

# PAINFUL TRANSITIONS

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.

 **Arthritis**  
VICTORIA  
inc. OSTEOPOROSIS VICTORIA

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Osteoporosis**  
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*Prevent it. Manage it. Cure it.*

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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 <sup>1,2</sup>. 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)<sup>1,3</sup>, international data suggest higher rates for musculoskeletal pain <sup>4</sup> (e.g. 37% for back pain), particularly in girls <sup>5</sup>.

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 condition <sup>6</sup>. Higher prevalence rates of pain in cohorts with depression and depression in cohorts with persistent pain, are reported than when these conditions are individually examined <sup>7</sup>. 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 <sup>8,9</sup>. 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.



# Background

## The problem of persistent pain in young people

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. Against this critical temporal backdrop, persistent musculoskeletal pain imposes a significant health and economic burden on young people<sup>1,2</sup> and society, creating a major threat to future human capital. 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)<sup>1,3</sup>, international data suggest higher rates for musculoskeletal pain<sup>4</sup> (e.g. 37% for back pain), particularly in girls<sup>5</sup>. The observed inconsistency in prevalence data is likely due to a combination of differing case definitions, different prevalence time points and musculoskeletal conditions<sup>10</sup> as well as a lack of quality criteria<sup>4</sup>. Together with improved prevalence reporting, more targeted and comprehensive reporting of impact is critical.

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It is important to explore the experiences of young people with persistent pain during their transition to adulthood and identify the barriers and enablers to better managing their persistent musculoskeletal pain and enhancing their wellbeing.

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## Pain and mental wellbeing: the two way street

Of additional significance is the prevalence of mental health problems also peaking in this young age group, with up to 25% of adolescents experiencing some kind of mental health condition<sup>6</sup>. Higher prevalence rates of pain in cohorts with depression and depression in cohorts with persistent pain, are reported than when these conditions are individually examined<sup>7</sup>. Furthermore, up to 75% of those people who experience mental health problems also experience pain<sup>11,12</sup>, and coexistent psychiatric symptoms have been shown to increase the prevalence of persistent, multisite pain<sup>13</sup>. 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, especially given that current adolescent pain may predict musculoskeletal pain in adulthood<sup>8,9</sup>. Despite this high burden, young people are the least likely population group to seek help or to access professional care for mental health problems<sup>14</sup>.

## One size does not fit all: the need for tailored health services

While a variety of primary care services and resources are available to young people to address mental health problems in Australia<sup>14</sup>, there is a lack of age-appropriate, engaging, accessible and reliable resources to address pain<sup>15</sup>. Despite the identified burden of persistent pain in young people, and particularly that of musculoskeletal origin<sup>5,10</sup>, a substantial burden-service gap exists in both Australia<sup>1,15</sup> and internationally<sup>16,17</sup>. Tertiary pain medicine and rheumatology units are grossly under-resourced across Australia<sup>15,18</sup>, while primary care services remain fragmented in terms of service consistency and workforce capacity<sup>19,20</sup> with care disparities particularly acute for young people living in rural and remote areas<sup>21,22</sup>. In order to improve services, a better understanding of young people's needs in this area is important. While research in paediatric rheumatology has explored this issue<sup>18,23</sup>, it is critically important to broaden our perspectives and extend our understanding beyond specific rheumatic or pain conditions in young people as these conditions represent only a small proportion of the range of musculoskeletal pain conditions experienced by young people.

## Digital technologies as a mechanism to help bridge pain management-service gaps

Given young people are technologically sophisticated in using information and communication technologies (ICT), including social and e-technologies<sup>24</sup>, digital technologies present an unprecedented opportunity to disseminate e-health information and resources in a sustainable way. Digital technologies provide a mechanism to help mitigate care disparity, and provide accessible, and reliable holistic information about pain management and mental well being<sup>25</sup>. This opportunity highlights the need to explore in young people with persistent pain, their perceived health needs and preferences for the ways in which these needs are supported, with particular focus on the use of digital technologies.

## Why this study and why now?

It is important to explore the experiences of young people with persistent pain during their transition to adulthood and identify the barriers and enablers to better managing their persistent musculoskeletal pain and enhancing their wellbeing. Appropriate support and information at this critical time may help mitigate the risk to young people with persistent pain succumbing to potentially preventable declines in their health and unhelpful coping behaviours, such as the abuse of alcohol, use of illicit drugs and inappropriate use of pain medications.

This report seeks to inform Arthritis and Osteoporosis Victoria, Arthritis and Osteoporosis Western Australia and other agencies about the experiences of young adults with persistent musculoskeletal pain, and their needs and preferred modes of delivery for pain management services with a focus on the use of 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 (Pty Ltd) and Wisdom Health.

# Methods

## Aims

The aims of this project were to explore young people's:

- 1) experiences of living with persistent pain
- 2) their needs for information, skills and support, particularly as they relate to the use of digital technologies and, in the context of managing their musculoskeletal pain condition(s)
- 3) their preferred modes of service delivery, particularly as they relate to the use of digital technologies.

## Study design

A mixed-methods study was undertaken in two phases between October 2014 and April 2015 in Australia. Mixed-methods designs incorporate qualitative and quantitative research and seek to integrate the findings of each mode of research. Phase 1 involved participants completing questionnaires to clinically and demographically characterise their musculoskeletal pain. Phase 2 involved a subset of participants from Phase 1, undertaking an in-depth qualitative interview.

## Human Research Ethics approval

The study had institutional ethics approval (Curtin University; Melbourne University) and adhered to the Declaration of Helsinki.

## Reporting

The manuscript aligns with reported recommendations from the COREQ-32 criteria <sup>26</sup> for qualitative research.

## Recruitment and sampling

Participants were recruited from the community via a variety of sources, primarily online including:

- Arthritis consumer organisations: (Arthritis and Osteoporosis Victoria; <http://www.arthritisvic.org.au/>; Arthritis and Osteoporosis Western Australia: <https://www.arthritiswa.org.au/>)
- Pain consumer groups (painAustralia: <http://www.painaustralia.org.au/>; Chronic Pain Australia: <http://www.chronicpainaustralia.org.au/>)
- Neuro-Orthopaedic Institute: <http://www.noigroup.com/en/Home>);
- Young adult mental health services (Headspace: <http://headspace.org.au/>; the Young and the Well CRC: <http://www.youngandwellcrc.org.au/>)
- The Young Female Health Initiative Research Programme: <https://www.yfhi.org/useful-links/>).

For the Phase 2 subset, sequential, consecutive recruitment was undertaken. The sample size for Phase 2 was dictated by qualitative data redundancy. At the completion of the interview or focus groups, participants were sent an AUS \$50 gift voucher.



## Inclusion and exclusion criteria

Participants were required to have musculoskeletal pain of greater than 3 months duration with an average of  $\geq 3$  on the Visual Analogue Scale<sup>i</sup> over the preceding three months including, but not limited to, non-specific conditions such as low back pain (LBP), spinal pain, and specific conditions including juvenile idiopathic arthritis, and other systemic arthritides with/without pre-existing or current co-morbid depression or anxiety. Males and females were included with ages ranging from 16-24 years. Participants were required to be able to read and comprehend English. Exclusion criteria included pregnancy and a history of previous or current active psychosis as diagnosed by a health professional.

## Consent

Those who met the inclusion criteria were invited to consent to participate. A dedicated consent page on a custom Qualtrics™ survey platform provided a clear explanation of what they were consenting to and their rights to withdraw at any time. This consent was for both phases of the study. Following completion of the quantitative survey, an additional option was provided for participants to opt out of Phase 2 should they wish only to provide the quantitative data. Participants aged 16-17 years were asked to discuss the study and consent with their guardian or parent prior to consenting. This age group was also invited to have a guardian or parent join them for qualitative interview if they so wished.

## Data collection

### PHASE 1 (SURVEY QUESTIONNAIRE)

Initial screening was undertaken for young people who indicated their interest in participating in the study to ensure that the inclusion/exclusion criteria were checked. This initial screening was undertaken directly through the Qualtrics™ platform using a binomial response checklist according to inclusion and exclusion criteria.

Following consent, participants were asked to complete an online survey that collected quantitative demographic and clinical data. This step was essential to enable capture of a representative cohort of the broader young population from urban and regional areas of Australia, given the nature of the online recruitment strategy. Standard demographic and clinical (self report) data were collected including age, sex, education, occupation, school/work/employment status and diagnosis for musculoskeletal and mental health conditions, pain duration, pain severity over preceding 3 months, area(s) of pain. Participants were asked independent questions about diagnosis for both pain and mental health conditions: 'Do you have a diagnosis for your pain/mental health problem?'. Where participants nominated 'Yes', they were asked 'Was this diagnosis made by a health care professional?' (Yes/No). Specific DSM-5 or ICD-10 disorders were not reported<sup>27</sup>.

Quantitative outcomes included validated instruments for use in primary care as follows:

#### Visual Analogue Scale

A visual analog scale (VAS) was used to capture pain intensity / severity data with a range from 0 (no pain) to 10 (unbearable pain). VAS appears to be the best measure for clinical trials with adolescents preferring this to faces scales<sup>28</sup>.

#### Örebro Musculoskeletal Pain Screening Questionnaire-Short Form (OMSPQ-SF)<sup>29</sup>

The short form (10 items) of the ÖMSPQ is appropriate for clinical and research purposes, as it demonstrates near equivalent accuracy compared to the longer version<sup>29</sup>, which has demonstrated reliability and validity. The items are scored 0-10, where 0 refers to absence of impairment and 10 to severe impairment. Three items are reversed in order for all the questions to be oriented in the same direction. The total score will range between 1 and 100, with a score  $>50$  indicating higher estimated risk for future work disability. The short-form has been tested in both occupational and musculoskeletal clinical cohorts in primary care. Of those who developed disability, a cut-off of 50 on the short version identified 85% in the occupational and 83% in the primary care samples which was nearly as good as the full version<sup>29</sup>.

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<sup>i</sup> A visual analog scale (VAS) is a psychometric measure used to self-report pain with a range from 0 (none) to 10 (unbearable pain).



### **Coping Skills Questionnaire (CSQ: subscale 2; catastrophizing)<sup>30</sup>**

The catastrophising subscale of the (CSQ)<sup>30</sup> was used to measure general pain catastrophising beliefs, as the subscale appears to demonstrate greater utility in terms of examining coping, appraisals, and pain adjustment compared to the composite scores<sup>31</sup>. This subscale lists six items which are scored using a 7-point Likert scale with responses 0 indicating 'never' to 6 indicating 'always'. Scores can range from 0–36 with higher scores indicating greater catastrophising beliefs. One item is not included in the calculation of the total score. The internal consistency of the subscale is reported to be  $\alpha=0.85$ <sup>32</sup>.

### **Hospital Anxiety and Depression Scale (HADS)<sup>33</sup>**

The Hospital Anxiety and Depression Scale is a 14-item measure of self-reported symptoms of anxiety and depression, widely validated and with good psychometric properties demonstrated for musculoskeletal pain populations<sup>34,35</sup>. The anxiety and depression scales each have seven questions, and scores are categorised as normal (0-7), mild (8-10), moderate (11-14) and severe (15-21). The total score for each subscale ranges from 0-21, with higher scores representing greater symptoms. The HADS has also been validated in adolescents<sup>36</sup>.

### **Pain Self Efficacy questionnaire (PSEQ)<sup>37</sup>**

A valid and reliable measure of a person's beliefs and confidence regarding their ability to undertake activities despite pain<sup>38</sup>. There are 10 items, using a 7-point Likert scale ('Not at all confident '0' to completely confident '6'), with all items summed for a total score with a possible range from 0 to 60 with a higher score indicating higher self efficacy<sup>37</sup>.

