Sound of Care: Towards a Co-Operative AI Digital Pain Companion to Support People with Chronic Primary Pain

BLEIZ M. DEL SETTE, Queen Mary University of London, UK
DAWN CARNES, University College of Osteopathy, UK
CHARALAMPOS SAITIS, Queen Mary University of London, UK

This work investigates the role of sound and technology in the everyday lives of people with chronic primary pain. Our primary goal was to inform the first participatory design workshop of *Sound of Care*, a new eHealth system for pain self-management. We used an ethical stakeholder analysis to inform a round of exploratory interviews, run with 8 participants including people with chronic primary pain, carers, and healthcare workers. We found that sound and technology serve as important but often unstructured tool, helping with distraction, mood regulation and sleep. The experience of pain and musical preferences are highly personal, and communicating or understanding pain can be challenging, even within family members. To address the gaps in current chronic pain self-management care, we propose the use a sound-based AI-driven system, a *Digital Pain Companion*, using sonification to create a shared decision-making space, enhancing agency over treatment in a co-operative care environment.

CCS Concepts: • **Human-centered computing** → **Human computer interaction (HCI)**; **Interactive systems and tools**; *Sound-based input / output*; • **Computing methodologies** → *Artificial intelligence*.

Additional Key Words and Phrases: Sonification, Chronic Primary Pain, Participatory Design, Person-Centred Design, Generative AI, Affective Computing, eHealth

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1 INTRODUCTION

Chronic pain is a complex condition that can significantly impact a person's daily life and psychosocial wellbeing. More than 10% of the global population experiences some form of chronic pain [8], posing a substantial threat to global health. *Chronic Primary Pain* (CPP) encompasses various pain syndromes considered as independent health conditions. This category includes prevalent forms of chronic pain such as fibromyalgia and non-specific low back pain [27].

One of the primary objectives in current chronic pain care is to enable people to live their lives despite pain, positioning the person as an active problem solver in the intervention model. This practice is commonly referred to as self-management [30]. *Digital Health* (eHealth) technologies are becoming a prominent tool in chronic pain self-management care thanks to their ability to be delivered ubiquitously and asynchronously [17]. Current eHealth applications for chronic pain mainly focus on pain self-reporting strategies, which require the person to manually input data into the system. This hinders the ability of eHealth solutions to have a direct real-time impact on activities of daily

Authors' addresses: Bleiz M. Del Sette, b.delsette@qmul.ac.uk, Queen Mary University of London, London, UK; Dawn Carnes, dawn.carnes@uco.ac.uk, University College of Osteopathy, London, UK; Charalampos Saitis, c.saitis@qmul.ac.uk, Queen Mary University of London, London, UK.

living, a limitation that can be addressed by employing embedded features or wearables that automatically gather and record data [24].

With *Go-with-the-Flow* [22], sonification has been successfully introduced as one of the first effective real-time interventions in chronic pain self-management. However, like most of the current eHealth solutions, it primarily focuses on the movement-related and musculoskeletal aspects of chronic pain. Complementary therapies in chronic pain aim to benefit both physical and psychological quality of life, acting also as pain and emotional regulators. CPP, in particular, is characterised by a significant emotional distress and the influence of psychological determinants [19], a crucial element that is largely unmet in real-time interventions.

Sound and music have long been utilised to modulate and regulate mood and pain [20], and arousal-regulation and psychosocial mechanisms have been proposed as potential characterisations of the emotional-motivational dimensions of musical engagement [21], all of which are directly connected to chronic pain self-management strategies. *Artificial Intelligence* (AI) not only has the potential to interact with the valence-arousal space to detect emotions [32] but can also be used to generate music directly [23], a novel approach that has yet to be actively explored in sonification. Promising results have been observed in using AI to directly condition sound generation [6] and enhance users' agency in the mapping process [16]. AI-driven sound interventions can potentially be applied in various health scenarios and further support the development of technology for person-centered care and evidence-based treatment [1].

In chronic pain care, most current complementary therapies require trained clinicians for administration [18], increasing their overall cost and making them more difficult to administer digitally. Music and sound, on the other hand, if properly guided by AI and paired with effortless emotion-recognition models, can directly communicate and interact with a person's current emotional state. With *Sound of Care*, our goal is to address the real-time emotional and human aspects of chronic pain, particularly focusing on the psychological determinants of CPP.

