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

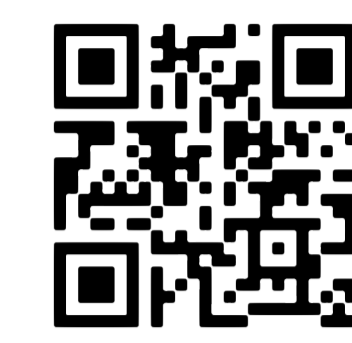Bleiz Macsen Del Sette*, Dawn Carnes†, and Charalampos Saitis*

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*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.*

Key References

Audio Version

❓ Research questions

How sound and technology are currently used and experienced in CPP care and daily life?

🎯 Our actionable objective

Assemble the necessary tools that would serve as the foundation for our initial Participatory Design workshop towards *Sound of Care*

Current chronic pain care aims at enabling people to **live their lives despite pain**, positioning the person as an active problem solver in the intervention model

Our goal is to address the real-time **emotional and human aspects of chronic pain** and its psychological determinants

Sound of Care is a new Digital Health system for **pain self-management**

Methodology box

Additional Materials

Ethical Stakeholder Analysis

We conducted a stakeholder analysis using the **EASE Framework** (see references)

Institutions like the **NHS** possess significant *Power* over the project, but low *Interest*. **Carers, healthcare workers,** and **families**, despite having one of the highest *Interest*, held little to no *Power*. There is a gap in our project's accessibility for people with **hearing disabilities**.

Exploratory Interviews

We conducted interviews with the three highest Interest stakeholders of the project: **people living with chronic primary pain, healthcare workers,** and **carers.**

8 Participants
mixed age, ethnic and social backgrounds

The interviews followed a semi-structured protocol that focused on the technology usability items emerged from the extension of the **UTAUT2** framework

RESULTS

Daily impairment, distraction and personal experience

"We shouldn't judge every person similarly, and the pain similarly as well, chronic pain as well as everyone pain is totally different" (Pain Participant)

Technology mostly serves as a distraction, often through an unstructured use of mobile phones. Music and sound are a daily life companion, helping with mood and activity support, relaxation, and improved sleep. Pain is perceived as very individual, and people look for personalised strategies and solutions.

Music is often chosen based on personal taste and preferences rather than relying on genres or sounds that are conventionally considered relaxing. Music and sound can also serve as a mediator by facilitating communication during therapy sessions.

Music: preference, mood, and guidance

"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" (Pain Participant)

Understanding and explaining the pain

"When she got pain like she can't explain and we can't understand because you can't see the pain" (Carer Participant)

Not being able to communicate one's own pain and the parallel difficulty of carers and professionals to understand it, might end up generating feelings of loneliness and frustration.

When considering accessibility issues in eHealth we are often pointed towards eLiteracy and its empowerment ability. Not being able or willing to invest money should not impair accessibility to treatment, but it remains a concrete worry, particularly for those who may already face financial challenges.

Economical accessibility

"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" (Pain Participant)

