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Disability and Rehabilitation

ISSN: 0963-8288 (Print) 1464-5165 (Online) Journal homepage: www.tandfonline.com/journals/idre20

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To cite this article: Jason Chua, Helen Slater, Samantha Rowbotham, Nardia-Rose Klem, Susan M. Lord, Peter B. O'Sullivan, Breanna Tory, Anne J. Smith, Jennifer N. Stinson, Paul Hansen & Andrew M. Briggs (18 Nov 2025): What informs the choices young people living with chronic musculoskeletal pain make about their care? A qualitative analysis of focus groups with young people in Australia, Disability and Rehabilitation, DOI: 10.1080/09638288.2025.2585762

To link to this article: https://doi.org/10.1080/09638288.2025.2585762

DISABILITY AND REHABILITATION
https://doi.org/10.1080/09638288.2025.2585762

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RESEARCH ARTICLE

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What informs the choices young people living with chronic musculoskeletal pain make about their care? A qualitative analysis of focus groups with young people in Australia

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ABSTRACT

Purpose: To explore how lived and care experiences of young people (aged 16–24 years) who experience chronic musculoskeletal pain (CMP) influence their choices about CMP care, and *how* and *where* a digital health solution (DHS) could support their care.

Methods: A cross-sectional, exploratory qualitative study involving 20 young people (16–24 years) experiencing CMP. Eight focus groups were conducted, guided by a focus group schedule. Data were analyzed using thematic analysis.

Results: Three main themes emerged describing young people's experiences and CMP care choices. For each main theme we identified how a DHS could support their care: (1) "*Experiences of living with and managing their CMP.*" A DHS could buffer self-care needs by providing timely support and creating a sense of community. (2) "*Experiences with healthcare providers and healthcare services.*" An app-based DHS could potentially help to coordinate CMP care and support health services navigation. (3) "*Young people's choices about their CMP care options.*" DHSs can support young people prioritize their CMP care options.

Conclusions: Understanding young people's values, alongside their care needs is critical to delivering person-centred care. A tailored DHS can value-add to young people's CMP care by helping to minimize the burden of self-care, health service navigation and interactions with healthcare providers.

IMPLICATIONS FOR REHABILITATION

- Young people (16–24yrs) living with chronic musculoskeletal pain make choices about their pain care that reduce their self-care burden and enable them to pursue their valued life activities.
- To provide person-centred and holistic pain care to young people, rehabilitation providers need to understand what young people's life goals and ambitions are, alongside their needs and preferences for their pain care.
- Digital technologies may be a useful adjunct to clinical rehabilitation services to provide time-sensitive, accessible and meaningful education and self-management skills to young people to support their pain self-care.

ARTICLE HISTORY
Received 19 March 2025
Revised 6 October 2025
Accepted 1 November 2025

KEYWORDS
Musculoskeletal pain; young people; care choices; digital health; health services; trade-off; decision making; qualitative research

Introduction

Chronic musculoskeletal pain (CMP) imposes a substantial burden across the life course. Approximately 1 in 5 young people (defined here as aged 16–24 years) experience CMP[1,2], impacting their physical, social and emotional wellbeing [3–7]. These impacts are particularly important to the wellbeing of young

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Supplemental data for this article can be accessed online at https://doi.org/10.1080/09638288.2025.2585762.

people as they navigate complex biological, emotional and social transitions from adolescence to young adulthood. During this developmentally sensitive period, young people commonly experience co-existing CMP and mental health conditions, manifesting as a bi-directional burden [3,4]. CMP also has significant economic implications. While the societal direct cost of chronic pain among 16–24 year olds in Australia was estimated at $AUD 4 billion in 2018, the impact on national productivity is even greater [8]. Accounting for lost productivity due to parental caregiving and its long term financial effects, total losses are estimated between $AUD 15 to $27 billion or more each year [9]. These factors highlight a need for health services that are timely, accessible, integrated and responsive to young people's needs [10].

Design of evidence-based health services and supportive health systems for young people living with CMP need to be informed by their needs, values and preferences [11]. Yet, little action has been taken to co-create such health services for young people living with CMP [1,12]. Co-creation positions young people as equal partners in developing health solutions that are meaningful to them and that encourage agency, enablement and promote adoption, which is particularly important for the design digital health solutions (DHSs) that serve young people as digital natives [11–14]. Genuine co-creation should optimize the "fit" between effective evidence-based care options (interventions, services) and young people's values and preferences for care and how care is made accessible to them [13,15–17]. This is important because improved "fit" is more likely to increase care adoption, reduce inequities, and ultimately improve health and wellbeing outcomes for young people, who often "fall between the gap" when transitioning from pediatric to adult health services [1,4,18–20]. Consequently, to inform the design of supportive CMP care systems, there is a need to understand how young people make choices about their CMP care, drawing on their lived and care experiences.

