

# BMJ Open Young people's experiences of persistent musculoskeletal pain, needs, gaps and perceptions about the role of digital technologies to support their co-care: a qualitative study

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**To cite:** Slater H, Jordan JE, Chua J, *et al.* Young people's experiences of persistent musculoskeletal pain, needs, gaps and perceptions about the role of digital technologies to support their co-care: a qualitative study. *BMJ Open* 2016;**6**:e014007. doi:10.1136/bmjopen-2016-014007

► Prepublication history and additional material is available. To view please visit the journal (<http://dx.doi.org/10.1136/bmjopen-2016-014007>).

Received 24 August 2016  
Revised 20 October 2016  
Accepted 16 November 2016



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## ABSTRACT

**Objective:** To investigate young people's experiences of persistent musculoskeletal pain, including care needs and current service gaps as well as perceptions about the role of digital technologies to support their co-care.

**Methods:** A qualitative study employing two independent data collection modes: in-depth individual semistructured interviews and focus groups.

**Setting:** Community settings throughout Australia.

**Participants:** Participants were included if they had experienced persistent musculoskeletal pain of >3-month duration with an average of  $\geq 3$  on the visual analogue scale over the preceding 3 months, including non-specific conditions (eg, low back pain) and specific conditions (eg, juvenile idiopathic arthritis and other systemic arthritides), with/without pre-existing or current diagnosed mental health conditions. 23 young people (87.0% women; mean (SD) age: 20.8 (2.4) years) from across 6 Australian jurisdictions participated. Almost two-thirds of participants with persistent musculoskeletal pain reported comorbid mental health conditions.

**Main outcome measures:** Inductive and deductive approaches to analyse and derive key themes from verbatim transcripts.

**Results:** Participants described their daily experiences of living with persistent musculoskeletal pain, their fears and the challenges imposed by the invisibility of pain, and the two-way relationship between their pain and mental well-being. A lack of relevant and accessible information and resources tailored to young people's unique needs, integrated and youth-relevant healthcare services and adequately skilled healthcare practitioners were identified as key care gaps. Participants strongly advocated for the use of digital technologies to improve access to age-appropriate resources and support for co-care.

**Conclusions:** Young people living with persistent musculoskeletal pain described the absence of age-appropriate pain services and clearly articulated their perceptions on the role of, and opportunities provided by, digital technologies to connect with and support

## Strengths and limitations of this study

- In-depth interviews with 23 young people with persistent musculoskeletal pain recruited through purposeful sampling from across Australian jurisdictions.
- Data redundancy achieved and qualitative data complemented by clinical characterisation of the cohort.
- Generalisability to a wider young population with persistent musculoskeletal pain, given the dominantly female sample.
- Possible selection bias as we did not ascribe 'a priori' to maximum heterogeneity sampling, although it was achieved.
- Possible lack of transferability of findings to health systems in other countries, particularly those of middle-income and low-income economies.

improved pain healthcare. Innovative and digitally-enabled models of pain care are likely to be helpful for this group.

## INTRODUCTION

Living with persistent musculoskeletal pain is challenging, even more so during the transition from adolescence to adulthood when young people are juggling complex biological, psychological and social changes and attempting to make sense of their identity.<sup>1</sup> The problem of persistent musculoskeletal pain is big, imposing a substantial health and economic burden on young people and the broader community.<sup>2 3</sup> The scale of the problem is highlighted by the Global Burden of Disease (GBD) study data for musculoskeletal conditions, with years lived with disability for ages 10–14 years reported as 8.6% (uncertainty interval (UI): 7.2 to 10.3), increasing to 20.3% (UI: 18.1 to 23.0)



between the ages of 20–24 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 (ie, ~20%),<sup>2–4</sup> international data suggest higher rates for musculoskeletal pain<sup>5</sup> (eg, 37% for back pain), particularly in girls.<sup>6</sup> The prevalence of mental health conditions also peaks during this period, with up to 25% of adolescents experiencing a mental health condition.<sup>7</sup> Higher prevalence rates for comorbid pain in cohorts with depression and for depression in cohorts with persistent pain are reported than those for the individual conditions alone.<sup>8</sup> Furthermore, up to 75% of people who experience mental health problems also experience pain,<sup>9–10</sup> and coexistent psychiatric symptoms increase the prevalence of chronic multisite pain.<sup>11</sup>