DISCUSSION

Sonification as a medium for a co-operative AI

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, by directly translating their body into music.
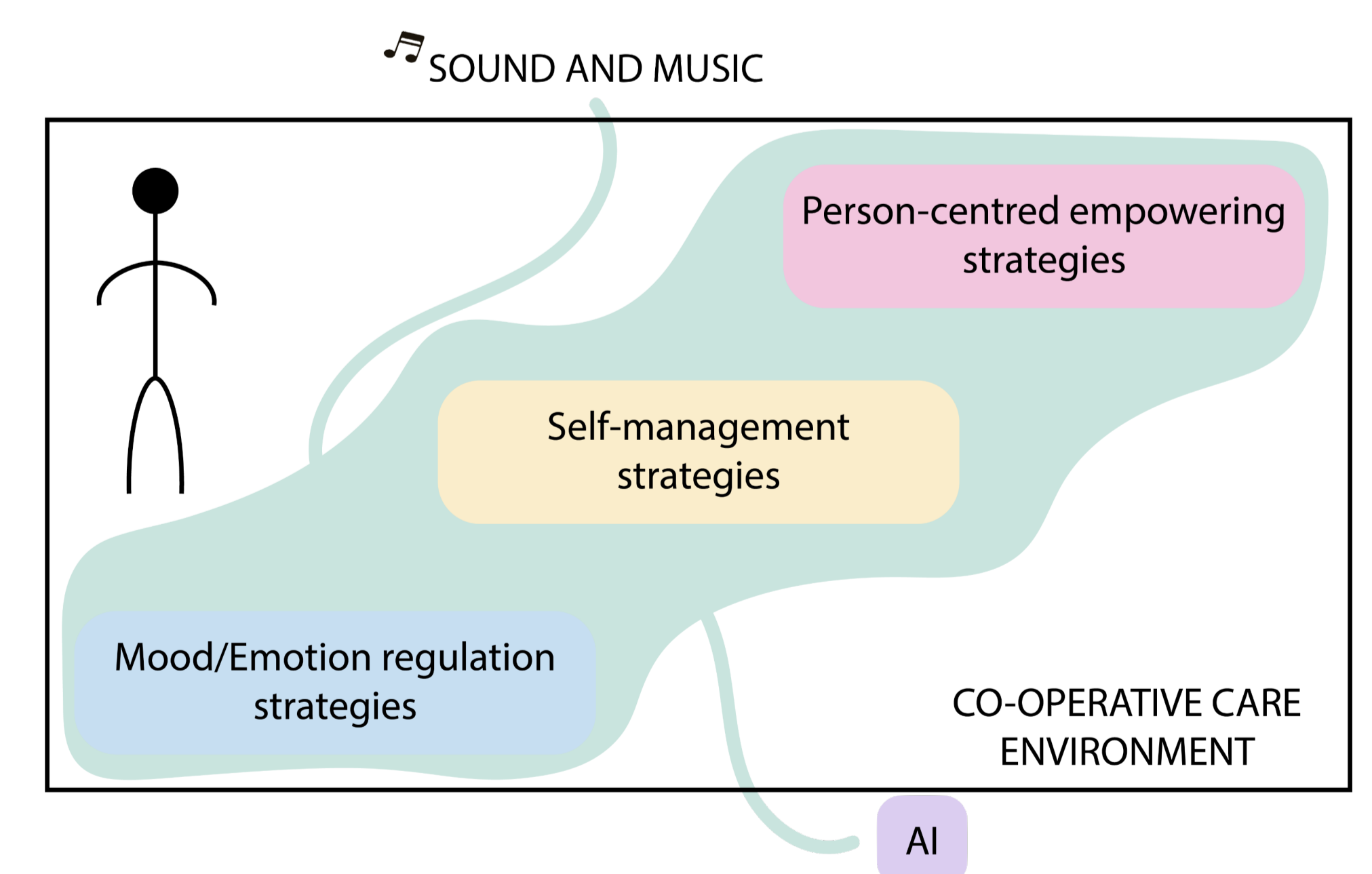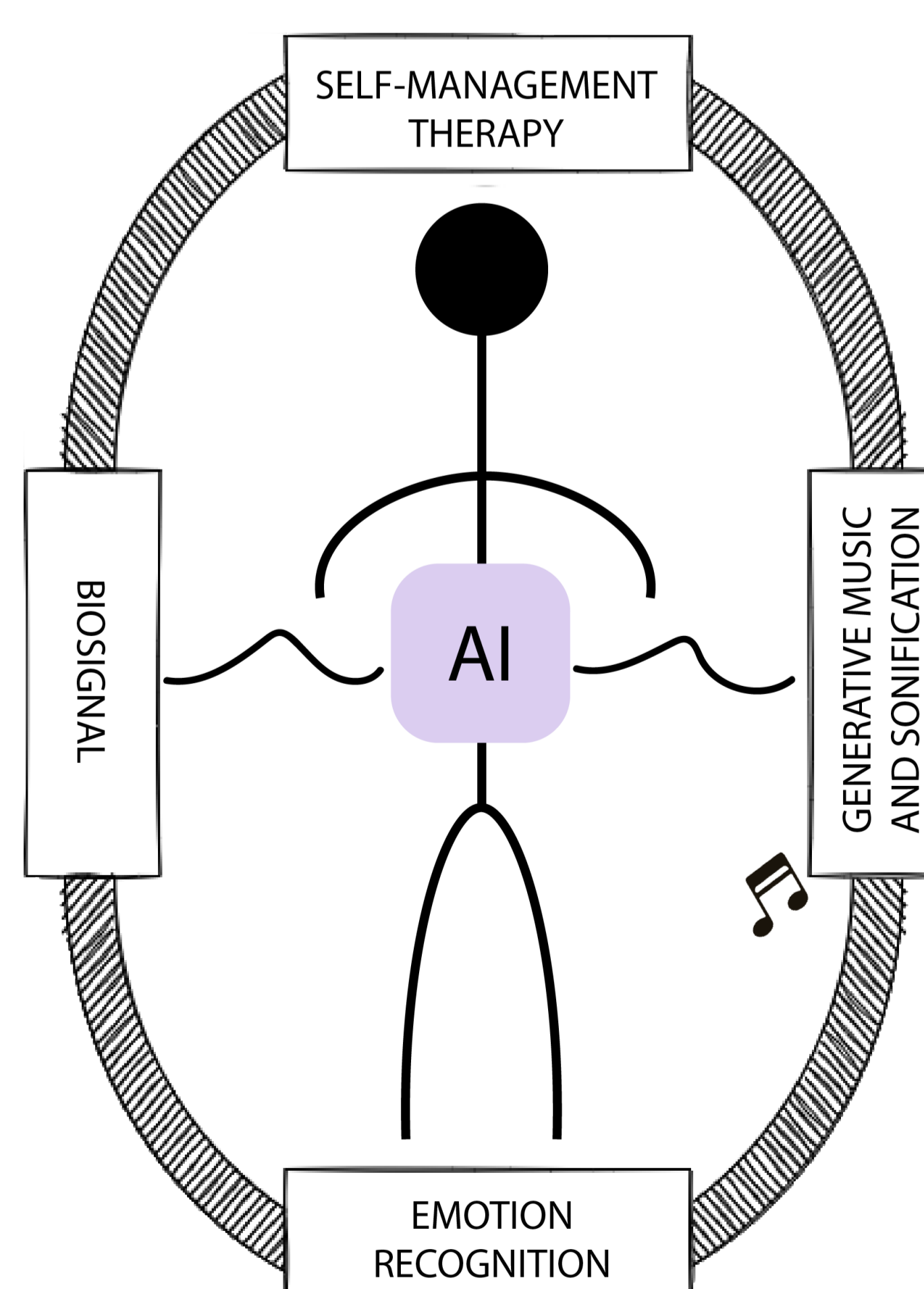
Person-centred and accessible technology