Young people have indicated a preference for affordable, age-appropriate, integrative pain care involving multidisciplinary health teams and services that support them as they transition from pediatric to adult health services [4,15,21,22]. However, substantial burden-service gaps exist for pain care in Australia, especially for young people. Access to pain services is challenging for people from disadvantaged backgrounds or geographically remote areas [23,24]. Moreover, current and projected workforce shortages limit access to care [25,26]; lengthy wait times are common [23]; and unhelpful healthcare provider interactions are often experienced, resulting in young people feeling ignored, invalidated or dismissed, magnifying their lived experience impact and burden [4,12,27]. To help address this need, it has been proposed that DHSs can help overcome barriers to accessing timely, age-appropriate and tailored pain care for young people [10,13,28–32]. Whilst young people's lived and care experiences are described well in the literature [4,27], there is little evidence informing how these experiences influence or inform their choices about CMP care, and *how* and *where* digitally-supportive care can assist in their care journey. This evidence is important for designing care pathways and technology solutions that are person-centred, responsive and acceptable. In this context, qualitative research methods are indicated, particularly where group discussions are enabled [33].

The aim of this study was to explore how lived and care experiences of young people (aged 16–24 years) who experience CMP influence their choices about CMP care, and *how* and *where* a DHS could support their CMP care.

Methods

Design

A cross-sectional study using qualitative methods was conducted, co-designed with a young person research partner (BT). A constructivist perspective was adopted because it acknowledges the possibility of multiple unique realities constructed through individuals' experiences and the influence of the interaction between the researcher and the research [34,35]. Aligned with a constructivist perspective, an exploratory qualitative methodology enabled the collection of rich, in-depth data about how young people construct choices about their pain care [34,36]. Constructivism positions the researchers to consider each young person's construction of experiences as truth, with multiple truths (realities) possible across participants [34]. Knowledge is generated through the inquirer and the knowable, not "out there" to be discovered.

This study is positioned within a broader research programme (myPAinhealTH (myPATH): a digitally enabled adaptive learning system to support quality care of young Australians living with CMP), and the data collected were intended to serve two purposes: 1) to explore how young people make choices about their CMP care and *where and how* DHSs can support their pain care (the current study); and 2) to identify young people's preferences for specific attributes of DHSs to support pain care (reported separately). These components align with the World Health Organization's framework for planning, developing and implementing youth-centred digital health interventions [13].

The research was approved by Curtin University's Human Research Ethics Committee (HRE2022-0588) and is reported according to the COnsolidated criteria for REporting Qualitative research (COREQ-32 [37]), the Checklist for Reporting Results of Internet E-Surveys (CHERRIES [38]) and the Checklist for reporting research with adolescent and youth engagement [39] (see Appendix A).

Sampling

A convenience frame was used to sample community-dwelling young people aged 16–24 years, resident in Australia and currently living with CMP (defined as self-reported pain experienced for >3 months, either continuously or intermittently, perceived as arising within musculoskeletal structures), irrespective of whether they had received a formal diagnosis for their pain from a health professional. Both primary and secondary CMP (aligned with ICD-11 classifications) were included in this definition [40]. We excluded individuals who did not self-report CMP, were unable to speak or understand English, or had a history of previous or current, clinically diagnosed psychosis.

Recruitment methods

To recruit a diverse pool of potential participants from across Australia we identified key national and jurisdictional government and non-government organizations with an interest in pain care in young people and contacted them *via* email. Organizations and key stakeholders identified through our networks (e.g. pain clinicians, allied health professionals) were asked to share the curated study recruitment materials (e.g. email invitation, social media block, poster) through their networks. The recruitment materials included a link and/or QR code to guide young people to the secure, Curtin-licensed e-survey platform Qualtrics™ (Provo, UT, USA), where they provided informed consent and responded to screening questions to verify eligibility. Additional details are reported in a separate but related study [3].

Data collection

Data collection comprised an online survey to collect demographic and clinical characteristics and video-recorded online focus group discussions. A young person partner with lived experience of CMP (BT) was involved in developing the research protocol and data collection methods and materials to verify they were appropriate and meaningful to young people.

The survey included demographic items (postcode, age, gender, education and socioeconomic background) and clinical profiling items, based on validated clinical measures utilized by the Australasian electronic Persistent Pain Outcomes Collaboration (ePPOC [41]) (see Table 2 for tools, score ranges, cut-offs and interpretation for each measure). We assessed the authenticity of survey responses using a suite of various features within the Qualtrics software (Appendix A, Checklist 2).

Focus groups were used to collect qualitative data on what factors young people consider when they make choices about their CMP care and *where* and *how* a DHS could support them. Focus groups facilitate conversation among participants and surface discussions and ideas that might not otherwise be identified through other methods [33]. This is aligned with a constructivist perspective as it enables co-creation of knowledge between participants, through exploration and shared dialogue of not only what young people value when they make choices about CMP care, but also why. This is relevant as decision-making is typically implicit or subconscious, rather than explicit [42].

A semi-structured focus group schedule (Appendix B) was co-designed with the multidisciplinary research team. Focus group discussions were guided by the Nominal Group Technique (NGT) [43]; a method that facilitates equal sharing of ideas, discussion, different styles of thinking (e.g. in silence vs group) and real-time member-checking.