### **The Assessment of the Quality of Life (AQoL)<sup>39</sup>**

Of this eight domain questionnaire (35 items)<sup>39</sup> the psychological super dimension subscales (i.e. subscales 4 to 8 inclusive) were used to capture overall psychological wellbeing<sup>40</sup> (<http://www.aqol.com.au/index.php/scoring-algorithms/2-uncategorised/228-spss-8d>). The psychological super dimension can be used as a stand-alone instrument, given this was derived to have independent content validity, however results from this subscale cannot be transformed to utilities as these are derived from the full set of subscales for the instrument<sup>40</sup>. By comparison with existing instruments, AQoL-8D has demonstrated advantages including greater coverage of mental and social dimensions of health; similar results with respect to convergent and predictive validity; and a higher correlation with subjective well-being<sup>40</sup>.

## PHASE 2 (QUALITATIVE INTERVIEW)

An interview schedule was prepared by the cross discipline clinical and research team (Joanne Jordan, Andrew Briggs, Rob Schütze, Helen Slater), piloted (n=3) and iterated. Participants involved in the piloting phase were not included in the study. The final interview schedule was used to guide the in-depth interviews and explore the lived experience of young people with persistent musculoskeletal pain (appendix).

Participants indicating their interest in participating in phase 2 were enrolled sequentially (n=28). Each participant was contacted prior to the interview by one of the interviewers to outline the interview process, to discuss any questions, to introduce the interviewer and their backgrounds and to establish a suitable time for the interview. Five participants did not respond to phone contact to arrange an interview, leaving a total sample of n=23.

Qualitative data were collected in two ways; i) via one-to-one telephone interviews, and ii) using a virtual focus group via teleconferencing. These approaches allowed participants across different geographic regions and socio-demographic backgrounds to be interviewed. Participants involved in the telephone interviews were independent from those involved in the focus group. These two qualitative methods were used to ensure validity of the findings, to minimise bias, and to achieve triangulation of derived themes <sup>41</sup>. The use of virtual focus groups using telephone and other communication modes is advocated for overcoming geographic disparity, and as a mechanism to provide participants with visual anonymity which may serve to elicit information not readily conveyed in traditional face-to-face group encounters <sup>42</sup>. Data obtained from telephone focus groups have been validated previously against data obtained from face-to-face focus groups <sup>43</sup>. Prior to commencement of the interviews, participants were reminded that the interview could be stopped at any time and they could withdraw from the study at any time.

Using the semi-structured schedule, 18 individual interviews and one focus group (five individuals) were conducted by telephone by either a senior qualitative researcher (Joanne Jordan) or a specialist musculoskeletal physiotherapist /clinical researcher (Helen Slater). No guardians or parents were present during the interviews. Durations for the individual interviews ranged between 20 and 50 minutes, while the duration of the focus group was 50 minutes, all of which were audio-recorded. In order to ensure accuracy of the content, participants later checked all transcripts (i.e. member checking).

## Data analysis

Given the small sample size and study aims, only descriptive statistics are reported for the quantitative outcomes. Demographic and clinical (including psychometric) variables for participants were described using mean and standard deviation (SD) for continuous variables or frequencies and percentages for categorical variables. All analysis was performed using Statistica (Dell, StatSoft Inc., Texas, USA).

Interview and focus group recordings were transcribed verbatim. The qualitative data were analysed using an inductive approach based on grounded theory by the senior qualitative researcher (Joanne Jordan), in two phases. In the first phase, thirteen interview transcripts were reviewed and key themes and subthemes inductively derived from the data over an iterative process <sup>44</sup>. For the second phase, the focus group and another five interview transcripts were inductively analysed to determine whether data redundancy of key themes and subthemes had been reached. For methodological rigour <sup>26</sup>, a third of the interviews were also analysed independently by a second researcher (Helen Slater) to confirm the themes identified and discuss any discordance. Where necessary, themes were refined to reach consensus. Results were structurally organised and presented in a hierarchy of meta-themes, themes and sub themes.

# Results

## PHASE 1 CHARACTERISTICS OF THE COHORT

### Participant demographics

Demographic characteristics of the study sample are shown in Table 1 for all participants, with a further breakdown into those undertaking Phase 1 (questionnaires) only (n=36), and those undertaking both Phases 1 and 2 (questionnaires and interviews) (n=23; 64%). Most participants were from Victoria (84.8%), although all six Australian states and one territory were represented. A majority of participants nominated English as their first language (98.3%), and most participants were currently studying at university or at technical and further education (TAFE) institutions (62.7%).

**Table 1. Demographic data for study participants. Data are shown as N(%) unless otherwise indicated.**

Demographic Characteristics	All participants (N=59)	Participants involved in Phase 1 only (n=36)	Participants involved in both Phase 1 and 2 (n=23)
Age (years) mean (SD) [min – max]	21.0 (2.5) [16-24]	20.8 (2.5) [16-24]	20.8 (2.4)[17-24]
Gender (Female)	54 (91.5)	34 (94.4)	20 (87.0)
<b>Australian State / Territory</b>			
<i>Victoria</i>	50 (84.8)	34 (94.4)	16 (69.6)
<i>New South Wales</i>	2 (3.4)		2 (8.7)
<i>Queensland</i>	2 (3.4)		2 (8.7)
<i>Western Australia</i>	2 (3.4)	1 (2.7)	1 (4.4)
<i>South Australia</i>	1 (1.7)	1 (2.7)	
<i>Tasmania</i>	1 (1.7)		1 (4.4)
<i>Australian Capital Territory</i>	1 (1.7)		1 (4.4)
English as a first language	58 (98.3)	36 (100.0)	22 (95.7)
<b>Highest current level of education completed</b>			
<i>University</i>	22 (37.3)	14 (38.9)	8 (34.8)
<i>TAFE<sup>a</sup></i>	7 (11.9)	3 (8.3)	4 (17.4)
<i>Year 12 (tertiary entrance)<sup>a</sup></i>	26 (44.1)	18 (50.0)	8 (34.8)
<i>Year 12 (other)</i>	4 (6.8)	1 (2.8)	3 (13.0)
<i>Less than 3 year secondary</i>	2 (3.4)	2 (5.6)	0
<b>Currently at</b>			
<i>School</i>	7 (11.9)	4 (11.1)	3 (13.0)
<i>University or TAFE</i>	37 (62.7)	23 (63.9)	14 (60.9)
<i>Unemployed</i>	3 (5.1)	2 (5.6)	1 (4.4)
<i>Employed (volunteer or paid work)</i>	12 (20.3)	7 (19.4)	5 (21.7)

**Legend:** <sup>a</sup> n=2 participants indicated being both at TAFE and undertaking tertiary examinations for year 12; TAFE= technical and further education institutions

## Clinical and psychometric data

The musculoskeletal conditions reported as primary diagnoses were diverse, including inflammatory (e.g. rheumatoid arthritis) and non-specific musculoskeletal conditions (e.g. fibromyalgia, low back pain, neck pain) (Table 2). Most commonly nominated as affected areas of the body included low back (64.4%) and neck (50.8%), followed by knees (42.4%), hips (33.9%) and shoulders (32.2%) (see table 3).

**Table 2. Pain conditions for participants (frequency (%))<sup>a</sup>.**

Pain condition	All participants, N=59	Phase 1 only; n=36	Phase 1 and 2; n=23
Clinical diagnosis yes n(%)	32 (54.3)	16 (44.4)	16 (69.6)
<b>Inflammatory arthritis</b>			
<i>Ankylosing Spondylitis</i>	4 (6.8) <sup>e</sup>	2 (5.6)	2 (8.7)
<i>Rheumatoid Arthritis</i>	3 (5.1) <sup>a b</sup>	3 (8.3)	
<i>Seronegative Inflammatory</i>	1 (1.7)		1 (4.3)
<i>Arthritis &amp; Osteoarthritis</i>			
<i>Inflammatory Spondyloarthritis</i>	1 (1.7) <sup>h</sup>	1 (2.8)	
Arthritis Juvenile Idiopathic	3 (5.1) <sup>a</sup>	1 (2.8)	2 (8.7)
Unspecified Connective Tissue	1(1.7)		1 (4.3)
Disease with Sjogren's features			
Systemic Lupus Erythematosus	1 (1.7)	1 (2.8)	
Fibromyalgia	7 (11.9) <sup>a b</sup>	3 (8.3)	4 (17.4)
Low back pain (including sciatica; n=2)	6 (10.2) <sup>c d</sup>	1 (2.8)	5 (21.7)
Scoliosis	2 (3.4) <sup>f</sup>	1 (2.8)	1 (4.3)
Neck pain	1 (1.7) <sup>g</sup>		1 (4.3)
Shoulder tendinopathy	1 (1.7)		1 (4.3)
Knee pain (ACL rupture and meniscal repair)	1 (1.7)		1 (4.3)
Repetitive strain injury (hands/wrists)	1 (1.7)	1 (2.8)	
Carpal tunnel syndrome	1 (1.7)	1 (2.8)	
Hips (labral lesions)	1 (1.7)	1 (2.8)	

**Legend:** <sup>a</sup> counts may be greater than 59 as some participants (n=4) identified more than one diagnostic condition; <sup>b</sup> one case comorbid with Postural Orthostatic Tachycardia Syndrome and fibromyalgia; <sup>c</sup> includes one case with scoliosis <sup>d</sup> includes one case with co-morbid endometriosis; <sup>e</sup> one case co-morbid osteoporosis; one case co-morbid reactive arthritis; <sup>f</sup> one case co-morbid with osteoporosis; <sup>g</sup> also experienced low back pain; <sup>h</sup> co-morbid abdominal pain

The reported duration of the pain condition was considerable (mean (SD); range 54.6 months (55.3); 3-250). (Table 3). Pain severity over the past four weeks was rated as moderate (VAS mean (SD); range 4.8 (2.0); 1.0-8.0). A considerable proportion of participants reported more than two areas of pain (69.5%), while 27.2% reported six or more areas, and 30.5% reported between zero and less than two areas. The OMSPQ-SF 10 mean (SD; range) score of 43.7 ((13.2); 20-73), fell just below the cut off of > 50 indicating a risk of future pain-related disability<sup>29</sup>.

Self-reported clinically diagnosed co-morbid mental health conditions were common (61.4%), with combined anxiety and depression most frequently reported (42.9%). Combined anxiety and depression was most frequently reported (42.9%). Mental health conditions frequently preceded pain (54.3%) and the duration of mental health conditions was considerable (mean (SD); range: 57.0 (42.4); 3-144 months). According to HADS scores, anxiety was classified as borderline (HADS-A), while depression fell within normal ranges (HAD-D). Confidence in doing a range of activities despite pain (as a measure of self efficacy; PSEQ), indicated only mild impairment. Negative thoughts and feelings in relation to pain (as a measure of catastrophising: CSQ), fell within the 'mild range'. Overall, the negative impact of pain on wellbeing was significant, as evidenced by the AQL psychological super dimension (self-worth, coping, relationships, happiness) score, with a group mean (SD); range of 58.9 (17.6); 11-91.