We aim to establish a **horizontal relationship** between the person and the technology, a dialogue between trusted peers rather than a vertical hierarchical system where either the machine controls the human or vice-versa.

Taking ownership of the pain

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**.

SELF-MANAGEMENT THERAPY

BIOSIGNAL

AI

GENERATIVE MUSIC AND SONIFICATION

EMOTION RECOGNITION

🎵 SOUND AND MUSIC

Person-centred empowering strategies

Self-management strategies

Mood/Emotion regulation strategies

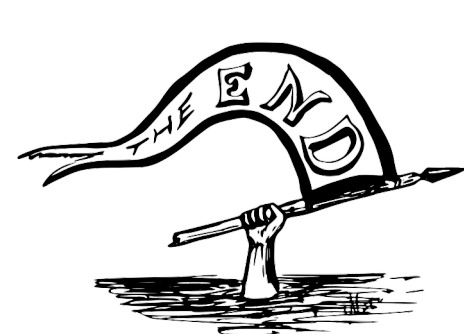CO-OPERATIVE CARE ENVIRONMENT

AI

Tailored AI-driven sound generation

Technology acts as a facilitator to the care process, providing the person with a set of tools to navigate their daily experience, adapting to their everyday needs

Conclusions box

With *Sound of Care* individuals will engage with a three-dimensional sound space. AI plays a central role in this process to create a dialogue among all elements of care within a **co-operative environment**

⚠ ownership of the pain
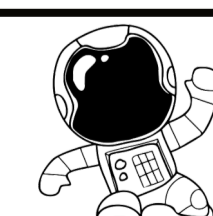
Future work

We will focus on exploring **"What is possible?"** using Participatory Design. We aim to delineate daily experiences and future visions, and inform the first steps of the sonification strategy.

In this work, we proposed a novel approach to experiencing and conceptualising AI and technology applications in healthcare through the **Digital Pain Companion**, contributing to the ongoing discussion on the use of technology and sound in chronic pain care and the broader healthcare sector.