We convened eight online focus groups, lasting between 60 and 90 minutes between April and November 2023. Focus groups were held and recorded *via* Zoom online videoconferencing software (Zoom Video Communications Inc., ver.5, San Jose, California) as an equitable way to overcome geographic, time and cost barriers to participation. Video recordings were transcribed verbatim using Zoom, checked for accuracy by JC, anonymized and stored on a password-protected cloud-based server.

To support member-checking and discussion, one facilitator (JC) led the group discussion, while a second (silent) facilitator (AMB) recorded field notes in real-time using screen-shared PowerPoint (Microsoft, Redmond, Washington) slides to summarize and translate young people's ideas into conceptually discrete points. A third researcher (HS) was present as a silent observer, to collect additional field notes. At the end of each focus group, field notes were aggregated, summarized and organized into content areas to create a written and visual summary of the focus group's discussion that was shared with the next group. Aligned with the constructivist approach and Braun and Clarke's concept of data saturation, which argues that data saturation is not fixed or objectively measurable [44], we considered data saturation using a reflexive approach. Here, we reflected on concept generation after each focus group and on whether redundancy of major concepts was achieved by the eighth focus group discussion. JC had no relationship with the young people; however, some young people had a relationship with AMB and HS from their prior involvement in research and co-design activities.

Data analysis

Survey data were analyzed using descriptive statistics (IBM SPSS Statistics for Mac, Version 29, Armonk, NY).

Thematic analysis was used to analyze the focus group data as it provides a flexible and systematic approach for identifying commonalities and differences across perspectives and enables the exploration of recurring topics, ideas, and emotions while engaging reflexively with the data [45]. Aligned within a constructivist approach, we followed a six-step process for thematic analysis, described by Naeem and colleagues [46], to inductively generate a thematic structure, supported by a visual display of findings, depicting how lived and care experiences of young people who experience CMP influence their choices about CMP care, and identify *where and how* DHSs can support them (Table 1). A coding tree to support data analysis is reported in Appendix Table 1, guided by principles described by Braun and Clarke [45]. To perform steps 1 and 2 of the data analysis approach, all transcripts were converted to Word documents, and a subset of transcripts were initially coded using Microsoft Word (Microsoft, Redmond, Washington). Steps 3 through 5 were supported by Microsoft Excel (Microsoft, Redmond, Washington) to create focused codes and categories and generate themes and subthemes.

Table 1. Summary of how the six-step method for data analysis, guided by Naeem and colleagues [46], was applied in the current study.

Step(s)	Description
1	Two authors (JC, SR) read through all transcripts to gain an understanding of the data.
2	Two authors (JC, SR) independently coded three transcripts to inductively generate initial codes.
3	Initial codes were refined to create focused codes and categories (where categories refer to a group of intuitively linked codes). This iterative process involved discussion between members of the research team (JC, HS, SR, AMB) to ensure categories were conceptually discrete and anchored to the primary data. Another author (NRK) independently coded two transcripts using the coding framework to assess whether it adequately represented the raw data.
4	Categories and codes were reviewed relative to the research objectives and organized into themes and subthemes. This iterative process involved going back and forth between the raw data, codes, categories, subthemes and themes and discussion within the research team (JC, SR, HS, AMB) to ensure emerging themes were conceptually distinct, relevant to the research objectives and faithfully reflected the data.
5 and 6	Theme and subtheme definitions and relationships were defined and refined to develop a conceptual model of the data which captured how the lived and care experiences of young people influence their pain care choices and where and how a DHS can support their care.

Table 2. Demographic and clinical characteristics of the focus group participants ($N = 20$).

Characteristic	Group-level summary
Age (years), mean ± SD	20.0 ± 3
Gender, n (%)	
Woman	14 (70)
Man	5 (25)
Non-binary/ third gender	1 (5)
Duration of chronic pain (years, median (IQR))	15 (14)
Clinical profiles, expressed as mean ± SD	
Kessler Psychological Distress scale (K10) score (scale range 10–50)†	29.6 ± 7.1
Pain Self Efficacy Questionnaire (PSEQ) score (scale range 0–60)††	36.0 ± 12.3
Brief Pain Inventory (BPI) pain severity subscale score (score range 0–10)*	5.0 ± 2.1
Brief Pain Inventory (BPI) pain interference subscale score (score range 0–10)**	4.6 ± 2.6
Brief Pain Catastrophizing (PCS) chronic scale score (score range 0–16)***	9.0 ± 4.3

† K10 [48] higher scores reflect greater psychological distress. Scores <20 are likely to be well, scores 20–24 are likely to have a mild mental disorder, scores 25–29 are likely to have moderate mental disorder, and scores ≥30 are likely to have a severe mental disorder. Scores are calculated as the sum over 10 items with ratings on a 1 to 10 scale, where "0" represents "none of the time" and "10" represents "all of the time."

†† PSEQ [49] higher scores reflect stronger self-efficacy beliefs. Scores are calculated as the sum over 10 items rated on a numeric rating 1 to 10 scale, where "0" represents "not at all confident" and "10" represents "completely confident."

* BPI-pain severity [50] higher scores reflect greater pain severity and are calculated as the mean score over 4 items (average, worst, least pain over the past week and pain right now) rated on a 0 to 10 numeric rating scale, where "0" represents no pain and "10" pain as bad as you can imagine.