**Table 3. Clinical and psychometric data for study participants for all participants and for each study phase.**

Clinical characteristics	All participants	Phase 1 participants <sup>a</sup> (n=36)	Phase 1 and 2 <sup>a</sup> (n=23)
Pain duration (months); mean (SD)[range]; N=59	54.6 (55.3) [3-250]	45.8 (56.2) [3-250]	68.4 (52.2) [5-240]
Current pain severity [0-10]; mean (SD) [range]; N=56	3.7 (2.1) [0-8]	3.4 (2.1) [0-7]	4.2 (2.2) [0-8]
Average pain severity past week; mean (SD)[range 0-10]; N=56	4.6 (2.0) [1-8]	4.4 (2.1) [1-7]	4.8 (2.0) [1-8]
Average pain severity past 4 weeks; mean (SD)[range 0-10]; N=56	4.8 (2.0) [1-8]	4.4 (2.1) [1-8]	5.4 (1.9) [2-8]
Duration current episode > 3 months; yes n(%); N=56	39 (66.1)	16 (44.5)	23 (100.0)
<b>Area(s) of pain; n(%); N=59</b>			
<i>Head</i>	10 (16.9)	5 (13.9)	5 (21.7)
<i>Jaw</i>	6 (10.2)	5 (13.9)	1 (4.3)
<i>Neck</i>	30 (50.8)	17 (47.2)	13 (56.5)
<i>Shoulders</i>	26 (44.1)	14 (38.9)	12 (52.2)
<i>Elbows</i>	8 (13.6)	2 (5.6)	6 (26.1)
<i>Wrists</i>	20 (33.9)	15 (41.7)	5 (21.7)
<i>Hands</i>	16 (27.1)	10 (27.8)	6 (26.1)
<i>Mid back</i>	16 (27.1)	9 (25.0)	7 (30.4)
<i>Low Back</i>	38 (64.4)	19 (52.8)	19 (82.6)
<i>Hips</i>	20 (33.9)	11 (30.6)	9 (39.1)
<i>Knees</i>	25 (42.4)	15 (41.7)	10 (43.5)
<i>Ankles</i>	16 (27.1)	10 (27.8)	6 (26.1)
<i>Feet</i>	12 (20.3)	8 (22.2)	4 (17.4)
<i>Leg muscles</i>	19 (32.2)	11 (30.6)	8 (34.8)
<i>Arm muscles</i>	8 (13.6)	2 (5.6)	6 (26.1)
<i>Muscles along the spine</i>	13 (22.0)	4 (11.1)	9 (39.1)
<i>Ribs</i>	5 (8.5)	1 (2.8)	4 (17.4)
<i>All over (whole body)</i>	8 (13.6)	5 (13.9)	3 (13.0)
<i>Other (abdominal; migraine; tooth pain)</i>	8 (13.6)	5 (13.9)	3 (13.0)



Table 3 continued

Clinical characteristics	All participants	Phase 1 participants <sup>a</sup> (n=36)	Phase 1 and 2 <sup>a</sup> (n=23)
<b>Total no pain areas n(%)</b>			
0 < 2	18 (30.5)	13 (36.1)	5 (21.7)
2 < 4	14 (23.7)	8 (22.2)	6 (26.1)
4 < 6	11 (18.6)	7 (19.4)	4 (17.4)
6 ≥	16 (27.2)	8 (22.2)	8 (34.8)
OMSPQ-SF 10 [1-100]; mean (SD)[range]; N=35	n=35 43.7 (13.2) [20-73]	n=12 44.3 (15.3) [20-62]	n=23 43.4 (12.3) [20-73]
Mental health condition: yes, n(%) N=57	35 (61.4)	21 (61.8)	14 (60.9)
Clinical diagnosis: yes, n(%)	31 (88.6)	19 (90.5)	12 (85.7)
<i>Depression</i>	3 (8.6)	2 (9.5)	1 (7.1)
<i>Anxiety</i>	12 (34.3)	6 (28.6)	6 (42.9)
<i>Anxiety and Depression</i>	15 (42.9)	12 (32.7)	3 (21.4)
<i>Other (PTSD, OCD, BPD)</i>	9 (25.7)	5 (23.8)	4 (28.6)
Duration mental health condition (months) mean (SD) [range]; N=34	n=34 57.0 (42.4) [3-144]	n=21 59.5 (42.2) [3-132]	n=13 52.9 (43.8) [6-144]
<b>Mental health condition started before pain</b>			
Yes; n(%)	19 (54.3)	12 (57.1)	7 (50.0)
<b>HADS mean (SD)[range]; N=33</b>			
<i>HADS-A subscale [possible score 0-21]</i>	8.6 (5.5) [0-19]	n=10 7.2 (6.5) [0-19]	n=23 9.4 (4.7) [0-19]
<i>HADS-D subscale [possible score 0-21]</i>	4.8 (4.0) [0-16]	4.6 (4.8) [0-16]	4.9 (3.5) [1-14]
<i>HADS total score [possible score 0-42]</i>	13.4 (8.8) [0-35]	11.9 (10.9) [0-35]	14.3 (7.3) [2-27]
PSEQ [0-60] mean (SD)[range]; N=33	38.2 (19.6) [0-60]	29.7 (25.4) [0-60]	43.5 (13.2) [10-60]
CSQ:(Factor 2 subscale: catastrophising); [possible score 0-36]; mean (SD)[range]; N=37	11.4 (8.1) [0-29]	10.6 (9.2) [0-28]	12.0 (7.5) [1-29]
AQoL8D <sup>b</sup> ; (possible score 0-100); mean(SD)[range]; N=33	58.9 (17.6) [11-91]	54.2 (22.9) [11-91]	60.9 (14.9) [29-87]

**Legend:** <sup>a</sup> Percentages presented as n/N within group; <sup>b</sup> AQoL8D=The Assessment of Quality of Life Eight Dimension Scale psychological super dimension only; Except where indicated otherwise, values are presented as n (percentages). OMSPQ SF 10=Orebro Musculoskeletal Pain Screening Questionnaire Short Form 10; HADS=Hospital Anxiety and Depression Scale; HADS-A anxiety subscale; HADS-D depression subscale; PSEQ=Pain Self Efficacy Questionnaire; CSQ=Coping Strategies Questionnaire-Pain Catastrophising subscale;

## PHASE 2 QUALITATIVE INTERVIEW FINDINGS

Qualitative results are presented under the following meta-themes:

1. Young people's experiences of living with persistent musculoskeletal pain.
2. Challenges, gaps and information needs in managing pain.
3. Perception of an optimal pain service with a focus on the use of digital technologies.

### Meta theme 1: Young people's experiences of living with persistent musculoskeletal pain

Participants provided detailed insights into how persistent pain affects their life on multiple dimensions. Whilst there was great variation amongst individuals in terms of the extent to which pain pervades their life, collectively, there were seven main areas (themes) that were consistently identified as being significantly impacted: study; ability to engage in the workforce; fear of living a life in pain; sleep; physical activity; simple day-to-day tasks; overall lifestyle. Of these, the ability to engage in the workforce, impact on study and fear of living a life in pain were the areas participants were most impacted by their pain experience. This is further discussed in detail below and a summary of all subthemes identified is presented in Table 4.

#### 1.1 Impact on study

Study activity was the area most disrupted due to persistent pain. Participants' experiences ranged from inability to attend classes or exams due to physical restrictions such as being able to sit or stand for extended periods, while others cited that extreme fatigue and lack of concentration affected their ability to engage in study. For several participants, this had resulted in them dropping out of school or university which negatively affected their future outlook.

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"...because I'm still at school I am challenged with trying to balance a lot of my school work with the rest that I need to recover from the pain and the fatigue that I get from the pain...It's already stressful enough doing, like, Year 12, let alone having the extra pain on top that nobody else has to seem to worry about." (FG1)

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"As of the last three years, it's just [pain in] all joints all the time, seems like regardless of what I do, you know, there's just not a lot of control...it really messed around all my study on - and just how I was thinking about the future for years...I'm not studying at the moment. I've tried a few times, but just combination of hurting so much and while you've been depressed, it's just, you know...the motivation has never been great. It's just always that feeling of none of this feels right and it's just really hard." (IP04)

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## 1.2 Ability to engage in workforce

The majority of participants were engaged in part-time work to financially support themselves through school/university and often held roles in the hospitality, communications and retail industries which involved undertaking many physical tasks. Consequently, persistent pain had a detrimental effect on participants' ability to perform their duties to the extent they wished and in some cases resulted in them having to stop work. However, the vast majority indicated that they carried out their roles, despite being in pain, due to fear of losing their job and/or the perception that their employers would not be understanding of their situation. For some, this resulted in engaging assistance from friends and families to fulfil work obligations.

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"I still do the stuff that I was, well... I suppose for me, which is not very good so I wouldn't recommend it to other people, but I do the jobs that I have to do in terms of the employed by other people sort of thing. So I would never cancel a shift at work..." (IP07)

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## 1.3 Fear of living a life in pain

A consistent theme to emerge across participants was the fear that they were destined to live a life in pain, and that it would only get worse over time. For some participants, the prospect of how they would manage their condition when they were older was particularly daunting given that they were yet to find ways to manage or treat it effectively.

*"Just that it might not go away. It would be a bit stressful thinking that I might have to do this sort of rehab for the rest of my life. But mainly – I'm not worried at the moment, it's more when I'm say 50 or 60 years old...will the arthritis and all that sort of stuff set in, in my back area or – I don't understand it..." (I5)*

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"I work as a barista in a café and I can't bring the tables out in the mornings, so that's – at 5.30am one of my parents accompanies me to work and pulls them out for me, and then either a co-worker or a friend comes down in the afternoons to help..." (IP02)

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"That it'll just keep going for like the rest of my life; that worries me. I don't think anyone wants to live a life in pain. But because I don't want it to be ongoing, if left untreated, but then again, so like if it's untreated, it'll evolve into something more serious, but then again I've seen doctors about it and you know, they're saying to you, anti-inflammatories, cream to relieve the pain, but that's just like a quick fix really, it doesn't do anything. So I don't really know. It worries me that if left untreated it'll turn worse, but then again I don't know what treatment to go for because I've tried it all." (I1)

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**Table 4: Summary of themes identifying areas of young adults' lives significantly impacted by persistent pain**

STUDY	Quotes
<p>Study activity was the area most prominently identified by participants as being disrupted due to persistent pain. Participants' experiences ranged from inability to attend classes or exams due to physical restrictions such as being able to sit or stand for extended periods, while others cited that extreme fatigue and lack of concentration affected their ability to engage in study. For several participants, this had resulted in them dropping out of school or University which negatively affected their future outlook.</p>	<p>"So I haven't been able to work or participate in any study really. I did one unit at the University down here in Tas last semester, which was just like a How to Research unit, just to try and be a bit more social..." (IP18)</p> <p>"I guess like concentration. Because a lot of the times fatigue is a huge contributor to these conditions, so focus and concentration and then being in pain makes it even harder to try and concentrate." (IP13)</p> <p>"...because I'm still at school I am challenged with trying to balance a lot of my school work with the rest that I need to recover from the pain and the fatigue that I get from the pain...It's already stressful enough doing, like, Year 12, let alone having the extra pain on top that nobody else has to seem to worry about. (FG1)</p>
ABILITY TO ENGAGE IN THE WORKFORCE	Quotes
<p>The majority of participants were engaged in part-time work to financially support themselves through school/University and often held roles in the hospitality, communications and retail industries which involved undertaking many physical tasks. Consequently, persistent pain had a detrimental effect on participants' ability to perform their duties to the extent they wished and in some cases resulted in having to stop work. However, the vast majority indicated that they carried out their roles despite being in pain due to fear of losing their job and/or the perception that employers would not be understanding of their situation. For some, this resulted in engaging assistance from friends and families to fulfil work obligations.</p>	<p>"I work as a barista in a café and I can't bring the tables out in the mornings, so that's – at 5.30am one of my parents accompanies me to work and pulls them out for me, and then either a co-worker or a friend comes down in the afternoons to help ..." (IP02)</p> <p>"It impacts my ability to work as well as study because a lot of jobs involve, you know, especially for students, being on your feet for like six to eight hours at a time and I just can't do that. There's no way I can do that as well as studying full time." (IP06)</p> <p>"The impact that it had on my life and my lifestyle, I'm still currently – even though my pain is a lot more manageable, due to everything else to do with my health as well as the pain, I'm currently not able to work." (IP08)</p>
FEAR OF LIVING A LIFE IN PAIN	Quotes
<p>A consistent theme to emerge across participants was the fear that they were destined to live a life in pain and that it would only get worse over time. For some participants, the prospect of how they would manage their condition when they were older was particularly daunting given that they were yet to find ways to manage or treat it effectively.</p>	<p>"Look, I live in fear of it being something worse because I'm a medical student...You know, you constantly go, "Oh, maybe it's a tumour." Even though the MRI had nothing, you're still like, "Oh, maybe!" (IP03)</p> <p>"Just that it might not go away. It would be a bit stressful thinking that I might have to do this sort of rehab for the rest of my life. But mainly – I'm not worried at the moment, it's more when I'm say 50 or 60 years old, what -will the arthritis and all that sort of stuff set in, in my back area or – I don't understand it..." (IP05)</p>

