

PAINFUL TRANSITIONS

EXECUTIVE SUMMARY

Young people's experiences of living with persistent pain, their interactions with health services and their needs and preferences for pain management including digital technologies.



Figure 1. Word cloud generated from interviews with young people and reflecting common words used. Note: the larger the font size, the greater the frequency of the word.

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Executive summary

This report seeks to inform Arthritis and Osteoporosis Victoria, Arthritis and Osteoporosis Western Australia and other relevant agencies about the experiences of 16-24 year old Australians with persistent musculoskeletal pain, and their needs and preferred modes of delivery for pain management services with a focus on digital technologies.

This report represents a collaborative initiative between Arthritis and Osteoporosis Victoria and Arthritis and Osteoporosis Western Australia and the School of Physiotherapy and Exercise Science, Curtin University, Perth Western Australia. Other partner organisations included HealthSense (Aust) Pty Ltd and Wisdom Health.

About this report

We explored:

1. young people's experiences of living with persistent musculoskeletal pain
2. their perceptions about the associated challenges, service gaps, and their perceived needs and
3. their preferences for modes of service delivery, particularly as they related to the use of digital technologies.

What do we know about young people and persistent pain?

Living with persistent pain is challenging, potentially even more so during the transition from adolescence through adulthood when young people are juggling complex biological, psychological and social changes and attempting to make sense of their identity and place in the world. Persistent musculoskeletal pain imposes a significant health and economic burden on young people^{1,2}. Current Global Burden of Disease Study (GBD) data for musculoskeletal conditions in the developed world highlights this well, with years lived with disability for ages 10-14 years reported as 8.6% (UI: 7.2-10.3), and increasing to 20.3% (UI: 18.1-23.0) between the ages of 20 to 24 years (<http://www.healthdata.org/gbd/data-visualizations>; accessed 18 November, 2015). While Australian data suggest persistent pain rates for young people approach those of adults (i.e. one in five)^{1,3}, international data suggest higher rates for musculoskeletal pain⁴ (e.g. 37% for back pain), particularly in girls⁵.

The prevalence of mental health problems also peaks in this young age group, with up to 25% of adolescents experiencing some kind of mental health condition⁶. Higher prevalence rates of pain in cohorts with depression and depression in cohorts with persistent pain, are reported than when these conditions are individually examined⁷. Critically, an experience of mental health and pain conditions in adolescence, substantially increases the risk of an ongoing trajectory of depression, anxiety and pain in adulthood, significantly impacting on a young person's wellbeing and future productivity^{8,9}. Persistent pain and mental health conditions are intimately related, however health services for these conditions tend to manage them independently.

Key insights from this research

Young people eloquently described the complex, multidimensional, disruptive and nuanced nature of persistent pain associated with musculoskeletal conditions. Their narratives, set against the temporal backdrop of the transition from adolescence to their present and future self, expand our understanding of the constant tension between vulnerability and resilience of young people living with persistent pain, and for the majority, co-existing mental health conditions.

1. Young people experienced a significant impact of pain on every aspect of their young lives, particularly on their capacity to study, work, socialise and manage the financial burden of pain.
2. The intimate bidirectional relationship between pain and psychological wellbeing emerged as a dominant issue, with almost two thirds of young people experiencing co-morbid mental health conditions.
3. The repeated failure by health professionals to legitimise young people's pain, especially in the absence of a clear diagnosis for some (i.e. non-specific musculoskeletal pain conditions such as low back pain), highlighted the corrosive effect of uncertainty, further fuelling fears about their future.
4. Health services and resources oriented to the specific needs and preferences of young people were described as largely absent.
5. The opportunities provided by digital technologies to provide accessible, free, reliable resources were seen as a key lever for the active engagement of young people in developing shared solutions to improve their health and wellbeing.