** BPI-pain interference [51] higher scores reflect greater pain interference with activities of daily living based on the patient's self-reported BPI scores for the items measuring interference. The interference questions are rated on a 0 to 10 numeric rating scale, where 0 represents "Does not interfere" and 10 represents "Completely interferes." The interference subscale is an average of the seven interference questions.

*** Brief pain catastrophizing scale [50] (BriefPCS-chronic) score (range 0–16). Higher scores reflect high levels of catastrophic thoughts. Scores are calculated as the sum over 4 items rated on a 5-point Likert scale ranging from 0 to 4, where "0" represents "never" and "4" represents "always."

Rigor statement

Credibility and trustworthiness are supported in several ways [47]. The philosophical perspective, methodology and methods were congruent with our research question which seeks to construct how young people make choices about their CMP care through their experiences and perspectives. Data analysis was also supported by several steps involving researcher triangulation in the development of the visual display of findings from code and category development, through to theme and subtheme development. Throughout this process, the research team collaboratively defined, refined and iterated the content of the codes, subthemes and themes to ensure they were anchored to the raw data. This involved going back and forth between the raw data, codes, categories, sub-themes and themes to ensure that they were internally coherent, conceptually discrete, exhaustive and not repetitive. Throughout the process, we communicated with each other to discuss how our viewpoints could influence the analysis and were cognizant of how cultural and professional background could influence our work (see Reflexivity statement). Where discrepancies in data interpretation were encountered, team discussion continued until consensus was reached. To support the credibility of our findings, we report rich descriptive summaries supported by exemplar quotes from the study participants and a coding tree (see Appendix Table 1). Additionally, we have used data-triangulation to support where findings of our research intersect with the extant evidence concerning young people's lived and care experiences and *where* and *how* digital health solutions can offer support. Further, we have offered an interpretation of what the analysis means in the form of a visual display of findings, rather than paraphrasing or repeating the results. Lastly, we aimed to improve the transparency of reporting through adherence to established criteria including the COREQ-32 (see Appendix A).

Researcher characteristics and reflexivity statement

Our international research team comprises authors from Australia, Canada and New Zealand who hold a collective aim to enhance the understanding of how young people make choices about their CMP care. The research team comprises a mix of clinical and non-clinical researchers with an interest in health systems, health services, clinical pain care, digital therapeutics and economics. The diverse cultural and professional backgrounds of the research team acknowledge that each author influences the cocreation of knowledge based on their previous knowledge and experiences through the data collection, analysis, interpretation and reporting. JC is a bi-cultural, Australian-Chinese, non-clinical researcher with an interest in health services research. All other researchers are Caucasian. Collectively, we acknowledge that our perspectives are limited by our cultural perspective, experience across variable economic development and worldview as we are not young people (excluding BT).

Results

Twenty-two young people were recruited; two withdrew (1 due to illness, 1 lost to follow-up). Twenty young people participated (75% residing in metropolitan locations) from five Australian states. Participants primarily identified as women (70%) and most (70%) self-reported having received a diagnosis for their CMP condition(s). Most (90%) self-reported an impact of their CMP on their mental health. Among these, two-thirds (67%) self-reported a diagnosed co-existing mental health condition. Tables 2 and 3 provide the cohort-level and individual-level demographic and clinical characteristics, respectively.

Results of the thematic analysis

Three interacting themes emerged concerning young people's lived and care experiences and their choices about their CMP care, and how a DHS could support them, relative to each theme. The three main these were: 1) young people's experiences of living with and managing their CMP; 2) young people's experiences with healthcare providers and healthcare services; and 3) young people's choices about their CMP care.

A visual display of findings (Figure 1) was generated depicting how young people's choices about CMP care are driven by their lived experiences, including the way they want to live and balancing the burden of CMP, and their interactions with healthcare providers and services. Young people's choices about their CMP care were influenced by a desire to live how they want to, whilst minimizing the impact of CMP on their life (main theme 1) and seeking and experiencing supportive interactions with healthcare providers and services (main theme 2). When making choices about their CMP care (main theme 3), young people considered the features of CMP care that maximized their opportunities to engage in valued life activities and minimized the burden of self-care (e.g. effort required, impact on quality of life, financial cost). Young people's lived and care experiences and care expectations influenced their choices about CMP care, and vice versa. Similarly, their lived and care experiences were influential on each other. A cross-cutting dimension was identified, illustrating *where* and *how* young people identified DHSs could augment their CMP care through self-care support; helping care coordination, clinical encounters, and supporting health services navigation; and supporting young people to prioritize CMP care options that align with their values and preferences.

A narrative summary of each theme and its subthemes is provided below, followed by an expanded commentary for each sub-theme with supporting quotes. Within each theme we describe *where* and *how* digitally-supportive care was valued by young people. Appendix Table 2 provides a summary of the sub-themes and supporting quotes.