## SLEEP

The impact of pain on sleep was highly variable across participants. Some reported little to no effect whilst others noted the detrimental impact pain-related fatigue had on energy levels and mood

## Quotes

"Often - well I've never slept well. I've tried basically everything that you can take to help me sleep. I don't - I sleepwalk, I don't stay asleep, I have vivid nightmares, I have a lot of trouble getting to sleep, kind of never wake up refreshed." (IP13).

"Yeah, because it seems like, well, I'm really tired all the time but then when it comes to night I can't get to sleep. And even if I get to sleep now I'll just keep waking up, so it's a bit annoying, because you sort of – in the day you're like desperate to sleep but then when you're home then I'm wide awake..." (IP07)

## OVERALL LIFESTYLE

Participants strongly agreed that pain restricted their ability to lead the lifestyle they wanted, particularly in relation to their social life and undertaking international travel. Adolescent participants were particularly worried about the toll on their social life and lack of understanding by their peers whereas young adults tended to be more pragmatic in acknowledging their limitations although they still expressed frustration.

## Quotes

"... I worry about my friends want to make plans to go out for a party or something in, like, a week's time and I don't know if I'm going to be able to physically get out of bed and feel okay to do that kind of thing. So it takes a big toll on, like, my social life in that nobody understands it so it's quite difficult in that aspect." (FG1)

"...you know, I've kind of aged out and you just watch other people's lives, you know, speed off. That's kind of the way it feels, just kind of catches up to that like oh wait, my life is going to be entirely different to all the people around me and ... no one's going to really understand that." (IP04)

## PHYSICAL ACTIVITY

Despite the majority of participants being cognisant of the benefits of physical activity for pain management, the realities of juggling a busy lifestyle whilst concurrently managing pain and fatigue often resulted in infrequent physical activity or a protracted absence. This had varied consequences from affecting participants' self-esteem in relation to body image and weight management, their psychological wellbeing and social interaction with friends.

## Quotes

"It's really hard because I like exercising, but particularly when I'm in back pain I don't want to do anything in case it makes it worse, you know ...Yeah, I'm worried about – because, like, they say, "Go to yoga or Pilates," but every now and then if I do the wrong stretch I'm worried that – because usually when the pain's bad I'm more like worried that it's going to set it off and make it worse" (IP03)

"...it's hard when you want to get fit, you want to be healthy and stuff, and yet feeling good and being healthy don't always align, like exercise will make you wake up the next day not necessarily feeling as good...Or you're miserable so you want to eat yummy food, which contributes [to weight] you know? Yeah. It's making it hard for me to be healthy and do everything I want to do, I feel, and I feel that it's ... By stopping me exercising, I feel so much more tired than I felt last year, and that's been really frustrating" (IP03)

Continued next page



Table 4 continued

SIMPLE DAY-TO-DAY ACTIVITIES	Quotes
<p>For several participants, the chronic pain they experienced created difficulties in carrying out simple tasks such as standing up from a chair, taking a shower or even brushing their teeth which resulted in them having to plan and pace each activity in their day.</p>	<p>“...it was hard enough to wake up and get out of bed each day, and then with being really stiff and having a sore neck and everything just made it a whole lot worse.” (IP05)</p> <p>“It makes it hard to do things that I used to take for granted a few years back...If I drop something, a few years ago in high school I’d just bend over and pick it up, no dramas, but now it’s a big hassle, you know? I have to get down slowly and sort of ease myself down and then pick it up, and it’s a lot of effort and pain it takes, you know. It takes a lot longer to do simple things like that and getting up. Like getting in and out of chairs, in and out of bed, just things generally I notice, when I go down the stairs and get in the shower and that sort of thing. So fear of falling over and injuring myself even more. I worry a bit like that, yeah.” (IP02)</p>

**Legend:** brackets after quotes indicate IP = individual participant and participant number; GF = focus group and particular number.



## Meta-theme 2: Challenges, gaps and information needs for managing musculoskeletal pain

The meta-theme includes three themes: challenges (2.1), gaps (2.2) and information needs for managing musculoskeletal pain (2.3). Each of the themes represents a number of sub-themes.

### 2.1 Challenges

Key challenges identified by participants in managing their pain were:

- 1) the invisible nature of their condition which often led to internalisation of coping with pain
- 2) the two way relationship between pain and mental wellbeing
- 3) the financial burden of persistent pain.

#### 2.1.1 Invisibility of pain

The invisible nature of pain severely hampered participants' experiences in receiving understanding, empathy or even acknowledgement from family, friends, work colleagues or health care professionals. Participants consistently identified that a lack of physical evidence, such as a deformity, often resulted in others perceiving that they were exaggerating or even faking their pain experience. Additionally, several participants were frustrated that people could not accept that young people could experience persistent pain.

Consequently, participants coped with their pain privately and tended not to discuss it, even with family members. Reasons for internalising pain were varied with some citing that they did not want to be seen to be complaining all the time, whilst others felt that people could not relate or understand, and therefore did not see value in mentioning it, particularly in an employment context where it was perceived that it could affect their employment prospects. One participant did not want to be defined by their condition and therefore did not talk about her persistent pain.

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"Generally I don't normally tell people unless I trust them, because I kind of don't want it to be my identifier." (IP13)

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"...what I've sort of found with other young people, unless they've got the same sort of mystery pain situation that I do, a lot of people, I don't know if this will sort of make sense, but a lot of people don't sort of believe you. Because it's not visible, so it's like, say if you have chicken pox then everyone would be like, "Oh my God, are you alright?" you know? But if you're always just sort of saying, "Oh, you know, I've got a really sore back," or something like that, it's sort of like you're always complaining. So I just try to not mention it, ever." (IP07)

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"I got a new job in December and I haven't actually even told them that I have the condition because I'm just hoping I don't get a flare up and that I can keep going to work, because there is that lack of understanding and that it is a casual position, so I didn't really want to start off on that foot with something so serious and risk sort of being let go. I'm sure they wouldn't label that as the reason, but there's that sort of niggly in the back of my mind that you know, if they weren't understanding of it and it caused problems, that they would let me go. I did actually lose my previous job over an argument about my back." (IP15)

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## 2.1.2 The two-way street between pain and mental wellbeing

The majority of participants strongly felt that there was a two-way relationship between their pain and mental wellbeing, with many observing that their pain was often worse if they were emotionally upset or anxious. Similarly, they were likely to be more downcast or depressed if they were experiencing heightened pain. Many participants found it difficult at times to cope, both physically and psychologically, as they described that life was passing them by and that they were missing out on many of the experiences that 'normal' young people enjoy. Additionally, for those participants who had yet to be given a diagnosis or find effective treatments for their pain, the continual worry over whether they were making the right decisions about their treatment and whether their pain was ever going to subside, also negatively impacted on their mental wellbeing.

"...I get quite upset sometimes just because it feels like my body's kind of failed at being a body if that makes sense, and so I find that emotionally I struggle with that...to just get over the fact that my body is never going to work the way that everyone else's does, and that's had a massive effect on my wellbeing. Like, I've gone from being, like, confident in what I can do and who I am to having no idea what I can do now or next week or tomorrow. Like, it's crazy how big of an effect just, like, one diagnosis can make." (FG1)

"It was more debilitating than the pain was, in a sense, just because either you were so depressed, so downtrodden, so just you know didn't feel like fighting. It's almost like everything is a fight and you have no fight in you...So it kind of retards any enthusiasm or incentive, like there's just no motivation and then the other thing would be anxious about, you know, is this the right path, am I doing the right thing...you know, it's that worry that it's all wrong because it feels wrong. Or like, you know, you're just panicky and so you don't really want to take a risk. Because any risk, you're just - you know, all you can think about is it's already so s\*\*t, you know, I'm going to make it worse." (IP04)

Participants described an array of different approaches to management of both their pain, as well as their mental wellbeing. In relation to the former, many employed a combination of passive and active coping methods including use of medication, hot/cold compression, stretching and exercise, acupuncture, mindfulness, breathing techniques and massage, as well as ongoing assistance from health professionals. A large proportion of participants indicated seeking a holistic approach to management, rather than sole reliance on pain medication.

"I have Enbrel injections once a week and I've just started methotrexate about three months ago, but it's still too early to tell the um - how it works. I've got a TENS unit... loan one which I use sometimes for my back when it gets really bad...I've got a really good masseur, sports, you know, so I get that done from time to time as needed, you know, stretching a lot quite often helps or even, you know, exercising or moving I've found. I've kind of floated with meditating, but you know, I haven't stuck with it so much. I still use breathing techniques, meditative rest, focusing on, you know, not to ignore the pain, but just to kind of put it in perspective almost, because when it starts hurting and you start thinking about it, it does get worse." (IP04)



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"...and apart from that and like supplements and things that I tried, I tried a lot of just, like mindfulness, like I've found that using Buddhist like influenced mindfulness techniques and kind of beliefs was helpful for me just to not become like really devastated emotionally in a bad flare up. And just thinking you know, this is likely to pass, then I just have to focus on good things and get through this. And besides that, yeah, just all the exercise things that I tried and I used heat packs...which is microwaveable heat packs and I found that they were sometimes helpful, even if it was just putting it on the area and making it like feel like it was burning." (IP08)

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Similarly diverse strategies were cited to manage mental wellbeing including exercise, meditation and socialising with friends and family. Some also drew comfort from listening to or reading other people's experiences in coping with their persistent pain, whilst others had sought professional assistance to manage their mental wellbeing.

*"I don't think I've said that I actually use exercise as a way of managing it. That's got to be the – if not the biggest thing that I use is exercising every day. It makes me feel better, emotionally and physically."* (IP05)

*"...watching testimonials of people on YouTube who've had the surgery that I'll probably need and everything, and their recovery and everything. Just those sorts of things make it worthwhile."* (IP02)

## 2.1.3 The financial burden of pain

Another key challenge was the enormous financial impact on participants in accessing services and treatments to assist them in managing their pain. The majority of participants were students working part-time to finance their studies, housing and living and they indicated that they were unable to afford the necessary health care services to assist them to

manage their pain. Only a few participants indicated that they received financial assistance from their family with many expressing frustration at having to pay for expensive consultations and services that provided them with little information or assistance. Additionally, several participants experienced difficulty in finding a General Practitioner (GP) who provided bulk-billing services.

