Public contributor and stakeholder research priority setting for cancer survivors with chronic cancer-related pain

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Background: Approximately 40% of cancer survivors experience chronic pain[1]. To better support people with chronic cancer-related pain (CCRP), a set of evidence-based clinical recommendations have been generated[2-4.] and summarised as PAINS (Figure 1). To help drive the focus of future research, the recommendations need to be prioritised.

Aim: To prioritise PAINS recommendations with public contributors and stakeholders

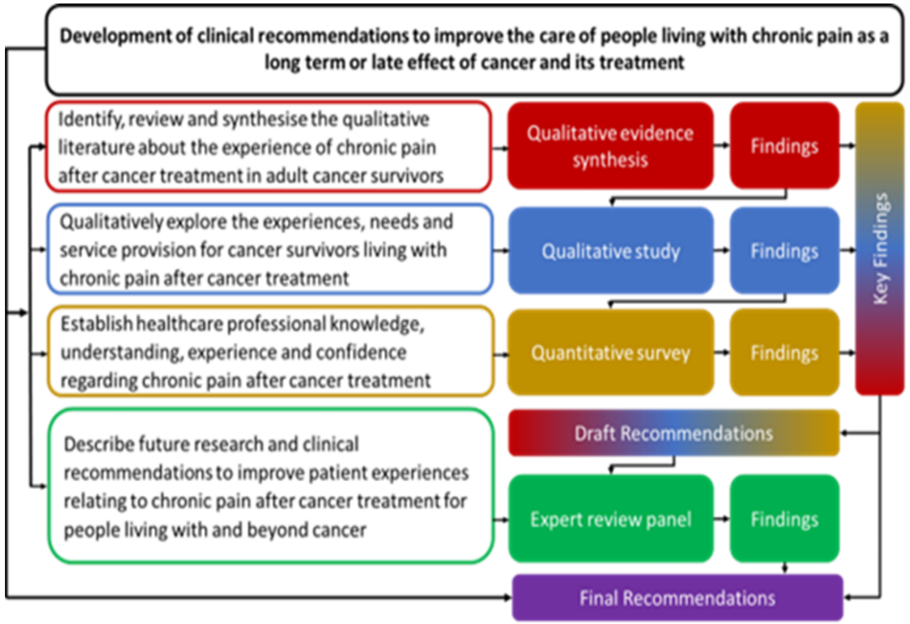
Method: Recommendations ranked by public contributors (people with living with CCRP) and stakeholders (healthcare professionals (HCP), educators, researchers) in order of priority in 'ideal' and 'real' world.

Phase 1: Online Nominal Group Technique (NGT) workshops with public contributors and stakeholders. Workshops included introduction, silent generation, clarification, ranking and round robin.

Phase 2: Ranking questions transferred to a Qualtrics survey. Survey distributed via professional networks such as UK Oncology Nursing Society and Pain Nurse Network.

Analysis: Data were analysed to 1) identify recommendation chosen most often as top priority, and 2) calculate weighted score for all five recommendations (with 'first' = 10, 'second' = 8. 'third' = 6, 'fourth = 4, 'fifth = 2).

Figure 1: Development of clinical recommendations



	Clinical recommendations	
P	Prepare and inform	Prepare and inform people living with and beyond cancer about the risks of chronic pain after cancer treatment
A	Assess, acknowledge and listen	Assess for pain and acknowledge and listen to experiences of living with chronic pain after cancer
I	Increase healthcare professional awareness	Increase healthcare professional knowledge about the risks, impact and management of chronic pain after cancer treatment
N	Name and diagnose	Name and diagnose chronic pain after cancer treatment to educate, inform and validate experiences
S	Services and supported self-management interventions	Services and supported self-management interventions are required to provide support and rehabilitation for people living with and beyond cancer who experience chronic pain

Results: 12 public contributors and 53 stakeholders participated, of which 28 (48%) were based in the community, 23 in hospitals (42%) and three in universities (10%). Six public contributors (50%) and most stakeholders (n=16, 30%) chose 'Increase HCP awareness' as top priority in an 'ideal' world. In a 'real world' six public contributors (50%) selected 'Assess, acknowledge and listen' as top priority (Figure 2) whereas only 11% (n=6) of stakeholders did (Figure 3). Stakeholders selected 'Prepare and inform' as top priority (n=17,32%) (Figure 3) but only two (17%) public contributors did (Figure 2).' Based on weighted scores, the top priority for public contributors was 'Assess, acknowledge and listen' in an 'ideal' and 'real' world and for stakeholders it was 'Increase HCP awareness' in an 'ideal' world and 'Prepare and inform' in a 'real' world.

Figure 2: Recommendations chosen as top priority for public contributors (n=12) in 'real' world

Ranked priorities	n	%
Assess, acknowledge and listen	6	50
Increase HCP awareness	4	33
Prepare and inform	2	17
Name and diagnose	0	0
Services and supported self-management	0	0

Conclusions: Priorities for research differ between stakeholders and public contributors.

Figure 3: Recommendations chosen as top priority for stakeholders (n =53) in 'real' world

Ranked priorities	n	%
Prepare and inform	17	32
Increase HCP awareness	14	26
Services and supported self-management	13	25
Assess, acknowledge and listen	6	11
Name and diagnose	3	6

References: [1] C. Jiang *et al.*, "Prevalence of Chronic Pain and High-Impact Chronic Pain in Cancer Survivors in the United States," *JAMA Oncol*, vol. 5, no. 8, 2019 [2] J. Armoogum *et al.,* "The experience of persistent pain in adult cancer survivors: A qualitative evidence synthesis," *Eur J Cancer Care (Engl)*, vol. 29, no. 1, 2020 [3] J. Armoogum *et al.*, "'I think it affects every aspect of my life, really': Cancer survivors' experience of living with chronic pain after curative cancer treatment in England, UK," *PLoS One*, vol. 18, no. 9, 2023 [4] J. Armoogum *et al.*, "Healthcare professionals' knowledge, understanding and confidence to manage chronic pain after cancer treatment: A UK survey," *European Journal of Oncology Nursing*, vol. 71, 2024