Recommendations

We came to this study with our own experiences of young people with musculoskeletal pain. What we more clearly recognize now is that as Australians we must transform the way we think and what we do regarding our approach to young people living with persistent pain. Young people living the experience of persistent pain want and need developmentally-sensitive health services. Such services must resonate with them and ideally leverage the social currency of digital technologies to engage and connect them to appropriate evidence-based care, at both an individual and broader population levels. Young people want to be part of any solution to improved pain care.

We make five main recommendations based on our findings. These are presented as 'what' we recommend and 'how' this might be achieved. These recommendations are designed to address the key burden-service, and policy-practice gaps identified for young Australians living with persistent musculoskeletal pain. Pain care for young Australians needs re-orienting and the recommendations focus on the use of innovative digital technologies to enable e-health systems and drive critical transformation. The recommendations are relevant across sectors including non-governmental organisations, consumer organisations, policy makers, health service providers, professional associations and researchers. Non-governmental organisations such as Arthritis and Osteoporosis Victoria (A&OV) and Arthritis and Osteoporosis WA (A&OWA) could play leadership roles, in assisting the implementation of these recommendations in particular around advocacy, resource development, and partnership approaches to research, policy and education.

Key recommendations

RECOMMENDATION 1

Transform systems for delivery of pain care for young people in Australia

Cost effective delivery of pain care for young people in Australia urgently requires transforming with the development and implementation of e-health systems that provide readily accessible, flexible, efficient and developmentally sensitive evidence-based best practice care, regardless of where in Australia young people live. The development of e-health systems needs to avoid duplication, be sustainable and be developed within a nationally consistent framework.

How could this be achieved?

a. Engage young people in e-health system ‘user-centric’ redesign of pain care

Models of care need to be truly collaborative, working with young people to co-develop, implement, evaluate and iterate age-sensitive, appropriate e-health pain services. This approach aligns with emerging 2nd wave health care systems that co-design care with, rather than for, consumers and which include self-management as a key component of care. Access to reliable information (knowledge and skills) and resources can be enabled through the use of digital technologies (such as apps, sensors, blogs, e-interventions, peer support groups, social media) that ideally also interface with other e-health systems.

b. Utilise new and emerging technologies to capture data, streamline care and enable integrated systems of pain care

Development and implementation of e-health systems to enable high level systematised data capture (e.g. minimum data set (MDS)) and streamline the delivery of integrated interdisciplinary pain care, is required. Re-orientation of systems through the use of new and emerging digital technologies must provide health solutions that encourage young people to actively engage in using their own data to inform self- and co-care. Opportunities to co-develop such systems between public, private and partnership sectors should be explored with funding models that encourage active engagement of both consumers and health professionals.

c. Build research capacity to support innovative e-health pain care.

Building research capacity is essential in order to encourage the development, testing, implementation and evaluation of evidence-based interventions specifically for young people that are designed for use on e-health platforms. Seeking cross-sector partnerships models that connect consumers, researchers, policy makers, health service providers and funders, professional associations and non-governmental organisations (NGOs) could be very effective in driving innovation in this area.

RECOMMENDATION 2

Address pain literacy from a broad community perspective

Pain fails to be well understood by the broader community - consumers, health professionals, employers, and families and friends. Increasing pain literacy across all sectors is essential. Understanding the multidimensional nature of pain, the complexity, the nuance and the individuality of persistent pain is essential to informing truly 'user-centric' pain care.

How could this be achieved?

a. Utilise cross-sector buy-in.

Buy in from NGOs like A&OV and A&OWA, health professional bodies, universities, schools, industry and the broader community is required to help drive community-wide changes in understanding and beliefs about pain, moving away from the failed biomedical model to a contemporary understanding of pain from a biopsychosocial perspective.

b. Develop public health campaigns aimed at better informing the public about pain.

These campaigns could be coordinated through cross sector partnerships involving NGOs, advocacy groups, industry, universities and schools to ensure consistent, contemporary messages are delivered throughout the community. Such campaigns could use social media platforms as a cost effective, time efficient strategy with ability to upscale and reach the wider community.

c. Build capacity for the dissemination of information and skills for evidence based pain care.