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“So that can be, like, you know financially very stressful – I guess financially it is very stressful for everyone, but when you are having a health issue and you’re not sure if you’ll be capable of working in the future, that’s like a long term issue for me. I don’t know whether I’ll be able to afford to do a lot of things.” (IP08)

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“I think it’s really hard, like it’s hard to find a GP who doesn’t move on these days. And as a young person, when you’re looking for a bulk-billing practice, all of my friends find it very difficult to find, you know, their GP.” (IP03)

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## 2.2 Gaps

A healthcare system that effectively caters to the needs of young people with persistent pain and which provides age appropriate support groups, were the two biggest things missing for participants in their management.

### 2.2.1 Lack of healthcare services that effectively cater to the needs of young people

Participants’ experiences with health professionals in the diagnosis, treatment and management of persistent pain, was overwhelmingly negative. Three main gaps were identified: (i) lack of progress in diagnosis and management of persistent pain; (ii) lack of understanding and legitimacy of pain by health professionals; (iii) no holistic approach to, or continuity of, care.

Regarding ‘lack of progress in diagnosis and management of chronic pain’, several participants had yet to receive a definitive diagnosis for their pain and had endured months, or in some cases, years, of consultations with different health professionals without a cogent explanation for their persistent pain. These experiences had left them frustrated, powerless and cynical, particularly towards GPs, who they perceived to be dismissive and unwilling to assist in obtaining a diagnosis, or provide guidance about why their pain

persists or provide treatments other than medications, that resonated with the patient.

*“I’ve sort of been very disheartened by the fact that there’s, yeah, they don’t really look into it and, you know, there’s GPs out there who just seem to brush off every condition that you have but um, yeah I think sort of I’ve got a very negative attitude about doctors now...just generally GPs don’t seem to, the ones that I’ve been to, don’t really seem that interested in actually getting you better, they just want to prescribe you antibiotics and painkillers and, you know, they’re not actually treating it. So I think that’s, yeah my personal attitude has become very negative and that’s probably why.” (IP10)*

A lack of legitimate compassion and support from health professionals towards young people was also consistently reported. Health professionals were described as dismissive of participants’ reported symptoms and unwilling to accept that young people could experience persistent pain, especially in the absence of a definitive diagnosis. Whilst participants acknowledged that there may be people who tended



to fake symptoms to gain benefit, there was a perception that medical practitioners were too willing to attribute their pain experience to a mental health issue, rather than to investigate their pain in detail. Additionally young people described that information and treatments that were provided were not tailored specifically to their needs, or to their younger age group, and failed to take into account the issues they faced in juggling work, study, finances and in becoming independent.

*"I've got a pain condition and when I see doctors they don't believe me that I've got it. They believe that it doesn't exist and they basically just tell me that it's all in my head and I'm making it up which is frustrating to say the least." (FG5)*

*"...just the extra understanding and support. Perhaps if GPs – I don't know what they actually undergo in their training, but maybe there needs to be a specific module that they undergo where they speak to young people with chronic pain...Maybe someone could source genuine, proven diseases in young people and get those particular people to speak to these doctors or something so that they can actually understand it. Because I know there are unfortunately those that ruin it for the rest of us, that do put on things and you know, there's always going to be people that fake things for WorkCover... so there are those that ruin it which probably makes the GPs quite sceptical because they do actually see those people...I think those of us that are really actually in pain probably are reluctant to go there all the time and annoy them...so that's probably the gap, it's just understanding and a legitimate compassion I suppose for people that of this age group." (IP15)*

Regarding 'no holistic or continuity of care', participants were often overwhelmed with the specialised and varied information provided by different health professionals, and experienced difficulty in fitting it all together to provide a holistic approach to the management of their pain. Consequently, it was identified that a case manager to assist young people to coordinate and co-manage their chronic condition would be of valuable assistance. Several participants commented that they had been unable to find a GP who was affordable and was able to coordinate care or follow up on a regular basis.

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*"It's just - it's too scattered if you like...I don't know, it's just you go in and you know maybe your knee hurts really bad and they say, have this rub, do this stretch, do that and you go out and then maybe that goes away and there's a new thing and you go to a different specialist and they've got a different take and none of it feels kind of like a holistic treatment or you know, overarching or long term. But it is, it's all very specific and categorised and it's almost like treating an injury or treating a cold or a virus. It just does feel like no one's really saying to me, hey look, this is 20, 30, 40, you know, this is a lifetime thing, here are the things you need to do to begin with. I think some kind of case manager is the thing that's missing because like I said, you have to instigate it yourself and then go to all these different appointments and then weigh up their opinions and get someone else's opinion, even someone to help you manage your medication because they all prescribed medication just off what you're saying but don't speak about what other people have prescribed." (IP04)*

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## 2.2.2 Age appropriate support groups

Participants perceived peer groups as valuable in providing opportunities to relate and share similar experiences as well as provide different aspects or ideas on pain management. Whilst several participants had joined support groups, they felt these were mostly irrelevant as members tended to be much older, and therefore discuss issues that were not applicable to their current situation.

*"Probably there's a lack of resources for people like 18 to 25...I don't know a single other person that has a chronic pain condition in that age group. So I think there's like lack of any sort of support network and especially for people that age that possibly are moving out of home and taking responsibility for their healthcare and all of these different things and there's nothing there to help." (IP13)*

## 2.3 Information needs

Participants identified a vast array of information that would assist them in managing their pain. Topics included self-management strategies; online screening/diagnostic tools; prevention; education (addressing patients, health professionals, parents/carers, employers and teachers); pain physiology education, including the importance of mental wellbeing; support avenues including online forums and information about relevant healthcare services (see Table 5).

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"I think just like resources on explaining what the pain you're experiencing is. Like some people get achy, blah blah blah or just because they're sick and things like that, but there's nothing to explain – you know, this is because of this chemical or this reaction in the body and this will affect you in x, y, z ways. Like instead of just saying the symptoms are pain, swelling, blah, blah, blah, like explain that this pain happens because of this and it will go on to affect this part of your body later on, things like that. I guess, like going through and explaining what's happening in your body." (IP12)

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"...so information for parents saying, you know, there are things that they can do as well and, you know, getting them to health professionals and ensuring they get the proper diagnosis or they're doing as much as they can and then just sort of how they can socially support their children, like psychological wellbeing. Because they're going to find that their children are going to be depressed and anxious because they're not able to do the things that other people their age are doing. So I think information about how to deal with the mental health issues as well." (IP10)

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"Well I guess like a section for pain management things that you can do yourself that don't require medications or something like that, so you don't need a prescription or even, you know, so like just, so ways you can manage your pain and then obviously education." (IP10)

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**Table 5: Topics identified by participants where more information was desired to assist with the management of persistent pain**

TOPIC AREA	Specific information components
<b>1. Self-management</b>	<ul style="list-style-type: none"> <li>o Assist with managing information, actions and medication from all health professionals involved in care</li> <li>o Pain management strategies</li> <li>o Practical tips and strategies</li> <li>o Tracking pain levels</li> </ul>
<b>2. Online screening tools</b>	<ul style="list-style-type: none"> <li>o Screening/diagnostic tools</li> </ul>
<b>3. Prevention</b>	<ul style="list-style-type: none"> <li>o Prevention of injury</li> </ul>
<b>4. Education</b>	<ul style="list-style-type: none"> <li>o Education for health professionals</li> <li>o Enhance patient health literacy</li> <li>o Section for parents/carers</li> <li>o Education for employers and employees</li> <li>o Education for teachers and employers</li> </ul>
<b>5. Pain physiology</b>	<ul style="list-style-type: none"> <li>o Insight into what causes pain and affects on the body</li> </ul>
<b>6. Medication information</b>	<ul style="list-style-type: none"> <li>o Drug efficacy</li> </ul>
<b>7. Support</b>	<ul style="list-style-type: none"> <li>o Online chat with peers</li> <li>o Online chat/access to health professionals specialising in pain</li> <li>o Motivational/inspirational spaces</li> </ul>
<b>8. Available healthcare assistance</b>	<ul style="list-style-type: none"> <li>o Directory of health professionals specialising in pain management</li> <li>o Online repository for best practice</li> </ul>

## Meta-theme 3: Perception of an optimal pain service with a focus on the use of digital technologies

While participants articulated clear preferences for delivery of information, both in terms of technology and formats, their perceptions of what an ideal pain service should provide for young people varied greatly. These are discussed in further detail below across the two themes identified.

### 3.1 Preferences for delivery of information

Participants were unequivocal in their endorsement of apps and websites as the most effective way to deliver health information to adolescents and young adults. However, several participants cautioned the need for apps to be well designed, have useful functions, and be affordable and available to all smart phone platforms to optimise uptake. Similarly, it was perceived that websites should also be cross-platform compliant (mobile and desktop) to ensure reach across urban and rural areas and should include interactive features to actively engage users.

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**"I suppose you'd have to go with app at this stage because it's very freely accessible, the rate of people that have smart phones at the moment, particularly if we're looking at 16 to 24 age group." (IP16)**

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**"A website that is formatted for the mobile as well as desktop because it's easier than having to download an app that you might only use once."(IP09)**

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**"I'm on the iPhone and the iPad and the iMac, all of those. So I know a lot of people are on the android though, like the phones that aren't iPhones, but – or Samsungs, I think they're the two major players. So if you could develop an app that is not just for iPhones and it can be bought for both because I would definitely feel excluded if I had not got an iPhone and you developed something...It is quite frustrating and vice versa, sometimes they do develop them for the androids and they don't develop them for the iPhones, so...it is that barrier that you can't buy it because it's on the other system...and something preferably free if possible or super cheap, like 99 cents or \$1.99, I'm sure we'd be willing to fork out, but anything over that, I think a lot of people become more hesitant to buy it." (IP15)**

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Participants also preferred a variety of information formats including videos, blogs, podcasts, online surveys and traditional text. Whilst videos were noted as useful for hearing people's stories or understanding practical information such as exercise activities, several participants expressed concern about the length and potential download cost, recommending that videos should be no longer than three to five minutes.

*"...podcasts would be good because then you might be able to listen to them on your phone like when you're in the car or when you're out walking... videos if they were short but not if they were like a lecture-y kind of long video, I probably wouldn't do it". (IP07)*

*"I think [a] combination – the forums would be good for other people to find you know, sort of forum support groups, that sort of thing. Like videos could definitely implement as education and sometimes people have like different ways of learning. Some people can read the whole thing and totally get it, but other people need to have a more visual explanation, that sort of thing." (IP12)*

## 3.2 Components of an ideal pain service for adolescents and young adults

Responses across participants varied greatly with young adults (20-24 years) conveying a stronger conceptual understanding of what an ideal pain service might include compared to adolescents (17-19 years). However, a key feature of an ideal pain service that was strongly endorsed across ages was having age-appropriate services delivered at one location including access to a multidisciplinary health professional team, exercise activities/gym/recreational facilities and tailored education and self-management support (including support groups).

