Mobile Decision Support and Data Provisioning for Low Back Pain

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The authors present Back Pain Buddy, a mobile application offering decision support and coaching for people with low back pain (LBP). The application takes advantage of smartphones' powerful capabilities and provides a crowd-sourced decision support system for discovering treatments and a mobile sensing solution for collecting data about users' activities that are crucial in LBP research.

Low Back Pain (LBP) is the leading cause of activity limitations and missed work throughout much of the world. LBP is a complex issue, and several factors contribute to the condition. LBP has no silver bullet solution, and its global economic ramifications and negative impact on the quality of countless lives, communities, and families is massive.[1] In 1990, LBP ranked as the sixth most burdensome condition in the US contributing to poor health; and two decades later, it causes more disability globally than any other medical condition.[2]

The rise of personal and affordable health trackers has enabled studying, tracking, and even proactively improving several types of health issues. In particular, the so called "medicalized smartphone"[3] is revolutionizing several aspects of medicine. Surprisingly, and despite its massive global burden, LBP is one of the few major medical research areas where not much work has been

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conducted with smartphones. Thus, exploring their potential role in LBP yields a fascinating research avenue.

Our work is highly exploratory in nature, and our overarching aim is to build toward using people's personal smartphones to address two issues specific to the LBP research field. First, the lack of clear therapeutic consensus—despite the condition being extensively documented—results in a plethora of recommended treatments, advocated by various clinicians, practitioners, and commercial operators.[4] The absence of agreement makes it difficult for patients with LBP to select a treatment, especially if they lack access to healthcare (for example, due to a lower socioeconomic status[1]) or turn to the Internet seeking help (for a majority of patients[5]). And second, patients lack sufficient knowledge of LBP-relevant contextual information and lifestyle factors (such as activity levels, physical environment, ambient noise, and subjective experience of LBP).[2]

To address these issues, we present *Back Pain Buddy*, which is a mobile application that provides crowdsourced and trustworthy decision support to address the first issue, and incorporates a powerful mobile sensing solution to address the second issue. Back Pain Buddy is being developed as a partnership among the University of Oulu in Finland, the University of Melbourne in Australia, the Finnish Institute of Occupational Health, and Oulu University Hospital. It is the end user's entry point to a larger scheme to start collecting—for the first time—LBP-relevant contextual information using people's mobile devices in large-scale, longitudinal cohort studies. As an academic venture, we aim for openness of data and free use of the developed technologies. This is crucial, as for-profit corporations are increasingly dominating the personal user data market and pose a direct threat to science and equality (see for example the *Nature News* opinion piece that was published in 2016).[6] Indeed, we predicate our work on legacy and establishing a foundation for future value creation instead of immediately seeking answers to sharply formulated research questions.

The results from our user studies show that the decision support system provides value to its users and that potential Back Pain Buddy end users also thought the mobile sensing solution was feasible. However, users have reservations regarding privacy, ethics, and harmful commercial use of the data, which all need addressing before we can proceed to larger international trials.

LBP IS ONE OF THE FEW MAJOR MEDICAL RESEARCH AREAS WHERE NOT MUCH WORK HAS BEEN CONDUCTED WITH SMARTPHONES.

BACK PAIN BUDDY APPLICATION

The application consists of two components: decision support and mobile sensing. The first prototype of the application contained only the sensing component. We quickly learned, however, that it was challenging to recruit participants to a study where they would not receive any immediate value with the application but instead were "just" donating data. Our best efforts with a collaborating medical organization (Oulu University Hospital) resulted in just a handful of LBP patients installing the application. This was not a sustainable long-term approach toward our goals (outlined in Figure 1).

Nevertheless, this pre-study was encouraging because participants completed self-reports about their LBP condition for several weeks, and we also collected sensor data. However, we need to offer better incentives to scale up participation. To this end, we decided to include the decision support system as an added feature that provides immediate value for end users, so that we could then ask them to donate their contextual data.

