

ESTABLISHING A LARGE PUBLIC INVOLVEMENT NETWORK FOR A CHRONIC PAIN RESEARCH CONSORTIUM

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Background and aims

- The Consortium to Research Individual, Interpersonal and Social Influences in Pain (CRIISP) is a United Kingdom (UK) collaboration of eight universities investigating how thoughts, feelings and social factors, can affect chronic pain (see QR code).
- This work sits within the UK Research and Innovation and Versus Arthritis funded Advanced Pain Discovery Platform (APDP). Five work packages (WPs) within CRIISP investigate a single set of topics to identify which psychosocial factors influence the development, maintenance and outcome of chronic pain (Fig.1). A sixth overarching WP oversees integration and translation of the CRIISP research within CRIISP and more widely.
- In addition, a public involvement work package (PI WP), co-led by people with lived experience, ensures the views of people with experience of chronic pain are fully integrated throughout the CRIISP research (Fig.1).
- The PI WP has established a network of public contributors to work in equal partnership with researchers across all workstreams.

Methods

- Adults with chronic pain, or caring for someone with chronic pain, were invited to apply for public contributor roles via a targeted UK advertising campaign which commenced in March 2022.
- An inclusive and wide-reaching recruitment strategy promoted diversity including gender, age, ethnicity, and a passion for public involvement work.
- Interested individuals were directed to a bespoke website with a 'Find Out More' video and role description.
- Public contributors were informed they would be paid for meeting attendance and pre and post meeting activities, except where involvement on a voluntary basis is requested by the public contributor.

Result

- Applications were reviewed by members of the PI WP and screened to ensure public contributors were from a range of backgrounds and experience. Allocation to WPs was based on interests and experience.
- All public contributors received general training about CRIISP plus WP induction training sessions delivered as a video or 'live' via MS Teams.

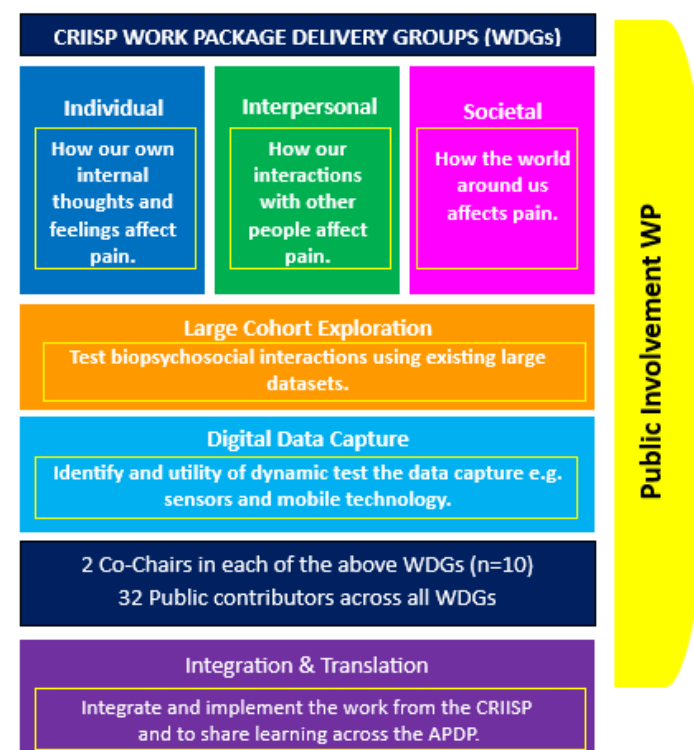


Fig 1: CRIISP work packages

- Two people from each of the five core WPs took on the additional role of co-Chair with Chairing skills training provided. The ten co-Chairs comprise the membership of the overarching Integration & Translation WP.
- Recruitment continues when required due to the natural attrition of public contributors, expected in a long-term project.
- Governance documentation was produced by the PI WP and included: data management plans, PI guidelines for researchers, and guidance for public contributor wellbeing and safe practice. The perspectives, leadership and contribution of the public contributors were integral to all processes.

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Conclusion

The PI network has successfully worked in collaboration and equal partnership with the CRIISP research teams during Year 1 of the project, to ensure the voices of people with chronic pain are heard in all aspects of CRIISP.

As we progress into Year 2, public contributors are extending their involvement activities to include contributing to online blogs, contributing to the preparation of manuscripts, and presenting and Chairing at national and international conferences.

Working in partnership with people with lived experience of pain, will fully embed their contribution across all workstreams, and help to ensure CRIISP outputs are relevant to people with chronic pain.

Relevance to Patient Care: The CRIISP consortium research, led by the work package teams, should have significant impact on improving the lives of those living with chronic pain. Involving members of the public has provided us with an opportunity to change how we think about pain and how we research it. The PI-specific learning will be shared via a wide-reaching dissemination strategy. The exemplary work of PI in this consortium will mark the importance of how research can be strengthened through involving people with lived experiences.



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