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"I'd like to see probably a variety just because you know, so that it's only a one stop shop for people with different chronic pain issues. Like there are some people that might find a physiotherapist really useful whereas other people might find, like you know, their GPs, they're just going there to have like a regular check up on things, that would be most useful for them and that would mean they wouldn't have to keep going around to a variety of different people individually, like having a few different types of health care professionals in the one area would be really convenient, because you can also have like appointments set up one after the other and not have to keep coming back at different days during the week, which can be difficult if you flare up after exercise or exertion." (IP08)

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"I think a place where you could go and see all your specialists and, you know, possibly they could all be in one room and discuss everything in one go and come up to one answer across the board. That would be very helpful." (IP14)

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"I think so much of education is focused on old people and old diseases and degenerative stuff. And I'm not saying that's not important, but I'm saying there needs to be a level of education about what young people experience and how that affects what they can do with their life...because I think, as you are trying to work out who you are as a young person too, it's quite difficult to manage yourself and your pain and work out where you fit and what you're doing." (IP03)

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Other features considered valuable included:

- having a venue that was disability friendly (particularly in relation to seating in waiting and consultation rooms)
- flexibility with appointments, including ability to book and manage appointments online
- delivery of services by different modes (i.e. face-to-face, Skype, telehealth).

*"...like a chronic illness person friendly area...in the waiting area, having like different options for seating, not just one specific black chair with a straight back type." (IP08)*

*"...well I mean there's always online resources, in which case I still think even if it's not face-to-face, it would be nice, even if it's done online, if people can actually, you know, talk to real people. Like talk to a real psychologist, talk to a real pain specialist, even if it's just like Skype or a chat mechanism or something." (IP06)*

Financial burden was also an important concern, with participants nominating a range of options including services being means tested, billed without an additional gap fee to pay (i.e. 'bulk billed') or where services could be provided on a loan basis.

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"Well, I obviously think it would be free, but...I suppose any sort of thing like that you'd obviously want to make it free but not everything in the world can be free. So it probably depends on if you could get funding for it, or maybe there could be like parts, sort of like a reduced cost, like part-payment kind of thing. I reckon make it as cheap as possible because just in my experience I'm pretty inclined to try anything that's not really going to cost me anything or much. But it's all the other doctors and things, because I've already wasted so much money on seeing specialists that will talk to you for about five minutes and charge you like \$AUD200, so if it's, yeah, as cheap as possible... maybe make the initial bit free, maybe when you might speak to a pain specialist or something, but then if they say, "Oh, you want to come to our class or support group with other young people?" and when, you know, you might do Pilates or meditation, I'd probably be inclined to pay a bit toward that." (IP07)

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"Maybe a health fees based system like university where you can sort of access the services immediately, so you can get immediate relief and then get on living your life so you can pay it back eventually. Like I think maybe you should be given a loan if you can't afford it on the spot. So and then pay it back when you can, when your back – when your pain's better and you can go back to work and start paying it off sort of thing." (IP02)

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GPs were nominated as the main reference point for referral to a pain service although other routes were advocated including social media, advertising through radio and television and information leaflets made available at schools and universities.

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"I actually think that as soon as a doctor tells someone that they have a chronic pain illness or they might have it, telling them straight away about this place that you can go to that will tell you everything you need to know would be awesome, but as well as, like, a lot of younger people are on technology these days, so advertising it on, like, you know, Facebook or YouTube and things like that but if they're a regular user it would just make it like, everyone would know about it." (FG1)

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*"I guess you'd have to go the traditional channels of making sure GP's know about it so they can refer people, and I guess letting other specialists know, so for example my rheumatologist could tell me a pain clinic, get your GP refer you, that kind of thing." (IP14)*

*"I would say the basic things like television advertisements, hospital, newspapers, radio... and also having a social media presence. Like it's pretty easy to set up a Facebook page or you know something similar to spread the word these days. Like a Twitter account or something." (IP08)*



# Discussion

We explored young people's experiences of living with persistent musculoskeletal pain, their perceptions about the associated challenges, burden-service gaps, and their perceived needs and preferences for modes of service delivery, particularly as they related to digital technologies. Young people eloquently described the very personal, complex, multidimensional, disruptive and nuanced nature of persistent pain associated with both specific and non-specific persistent musculoskeletal conditions. Clinical pain and psychological data triangulated with these unique idiographic recounts, further reinforce the impact of pain on wellbeing and highlight the individual variability of the lived experience of pain for young people. 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.

## Main findings

The 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, was clearly articulated. The intimate and 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 which for most, preceded their pain experience. The repeated failure by health professionals to legitimise young people's pain, especially in the absence of a clear diagnosis (i.e. non specific musculoskeletal conditions such as low back pain), highlighted the corrosive effect of uncertainty. This further fuelled fear, worry and anxiety about their future lives. Health services and resources aligned with developmentally-sensitive needs and preferences of young people were described as largely absent. The breadth of topics discussed clearly highlighted the profound lack of age-relevant and accessible information on chronic pain in young people, despite potential access to such resources through the use of digital technologies. The opportunities provided by digital technologies to provide accessible, affordable, reliable resources were seen as a key lever for active engagement of young people in developing shared solutions to improve their health and wellbeing.

## The impact and challenge of living with persistent musculoskeletal pain as a young person

Persistent pain impacts lives. We know this from unequivocal macro-level evidence from the GBD study (<http://www.healthdata.org/gbd/data-visualizations>; accessed 18 November, 2015) and also at the micro-level from this study and others<sup>15,21,45-57</sup>. Evidence for the enormity of impact is highlighted in our qualitative data, by the intersection of pain with every important part of young lives including sense of self now and in the future: the ability to study, to work, to financially support themselves, to socialise and to maintain relationships, on general wellbeing (psychological and physical), and lifestyle (functioning as a healthy young person, sleep, physical activity and exercise). This impact is equally reflected in our quantitative findings. For example, in comparison with normative data for the AQoL tool (Psychological Super Dimension: specifically capturing psychosocial dimensions) for the 16-24 year age group which has a reported mean (SD) of 80.5 (11.6) (Iezzini A; pers comm), our cohort mean (SD) values were substantially lower at 58.9 (17.6), data reflecting poorer psychosocial elements of health. The elevated symptoms of anxiety evident from the HADS scores, along with the finding that most people (61.4%) reported a diagnosed mental health condition at some point, is consistent with this interpretation. These quantitative data also align with the sense of fear and uncertainty described qualitatively by participants, which is evidenced by the theme of the fear of living a life in pain. Collectively, these impacts reflect the 'adversarial struggle' of living with persistent musculoskeletal pain, a term described by Toye et al<sup>58</sup> in a qualitative systematic review of patients' experiences of chronic musculoskeletal pain and highlighted by others<sup>1,2,16,45,59,60</sup>.



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The intimate and 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 which for most, preceded their pain experience.

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## It's not just about pain but all the other things it affects

Consistent relationships between different lifestyle factors, anxiety and depression, and chronic non-specific pain, multisite pain, and pain with high disability, have also been demonstrated in other adolescent populations<sup>9,61-63</sup>, similar to our findings. Understanding that as pain persists, brain networks can become disrupted, including key areas associated with regulation of cognition, affect, movement, reward, nociception, immune and autonomic function, helps to make neurobiological sense of such associated multidimensional manifestations and behaviours<sup>64</sup>. These changes vary across musculoskeletal pain conditions<sup>65,66</sup>, and within individuals<sup>64</sup>, and when combined with genetic and epigenetic factors, helps to explain the individuality of the lived experience of pain. Clinical and psychometric data further validated the inherent variability demonstrated through these personal accounts, and was reflected most tellingly by the wide range of scores (versus mean values) for pain intensity (VAS), psychological wellbeing (HADS-total; AQoL), self-efficacy (PSEQ) and catastrophising (CSQ).

## Pain gets in the way of study

Pain had a profound impact on the ability to study. Many participants were either transitioning through their final year of secondary school or undertaking university or TAFE studies. Pain interfered with their ability to effectively study, with some young people dropping out of studies. Combined with associated symptoms such as fatigue, altered sleep, low mood, and cognitive difficulties, this impact reflects the broader and complex body system interactions that occur when pain persists, highlighting the challenges for young people, especially at peak study times. Our findings align with those of a large Australian prevalence study showing that younger respondents with persistent pain were proportionately most likely to report interference due to pain, affecting 84.3% of females and 75.9% of males aged 20-24 years<sup>67</sup>. Similar findings have also been demonstrated in 17 year olds Australians with low back pain, and specifically chronic LBP, with significant negative impact on their wellbeing<sup>54</sup>. This pain-related interference with daily activities was significantly associated with younger age; female gender; and not having private health insurance<sup>67</sup>, themes resonating with those derived in our synthesis.

## Pain is a cost stress

Financial stress was an issue raised by young people, as they struggled to support themselves, frequently while studying and concurrently trying to maintain work. Persistent pain or mental health conditions alone impact the capacity to work, even more profoundly when combined<sup>7,68</sup>. The combination of these factors, in parallel with the cost of health services to support their wellbeing, meant that many could not afford to seek care, or consistently utilise care when needed. Fear of losing their job, emerged as one of the prime motivators for not revealing their pain to employers, an issue for young people with persistent pain raised previously by others<sup>69,70</sup>.

## Pain and fear: an unhelpful mix

Fear is pervasive in pain, and diverse in reach. The links between fear and pain evident in our study, including fear and beliefs about pain, fear of future self, fear about the inability to support themselves financially, fear about others' perceptions and (dis)beliefs, fear about whether '*hurt means harm*' have also been more widely acknowledged for young people with persistent pain<sup>45,59,69,71-74</sup>. High levels of pain-related fear may be a risk factor in relation to poorer treatment outcomes for children and adolescents with persistent pain, with the relationship between fear of pain, and changes in disability and depressive symptoms, closely linked<sup>71</sup>. Similar findings regarding fear about the future are also evident for young people in relation to mental health conditions<sup>14</sup>. In the context of our findings, the potential for pain-related worry to dominate cognitions about pain, and further contribute to catastrophic worry and negative health outcomes<sup>75</sup> is relevant for some young people, as evidenced by the higher scores for catastrophising (CSQ), some reaching close to the upper limit of the questionnaire.



## The invisibility of pain: not seeing, shouldn't mean not believing

Participants also described the tension created by the invisibility of pain. Lack of credibility or understanding about pain, can negatively impact self-esteem and confidence, with resultant stigmatisation and negative empathy in social, work and healthcare interactions <sup>76</sup>. While these themes were reflected in our findings, and mean scores for pain self-efficacy and catastrophising suggested only mild impairment, the range of scores also highlighted the individual variability and reinforced the need to target each young person's specific needs. Collectively, these findings may reflect resilience in these young people, despite living with persistent pain (and for many, with co-morbid mental health conditions), especially given most continued to endure with work, study and socialising. Pain self-efficacy beliefs are recognised as an important determinant of pain-related behaviours and disability, with higher pain self-efficacy beliefs being predictive of reduced avoidance behaviours <sup>38</sup>. Whether or not this resilience is protective across time in this cohort is an interesting question to consider.