CROWDSOURCED DECISION SUPPORT TO DISCOVER LBP TREATMENTS

Crowdsourcing decision support via digital applications is a relatively young but inherently powerful concept: generally, people trust other people who have experienced the issue at hand. Consider the influential nature of customer reviews on Amazon, for example. The same principle helps to offer decision support for any arbitrary multi-answer question, as we have explored in previous work.[7] The decision support system we developed uses crowdsourcing to first break down a question into

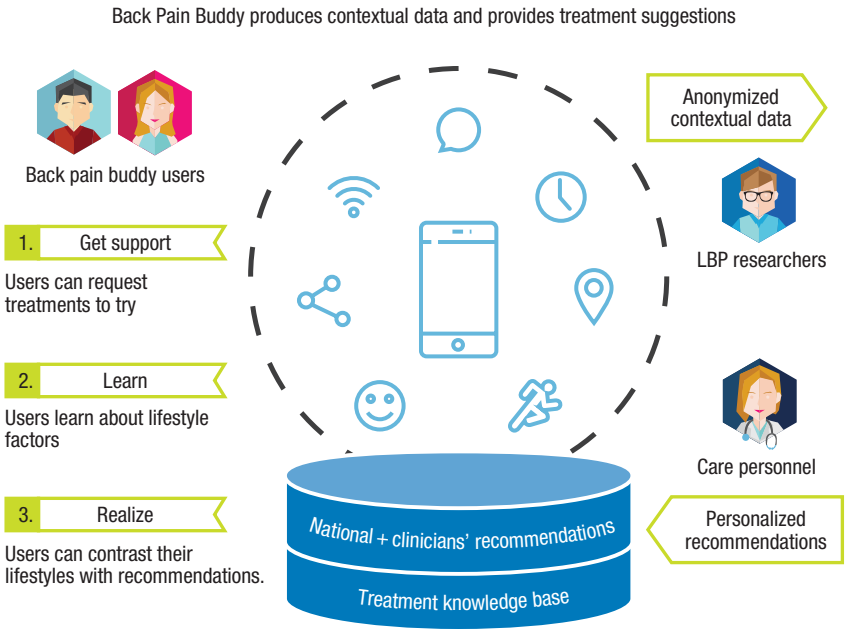

FIGURE 1. Conceptual diagram of our data exploitation plans for the Back Pain Buddy, which collects contextual data and provides treatment suggestions. Users get decision support in the form of ideal back pain treatments. They can also contrast their lifestyle characteristics to clinicians' and government recommendations. Researchers, on the other hand, benefit from collecting contextual information data about the lives of people with LBP.

sets of candidate answers and possible criteria that can be used to assess the answers. Then, the crowd-users assess every answer in light of every criterion, using a "goodness" scale of 1–100. The collected knowledge base encapsulates the wisdom of the crowd that can be used to compute a list of answers that best match the user's ideal solution to the question. Our previous work provides more information on the concept and examples of different computational means to obtain knowledge base decision support.[7]

LBP presents an excellent example of a multi-answer problem that is suitable for use with our decision support concept. Here, we are interested in assisting users to find solutions to the question: *What is a good way to treat low back pain*? To this end, we redesigned the system introduced in our previous work[7] into a mobile-first back-pain–themed decision support component, embeddable in a mobile application. We upgraded the back end to support multiple knowledge sources (crowds), to let end users choose if they want decision support from LBP experts (doctors, physiotherapists), other non-experts (non-experts), or a combination of the two.

The decision support interface is simple and only asks the user to define her ideal back pain treatment using any or all of the criteria available in the system. To achieve this through the app, the user defines ideal criteria for a treatment using slider input elements (Figure 2b). The interface also contains radio buttons to choose the source of the retrieved treatments (experts, non-experts, combination). After setting the ideal criteria in the app, the decision support system fetches the best-matching LBP treatments from the underlying knowledge base (Figure 2c).

Mobile Sensing Component

Smartphones have emerged as powerful research tools for studying human behavior and conditions, thanks to their ubiquity and increasing sensing capabilities. Mobile sensing has risen as a research domain that refers to acquiring and understanding data captured using the array or onboard sensors. Due to a fragmented device (and even OS) base, this is far from trivial, however, and several mobile sensing platforms have been built to ease the data harvesting and aggregation processes.

