pain self-management? Are there any used by the clinic organisations?
     (Show the main information and features in the apps)
   - How do you think about the existing apps specialising in helping patients manage their chronic pain, in terms of the contents and the form?
   - How would you evaluate their effect?/Are those apps helpful?
   - How would you rate their reliability?
   - Please evaluate the following functions. And What should be pay attention to when include these functions?
     11. Pain tracking/self monitoring
     12. Goal-setting function
     13. Pain-related education
     14. Skill training – specific
     15. Social support
5. Criteria or regulations that should be followed in the design and development of those health apps
6. Can you conclude some key factors in designing such apps from your perspective?
7. What will be the key factors for the design of future app form their perspective

(Introduction: The goal of our study is to inform the design of prospective smart apps that support users' self-management of their own chronic condition. In general, we try to combine the information provision and the tracking function. This means we hope the information provided can be tailored for individual users, involving distinguishing different conditions and providing information matching their emotional and physical needs. This can save them from the labour in picking up information.)

- Do you have any comments on our thought?
- What do you think is the key factors in designing such apps from your perspective?
- The bunch of suggestions for chronic pain patients you mentioned just now, do you think they are necessary to be reflected in the design of the apps?
- How do you think the apps should work? Should they connect with the clinicians in order to provide in-time supervision and feedback? Or should they just work as a tool exclusive for the patient group, besides the records of the pain history.
- How do you think about the idea that the apps provide connections between patients with similar encounters?

End

Thank you for your participation of the experiment. Do you mind if we contact you later if there is something unclear during the conversation? Also, if you have any questions about the study afterwards, feel free to contact through email.