

Language of Pain

Merging multiple voices for improved chronic pain management

The experience of living with, and delivering care for chronic pain requires a management strategy that responds effectively within a complex context.

Consequently, management strategies should be interdisciplinary and take into account the many stakeholders involved, including the person experiencing chronic pain.

Language of Pain is a collaborative research project between the Digital Health and Care Institute (DHI), Glasgow School of Art and the Norwegian University of Science and Technology.

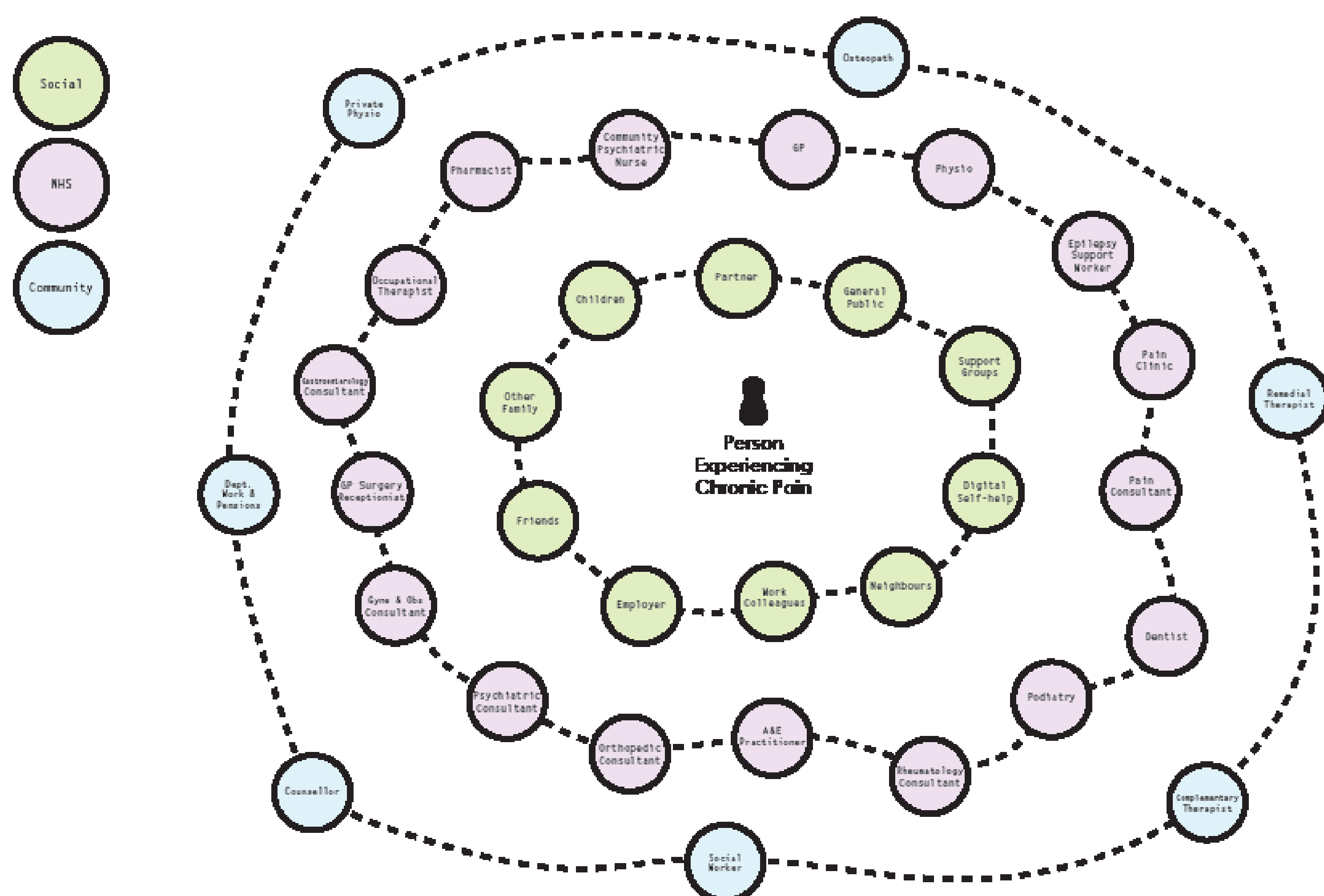
Using design as a methodological approach, the project aims to co-design new ways of promoting open dialogue and shared learning between people experiencing chronic pain and health professionals providing care.