Especially in the context of LBP, accurate contextual information for patients and potential patients is a key challenge to tackle.[8] Back Pain Buddy is designed to fill this gap. To do this, we make use of the AWARE mobile sensing platform,[9] which is open source, secure, and extensible. This platform enables us to collect and provide access to data on our own servers. It supports plugins, thus we can implement and run any custom native code—a crucial feature for our custom data collection needs. This also allows the user to be in full control of what data is collected, as can be seen in Figure 2e. Using AWARE as a library in Back Pain Buddy, we can capture the following 10 types of contextual data,

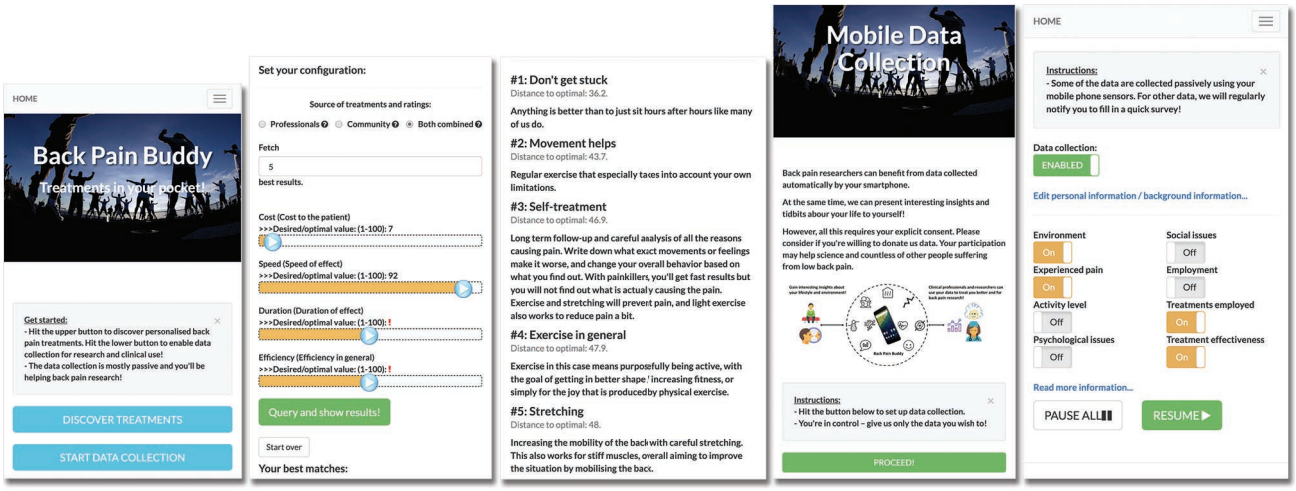

FIGURE 2. Screenshots of the "Back Pain Buddy" mobile application. Images reflect: (a) start screen, (b) decision support system to discover back pain treatments, (c) example list of retrieved treatments, (d) intro screen to data collection, and (e) on/off toggles to control the collection of a given type of contextual data.

which are all identified as highly relevant to LBP research:[8]

- Employment (documenting type of work, effects caused by LBP in the workplace, effects of LBP to employment situation)
- Environment (ambient information, weather, wind, temperature)
- Pain characteristics (type, intensity, speed, level of recovery)
- Demographics (age, gender, height, weight, country, etc.)
- Disability (type, extent)
- Physical condition (current activity levels, maintenance, body function)
- Psychological (effort of living, feelings of loss, disempowerment, worry)
- Social (psychosocial challenges, negative reactions by friends and relatives)
- Treatment (treatment burden, treatments being attended to)
- Medical history (records, past treatments)

Although the capabilities of mobile sensors are improving all the time, not all of these can be harvested passively but require self-reporting by the user.[10] For instance, sensors are great for inferring data on environment or a user's physical activity, but self-reporting is needed for gathering information on LBP's effect on work, or social and psychological conditions. For this, AWARE provides the Experience Sampling Method, offered via a simple query builder and questionnaire scheduler. Together, the 10 factors encompass a rich array of internal and external influences, factors about current activities, and other information that could be useful for LBP research and can be used to provide coaching in the form of lifestyle recommendations and encouragements. For instance, the comparison of a user's activity levels to those recommended by the user's personal care provider transparently provides useful information to both parties. Yet we emphasize that the user is in control: each of the data types is an optional feature in the application, users can simply turn the said collection feature on or off (Figure 2e).