## Diagnostic uncertainty about pain challenges legitimacy and sense of self

For people with musculoskeletal pain, fear about not being believed in association with diagnostic uncertainty, is common <sup>59,77</sup>, and was clearly described by young people in this study. Musculoskeletal conditions are frequently described as 'non-specific', meaning no clear pathobiological cause can be identified, and this can create tension between young people and their treating clinicians <sup>78</sup>. This does not mean that their pain is not real; however hunting for a tissue-based source for persistent pain is typically futile, and fails to acknowledge a more contemporary, neurobiologically plausible explanation for persistent pain <sup>79-81</sup>. Challenges to legitimacy for those with persistent undiagnosed pain are reflected by a desire for a biomedical diagnosis, outward and overt behavioural expressions of pain or illness, and reinforced credibility through meeting others with unexplained pain <sup>77</sup>. Diagnostic uncertainty can disrupt the 'sense of self' in the present, including a heightening of fears about what might happen in the future, and this was a common theme to emerge from our data. This disrupted sense of self has been conceptualised by others as a 'biographical suspension' <sup>58,77</sup> or putting 'lives on hold' <sup>45</sup>. Offering a cogent explanation to young people about why pain can persist, and how various mind-body systems can get intertwined, could help to provide a reassuring, meaningful, biologically plausible explanation for their experience <sup>82,83</sup> and provide legitimacy <sup>77</sup>. Evidence-informed educational resources grounded in conceptual change are available to move a person's conceptualisation of pain from that of a biomarker of tissue damage, to that of a biomarker of the 'perceived need to protect body tissue' <sup>83</sup>, thereby providing a rationale for a biopsychosocial approach to pain care.

## Pain and mental wellbeing are intimately related: both must be addressed

In over half of our study cohort, pain onset was preceded by mental health conditions, most commonly combined anxiety and depression. Similar findings have been reported in a population based Australian study of 16-24 years age group, with 49% experiencing co-morbid musculoskeletal pain and mental health conditions <sup>68</sup>. Pain and depression/anxiety co-morbidities are well-defined bedfellows <sup>6,7,62,84</sup>, with shared biological pathways <sup>6,64</sup>. Stress exposure during windows of vulnerability, such as the transition through adolescence to adulthood, can also initiate a cascade of events that make adolescents highly susceptible to the development of depression <sup>6</sup>. Perceived stress (for example, study pressures and demands) correlates strongly with reported health complaints in young people <sup>85</sup>. Of importance, prior disorder status is typically the strongest predictor of having the same disorder, with anxiety and depression tending to cross-predict from childhood/adolescence to adulthood <sup>9,61,68,86</sup>. This applies to both a disorder predicting itself over time ('homotypic' prediction, for example, earlier depression predicting later depression), and to different disorders predicting one another over time (for example, anxiety predicting later depression) <sup>86</sup>. Furthermore, anxiety and depression have been shown to interact synergistically with arthritis and neck/back disorders to increase the odds of reporting persistent pain beyond an additive model <sup>46</sup>.

## Gaps in service and perceived needs for pain management for young people

Young people's perceptions of an optimal service for pain management varied, with some able to articulate a more sophisticated understanding of what services were available and where service gaps lay. This finding is not surprising, given their different ages, diverse clinical pathways and experiences. In particular, a desire for integrated, holistic care that supported young people to actively self manage and take control of their care was evident. Care would ideally be accessible in primary care settings, with access to a multidisciplinary team, similar to our findings for adults living with persistent musculoskeletal pain<sup>21,23</sup>. Digital technologies were described as an intuitive choice to lever capacity for the delivery of evidence-based pain care, provide accessibility 24/7, and bypass the geographic and financial barriers associated with face-to-face health services.

## An absence of youth-friendly pain services

Young people articulated their desire to share decisions around their pain management; to be actively engaged in their management; to assume greater responsibility; all of which helps to build confidence in their own ability to effect positive change and strengthens their self-confidence<sup>87</sup>. The PSEQ mean score also supports this interpretation although the range of scores, also indicate individual variability. Being in control is important, as self-efficacy is a potential resiliency factor that can mitigate the influence that pain-related fear has on outcomes in youth with chronic pain<sup>69</sup>. These preferences are important to incorporate into service reform, as the use of digital technologies offers another option for young people to get timely access to e-health evidence-based, resources and services. Looking for ways to engage young people is critical, as despite the high burden of persistent pain and co-morbid mental health disorders in young people, they are recognised as the least likely to seek help or to access professional help<sup>14</sup>. Reasons for this are likely complex, but our findings support factors including inadequate service provision, inadequately trained health professionals, fear of stigma and lack of credibility, associated with the invisibility of pain, lack of accessibility, and the considerable financial burden. Furthermore, as highlighted by McGorry<sup>88</sup>, '...the pattern of peak onset and the burden of mental disorders in young people, means that the maximum weakness and discontinuity in the system occurs just when it should be at its strongest'. This is equally true for pain, when trajectories for adulthood are being mapped, and yet there is an absence of youth-friendly services that identify and respond to their age-specific biopsychosocial needs<sup>15</sup>.

## Bridging the service-burden gap to improve young lives

In Australia, around the age of 16 years, adolescents exit the paediatric health service and do not seamlessly integrate into the adult health services. Consequently, during this period of transition, adolescents frequently disconnect with health service providers, and are thus inadequately supported to manage health conditions, particularly highly impacting conditions such as pain and mental health. This is most critically evident in rural and remote areas of Australia, where geographic isolation and health resources often impose additional barriers to best practice care. Furthermore, given that emotional coping is recognised as a critical variable in the distress associated with adolescent persistent pain<sup>48</sup>, there is a clear need to bridge this service-burden gap. This is reinforced by the high variability of our catastrophising data, where some young people scored very highly. Potentially disadvantaged groups in Australia who are especially vulnerable include young people identified as Aboriginal or Torres Strait Islander; culturally and linguistically diverse; lesbian, gay, bisexual, transgender, queer, or intersex; homeless; substance using; and youth residing in rural or remote areas<sup>89</sup>. To avoid potentially preventable declines in health and unhelpful lifestyle choices, such as the abuse of alcohol, illicit drugs and inappropriate use of pain medications, appropriate support and information to help young people co-manage their health conditions, is therefore essential. Services need to actively incorporate and encompass the vital roles for social systems, including parents, family and friends and include young in the design of such services.

## Waiting in pain: we do have evidence, why is it not routinely applied?

As a result of the burden-service gap in mental health, Australia has recently been more progressive in implementing specialised services to treat and support young people with mental health problems <sup>88,90</sup> such as headspace <sup>91,92</sup>. This progressive approach stands in stark contrast to those 'waiting in pain' in Australia, with few dedicated paediatric pain clinics and limited dedicated, specialised services for young people with persistent pain outside paediatric rheumatology services <sup>15</sup>. Many of the issues raised in our study can be sensibly and pragmatically managed: we do have evidence for managing persistent pain, but it is not routinely applied <sup>93</sup>. Supposedly simple things like education about pain; reassurance; addressing beliefs about pain and pain-related fear require skill to articulate in a language and way that resonates with young people, and yet are frequently not done <sup>94</sup>. In the context of a lack of understanding about pain from health professionals, it is easy to see why.





# Where to

## Understanding pain as a whole community is a priority

Developmentally-sensitive, holistic and integrated healthcare services and dedicated resources for young people, were described as largely absent. While our understanding about pain and why it persists continues to evolve<sup>64,81</sup>, many of our health services, and training for health professionals and the general community, lag behind and remain oriented towards a biomedical model. This approach to pain has consistently failed, as well documented in recent high level reports<sup>1,2,17</sup>. Not one young person in our study reported a plausible, contemporary explanation for why pain can persist, or demonstrated what might be termed good 'pain literacy'.

Appreciating that pain is '...a conscious experience that can be, and often is, associated with nociception, but it is always modulated by a myriad of neurobiological, environmental, and cognitive factors'<sup>81</sup>, should help to extend our understanding from a biomedical, reductionist and simplistic view of pain, towards a more integrated, holistic self-referential perspective<sup>79</sup>. What is designed to be an adaptive, early warning system that is protective, can rapidly become maladaptive. The neurobiology underlying such changes is complex, non-linear and can include disruption of multiple systems (endocrine, autonomic, immune system, nervous system including brain networks associated with sensory, emotional, cognitive and interoceptive processing<sup>64,95,96</sup>). These changes are thought to underlie the link between emotional (cognitive and affective), behavioural and sensory expressions of pain. Factors such as disturbed sleep, nominated by our cohort, can also have profound feed forward negative impacts on pain and mood. Furthermore, the way in which the nervous system responds to both normal and noxious inputs (sensitisation<sup>97</sup>) changes, such that pain persists beyond an initial noxious event. Why this happens is unclear. Faulty encoding of an event may lead to overgeneralization, meaning that pain is evoked by events that are not in fact dangerous, rather the brain "overprotects" the person<sup>81</sup>. What is clear is that unimodal approaches for persistent pain are doomed to fail. Treatments must address the multidimensional components of pain and associated disability, in the context of what is important to the individual<sup>2,17,64,98</sup>.



# from here?

## Capacity building through the use of digital technologies

Given the increasing burden imposed by musculoskeletal pain, and the lack of skilled health workforce <sup>2,98</sup>, capacity building for improved pain management in Australia is critical. The use of digital technologies is one mechanism that can help to lever capacity building, enabling ready access to timely, evidence-informed e-health treatments for pain that complement traditional face-to-face services. However, rigorous testing for effectiveness on pain-related health outcomes, is a necessary requirement when implementing novel technologies <sup>99</sup>. Technologies extend to biometric devices, virtual reality, apps and e-interventions, web-enabled chat and online peer support. Given that young people are strongly socially-driven (including through social media and peer support/support groups) <sup>24</sup>, the use of digital technologies is an obvious lever to encourage their active engagement in developing age-appropriate pain management services and resources. In fact, the use of digital technologies was a preference articulated by young people in our study, and is an obvious choice of management tool given that 99% of young people in Australia use the internet, with 95% connecting daily and using this as their main source of information including health and mental health information <sup>14</sup>. Reimagining pain services with the use of digital technologies and social media as 'agents of change' can extend to broader social constructs around pain. While discrepancies in public belief systems may also impact health seeking behaviours and treatment adherence for mental health <sup>100</sup>, population based campaigns can also target unhelpful beliefs for example about back pain <sup>101</sup> and effect sustained change that translates into improved health and system outcomes <sup>102</sup>.

## Young people co-designing pain management solutions

Digital technologies also provide an opportunity for the development and implementation of innovative, responsive, flexible, agile health systems that more actively and deliberately engage with young people <sup>103</sup>. Innovation is needed to shape services that are evidence-informed and capable of delivering timely, affordable, integrated, evidence-based pain care. High-level contemporary guidance about what best practice models of care for musculoskeletal pain look like, is available <sup>104</sup>. This confluence of factors (service-burden gaps; policy-practice gaps; technologies-into-practice) could be seen as serendipitous: the digital disruption provides an opportunity to shape services by using the input of young people as integral part of service design and evaluation. These are the same young people who will be the mainstay of our workforce in the future, and act as 'role models' for the forthcoming generation of digital natives <sup>24,103</sup>. They will form part of the emerging workforce, including the health workforce and health administrators. In this context, a health economic analysis or modelling of utility for implementing appropriate accessible and sustainable care through e-health systems would be of significant interest for policy makers, health insurers, employers and clinicians.



## Online interventions as a component of pain management

Transitioning from adolescence to adulthood is a critical period of great change, so equipoise between over-medicalising conditions when inappropriate/not helpful, and failing to offer/deliver evidence-based services to meet needs in a timely manner, is needed. Future research will need to examine and explore adapting treatments for children/adolescents, and use non-inferiority designs to compare with established forms of treatment <sup>105</sup>. The evidence for use of internet-based interventions for young people with pain is evolving, but lags behind demands, an unacceptable situation. Emerging evidence shows promising support for social networking programs that can reduce pain in children and adolescents <sup>106</sup>. Further, there is also support for the efficacy and acceptability of internet delivery of family Cognitive behavioural therapy (CBT) for reducing pain and improving function among children and adolescents with persistent pain <sup>107</sup> and for treating and preventing anxiety and depression in clinical and general populations of young people <sup>108</sup>. Clinician-guided internet CBT for managing persistent pain is another possibility to adapt for application to young people, with evidence for significant improvements in disability, anxiety, depression, and average pain levels at post treatment compared with a control group <sup>109</sup>.