Theme 1: Young people's experiences of living with, and managing their chronic musculoskeletal pain

Young people described the significant impacts that living with, and managing CMP had on many aspects of their life. Young people described the impact of CMP on their daily life and valued life activities (subtheme 1.1). They expressed emotional and cognitive loads associated with living with CMP and the requirement to self-manage their health (subtheme 1.2). CMP interfered with young people's functioning and their ability to pursue valued life activities, which further impacted their cognitive and emotional wellbeing. The cognitive burden of CMP manifested in terms of the mental effort required for self-care. Specifically, young people identified self-care as an important component of their CMP care and a responsibility of living with CMP. They perceived that effective self-care minimized the impact of CMP on their life. However, self-care was also reported as a source of stress due to the requisite cognitive

Table 3. Individual characteristics of the study sample ($N = 20$).

Participants^ø^	Gender	Age (years)	CMP pain duration	Primary self-reported CMP diagnosis(es) (with or without non-musculoskeletal co-morbidities)$^{\Sigma}$	K10 score†	PSEQ score††	BPI pain severity sub-scale score*	BPI pain interference sub-scale score**	BriefPCS-chronic score***	State^	SEIFA index of relative socio-economic advantage and disadvantage (decile) in 2021^^	Geographic area#
P01_W20	Woman	20	1.5 years	No diagnosis reported	26.0	38.0	13.0	20.0	6.0	WA	10	MM1
P02_M18	Man	18	6 months	Back pain (disc herniation)	20.0	50.0	4.0	9.0	5.0	WA	8	MM1
P03_M23	Man	23	3 years	No diagnosis reported	26.0	51.0	8.0	8.0	1.0	WA	Not provided	Not provided
P05_W19	Woman	19	1.5 years	Back and leg pain (scoliosis, disc herniation, degeneration, sciatica)	30.0	27.0	19.0	49.0	15.0	WA	10	MM1
P06_W22	Woman	22	10 years	No diagnosis reported	32.0	21.0	31.0	38.0	15.0	WA	10	MM1
P08_W22	Woman	22	2 years	Spondylarthritis (with co-morbidities)	30.0	37.0	16.0	26.0	10.0	VIC	3	MM2
P10_M23	Man	23	8 years	Ehlers-Danlos syndrome	20.0	42.0	17.0	24.0	9.0	NSW	10	MM1
P11_W21	Woman	21	7 years	Fibromyalgia	19.0	49.0	14.0	10.0	3.0	NSW	9	MM1
P12_W17	Woman	17	6 years	Ehlers-Danlos syndrome, fibromyalgia, complex regional pain syndrome, osteoarthritis	33.0	30.0	22.0	44.0	10.0	WA	9	MM1
P13_W21	Woman	21	7 years	No diagnosis reported	40.0	36.0	35.0	58.0	15.0	WA	10	MM1
P14_W16	Woman	16	14.5 years	Ehlers-Danlos syndrome	Not applicable	55.0	24.0	10.0	4.0	WA	9	MM1
P15_W16	Woman	16	10 years	Ehlers-Danlos syndrome, pars defect (with co-morbidities)	46.0	3.0	35.0	66.0	15.0	QLD	2	MM2
P16_W16	Woman	16	11.5 years	Juvenile idiopathic arthritis	35.0	26.0	18.0	13.0	10.0	WA	8	MM1
P17_W17	Woman	17	7 years	Hypermobility syndrome	26.0	44.0	29.0	50.0	13.0	WA	6	MM1
P18_W21	Woman	21	9 years	Joint hypermobility syndrome, fibromyalgia, subluxing forearm tendon, chronic neck pain, (with co-morbidities)	31.0	48.0	13.0	29.0	5.0	TAS	4	MM2
P19_NB24	Non-binary/ third gender	24	4 years	Abdominal wall pain (with co-morbidities)	33.0	29.0	18.0	24.0	8.0	WA	9	MM1
P20_W23	Woman	23	9 years	No diagnosis reported	35.0	26.0	27.0	58.0	13.0	NSW	10	MM1

(*Continued*)

Table 3. Continued.

Participants[ø]	Gender	Age (years)	CMP pain duration	Primary self-reported CMP diagnosis(es) (with or without non-musculoskeletal co-morbidities)[Σ]	K10 score[†]	PSEQ score[††]	BPI pain severity sub-scale score*	BPI pain interference sub-scale score**	BriefPCS-chronic score***	State^	SEIFA index of relative socio-economic advantage and disadvantage (decile) in 2021^^	Geographic area[#]
P21_W18	Woman	18	18 years	Hypermobility syndrome (with co-morbidities)	Not applicable	34.0	25.0	42.0	8.0	NSW	10	MM1
P23_M19	Man	19	17 years	Arthritis (with co-morbidities)	28.0	37.0	15.0	33.0	7.0	NSW	4	MM5
P24_M23	Man	23	5 years	Hip dysplasia, arthritis	22.0	36.0	13.0	28.0	8.0	WA	5	MM1

ø As indicated in "recruitment," participants could elect to take part in one or more studies as part of the overall myPATH program of research. Participants were assigned identifiers upon completion of the baseline survey. As not all participants who completed the baseline survey opted to take part in this study the participant numbers are not consecutive.