STUDIES

Study 1: Opinions on Decision Support Component

To develop the LBP knowledge base (potential treatments, criteria, and their relations), we bootstrapped the system together with both clinical experts (doctors, physiotherapists) and non-experts (everyone else). This was conducted online, using a custom one-page Web application. On the site, users could contribute new treatments and rate others' treatment suggestions to the question: "What's a good way to

treat low back pain?" Inputting new treatments was enabled by standard HTML-form input fields, and rating values happened with slider inputs (one slider per criterion), very similar to the UI depicted in Figure 2b for obtaining decision support. For more information on the implemented system, we refer the reader to our previous work.[11]

Instead of tapping into an existing labor market (which would not provide us with the required expertise), as is the case in a typical crowdsourced system, we had to use a great deal of imagination to reach medical doctors and physiotherapists. We contacted a back pain researcher (who is a senior professor at a local university hospital) who was able to provide us with access to a national organization for doctors and physiotherapists specializing in back pain. Before initiating any communication to their mailing lists, we used the local collaborators to identify the four criteria that back pain patients typically find as important when looking for treatments. We did not want to have a dynamic list of criteria in the system, as the data collection needs rise linearly each time a new criterion is added. Nevertheless, the four most important ones, as judged by real practitioners, seemed like a reasonable compromise.

Using the email list of the national organization, we promoted our system to medical doctors and physiotherapists. Then, our local expert collaborators curated the options into a "gold standard" LBP treatment collection, and we sent this collection to the same mailing list for assessment. Then, to collect non-expert knowledge on LBP, the system was promoted publicly online in back pain–related Facebook groups and several relevant social media profiles. As a reward, we raffled one $100 gift card to a health-themed online market.

Then, for the actual DSS evaluation, we invited those who had contributed data to the knowledge base to use the now-bootstrapped decision support system. Their task was to play with it, get decision support, and simply see what it could do and what thoughts would arise when using crowdsourced knowledge on LBP. Everyone using the system was invited to complete an online survey, evaluating the value proposition, perceived trustworthiness, and overall usefulness. Second, Back Pain Buddy (the mobile application embedding the DSS component) was featured for a full day at a technology fair/exhibition of a local prototype "future hospital," which was managed by the local university hospital's research division. There, we interviewed final-year medical doctors and physiotherapists touring the fair as part of a course on future medical technologies.

Study 2: Acceptability of Contextual Data Collection

To study the acceptability and future issues of the contextual data collection component, we deployed surveys online to people with personal interest in LBP. We mainly used the list of our already-devoted participants from the previous user study. We listed the 10 contextual elements we are preparing to include in our data model as a Likert-scale, requesting users to consider their willingness to donate this data type for each item. Each item was ranked on a scale from 1 to 7 as "not at all willing" to "extremely willing." We clarified in the survey that not all data types can be collected passively using sensors but would require manual input from time to time. Another purpose of introducing the data types to the user was to make them think about the concept more deeply. We reasoned this would help them provide better open-ended commentary. We also included items about general acceptability of the concept, demographic data, mobile tech savviness, past personal experience with LBP, and open-ended items to provide feedback.

To further stimulate participants' thinking, we adopted elements from the Expectation Disconfirmation Theory (EDT), which is used in marketing sciences to predict consumer satisfaction with future products. EDT has been recently extended to predict technology trust and usage continuance intentions for technological products.[12] We adopted and described the following four factors to the participants.

1. **Ease of use:** the degree to which the sensing solution will require mental effort to use.
2. **Functionality:** the degree to which the solution will have the capability, functions, or features needed to accomplish its tasks.
3. **Reliability:** the degree to which the solution will continually operate properly, or will operate in a consistent, flawless manner.
4. **Usefulness:** the degree to which the user trusts that the solution is beneficial for its purpose.

Again, the items were presented as a Likert-scale where each item was ranked from 1 to 7, and 1 was equal to "not at all," and 7 was equal to "extremely" (for example, from "not

at all easy to use" to "extremely easy to use"). This section was also complemented with an open-ended item to provide feedback. Together with information on users' technology savviness, these items help predict issues in the system's future acceptability.[12]

RESULTS

Active Decision Support System: Value for All Stakeholders (Study 1)

Through the mailing lists that our collaborators gave us access to, we were able to recruit 65 experts (37 male, 28 female; ranging in age from 29 to 76 years; M = 53.0, SD = 11.4) to contribute 39 back pain treatments to bootstrap the decision support system. These were curated to 12 "gold standard" expert solutions that were then re-evaluated by the same expert pool. The experts inserted 610 unique ratings for the 12 treatments and four criteria that were already bootstrapped in the system by our collaborators.