The provision of accessible (24/7), sustainable resources related to preventing pain and managing pain should be available regardless of where in Australia young people live. Digital technologies (for example, mobile apps; body sensors) can be developed to underpin the delivery of e-health (including online interventions; telehealth) to fast track the use of evidence based best practice pain care in primary care.

RECOMMENDATION 3

Re-design musculoskeletal pain care to align with, and where possible seek synergies with, current innovations in e-mental health

Re-orientation of health services to provide integrated care for those with persistent musculoskeletal pain must consider the likely association of mental health and recognise the need to address both pain and mental health, in parallel.

How could this be achieved?

a. Integrate pain and co-morbid mental health care for the benefit of young Australians.

The recent commitment by the Australian Federal Government to invest in mental health reform provides a unique opportunity to better integrate mental health care with pain health care in new models of care. Pain and mental health conditions such as anxiety and depression are strongly associated, yet largely managed independently. To ensure integrated care for chronic health conditions that co-exist such as musculoskeletal pain and mental health conditions, synergies with existing mental health systems (and others) such as The 'Young and Well Cooperative Research Centre' (<http://www.youngandwellcrc.org.au/>) should be actively sought by health service providers, health policy makers, advocacy groups and NGOs such as A&OV and A&OWA.

b. Enhance the interoperability of e-health systems across care settings.

This would allow better cross sector communication and better enable more seamless exchange of information and the potential for integrated care that is tailored to the individual.

RECOMMENDATION 4

Build health workforce capacity

Upskilling of the emerging and current health workforce about pain is required in order to meet the current and predicted future burden of care for young Australians.

How could this be achieved?

a. Build workforce capacity by targeting both the emerging and current health workforces.

Health professionals need to be upskilled in 'knowing' (knowledge) about persistent musculoskeletal pain, as well as 'doing' (skills). This requires active engagement of the universities in developing their curricula to incorporate evidence-based knowledge and skills within an interdisciplinary framework.

b. Upskill the health workforce within the context of a biopsychosocial framework.

This framework needs to acknowledge that one size does not fit all. Upskilling strategies should emphasise that consumers' needs may be low, moderate or high and systems need to be flexible to deliver care at an appropriate level. Training must acknowledge that treatments may require a multimodal approach and be delivered within an interdisciplinary team.

c. Use innovative digital technologies as levers to drive upskilling.

Providing readily accessible (24/7), sustainable and cost effective, evidence-based resources for upskilling can bypass time and access barriers for clinicians and ensure that best practice care is available for use across care settings. Professional training organisations can work collaboratively to develop, implement, monitor and evaluate professional development in this area. A similar model was recently adopted to develop 6 online training modules about pain by the Australian and New Zealand College of Anaesthetists (Faculty of Pain Medicine) and the Royal Australia College of General Practitioners, with funding from BUPA. These training modules were developed within an interdisciplinary framework and are freely available. Further initiatives using this cross-sector model could be directed specifically towards developing training resources about musculoskeletal pain in young people.

RECOMMENDATION 5

Build research capacity to support innovative e-health pain care

Building research capacity is essential in order to encourage the development, implementation and evaluation of evidence-based interventions specifically for young people that are designed for use on e-health platforms.

How could this be achieved?

a. Seek cross-sector partnership models.

Connect consumers, researchers, policy makers, health service providers, professional associations, funders and not for profit organisations in partnership models to assist in building research capacity. Development, evaluation and iteration of innovative systems require cross-sector engagement and support and would streamline the implementation of innovative care within current health systems.

b. Support the further innovative development of digital technologies to support improved pain care.

Bioinformatics for data capture and monitoring could be used to test novel online interventions and align with electronic medical records to capture patient reported outcomes.

c. Enhance the interoperability of e-health systems across care settings to improve health system efficiencies and patient reported outcomes.

Build research partnerships between health services sectors, policy makers, NGOs and universities to drive changes in system operability across health sectors.



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