Key Questions

Explore communities of practices within chronic pain management

Explore efficient management strategies for chronic pain

Communities of Practice for Chronic Pain: Patient Perspective



Key Findings

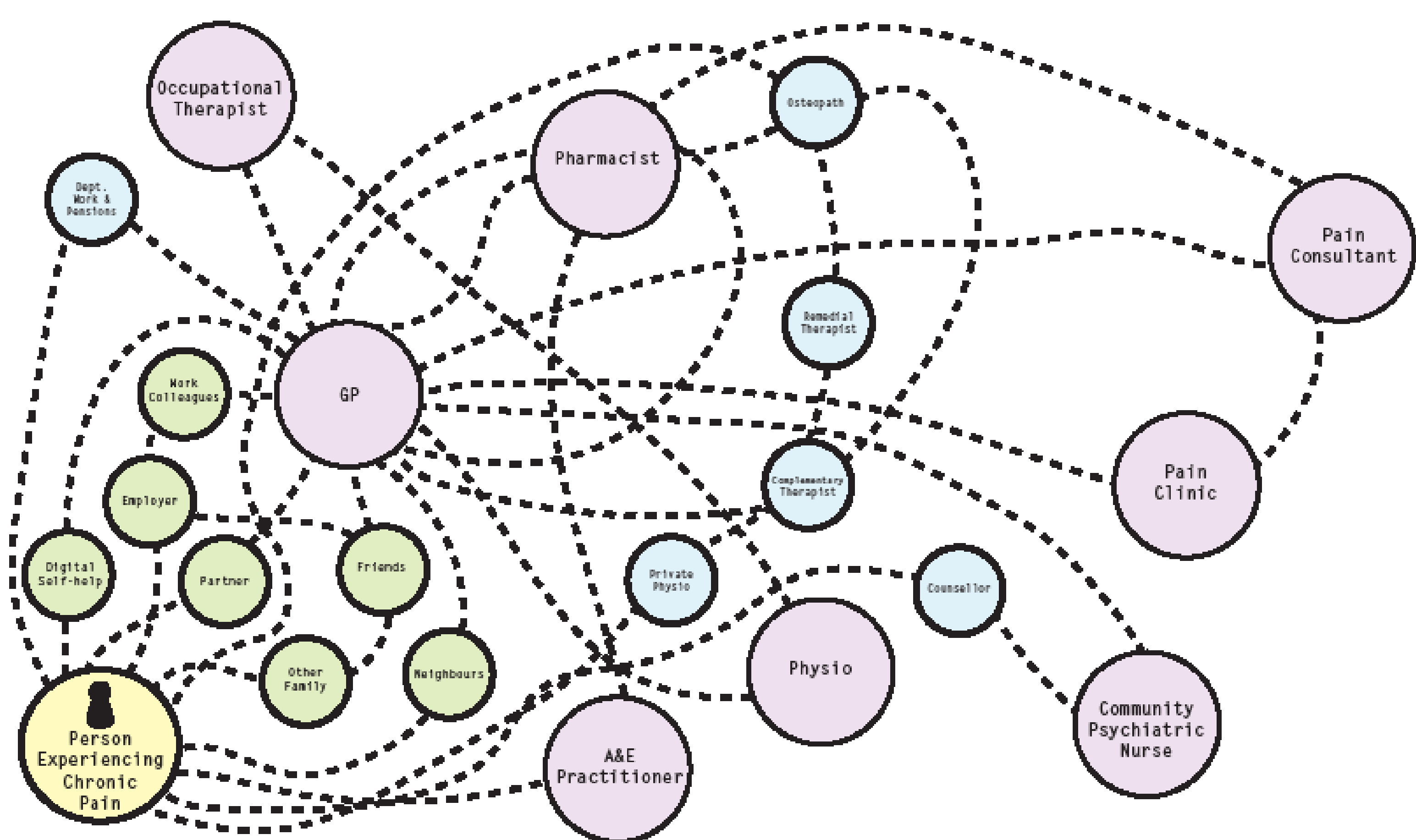
This research highlights the disparate and often contradictory voices emerging across the landscape of chronic pain management. Care pathways appear unclear to both health professionals and patients, resulting in fragmented delivery, decreased health literacy and unmet expectations. In visualising this area of complexity, the study recognises a number of core factors are involved:

- the acknowledgement of patient needs towards supporting a self-management approach;
- efficient interaction between the network of health professionals involved;
- the limitation of time and the subsequent impact on communication;
- alignment with notions of best practice across service delivery.

Findings suggest **standardisation of care** and **interdisciplinary team approach** as preferable strategies for managing chronic pain. However, existing pathways are not easily adopted in practice and there are gaps in how to visualise experience to support the identification of patterns and enable learning opportunities.

Further to this, a gap was identified in the ability of patients to play a **meaningful role** in understanding the complexity of the care pathways and contributing to self-management for chronic pain.

Visualising Complexity in Patient Experience: An Example



Conclusion

This study suggests that chronic pain management is an area of significant complexity for both patients and health professionals. The inability to visualise this complexity contributes to inconsistent and ambiguous communication; inconsistent clinical pathway implementation and fragmented application of strategies. As a consequence, patients remain dependant on health professionals to manage their conditions.

This research proposes that in order to shift towards the delivery of preferable service provision, for example models of interdependency and self-management, it is essential to visualise the complexity experienced. This could support patients and health professionals to map changes, compare pathways and promote learning opportunities through the aggregation of experience as health data. It is anticipated that this could then support all stakeholders to navigate a meaningful person-centred self-management approach to chronic pain.

Glasgow School of Art / Digital Health & Care Institute
Norwegian University of Science and Technology

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- Methodology:**
- 3 Research Sites
 - 7 Semi-structured Interviews
 - 5 Focus Groups
 - Journey Mapping
 - Visual Storytelling

- Participants:**
- 13 people living with chronic pain
 - 2 general practitioners
 - 1 out of hours GP
 - 1 pain consultant
 - 1 pharmacist
 - 1 remedial therapist
 - 1 chronic pain policy lead

2017/18

Location:
- NHS Grampian



12+ Hours of focus groups
14+ Hours of interviews

- Research Team:**
- Dr Leigh-Anne Hepburn
 - Dr Ellen A. A. Jaatun