Despite the identified burden of persistent pain in young people, particularly of musculoskeletal origin,<sup>6</sup> a substantial burden-service gap exists in Australia<sup>2–12</sup> and internationally.<sup>13</sup> While primary care services and resources are available to young people to address mental health problems in Australia,<sup>14</sup> age-appropriate, accessible and reliable resources to address pain are lacking and fiscal constraints limit service expansion.<sup>12</sup> Tertiary pain medicine and rheumatology units are under-resourced across Australia,<sup>12</sup> and primary care services remain fragmented in terms of service consistency and workforce capacity with care disparities, particularly acute in rural and remote areas.<sup>15–16</sup> Furthermore, the translation of paediatric models of care to young people and adult models of pain care to young people is not appropriate for many reasons, including the different developmental stages and what engages young people to facilitate their co-care.<sup>17</sup>

In parallel with these burden-service challenges, an opportunity exists to lever the implementation of key age-appropriate resources and tools for musculoskeletal pain care as young people are technologically sophisticated in using information and communication technologies.<sup>18</sup> Digital technologies provide a mechanism by which to provide accessible, sustainable information about musculoskeletal pain and comorbid health conditions.<sup>19</sup> This opportunity highlights the need to explore in young people their experiences of persistent musculoskeletal pain, their perceived health needs and preferences for ways in which these needs are supported using digital technologies. We aimed to explore young people's: (1) experiences of living with persistent musculoskeletal pain; (2) their needs for information, skills and support, to better manage their musculoskeletal pain condition(s); (3) their preferred modes of service delivery, particularly as they relate to accessibility and the use of digital technologies.

## PATIENTS AND METHODS

### Study design

This qualitative study was undertaken in Australia between October 2014 and April 2015, as part of a

broader mixed methods research study exploring the experiences of young Australians with persistent musculoskeletal pain.<sup>1</sup> The study had institutional ethics approval, adhered to the Declaration of Helsinki and aligned with reporting recommendations from COREQ-32 criteria<sup>20</sup> (see online supplementary file 1).

### Recruitment and sampling

Participants were recruited from community sources, including arthritis consumer organisations, clinical practices, youth mental health services, the Young and the Well Cooperative Research Centre: <http://www.youngandwellcrc.org.au/> and the Young Female Health Initiative Research Program: <https://www.yfhi.org/useful-links/>.

Initial eligibility screening was undertaken through an online survey platform Qualtrics (Provo, Utah, USA; <https://www.qualtrics.com/research-suite/>), which allows tailored survey design, data capture and analysis. Participants completed questionnaires to characterise their musculoskeletal pain and participated in in-depth qualitative interviews; either one-to-one or in a focus group. At the completion of the interviews, participants received an AUD \$50 gift voucher.

### Consent

Participants meeting the inclusion criteria consented through the Qualtrics survey platform. Participants aged 16–17 years were advised to discuss consent with their guardian/parent and were invited to have a guardian/parent join them for the qualitative interview.

### Inclusion and exclusion criteria

Young people aged 16–24 years were recruited, as this was the most appropriate age range for our variables of interest and aligned with the Australian Institute of Health and Welfare reporting on young people's health and well-being.<sup>21</sup> The clinical presentation associated with musculoskeletal conditions varies between individuals and across conditions, as does the associated pain, disability and psychological distress, notwithstanding a clinical diagnosis.<sup>22</sup> Therefore, participants with musculoskeletal conditions, specific and non-specific, were included consistent with a contemporary understanding of persistent pain, and the lack of consistent correlation between pain and tissue pathology.<sup>23</sup> Participants were required to report musculoskeletal pain of >3-month duration with an average of  $\geq 3$  on the visual analogue scale over the preceding 3 months including, but not limited to, non-specific conditions (eg, low back pain and fibromyalgia) and specific conditions, including juvenile idiopathic arthritis and other systemic arthritides with/without pre-existing self-reported mental health conditions. Reading and comprehension of English were required. Exclusion criteria included pregnancy and a history of previous/current active, clinically diagnosed psychosis.