Σ All participants met the inclusion criteria for the study, i.e., self-reported pain experienced for >3 months, either continuously or intermittently, perceived as arising within musculoskeletal structures, while only a sub-set of these had received a diagnosis for their CMP.

† Kessler Psychological Distress scale (K10) score (range 10–50). K10 higher scores reflect greater psychological distress. Scores <20 are likely to be well, scores 20–24 are likely to have a mild mental disorder, scores 25–29 are likely to have moderate mental disorder, and scores ≥30 are likely to have a severe mental disorder. Scores are calculated as the sum over 10 items with ratings on a 1 to 10 scale, where "0" represents "none of the time" and "10" represents "all of the time."

†† Pain Self Efficacy Questionnaire (PSEQ) score (range 0–60). PSEQ higher scores reflect stronger self-efficacy beliefs. Scores are calculated as the sum over 10 items rated ion a numeric rating scale 1 to 10 scale, where "0" represents "not at all confident" and "10" represents "completely confident."

* Brief Pain Inventory (BPI) pain severity score. BPI-pain severity higher scores reflect greater pain severity and are calculated as the mean score over 4 items (average, worst, least pain over the past week and pain right now) rated on a 0 to 10 numeric rating scale, where "0" represents no pain and "10" pain as bad as you can imagine.

** BPI-pain interference[51] higher scores reflect greater pain interference with activities of daily living based on the patient's self-reported BPI scores for the items measuring interference. The interference questions are rated on a 0 to 10 numeric rating scale, where 0 represents "Does not interfere" and 10 represents "Completely interferes." The interference subscale is an average of the seven interference questions.

*** Brief pain catastrophizing scale[50] (BriefPCS-chronic) score (range 0–16). Higher scores reflect high levels of catastrophic thoughts. Scores are calculated as the sum over 4 items rated on a 5-point Likert scale ranging from 0 to 4, where "0" represents "never" and "4" represents "always."

^ States: WA = Western Australia, VIC = Victoria, NSW = New South Wales, QLD = Queensland, TAS = Tasmania.

^^ SEIFA: Socio-Economic Indexes for Areas (SEIFA) is a product developed by the Australian Bureau of Statistics that ranks areas in Australia according to relative socio-economic advantage and disadvantage. The Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD). The IRSAD summarizes information about the economic and social conditions of people and households within an area. This index includes both relative advantage and disadvantage measures. Expressed in deciles (1–10), a low score indicates relatively greater disadvantage and a lack of advantage in general, while a high score indicates a relative lack of disadvantage and greater advantage in general [Australian Bureau of Statistics (2021), Socio-Economic Indexes for Areas (SEIFA), Australia, ABS Website, accessed 9 September 2024].

Geographic area was defined according to the Australian Modified Monash Model (MMM), which defines whether a location is metropolitan, rural, remote or very remote. MM 1 is classified as metropolitan, while areas classified MM 2 to MM 7 are considered outside metropolitan cites, including regional, rural or remote with increasing remoteness from MM 2 to MM 7.