Contemporary design practices in eHealth systems for chronic pain suggest how cultural and psychosocial factors should be tackled using a participatory action-research model [7]. In this preliminary exploratory study, we began by conducting a critical evaluation of the project through the lens of an ethical stakeholder analysis. Incorporating stakeholder-centered design approaches is crucial, particularly when working with individuals living with chronic conditions such as CPP, as it requires careful consideration of ethical implications, especially when introducing AI-related features [4]. We then directly engaged with our primary stakeholders through semi-structured interviews to address the research question: How sound and technology are currently used and experienced in CPP care and daily life? Additionally, we examined existing barriers to technology adoption to gain insights on how to make self-management interventions more accessible, inclusive, and seamlessly integrated into daily life scenarios. Our main actionable objective was to assemble the necessary tools that would serve as the foundation for our initial Participatory Design workshop towards *Sound of Care*.

2 METHODS

2.1 Ethical Stakeholder Analysis

Given our increased focus on the human factors of CPP and our intention to incorporate AI in our system, we chose to conduct the stakeholder analysis of the project using the newly developed EASE framework [9]. EASE helps the designer initially identify all project stakeholders, with particular attention to those who may be inadvertently or marginally damaged by it, thus identifying the most ethically pressing issues. Subsequently, the identified stakeholders

are placed in relation to their current level of *Power* and *Interest* in the project using a Cartesian grid, aiding in the identification of potential methodological gaps.

People with CPP are at the core of *Sound of Care* as its major stakeholders. Institutions such as the NHS and Pain Charities possess significant *Power* over the project, although their *Interest* may not be equally high. Audio-related professions, such as sound designers, and companies developing relevant technologies, like Pain Apps, may demonstrate reasonable *Interest* in the project without exerting notable *Power*. The analysis further revealed that carers, healthcare workers, and families, despite having one of the highest *Interest* in the project, were essentially excluded and held little to no *Power*. To immediately address this issue, we decided to expand our participatory design framework and involve them directly from the project's initial phase. Additionally, the analysis identified a gap in our project's accessibility for people with hearing disabilities. While we acknowledge the importance of inclusive accessibility and the presence of hearing impairments within our communities, we also recognize the limitations of our design process. Therefore, while acknowledging and addressing this gap in our current and future work, we have chosen to limit the population within the scope of the project.

2.2 Exploratory Interviews

To answer our initial research question, we decided to progress our work by conducting a series of interviews with the three highest *Interest* stakeholders of the project: people living with CPP (PP), healthcare workers (HP), and carers (CP). We recruited participants through charities, medical practices and other relevant channels. To date, we have conducted interviews with a total of 8 participants (6 PP, 1 HP, 1CP). The interviews followed a semi-structured protocol that focused on the technology usability items emerged from the extension of the UTAUT2 framework [28] to eHealth [15].

Participants were aged between 25 and 65 year-old, with the majority (5 out of 8) being under 35 and came from a diverse ethnic and social background. PP reported experiencing different forms of CPP, including chronic migraines, chronic widespread pain, and non-specific low-back pain. HP specialised in physiotherapy while CP was a family member. An outline of the topics and themes used during the interviews can be found at https://github.com/TKyubi/SoC-CSCW23.

The main objective of the interviews was to gain insights into the current use habits (if any) of music and technology in CPP therapy and everyday life, as well as to identify usability barriers alongside accessibility and inclusion issues. The results were analysed using thematic analysis [12].

3 RESULTS

3.1 Daily impairment, distraction and personal experience

During the interviews participants confirmed the known predominance of psychosocial factors in CPP [27]. Pain negatively affects PP activities of daily living, social gatherings and sleep. All participants acknowledged also the crucial roles of mood, motivation, and sleeping patterns in maintaining a delicate balance that not only impacts daily functioning but might play a role in moderating pain itself. *"If you've got good mental health you can kind of cope with anything, any situation, but as soon as the mental health starts to slip suddenly the physical pain just becomes overwhelming" (PP)*

The majority of PP reported using technology and music as a distraction. Distraction serves as a valuable tool to ease the mind off the pain and take a break from the ongoing struggle *"I'll also listen to music so I can be able to focus with what I'm doing and not focus [on] the things that I am feeling" (PP)*. The use of distraction aligns with current strategies in Cognitive Behavioural Therapy for pain self-management [25], however for our interviewees technology plays a

major, but mostly unstructured role in this process. Mobile phones are usually the favoured device, mainly used to play audio-video content that aids the distraction process. *"The mobiles give a relief from pain, she tried to forget the pain [...] she try to busy herself and I will try to make her busy" (CP)*