**Table 1** Psychometric measures used to characterise young people's musculoskeletal pain and psychological well-being

Psychometric tool	Scoring
ÖMSPQ-SF: the SF (10 items) of the ÖMSPQ is appropriate for clinical and research purposes, as it demonstrates near equivalent accuracy, compared to the longer version, <sup>25</sup> which has demonstrated reliability and validity.	Items are scored 0–10; 0 refers to the 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 of >50 indicating higher estimated risk for future work disability. The SF has been tested in occupational and musculoskeletal adult cohorts in primary care. <sup>25</sup>
CSQ (subscale 2; catastrophising). The catastrophising subscale of the CSQ <sup>26</sup> was used to assess general pain catastrophising beliefs.	This subscale lists six items that are scored using a 7-point Likert scale with responses 0 indicating 'never' to 6 indicating 'always'. Scores can range from 0 to 36 with higher scores indicating greater catastrophising beliefs.
HADS: HADS is a 14-item measure of self-reported symptoms of anxiety and depression widely validated and with good psychometric properties. <sup>27</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).
PSEQ: <sup>28</sup> PSEQ is a valid and reliable measure of a person's beliefs and confidence regarding their ability to undertake activities despite pain.	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.
AQoL: AQoL is an 8-domain questionnaire (35 items) psychological super dimension subscales (ie, subscales 4–8 inclusive) was used to capture overall psychological well-being. <sup>29</sup>	The psychological super dimension can be used as a stand-alone instrument, as it was derived to have independent content validity. 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.

AQoL, Assessment of the Quality of Life; CSQ, Coping Skills Questionnaire; HADS, Hospital Anxiety and Depression Scale; ÖMSPQ-SF, Örebro Musculoskeletal Pain Screening Questionnaire-Short Form; PSEQ, Pain Self-Efficacy questionnaire.

Following consent and eligibility screening, participants completed a questionnaire to capture demographic and clinical data. Validated psychometric measures used in primary care<sup>24</sup> and commonly collected in clinical pain research were included (table 1).

Twenty-three young people (87% women) from six Australian states and one territory were recruited (demographic data are summarised in table 2).

Participants reported a wide mix of musculoskeletal conditions; pain duration was typically of long (group mean (SD) range: 68.4 (52.2) (5–240)), and comorbid mental health conditions were common (60.9%), and persistent (group mean (SD), range: 52.9 (43.8) (6–144)). Collectively, the negative impact of pain on general well-being was evident through the Assessment of the Quality of Life (AQoL) score (psychological super dimension incorporating: self-worth, coping, relationships and happiness domains; table 3).

### Interview data collection

A semistructured interview schedule prepared by the multidisciplinary research team (JEJ, AMB, HS and RS) was piloted with three individuals within the target population (data not included in analyses) and, where relevant, content was revised to improve clarity and reduce item redundancy (see online supplementary file 2). Participants were contacted preinterview to outline

the process and discuss any questions. Five participants did not respond to phone contact. Qualitative data were collected via (1) one-to-one telephone interviews and (2) virtual focus group via teleconferencing. These two qualitative methods ensured validity of the findings,

**Table 2** Demographic characteristics of participants (n=23)

Age (years) mean (SD) [minimum—maximum]	20.8 (2.4) [17–24]
Gender (women)	20 (87.0)
English as a first language	22 (95.7)
Highest current level of education completed	
University	8 (34.8)
TAFE*	4 (17.4)
Year 12 (tertiary entrance)*	8 (34.8)
Year 12 (other)	3 (13.0)
Less than 3 year secondary	0
Currently at	
School	3 (13.0)
University or TAFE	14 (60.9)
Unemployed	1 (4.4)
Employed (volunteer or paid work)	5 (21.7)

\*n=2 participants indicated being at TAFE and undertaking tertiary examinations for year 12.