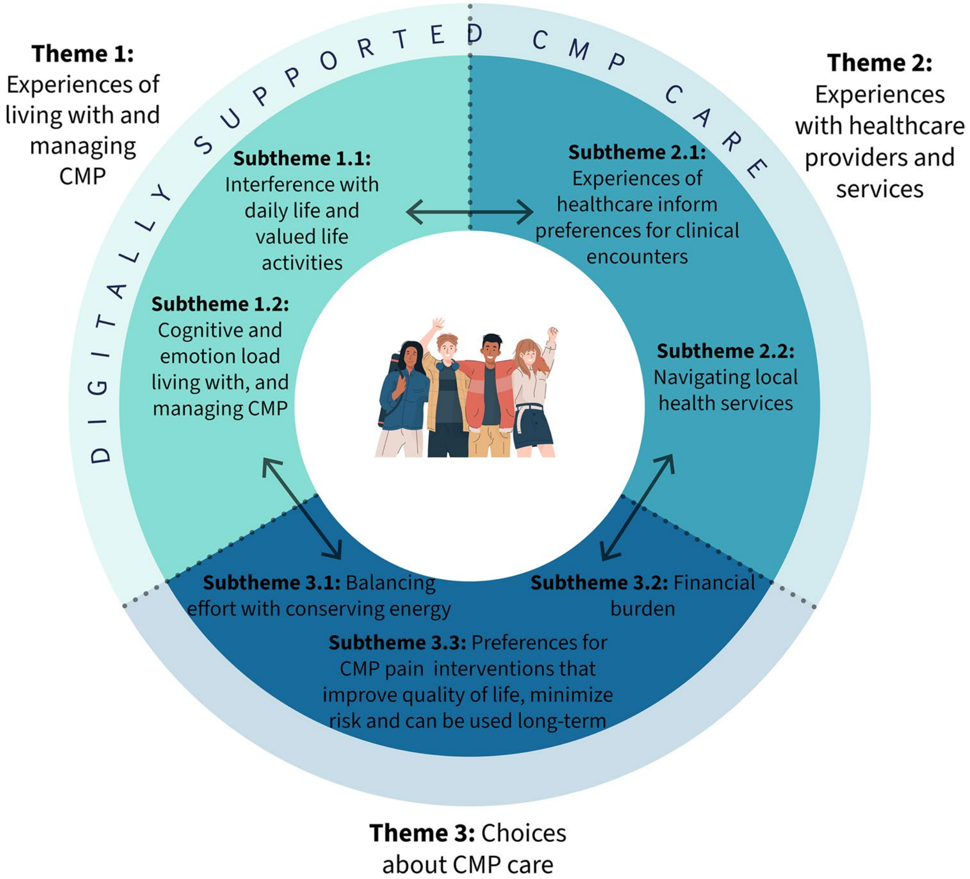

Figure 1. Depiction of the three interacting main themes describing how young people make choices about their CMP care. Each theme is represented by a different color shade in the inner circle. The cross-cutting dimension (outer circle extending with dotted lines from the center, shaded) illustrates *where* and *how* young people identified DHSs could augment their CMP care.

demands, such as finding and making sense of information about CMP care, and remembering what to do. Living with CMP was emotionally draining because of the difficulty young people experienced in judging progress with their CMP care, or recovery, because of the enduring nature of chronic pain. Further, CMP was described as limiting their social participation due to the functioning limitations and stigma associated with CMP.

Interference with daily life and valued life activities

Young people described how CMP impacted their day-to-day lives, interfering with their capacity to do the things they valued. CMP impacted young people's physical functioning and their ability to participate in valued life activities (including work, study, sport and socializing) and their ability to "*get out and do normal everyday things*."

> *"So before, when, when I was younger, I was; I love my sport and I was, I was playing lots of sport. And it was basically the, the main thing in my life that that brought me confidence and joy and, and having that kind of taken away was, it was a big factor in how I felt mentally." (P24_M23)*

The experience of pain itself, the fatigue of living with it, and managing their CMP, influenced their ability to participate in their daily activities.

> *"I get like really fatigued and I think it kind of takes it out of you, having to, you know, trek for ages [to see a healthcare provider] and then you don't want to do anything else with your day and you're like 'oh, is this even worth it?'" (P6_W22)*

CMP also impacted young people's mental wellbeing, which interfered with their social life and intimate relationships.

> *"Umm, I think, when I… I usually find appointments in person have always helped. Coz I feel like my, how I feel like with my pain is very yeah, connected to my emotions as well, and if I feel quite feel quite low about it, it'll usually be, because I'm not around people that help out with that." (P23_M19)*

For example, young people perceived that managing the burden of CMP limited the time and energy they could give to their relationships.

> *"I think there's definitely an impact on mood which you can take into relationships… And there's a level of understanding that you hope can be there with other people when you do have kind of these conditions, and and things like that." (P11_W21)*

Young people also reflected that they experienced stigma from living with CMP, and hoped others would understand the burden of CMP.

> *"I think the thing about chronic pain and actually just any, any medical condition is that if there's almost a stigma sometimes attached to having it." (P10_M23)*

Cognitive and emotional load living with, and managing CMP

Young people reflected that living with CMP was emotionally taxing and required substantial cognitive effort to constantly participate in self-care. Self-care activities were cognitively demanding for young people, including finding credible information about *what* to do and *how* to do it, and remembering this information (e.g. what medications to take, what to do next).

> *"And at the end of the day like, especially when you're dealing with pain you're always jumping around. This is always like so many people you have to see, or things you have to take or things you have to do, and it's like, can get really overwhelming. And I forget all the time." (P13_W21)*

Finding information about how to self-care was particularly draining for young people due to the large amount of often conflicting and low-quality information they encountered (e.g. from family, online) and had to make sense of. While some young people developed strategies to establish the credibility of information they gathered (e.g. reading academic papers, checking reference material), "making sense" was described as mentally taxing and time consuming. However, this "sense-making" was also considered an unavoidable, yet necessary part of their self-care responsibilities, in part, because they identified that simply following other's advice (e.g. social media influencers) could cause more harm than good.

> *"I rely on education, resources, reading academic papers because I have some access to those and stuff like that to try and find my best information, which isn't easy, and it is time consuming. But it's kind of what I need to do." (P20_W23)*

Living with CMP was emotionally demanding because of the enduring nature of chronic pain. Participants identified an emotional toll stemmed from a perceived sense of stigma from living with a chronic condition (in this case, chronic pain), no sense of improvement or progression, because "*you're always in pain*," social isolation, and the inability to participate in valued activities which impacted their sense of self.

> *"You feel like you've not gotten anywhere because you're always in pain. It would be nice to look back and be like, 'oh, actually like, I've come a long way,' … So, I don't know." (P13_W21)*

How a digital health solution could support young people's experiences of living with, and managing their chronic musculoskeletal pain

Young people identified how a DHS could support them in living well with CMP and buffer the burden imposed by CMP. DHSs were perceived as being potentially helpful in addressing a number of these challenges. For example, young people identified a role for DHSs in connecting them with timely self-care support when needed (e.g. for validation, for mood support, for pain flare help) and to help them to find credible information about their CMP and care options (e.g. information about my condition, making sense of medical jargon). In this sense, young people perceived that DHSs could help shift the burden of self-care by freeing them from having to think about what to do and how to do it (e.g. goal tracking, medication tracking, appointments, exercises).