Music and sound have also been reported as a companion in the daily lives of people with CPP, providing benefits such as mood enhancement, activity support, relaxation, and improved sleep. While music consistently assists our interviewees in various ways, pain is perceived as a highly individual and unique phenomenon, and personalised strategies and solutions are sought to alleviate it. *"We shouldn't judge every person similarly, and the pain similarly as well, chronic pain as well as everyone pain is totally different" (PP)*

3.2 Music: preference, mood and guidance

The theme of preferred music consistently emerged throughout our interviews, indicating that people with CPP often choose music based on their personal taste and preferences rather than relying on genres or sounds that are conventionally considered relaxing. *"The music choices I use may sound controversial generally but it's something that I enjoy not necessarily something that has been proven to calm your nerves" (PP)*

These choices are often directly connected to the individual's current mood, demonstrating their ability to make the selection process nuanced and choose specific tracks or artists to achieve their desired outcome. *"Listening to angry music, listening to happy music depending on your mood makes a huge difference. Listening to some sort of classical music and having a little cry, or listening to some Paramore thinking how the world screw you over, it's all great, it's always a good mood enhancer" (PP)*

Music and sound can also serve as a mediator by facilitating communication during therapy sessions, acting as a bridge between the treatment process and the individual. *"When I'm treating someone [...] I often make the sound [with my voice] so that they recognise what I am feeling in a sense" (HP).* The affordances of music extend beyond its hedonic or psychological effects, as it actively communicates with the body and its physical state. This anecdotal use of sound in connection with therapy practices may hold significance in that regard.

3.3 Understanding and explaining the pain

Explaining the pain is a key struggle experienced by participants across the board. Not being able to communicate one's own pain to the people around you and the parallel difficulty to understand the same pain yourself, might end up generating feelings of loneliness and frustration.

Communication within the family can be especially challenging, as individuals living with pain often struggle to effectively express their current emotional and physical state. Moreover, family members may find it difficult to fully comprehend and empathize with these feelings, as pain is often invisible and not easily observable. *"When she got pain like she can't explain and we can't understand because you can't see the pain" (CP)*

This difficulty to comprehend and communicate pain can also impact the person experiencing it, making it challenging for them to confront or navigate their own feelings at times or to understand the therapies administered by clinicians. *"[I have to] help them realise that I am actually feeling something, otherwise they're not seeing a screen, they can't see their muscles, they can't say what's going on" (HP)*

3.4 Economical accessibility

When considering accessibility issues in eHealth, we are often pointed towards eLiteracy and its ability to empower a person to take a more active role in their own pain management strategy using digital tools [3]. While this aspect did

emerge as a concern among some of our participants, we cannot oversee the more significant issue of limited financial resources. Not being able or willing to invest money should not hinder accessibility to treatment, but it remains a concrete worry, particularly for those currently living with CPP who may already face financial challenges. Therefore, it is pivotal to consider the cost factor as a major constraint of the design process, aiming to ensure the highest level of accessibility for the vast majority of the chronic pain population. *"I'm very open for using technology [but] I think it's also being aware of how much money the government can put into making practical and functional solutions at an affordable rate" (PP)*

4 DISCUSSION

4.1 Ubiquitous and on-demand therapy: taking ownership of the pain

While PP and CP generally held a positive attitude towards technology adoption, HP seemed to be more skeptical of its possible benefits. This difference in perception is accompanied by long and sometimes inconclusive journeys within the healthcare system. *"You go [to the] pain therapist and okay, [they say] manage, who suffer with pain, they're already managing, what they're gonna manage more? That's my question" (PP).* Despite the most recent NICE guidelines discourage the use of pharmaceutical therapies other than antidepressants [18], all PP reported a long history of using various medications and painkillers, often with little to no results and sensible side effects. The experience of CPP is also very personal, with individuals often facing a multitude of overlapping issues.