TAFE, technical and further education institutions.

**Table 3** Individual participant clinical characteristics (n=23)

Code	Sex	Age	Diagnosis*	Pain duration (months)	Mental health conditions (yes/no)	Mental health duration (months)	ÖMSQ (possible score 1–100)	HADS (total: possible score 0–42)	PSEQ [possible score 0–60]	CSQ (catastrophising subscale; [possible score 0–36])	AQoL-8D; (MSD; possible score 0–100)
IP01	F	21	JIA; fibromyalgia*	90	N		43	8	43	13	69
IP02	F	23	Fibromyalgia*	84	Y	12	53	17	40	18	49
IP03	F	24	Neck/shoulders/back	72	Y	48	45	15	46	3	61
IP04	F	22	Neck/back pain	58	Y	37	57	25	43	9	29
IP05	F	24	Low back pain	54	N		27	14	39	18	72
IP06	F	19	Bilateral knee pain	60	N		27	14	60	1	74
IP07	F	20	Back pain/sciatica*	38	Y	120	73	18	21	29	52
IP08	F	24	Shoulder/back*	14	Y	34	40	22	52	6	54
IP09	M	22	AS*†	84	Y	36	41	25	18	16	40
IP010	F	20	JIA*	240	Y	12	60	14	46	6	60
IP11	F	20	CTD*‡	35	Y	60	49	26	38	5	33
IP12	F	19	Hips/knees/back	60	Y	144	50	14	39	15	64
IP13	M	21	Back pain*	32	Y	32	36	10	57	18	71
IP14	F	24	Fibromyalgia*	37	N		42	10	46	18	74
IP15	F	24	Ankylosing spondylitis/OP*	54	N		33	9	37	6	70
IP16	M	22	Low back pain/sciatica*	56	N		33	5	60	8	87
IP17	F	23	Inflammatory arthritis§/OA*	126	N		31	4	56	4	79
IP18	F	19	Fibromyalgia*	87	N		52	10	45	18	59
FG01	F	18	Knee pain*	36	N		38	6	54	5	77
FG02	F	18	Scoliosis (back)*	90	Y	96	56	17	38	16	51
FG03¶	F	17		38	Y**		20	2	57	6	71
FG04¶	F	18	Low back/hip pain*††	8	Y	6	47	17	10	26	48
FG05¶	F	18		5	Y	39	45	27	54	11	56

Except where indicated otherwise, values are presented as n (percentages).

\*Clinical diagnosis made by health professional.

†Also pituitary adenoma and acromegaly.

‡Unspecified Connective Tissue Disorder with Sjogren's features.

§Seronegative.

¶No specific clinical diagnosis was available from transcripts due to confidentiality requirements of the FG.

\*\*Previously history of clinically diagnosed anxiety but now resolved.

††Comorbid endometriosis.

AQoL-8D, The Assessment of Quality of Life Eight Dimension Scale (psychological super dimension only); AS, ankylosing spondylitis; CSQ, Coping Strategies Questionnaire-Pain Factor 2: catastrophising subscale; CTD, connective tissue disorder; FG, focus group participant; HADS, Hospital Anxiety and Depression Scale; HADS-A, anxiety subscale; HADS-D, depression subscale; IP, individual participant; JIA, juvenile inflammatory arthritis; OA, osteoarthritis; ÖMSPQ-SF 10, Orebro Musculoskeletal Pain Screening Questionnaire-Short Form 10; OP, osteoporosis; PSEQ, Pain Self-Efficacy Questionnaire.

minimised bias and achieved triangulation of derived themes.<sup>30</sup>

Eighteen interviews and one focus group (five individuals) were conducted by a senior qualitative researcher (JEJ) and a senior specialist musculoskeletal physiotherapist/clinical researcher in the field of musculoskeletal pain (HS). Audio-recorded interviews ranged between 20 and 50 min, while the focus group was 50 min. Verbatim transcripts were participant-checked for accuracy.