There were 288 participants (63 male, 225 female; ranging in age from 23 to 75 years; M = 47.2, SD = 11.8) who contributed to the non-expert knowledge base. This crowd had an evident personal interest in the topic, as all but 18 of them had experienced back pain in their lives. The non-expert crowd contributed 69 new treatment ideas, out of which 56 were valid (we filtered out entries that were gibberish, such as "asdf" or empty submissions). Non-experts contributed 8,391 ratings for the available treatments.

There were 46 people (9 experts, 37 non-experts) who helped evaluate the actual decision support system after using it to discover treatments. In general, users perceived the DSS as highly useful in discovering back pain treatments (rating it an average 4.6, on a scale from 1 to 7). For an in-depth look into the collected data, we ask the reader to turn to our recent conference presentation.[11] We also conducted a lightweight qualitative analysis of the results. First, we loaded all the results in to a shared Google spreadsheet, in which two of the authors reduced the resulting set to items that were deemed as useful. Then, the same authors identified larger common themes independently, and finally again collaboratively discussed to finalize the themes and the items belonging to them. The usefulness of the system was supported by the qualitative findings:

> *P1, Female, 34: "The clinical care personnel get information of treatments that they do not know about, while the one with the pain learns about new options by others with pain."*

The inclusion of non-expert knowledge in the tool was seen as highly crucial for the system to be interesting: 30 respondents found the combined knowledge of experts and non-experts to be the most interesting knowledge source. The same sentiment was surprisingly shared between the experts as well:

> *P19, Male, 53, Expert: "Academic expertise alone does not provide a holistic view to the situation. It is good to understand what people in general think and how they experience the treatments to learn new viewpoints."*

However, critical viewpoints were also brought forward, especially regarding the ambiguity of the sliders used for indicating the desired criteria:

> *P11, Female, 50, Non-expert: "I would develop a better input mechanism than the slider. It is difficult. Traditional written scale works, as then there is no interpretation involved in giving the score."*

Mobile Sensing: Generally Acceptable, but with Reservations (Study 2)

We collected 192 survey responses (participants' ages ranged from 21 to 75 years; mean 46.1, SD = 12.2) to our survey on the mobile sensing concept. Of these, 88 respondents identified themselves as highly mobile tech savvy (scores 6 and 7 on a scale of 1-7 to the question "In your own assessment, how familiar are you with novel mobile technologies and their future potential?"). And 87 identified themselves as moderately savvy (scores 3-5); and 17 identified themselves has having as little or no savvy (scores 1-2). We also asked about participants' personal experience with back pain, and 61 identified themselves as heavily affected by back pain, 90 as moderately affected, and 41 as having little or no back pain affectedness.

Figure 3 plots people's willingness to allow data collection per each of the contextual data elements, and their enthusiasm to allow data collection in general. Below that, we plot respondent's future expectations toward the system's characteristics.

We observe that respondents were overall quite positive in allowing data collection, but that there were significant differences in the allowance of different data types (confirmed by a Kruskal-Wallis Test, $p<0.05$). More specifically, participants were more willing to donate pain characteristics