The power imbalances observed in the doctor-patient relationship [5] can have significant implications in this context, particularly regarding the ability of people with CPP to gain agency over their own therapy and diagnosis. Technology, and AI in particular, has the potential to shift this paradigm by creating a shared decision-making space. However, we should be mindful of the ethical risks involved, as AI can instead exacerbate existing disparities [13]. Our participants expressed a desire for an easily accessible and on-demand tool that is available in real-time, fits their unique pain experience, and serves as a meaningful support mechanism — a *Digital Pain Companion* (DPC).

4.2 Tailored AI-driven sound generation

Music and sound are known to carry emotional meaning, and have been shown to influence mood, emotional states, and even pain to some extent [1]. Active distraction have yielded significant results in reducing pain unpleasantness and intensity [29]. While music displayed the potential to be a powerful aid to current care practice in chronic pain, its direct effects might be limited and often very subject-dependent [26]. In order to improve them, it is crucial to incorporate successful complementary strategies into sound generation and view it as part of a comprehensive system rather than a standalone tool. In *Sound of Care* we aim to utilise sound in a 3-way strategy: use the influence of music on mood and emotion to target our mind and body (passive strategy), apply established self-management strategies, like distraction, and directly involve the person in the care process (active strategy), and finally utilise sound as an empowering tool to improve ownership of one's own pain and therapy (agency strategy).

The role of AI is to drive the generation process and build a truly person-centred care system. In its companionship role, technology acts as a facilitator to the care process, providing the person with a set of tools to navigate their daily experience, adapting to the everyday needs of a person living with CPP.

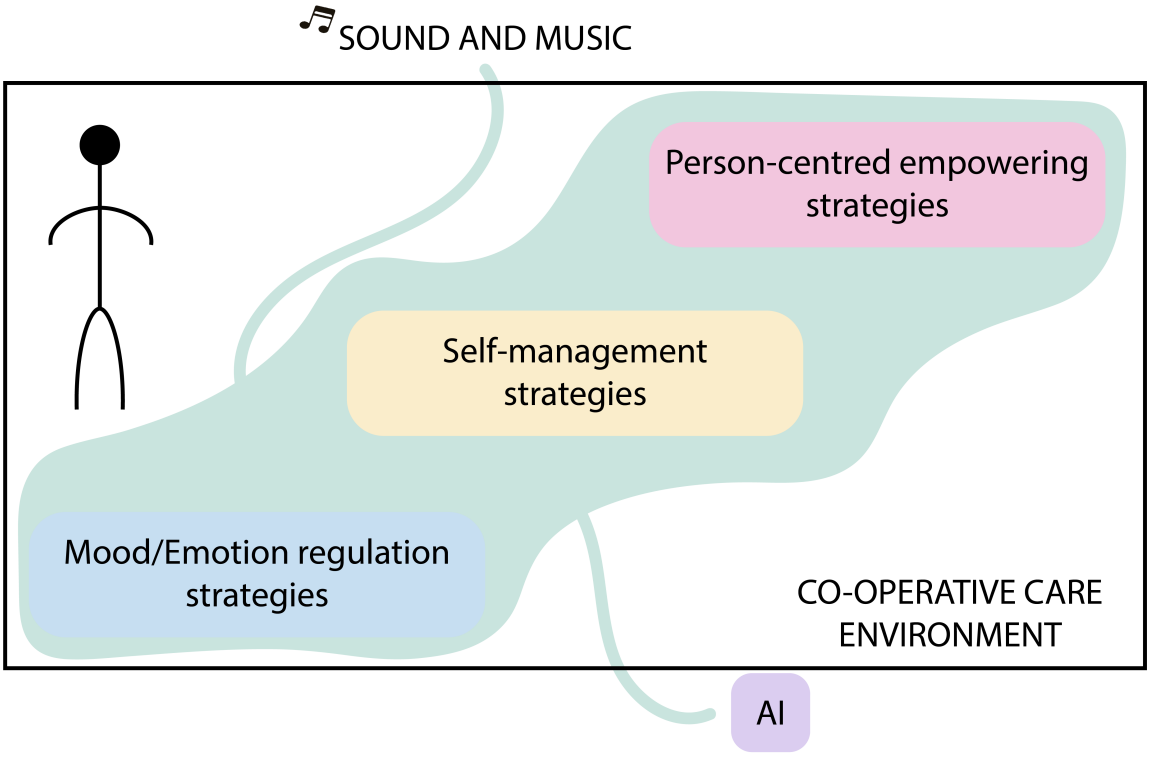

Fig. 1. Outline of the three-way therapy strategy, showing the dialogue between the key elements of *Sound of Care* in the co-operative care environment