### Analysis

Data were analysed in two stages using inductive and deductive approaches by one researcher (JEJ). In the first stage, an inductive analysis based on grounded theory was undertaken. The grounded theory approach was selected because it supports a method of developing theories and concepts without starting from a prior theoretical understanding of the issue; that is, concepts are derived inductively, or from 'the ground up'. This approach is critical in the context of our study, as understanding of young people's needs as they relate to persistent pain is poorly understood. Thirteen interview transcripts were analysed using a specified process<sup>31</sup> that begins with basic description and moves to conceptual ordering and then on to theorising.<sup>32</sup> This process involved constant comparison of data over a period of time until no new themes, dimensions or relationships emerged (data redundancy).<sup>31</sup> For the second stage, the focus group and another five interview transcripts were analysed deductively, using the derived coding framework from the first stage, to verify data redundancy. Where a new topic emerged from the focus group data, a corresponding theme was developed inductively. One third of the interviews transcripts (n=6) was analysed independently (HS) to confirm themes identified, and where necessary, refine to reach consensus. Data were structurally organised to present themes in a logical explanatory scheme.<sup>32</sup>

## RESULTS

This paper is drawn from a broader mixed methods study of persistent pain in young people (see <http://www.move.org.au/Research/Funded-Research/Completed/Painful-Transitions>). To provide a clear structure to understand this subset of unpublished data, key themes derived are discussed under the stated aims of the project.

### Aim 1: explore young people's experiences of living with persistent musculoskeletal pain

Persistent pain negatively impacted multiple and inter-related aspects of young people's lives, including study, workforce participation, fear of living a life in pain, sleep, physical activity, daily tasks and overall lifestyle. Online supplementary file 3 provides a summary of these themes. Below we discuss the strongest of the themes (subheadings) to emerge: fear of living a life in

pain, lack of understanding about what pain meant and fears around the lack of legitimacy.

### Fears

Many participants feared that they were destined for a life in pain. Participants described their beliefs about what pain meant, not only for them currently, but also in the future. For some, the prospect of managing their condition when they were older was daunting given previous ineffectual treatments.

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. (IP01)

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. (IP05)

Participants also expressed fear about others' perceptions and legitimacy about their pain.

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

### Invisibility of pain

The invisible nature of pain also hampered participants' experiences in receiving understanding, empathy or even acknowledgement from others. For some, the lack of physical evidence, such as a deformity, or a specific clinical diagnosis, resulted in more profound perceptions of exaggerating pain or doubt that young people could experience persistent pain. Consequently, some participants coped by internalising their pain, not wanting to complain.

What I've sort of found with other young people, unless they've got the same sort of mystery pain situation that I do...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?" ...But if you're always just sort of saying, "Oh, you know, I've got a really sore back," ... it's sort of like you're always complaining. So I just try to not mention it, ever. (IP07)

But especially people my age, but even from dorm parents and teachers who just—they can't see it so they can't believe it. Like it's one of those things that they go, "Oh, you're putting it on. It's not that bad", like, you know? (FG1)



## The two-way relationship between pain and mental well-being

Most participants reported a two-way relationship between their pain and mental well-being: pain was worse with emotional upset, anxiety or low mood. Low mood was reported to occur more commonly if pain was exacerbated. Coping, physically and psychologically, was described as challenging.

I think it's a two-way street, yeah. I think if I'm upset I more acutely feel—if I'm upset or miserable I notice when I feel bad. I notice that my back's more sore and I'm more likely to let it stop me from doing things. (IP03)

Some participants described life as passing them by, unable to enjoy 'normal' experiences.

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. (IP04)

For those lacking a specific clinical diagnosis, continual worry over making the right decisions about treatment and the reasons for persistence of pain also negatively impacted their mental well-being.

It was [worry] 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 shit, you know, I'm going to make it worse. (IP04)

Different approaches to managing pain and mental well-being were described. Many indicated seeking an integrated, holistic approach to managing pain and well-being, adopting active coping approaches (eg, stretching and exercise, mindfulness, breathing, socialising and listening/reading to peers' experiences in coping with persistent pain) and passive (eg, medication and hot/cold compression) strategies.