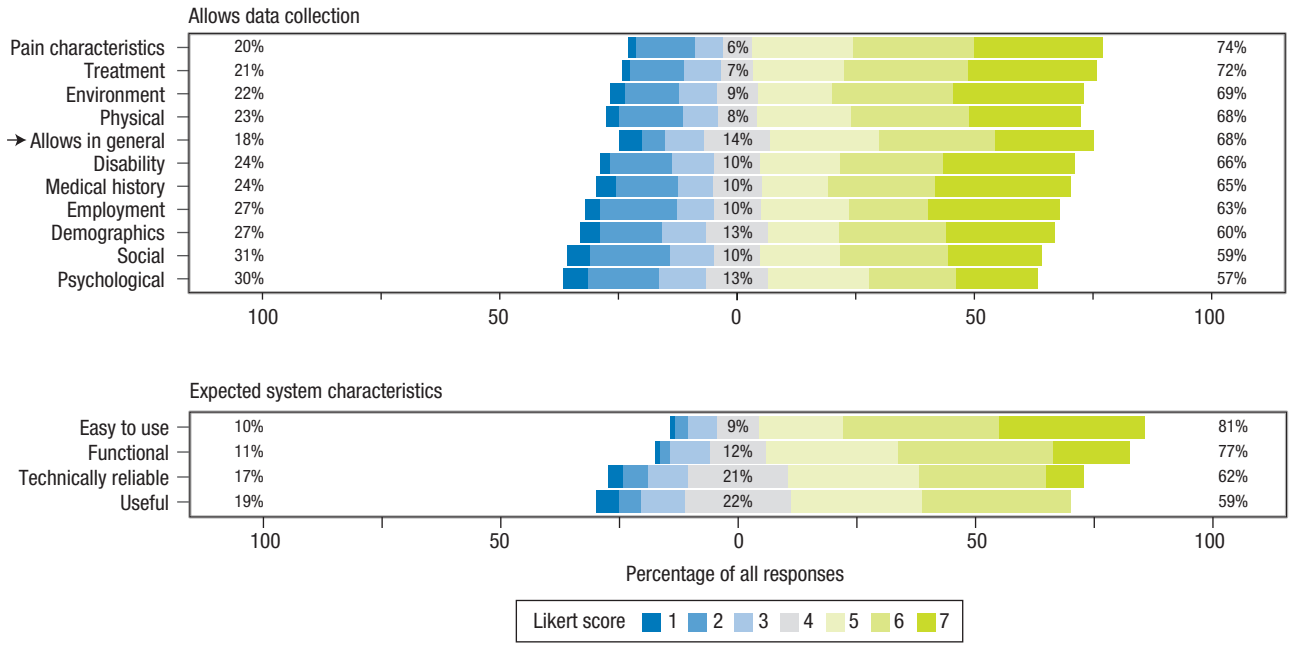

FIGURE 3. Top: data types plotted in order of willingness to donate. The arrow denotes overall acceptance of data collection. Bottom: expected characteristics of the final deployed system. The *x* -axes in the plots correspond to the percentage of responses.

and treatment data than data on psychological or social elements (Wilcoxon Rank-Sum Test for each of the four pairs, $p<0.05$). Interestingly, prior experiences with LBP, namely, having personally suffered from back pain, did not significantly affect data donation willingness. We discovered, however, that respondents' tech savviness affected the overall willingness to donate data (the item marked with an arrow in Figure 3). Those in the low-tech-savviness category scored an average of 4.3, whereas those in the moderate category scored 4.7, and those with high savviness scored 5.5. People with high savviness scored significantly higher than those with low or moderate savviness (Wilcoxon Rank-Sum Test for both, $p<0.05$).

Tech savviness also played a major role in future expectations. In all of the probed expected system characteristics (ease of use, functionality, reliability, usefulness), there were statistically significant differences between the tech savviness categories, as confirmed with Kruskal-Wallis tests ($p<0.05$). People with low tech savviness expected the future system to be less easy to use (average 3.8, on a scale of 1–7) than moderately or highly tech savvy people (5.4 and 6.1). As for functionality, the scores per savviness categories were 4.1, 5.1, and 5.7 (low-moderate-high tech savviness). Reliability scores were 3.9, 4.6, and 5.1 (low-moderate-high) and finally the usefulness of the system was anticipated as 4.6, 5.5, and 5.9 (low-moderate-high).

The overall response provided in the open-ended items toward the concept was excitement and welcoming. Some of the more optimistic comments are exemplified below.

> *P12, Female, 29: "I think it's only great if I can help others!"*

> *P97, Female, 39: "I'm willing to help in any kind of venture that aims for alleviating pain – and not just by giving more and more painkillers."*

Another 45 of the 192 respondents expressed major reservations toward the mobile sensing component that fell into three main categories: the idea of the collected data accidentally being leaked to the wrong parties; the system trying to exploit the data commercially; and ethics of the data collection in general. The following responses exemplify some of these concerns.

P109, Male, 28: "As long as the data stays only within the scientific or healthcare domains, I would donate my data."

P114, Male, 64: "Only a strictly sandboxed application has any chance to survive in the future 'cyber jungle.'"

ANALYSIS

In Finland, it is estimated that 80–90 percent of all people suffer from back pain during their lifetimes. This highlights pain's evergreen nature as the subject of empirical studies.[1] Our exploratory approach builds on capturing people's contextual data and using that to shed more light on the age-old and massively burdensome global problem of LBP. The long-term plan contributes to creating yet unforeseeable well-being assets that a greater understanding of people's lifestyles will yield. All this depends on ensuring the data are available and free for the scientific community to study.[6]

Back Pain Buddy is our contribution to the ongoing trend of leveraging the smartphone in the health domain.[3] It is a mobile end-user application that encompasses a powerful and trustworthy decision support system. As a component, it helps capture crucial contextual information as an entry point to a system that will provide data and insights to researchers and users alike on a global scale.