4.3 Sonification: sound as a medium for a co-operative AI

Communication is a key need, not only for people living with CPP to express their current feelings to those around them, but also to access therapy and make their own decisions in the care process. The definition of sonification involves communicating information [11], and sound can serve as a bridge not only between the various actors in the care process, but also as a new communication channel that connects us with our bodies through biosignals — the electrical activity coming from our bodies — and with the therapy process itself. When using *Sound of Care*, biosignal data will be used to generate personalised music and sound, employing the 3-way strategy model outlined in 4.2. Sound can establish a dialogue among all the actors in the care process, creating a shared decision-making space in which they can facilitate and help each other, increasing the agency of the individual by directly translating their biosignals into music in a co-creation space which allows their experience to be literally heard.

The design process itself can be also viewed as part of a larger empowerment process involving our key stakeholders. Participatory Design as long been recognised as an empowerment and democratisation tool [2]. Therefore, we will adopt it as a methodology to allow our more vulnerable stakeholders to design new technological approaches to treatment. By incorporating participatory design practice in *Sound of Care*, we aim to enhance the democratisation of eHealth strategies for CPP and address the power imbalances in the healthcare sector, mitigating the influence of some of the

higher *Power* stakeholders, such as the NHS, healthcare providers, and universities, identified in our initial stakeholder analysis (see 2.1).

4.4 Person-centred and accessible technology, towards a Digital Pain Companion

The need of a co-operative technology, that fosters a shared decision-making space for treatment and care, and enhances the individual's sense of ownership over their body and condition, calls for rethinking our approach to technology, particularly in the healthcare environment. We don't need to use technology to educate people on what is helpful for them, but we need to educate machines to learn what is helpful from the people.

The concept of a DPC, which actively supports individuals living with CPP by listening and responding to their everyday needs and emotions, aims to establish a horizontal relationship between the person and the technology. This relationship is characterized as a dialogue between trusted peers, rather than a vertical hierarchical system where either the machine controls the human or vice versa. AI is not only expected to adapt in real-time to the individual's needs but also to create a dynamic environment that safeguards the ongoing dialogue among the elements of care, therapy, and personal experience. In order to achieve this, the generated sounds should not only be able to transfer information and retain aesthetic values but also adapt to the listener's preferences and current emotional state.

To connect the individual's emotional experience to their DPC, biosignal emotion recognition can be applied as an effortless and dynamic approach to affective computing. Multimodal biosignal models have already achieved high accuracy scores [32], and similar integrated approaches have previously been explored in generating emotionally congruent music [31] and developing music classification systems [10]. Our challenge lies in utilizing deep learning to perform both the analysis and generation tasks, while incorporating relevant self-management aspects into the sonification process. By properly supporting the transition to a semi-automated technology with open-access and explainable AI practices, we can further reduce the need for complex user interfaces and difficult-to-operate devices, significantly reducing the eLiteracy and economical resources needed to access it.

5 CONCLUSIONS AND FUTURE WORK

Our interviews shown how people with CPP use sound and technology in an unstructured way to support their daily lives, employing them as distractors and to positively influence their daily mood and sleep. There is a strong tendency towards preferred music, with choices being often personal and unique. The difficulty of explaining and understanding pain emerges as a significant issue throughout the entire care process, often resulting in feelings of isolation and frustration. While many interviewees expressed confidence in their ability to navigate new technologies, eLiteracy can still pose challenges, particularly among older generations. Additionally, the economic aspect of any given system should be carefully considered to ensure accessibility for a wider population.