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)

## Aim 2: explore needs for information, skills and support to better manage pain condition

Participants were unequivocal in identifying the need for:

1. health professionals who understood persistent musculoskeletal pain and
2. an integrated (ie, responsive to a whole person approach to care) healthcare system catering specifically to young people's needs.

These themes are discussed further below.

## Health professionals who understand persistent musculoskeletal pain

Participants' experiences with health professionals in the diagnosis, treatment/management of persistent pain, were overwhelmingly negative with frustrations for some, at failing to receive a clinical diagnosis, or for others, failing to be given a cogent explanation for their persistent pain. Medical practitioners were perceived to be particularly dismissive and unwilling to assist in making a diagnosis, providing an explanation/guidance about persistent pain, or providing treatments other than medications.

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)

Some participants reported that health practitioners failed to show compassion for young people juggling work, study, finances and seeking independence.

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...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)

## Need for integrated healthcare system catering specifically to young people's needs

Participants described feeling overwhelmed with the specialised and varied information about pain provided by different health professionals, and experienced difficulty in fitting information together to provide an integrated, holistic approach to pain care. Several participants commented on difficulty in finding a general practitioner who was affordable and could coordinate care or follow-up on a regular basis.

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 (IP04)

**Table 4** Topics identified by participants where more information was desired to assist young people with the management of their persistent pain

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

Furthermore, a profound lack of age-relevant and accessible information on persistent pain for young people was reported. Participants identified a vast array of information and assistance needed, including self-management, online screening/diagnostic tools, education, most notably for health professionals, pain physiology, mental well-being and support avenues (table 4).

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)

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)

### Aim 3: explore preferred modes of service delivery with a focus on digital technologies

Digital technologies were perceived as the most effective way to deliver health information to young people with participants having clear preferences for using apps and websites. Several participants cautioned the need for apps to be well designed, have useful functions, be affordable and available to mobile devices to optimise

uptake. Similarly, it was perceived that websites should also be cross platform (mobile and desktop) to ensure reach across urban and rural areas, and content should include interactive features to actively engage users.

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)

I like apps on my phone...The problem with apps is they have to be well-designed; otherwise, you don't use them...which is, I think, an issue of cost. (IP03)

Use a website. Tailor a website specifically for [young] people. (IP11)

I think having like an online course would be nice, having one aimed at the actual young people like the patients as well as having either a component of that course or a separate course directed at the parents. (IP06)

Digital technologies were considered useful to assist in tracking medications, reminders for different healthcare appointments, as well as being able to connect with peers in similar situations or understand practical information such as exercise activities.

Yeah, blogs are important for I think hearing other people's stories. That's a really—all the pain management websites I've visited so far, that's been a really comforting thing, to read about people who have had chronic pain and overcome it, that's a really nice personalised touch to the site. (IP02)

I would be probably most likely to use—if it was an emotional support base thing I would like some kind of a social network/blogging platform...where young people can like you know, get together and share their own blog posts and ... where they can kind of customise their own page or whatever and share information with each other and support each other. (IP08)

Preferences for delivery formats were diverse, including videos, blogs, podcasts, online surveys and text, while the use of telehealth was also perceived as important.

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 on your, when you're out walking or whatever, but —yeah, so maybe, well, 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)

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)

## DISCUSSION

Young people with persistent musculoskeletal pain fear a life lived in pain and described the challenges imposed by a health system that is fragmented, health professionals who inadequately understood persistent pain and services that failed to meet their age-appropriate needs. While these experiences have similarities with adult populations with persistent musculoskeletal pain,<sup>33–37</sup> what is striking is that young people are frequently the least likely to seek help or to access professional help for their pain,<sup>38 39</sup> especially when they have comorbid mental health conditions.<sup>14 40</sup> In this context, the use of digital technologies to provide accessible, evidence-based resources was perceived as a key lever for actively engaging these young people in developing shared clinical solutions to improve their health and well-being and better connecting them with support from peers and health professionals.<sup>41</sup> Novel ways to engage young people with persistent musculoskeletal pain early on in their care are critical, given the complex biological and psychological changes that occur during this developmental phase and the potential for increased risk of ongoing pain and associated comorbidities.<sup>42–44</sup>