While we have a promising start, questions remain. How contributions be rewarded? How can the quality of incoming data be vetted? While long-term field studies with real subjects in their authentic everyday environments are not easy or cheap to conduct, they are well worth it in this case: LBP is a global problem. To this end, we also note that although the knowledge base collected by medical doctors should generalize relatively well outside Finland, there are a lot of questions about how to scale up the system to accommodate different countries, regions, and cultures. Here, we explore options such as prioritizing local data (national) or allowing users to filter data by country.

On the Uses of Contextual Knowledge

Our initial plans to exploit the collected contextual data span beyond just offering it to the LBP research community. First, when enough data exists on a Back Pain Buddy user, we can explore passive decision support in an attempt to nudge and coach the user toward healthier life choices. For instance, different countries have differing national recommendations in terms of recommended minimum exercise and activity levels or other optimal lifestyle choices that people should make in their life. Especially with LBP, keeping users informed about the benefits regarding activity and keeping up a "normal" life rhythm is beneficial.[4] Thus, we will build an automated solution to inform users when their activity levels drop below personalized recommendations, or if their activity patterns begin to decline over time. Second, when we bring the personal clinicians into the loop, for example by adding a field to the application where the clinician would simply enter her unique identification code to gain access to user data, we are able to provide patient data to the people who most need it, and care providers can also begin adding specific recommendations based on contextual data, for example recommendations about activity levels. All this, naturally, leads to a situation where we must be highly attuned to data management issues imposed by GDPR. For Back Pain Buddy, we rely on a modified back end of the AWARE mobile sensing toolkit,[9] an open source project that has been recently updated for GDPR as well.

Limitations

We also acknowledge limitations in this first exploration. First, the participants in Study 1 were mostly female, highlighting the challenge of studies where we simply recruit users online—there there is no easy way to guarantee an even sample of all genders. Further, Study 2 participants were recruited mostly from the same people who participated in Study 1. While this reduces the findings' generalizability, we argue that most of our system's end users are people interested in LBP in the first place. Recruiting among people who have already expressed interest in the topic is a suitable approach in this case (indeed, the two studies are very different, so there is no carryover effect).

A Roadmap Toward Open LBP Context Data

As our plan progresses, we continue to hear concerns from end users that introduce new design suggestions. For instance, we need to emphasize the fact that the decision support feature is a way to discover treatment suggestions and is not a replacement for visiting a doctor. The user is always responsible for her choices: Back Pain Buddy simply helps to discover treatments that can then be discussed with medical professionals. To this end, we also plan to tweak the UI to subtly steer the user to the treatments articulated

by medical professionals and show an additional warning dialog when the user wishes to discover treatments by non-professionals. The treatment knowledge base is indeed community-managed, and there are always quality issues involved in user-generated content.

However, we argue that the biggest upcoming challenge is a strategic one rather than a technical or design one. We must think long term, and not focus solely on immediate academic output. We are actively applying funding and looking for collaborators to focus on the obstacles described below.

- Unified definitions on how to describe the contextual data elements. Building a standard data collection scheme/language for storing the 10 contextual elements[8] will enable other research units to start contributing data and use other platforms and devices than our initial setup (Android + AWARE).
- Securing and designing the data storage/sharing facilities. As a starting point, we are using the open source AWARE server, modified to our needs. Here, crucial first issues to solve are how to ensure all contributed data adheres to the unified definition, and how to ensure automatic data quality checks. How can we allow clinicians access to a certain individual's data vault while keeping it closed to the rest of the world?
- Passive decision support based on sensed contextual data. We must investigate, in a series of studies, how to use the collected data so that it encourages the user to make better choices. Here, we also investigate how to best visualize users' activity levels and other lifestyle ingredients in contrast to national recommendations and other users.
- Scale up, initiate meaningful collaborations. Our collaborators at the Finnish Institute of Occupational Health can help us scale up the research, but before

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this, we need to run additional studies to validate the concept with real patients and people suffering from LBP.

Back Pain Buddy is a mobile application for providing decision support and collecting contextual data—both recognized gaps in LBP research and practice. Our results show that people are willing to donate their data, and that especially tech-savvy individuals expect no problems with adopting the application. This article introduces the idea, communicates promising first results to the community, and hopes to spark interest among interested international collaborators.

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