## Practice and policy considerations

This project has broad clinical, service delivery and policy implications. If we understood more about pain-related transitions from adolescent to young adults, including risk of co-morbidities, we might be in a better position to try out developmentally-sensitive methods of prevention and treatment <sup>86</sup>, prevent the transition from acute to persistent pain and align with policy calls for transforming health and education for young people <sup>110</sup>. There is a lot we can do and should be doing: access to pain management is a fundamental human right as outlined in the Declaration on Montreal <sup>111</sup>. Co-morbid pain and mental health problems are recognised in Australia as a problem <sup>68</sup>, yet managed typically in series rather than in parallel in an integrated manner. A common sense approach at the outset is a good starting point, with use of digital technologies for healthcare in an age group that sees technologies as an integral part of their lives. Such a model of care could be truly collaborative, working with young people to co-develop, implement, evaluate and iterate health services. This approach would also align with emerging 2nd wave health care systems that co-design care with, rather than for, consumers and which aim to improve health services across care settings. Not everyone needs everything: tailoring of pain services to individual needs would mean low, moderate and high level needs are differentially accommodated, consistent with a stepped approach to care. Digital technologies would be considered a complementary e-portal for pain management health services mitigating cost and access barriers. Digital technologies also provide a mechanism for active engagement of those who might otherwise fail to seek care, and encourage disclosure without fear of judgment by health professionals, while providing potential for greater input in their decision making <sup>112</sup>.

## Strengths and limitations

This is the first study to explore young Australian's views on their experience of persistent musculoskeletal pain, including challenges and perspectives on optimal services including the use of digital technologies. Strengths include purposeful sampling from urban and rural areas around Australia; quantitative data to inform the clinical casemix; iterative development of an interview schedule informed by pilot testing; data analysis by a content, as well as methods, expert; and data redundancy, in that the focus group was conducted to verify the individual interview data. The possibility of selection bias cannot be excluded, as we did not ascribe 'a priori' to maximum heterogeneity sampling, although it was finally achieved. Specific DSM-5 or ICD-10 mental health disorders were not reported. Our cohort was primarily represented by female participants: even when accounting for gender differences in prevalence for diverse musculoskeletal conditions (for example, fibromyalgia which has a dominantly female predilection), males were under-represented. While this may reflect selection bias, male participants were asked about why they perceived it was more difficult to recruit their gender: their perception included a statement that "pain is emasculating...men don't want to talk about it" (data not shown). This insight may align with data on gender differences in coping with persistent pain showing that girls use more emotional strategies whereas boys use more problem-solving strategies <sup>56</sup>.

## Conclusion

This in depth dissection exposes the complex, dynamic multidimensional nature of pain and highlights the burden-service gaps for young people with persistent musculoskeletal pain in Australia. Implementing care that is evidence-informed, developmentally-sensitive and with which young people will want to engage, requires innovation. Digital technologies provide an opportunity to provide reliable resources that are developed, tested, implemented, evaluated and iterated in collaboration with young people. Pain services and resources available through e-health portals could transform access to best practice pain care, mitigating care disparities imposed by geography, economic barriers or disability, and not simply complement conventional face-to-face services, but drive system efficiencies, enable rapid data capture to map health outcomes and offer individual tailoring of pain treatments to mitigate the default approach of 'one size fits all'. Driving innovation through the use of digital technologies to provide best practice management of musculoskeletal pain for the benefits of young people, and their future lives, requires a pragmatic, real world approach that is paralleled by, rather than retarded by, purist's approaches to clinical effectiveness trials and implementation science.



## KEY RESOURCES FOR YOUNG PEOPLE WITH MUSCULOSKELETAL PAIN

### Arthritis and Osteoporosis Victoria

<http://www.arthritisvic.org.au/>

Arthritis and Osteoporosis Victoria supports people with arthritis and other musculoskeletal conditions to live better with their condition.

### Arthritis and Osteoporosis Western Australia

<https://www.arthritiswa.org.au/>

The objective of Arthritis & Osteoporosis WA is to reduce the incidence and disabling effects of arthritis, osteoporosis and related conditions in the people of Western Australia.

### Arthritis Australia

<http://www.arthritisaustralia.com.au/>

The aim of AA is to bring quality of life to all people with arthritis and eliminate their suffering. AA provides support and information to people with arthritis as well as their families and friends.

### Painaustralia

<http://www.pinaustralia.org.au/>

Pinaustralia is a national not-for-profit body established to improve the treatment and management of pain in Australia.

### The Young and Well Cooperative Research Centre

<http://www.youngandwellcrc.org.au/>

The Young and Well CRC is committed to exploring and understanding the role of new and emerging technologies in the lives of young people. We believe that the risks of the online environment can be managed and that technologies can be deployed to improve the mental health and wellbeing of young people.

### eCentre Clinic The Pain Course (18 years and older) - Macquarie University, Sydney

<https://ecentreclinic.org/?q=PainCourse>

The Pain Course is a free, online and internet-delivered education program designed to provide good information about chronic pain and to teach practical skills for the management of chronic pain and emotional wellbeing.

### painHEALTH

<http://painhealth.csse.uwa.edu.au/>

The aim of the website is to help all Australian health consumers with musculoskeletal pain access reliable and usable evidence-informed information and skills to assist in the co-management of their musculoskeletal pain.

### ACI Pain Management Network (Youth Bytes) – NSW Agency for Clinical Innovation

<http://www.aci.health.nsw.gov.au/chronic-pain/painbytes>

This website is designed to help people gain a better understanding of their pain and help develop skills and knowledge in the self-management of pain in partnership with your healthcare providers. There's a youth channel with episodes for you to work through with a range of exercises and useful tips throughout.

## KEY RESOURCES FOR YOUNG PEOPLE WITH MUSCULOSKELETAL PAIN AND MENTAL HEALTH CONDITIONS

### Synergy

<https://www.youngandwellcrc.org.au/research/synergy/>

Synergy is a new e-mental health ecosystem of care for Australia's young people, incorporating complementary Young and Well CRC products, certified apps and web based interventions, running on an underpinning set of sector standards, digital interfaces and integrated technologies.

### headspace

<http://headspace.org.au/>

headspace is the National Youth Mental Health Foundation providing early intervention mental health services to 12-25 year olds. The service is designed to make it easy as possible for a young person and their family to get the help they need for problems affecting their wellbeing. This covers four core areas: mental health, physical health, work and study support and alcohol and other drug services.

### beyondblue

<https://www.beyondblue.org.au/>

beyondblue aims to provide Australians with the knowledge and skills to protect their own mental health: at work, home, school, university, online, and in communities across the country.

### Orygen Youth Health

<http://oyh.org.au/>

Orygen Youth Health (OYH) is a world-leading youth mental health program based in Melbourne, Australia. OYH has two main components: a specialised youth mental health clinical service; and an integrated training and communications program. OYH is part of the public mental health system in Melbourne and sees young people aged 15 to 25, with a focus on early intervention and youth specific approaches.

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# Appendix

## Appendix 1. Qualitative interview schedule

Understanding adolescent musculoskeletal pain and mental health

- Explain the study
- Confirm written consent
- Explain use of tape recorder and confirm that participants in the study will not be named or identified
- Advise that a word-for-word transcript of the interview will be sent to all participants to check for potential errors/misrepresentation.

### Preamble

Thanks again for agreeing to participate in this study. The reason we are conducting this interview/focus group is to try and understand the experiences and issues young people with pain face on a daily basis. What we want to achieve, by hearing your thoughts and views, is to develop useful resources, whether that be information, or skills and find out how you want these delivered so that they are relevant, engaging, usable and help young people, like yourself, to better manage your pain and emotions.

Before we start, I want to make sure you understand that all the information discussed with me today is strictly confidential and your recording will be de-identified. We are really interested in hearing your experiences and thoughts, no detail is too small and there are no right or wrong answers.

If you don't feel comfortable talking at any point, please let me know and we will stop. You are also free to pull out of the study at any time.

Do you have any questions or comments before I start the interview/focus group?

### Understanding your individual pain experience

1. Could you tell me about your experience with pain and how it affects your life?
  - (prompt) How has your pain changed your sleep/relationships/activity/school/work/goals?
2. Now we'll talk a bit about how you understand your pain
  - (prompt) so, what do you believe causes your pain?
  - (prompt) what does pain mean to you?
  - (prompt) what is your attitude to doing exercise or undertaking physical activities when you are in pain?
3. What are your main concerns about your pain?
4. What do you do to manage your pain?
  - (prompt) what about any social support i.e. family/friends/school/work?
  - (prompt) support from your doctor or other health professionals involved in your care?
  - (prompt) what about coping strategies? (relaxation, distraction, alcohol, medicine etc).
5. What things have you experienced that have made managing your pain difficult?
  - (prompt) so these are difficulties you have in managing your emotions/feelings/state of mind?



## Exploring relationship between pain and mental health

6. What effects has pain had on your general emotions or sense of wellbeing?
  - (prompt) so, for example does your pain impact on things like feeling down or upset, stressed, angry or confused?
7. Thinking about your pain and your emotions, do you think your emotions impact on your pain or does your pain impact on your emotions?
  - (prompt) so, for example, do you feel down or angry or stressed?
8. Can you describe how both your pain and emotions affect your daily activities?
  - (prompt) has pain/emotion affected sleep/relationships/activity levels/quality of life?
  - (prompt) has pain/emotion changed your ability to take part in things you like to do?
9. Do you think the combination of your pain and emotion affects your confidence to live the life you want to?
10. What things help you to manage your emotions?
  - (prompt) do these things change your pain?

## Exploring needs

[n.b. interviewer to tailor questions in this section so they refer to pain or emotion or both as appropriate]

11. Can you tell me about any healthcare services you have used for your pain or emotions or both?
12. Have you found the services helpful?
  - If yes, how?
  - If no, why not?
13. Have any of the healthcare services or information you have come across, been tailored specifically for you and your direct needs or have they been more general?
14. In your opinion, what is the biggest thing missing to help young people manage their pain and/or emotions?

## Designing an ideal service

I now want to give you a scenario, if you were asked to design a complete service that catered to the needs of young people with pain, what would it look like? I know that it is putting you on the spot so let's break it down into components.

15. So firstly, what types of things would you include in the service?
  - (prompt) knowledge/education, skills/self-management
  - (prompt) which people/professionals would you include?
  - polls/feedback and satisfaction surveys
16. How would the service work?
  - (prompt) how could people access it?
  - (prompt) what would the service do for people?
  - should it be costed or free?

## ICT solutions

OK, we are now at the last part of the interview. One of the things we are interested in is to develop some sort of IT solution, to help young people manage their pain and emotions. I'm now going to ask for your opinion and views on a few things relating to this idea.

17. What type of IT format would you be most likely to use?

- (prompt) for example, a website, app, blog

18. What features would you recommend including in this IT solution to help young people manage their pain and emotions?

- (prompt) for example, podcasts, videos, online surveys

19. Do you think that there should be a section for parents, carers or significant others within this IT solution?

- (prompt) what would you include in that section?
- (prompt) what about information for any other groups?

## Conclusion of interview/focus group:

- Reiterate that all participants will be sent a copy of the verbatim transcript of today's discussion in the next few weeks to check for potential errors/misrepresentation.
- Thank participants for their time



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