In order to close the gaps in current self-management solutions for chronic pain and create an easily accessible, on-demand tool, we need to move away from a mechanistic view of pain and enable people living with CPP to take ownership of their pain. With *Sound of Care* individuals will engage with a three-dimensional sound space, that includes the passive effects induced by sound listening, the active effects related to sound generation, and the agency provided through the information conveyed in the sonification process, creating a person-centred empowering system and increasing ownership over their pain and treatment. AI plays a central role in this process, guided by established self-management strategies, employing biosignal emotion recognition, generative music, and sonification, to create a dialogue among all elements of care within a co-operative environment. This transition moves our system from a

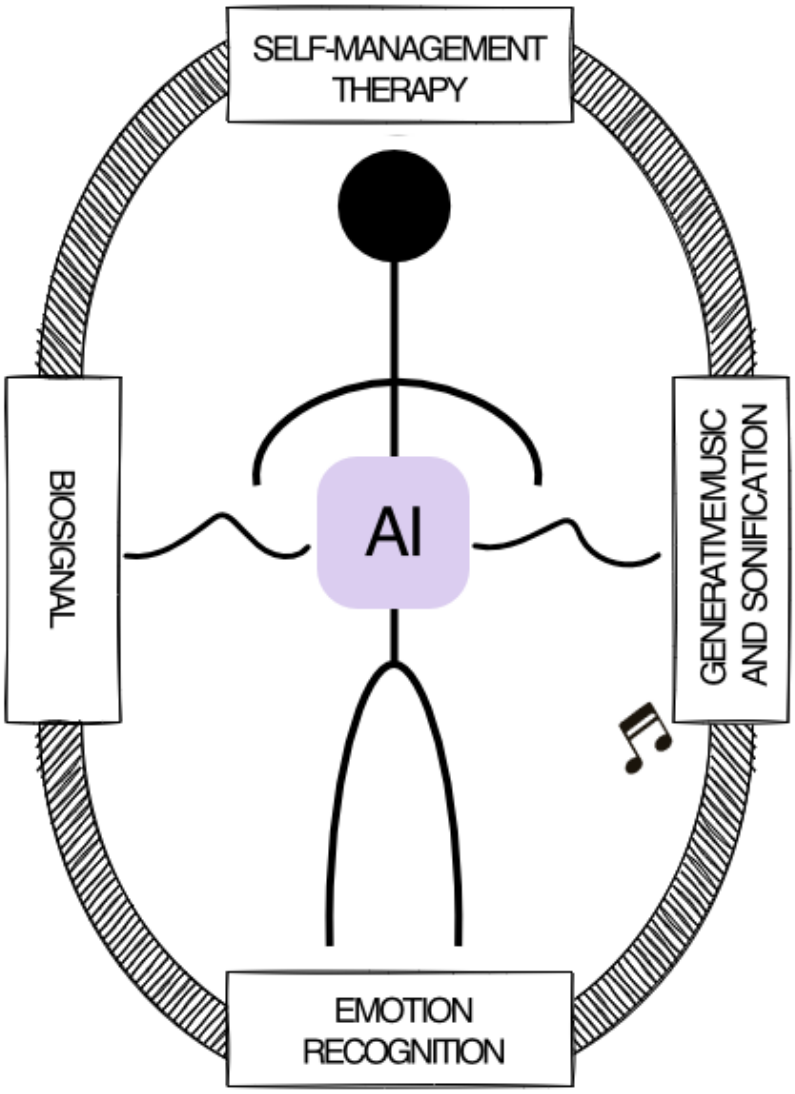

Fig. 2. Outline of the basic connections between the elements of *Sound of Care*

vertical perspective, in which technology controls or is controlled by humans, to a horizontal perspective where the system functions as a DPC.

Our findings contribute to the ongoing discussion on the use of technology in chronic pain care and the broader healthcare sector, emphasising the need for a fast transition towards a person-centred approach. Additionally, we are contributing to the growing literature on sound and sonification in pain management, further showing the practical potential of AI to solve some of the key current issues in CPP self-management care, particularly if efficiently integrated with sound and complementary therapy strategies. Finally, we propose a novel approach to experiencing and conceptualising AI and technology applications in healthcare through the DPC.

We are currently working on expanding the sample size of our interviews, particularly among healthcare workers and carers, to further validate our current findings. We anticipate that this will primarily strengthen our results and provide further nuances to our analysis. The key themes that have emerged from the interviews and are highlighted in this paper will serve as the foundation for our first participatory design workshop, a 2-hour session with 4 to 5 participants recruited from the interviewee of this work. Following the design process outlined in [14], we will focus on exploring "What is possible?" with our participants. We aim to delineate daily experiences and future visions to narrow our targets for the following prototype-oriented design workshop, as well as informing the first steps of the sonification strategy. To improve our recruiting ability we are also currently in the process of obtaining ethical approval from the NHS to collaborate with the University College of Osteopathy clinic in London.

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