Young people's nuanced experiences reflect the recognised 'adversarial struggle' of living with persistent musculoskeletal pain,<sup>2 3 33 45</sup> a term originally described by Toye *et al.*<sup>46</sup> Pain is not simple; pain is challenging to understand for the person experiencing pain and for their health professionals. As pain persists, brain networks can become variably disrupted, including areas associated with cognition, affect, movement, reward, nociception and immune and autonomic function.<sup>47</sup> This disruption helps to make sense of the individual,

complex, multidimensional manifestations of pain, an interpretation also reflected in the range of responses to standardised clinical questionnaires (see [table 2](#)). Collectively, these data indicate overall poorer psychosocial elements of health (AQoL: group mean (SD) 60.9 (14.9) compared with age matched normative age-matched values of mean (SD) 80.5 (11.6)).<sup>29</sup> Furthermore, these variable clinical responses of young people to pain regardless of their different musculoskeletal conditions necessarily challenges a biomedical interpretation of pain.

Links between fear and pain were evident, including fearful beliefs about pain, fear of future self, fear about others' perceptions and fear about whether 'hurt means harm'; all factors widely acknowledged among young people and adults with pain.<sup>33 48 49</sup> The potential for pain-related worry to dominate cognitions about pain, and escalate into catastrophic worry and negative health outcomes,<sup>50</sup> was relevant for some participants (see [table 2](#), Coping Skills Questionnaire scores). Fear about being not believed in association with the invisibility of pain, with and without diagnostic uncertainty, was a common theme, consistent with others' findings.<sup>37</sup> Musculoskeletal conditions are frequently described as 'non-specific' (meaning no clear pathobiologic cause can be identified). Here, diagnostic uncertainty can disrupt the 'sense of self' and heighten fears about the future, creating tension between young people and their treating clinicians,<sup>35</sup> as evidenced in our study. Therefore, offering a cogent explanation to young people about why pain can persist can help to provide a reassuring, meaningful, biologically plausible framework to explain their experience<sup>51</sup> and provide legitimacy.<sup>37</sup>

Mental health conditions, most commonly combined anxiety and depression, preceded pain onset in over half our cohort, findings consistent with population-based Australian data for this young age group, showing 49% experienced comorbid musculoskeletal pain and mental health conditions.<sup>52 53</sup> Pain and depression/anxiety comorbidities are well-defined bedfellows<sup>7 8</sup> with shared biological pathways.<sup>7 47</sup> Furthermore, anxiety and depression have been shown to interact synergistically with arthritis and neck/back disorders increasing the odds of reporting persistent pain.<sup>54</sup>

Age-appropriate, integrated healthcare services and dedicated resources for young people were described as largely absent, findings consistent with recent high-level reports.<sup>2 3 13</sup> For those 'waiting in pain', few dedicated, specialised services exist for young people in Australia.<sup>12</sup> Evidence for managing persistent pain, while available,<sup>55</sup> is not routinely applied.<sup>56</sup> Although our understanding about persistent pain continues to evolve,<sup>47 57</sup> many health services and training for health professionals and the general community's knowledge remain biomedically oriented, rather than aligned to a more contemporary, meaningful biopsychosocial model.<sup>51</sup> This aligns with young people's desires for integrated, holistic care that does not impose an older adult model on them, but



which resonates with their age group: supporting young people to self-manage; to share decision-making; to access peer support; to assume greater responsibility and to build confidence in their ability to effect positive change and strengthen their self-confidence.<sup>58</sup> The use of digital technologies to lever improved pain care is intuitive given 99% of young people in Australia use the internet, with 95% connecting daily and using this as their main source of health information.<sup>14</sup> Digital technologies provide an opportunity for the design of innovative, age-appropriate, flexible, agile health systems that actively engage young people,<sup>59</sup> complement face-to-face delivery of health services and provide 24/7 accessibility, bypassing geographic and financial barriers associated with traditional service delivery. Emerging evidence shows promising support for the use of social networking programmes to reduce musculoskeletal pain in young people;<sup>60 61</sup> internet delivery of psychological interventions for reducing pain and improving function<sup>62</sup> and clinician-guided internet cognitive-behavioural therapy with significant improvements in disability, anxiety, depression and pain levels.<sup>63</sup>

Strengths of this study include purposeful sampling from jurisdictions around Australia; clinical characterisation of participants; iterative development of an interview schedule informed by pilot testing; data analysis by a content/methods expert and data redundancy. The knowledge gap filled by this study is also timely considering the increased attention towards health system reform in primary care settings across the global, particularly as it relates to better managing chronic health conditions and comorbid mental health conditions and leveraging ehealth and mhealth to improve information and service delivery for young people.<sup>61</sup> The results should be interpreted in the context of some limitations. First, we recruited a dominantly female sample, suggesting different approaches to recruiting young men to such studies may be required. While the prevalence of musculoskeletal health conditions and pain is greater in women, we cannot exclude the potential for female bias. Second, the possibility of selection bias cannot be excluded, as we did not ascribe ‘*a priori*’ to maximum heterogeneity sampling, although it was finally achieved. Third, a participation bias may exist where only those young people who feel confident to share their perspectives or who are experiencing service or information gaps participated. Fourth, our sample represents that of residents in a developed country with an accessible and high-quality healthcare system. In this context, our findings are not necessarily transferable to nations with different healthcare systems or in middle-income or low-income economies where healthcare systems are fragmented and lack major resources.<sup>61</sup>

This in-depth dissection exposes the complex nature of pain and highlights the service gaps for young people in Australia with persistent musculoskeletal pain. Implementing evidence-informed, age-appropriate models of care with which young people want to engage

requires innovation. Digital technologies interfacing with contemporary health policy in this area provide an opportunity to lever implementation of such models, potentially transforming access to best practice pain care and potentially mitigating care disparities.

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#### Acknowledgements

The research team thanks the following people: Professor Jeff Richardson, Professor and Foundation Director, Centre for Health Economics, Monash University, Australia, for guidance on the use of The Assessment of the Quality of Life (AQoL) 8-domain questionnaire; and Angelo Iezzi, MSc BE(Civil) GradDipLang, Research Fellow, Centre for Health Economics, Monash University, and Clayton Victoria for assistance with the calculation and provision of age-specific normative data for the AQoL 8D (MSD). The study participants are gratefully acknowledged for their contribution to this project. For their assistance with recruitment: Dr David Butler, NOI Group; Ms Stefanie Hartley, Project Officer—Young Female Health Initiative, Molecular Microbiology, Infection and Immunity, Murdoch Children’s Research Institute, Molecular Microbiology Laboratory, The Royal Women’s Hospital, Parkville, Victoria.

**Funding** Funding to undertake this study was provided by partnership grants awarded by Arthritis and Osteoporosis Victoria and Arthritis and Osteoporosis Western Australia, with in kind support from Curtin University and the Department of Health (Government of Western Australia). The funding bodies did not influence decisions related to data collection, analysis, interpretation or submission of the manuscript for publication.

**Competing interests** AMB reports grants from Arthritis and Osteoporosis Victoria, grants from Arthritis and Osteoporosis WA, during the conduct of the study; AMB was a salaried employee of Arthritis and Osteoporosis Victoria at the time the study was undertaken; JEJ declares personal research fees from Curtin University, during the conduct of the study; JC declares personal research fees from Curtin University, during the conduct of the study.

**Ethics approval** This study was approved by the Curtin University Human Research Ethics Committee, Perth, Australia.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** Extracts from this data set may be made available by emailing the corresponding authors.

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# Young people's experiences of persistent musculoskeletal pain, needs, gaps and perceptions about the role of digital technologies to support their co-care: a qualitative study

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BMJ Open 2016 6:  
doi: 10.1136/bmjopen-2016-014007

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