> *"I kinda want it to be my brain when I can't be. So I want it to be essentially like the logical side of things… And just tell me what to do, so I don't have to think about what I should be doing or what's happening." (P11_W21)*

In addition, young people described the potential for DHSs to connect them with online communities of other peers living with CMP. These connections could expand their social support network to address feelings of loneliness (e.g. to share CMP care experiences, seek information about CMP care or broaden their support network).

> *"… if there was, like, a social like forum, or something that you could talk to other people who are experiencing similar circumstances. So, you don't feel like you're the only one, I guess." (P15_W16)*

Theme 2. Young people's experiences with healthcare providers and healthcare services

Young people living with CMP frequently interacted with different healthcare providers, leading to variable healthcare provider experiences (subtheme 2.1). They perceived the frequency of interactions and the multiple healthcare providers to be key factors contributing to the burden of managing their CMP. Young people often experienced challenges in finding the right provider and communicating effectively about their CMP care needs. Young people wanted care to be more aligned with their preferences, and information about local health services to be more readily available to them (subtheme 2.2). They considered how DHSs could help to align their experiences of healthcare and service navigation more closely to their preferences.

Experiences of healthcare inform preferences for clinical encounters

Young people experienced variable care encounters with healthcare providers. Young people characterized unhelpful healthcare experiences as: those which involved inconsistent or contradictory messaging about their CMP care; care that was time consuming; and care that was dehumanizing, either because it made young people feel disabled, medicalized or involved poor "bedside manner" (therapeutic relationships). These experiences made it hard for young people to trust healthcare providers.

> *"But, because I find it really hard; I've been in situations where there's heaps of people in like my treating team, and like a lot of them, have different opinions. And like, I find that so confusing because I'm like, meant to be like, listening to them - but they're all saying different things. So then I just feel more confused… when you hear all these conflicting opinions like that - I don't know who to trust - so I think I still have to work that out." (P1_W20)*

> *"I do think that having a rapport with a practitioner is really important because, like, I've had plenty of health practitioners that just kind of brush me off and not take me seriously." (P6_W22)*

Further, young people sensed that if they did not say the "right" thing they would not get the "right" help. Young people also explained that having to repeat their clinical history to new healthcare providers required additional effort because they had to prove their healthcare needs repeatedly.

> *"There's a lot of times when you go to an appointment, and you don't actually know how to describe where you're at or what you're doing, or you've had a huge week, and you're overwhelmed. You don't have the right words. And then you're worried that if you don't say the right thing you're not gonna get the right help. which has happened to me as well when you go there, and you don't know what to say." (P13_W21)*

Young people preferred healthcare providers who listened to their story, engaged with their perspective (not dismissive) and validated their experience.

> *"I think that's when, you know, healthcare practitioners dismiss you. You do feel disempowered and do feel like you, you know, you aren't validated. Whereas the flipside of that is actually being told – Yes! And what you're experience – that, that pain is normal…like it is known that you can have that type of pain. And so you do feel validated." (P10_M23)*

Young people wanted information that they shared about themselves (e.g. clinical history), and information that was shared with them by healthcare providers, to be streamlined to minimize having to repeat themselves or make sense of information.

> *"…the biggest thing is just I have to repeat myself every single time I got to a different clinician. It's just inconvenient and takes up time." (P03_M23)*

In this respect, young people recognized the benefit of a "central" health data repository which could be accessed by them and their healthcare team to support healthcare coordination (e.g. a digital interface that was used by all healthcare providers). In this way, their overall experience of healthcare could be "leaner" and less overwhelming.

> *"I prefer my healthcare to be relatively minimal. I don't wanna be in different doctors and specialists every day of the week, and things like that. It can feel almost a little bit obsessive and kind of taking over your life if there's a lot." (P11_W21)*

> *"I do think it would be great if there was a way to share data between multiple clinical options." (P3_M23)*

Navigating local health services

Young people described that while it was easy to find information about CMP care services from other countries online (e.g. from the United Kingdom, United States), information about their local health services was difficult to find (e.g. information about local support organizations, local healthcare providers with expertise in their condition) and/or too generic to be useful.

> *"I think a big thing like here is relevancy and like the relevancy of like resources and information that's provided. Because a lot of information and like resources that I've been able to access in the past have had some good like general information. And then all of this specific information has been relevant to the UK or to the US. Or, or like other places around the world. And so, finding specific, relevant information is pretty hard." (P20_W23)*

One young person explained how they spent years seeking specialist care, only recently finding a provider who they felt was appropriately skilled to support their CMP care.

> *"With my personal experience, like, we haven't been to the right specialists for like all these years. We've only just recently found like someone that knows what they're doing." (P17_W17)*

Young people valued practical information about navigating the care and services they could access, including the service fee subsidies available to them, service wait times, and information about accessibility (parking, physical location, noisiness of the practice).

> *"And then, even just like information, like practical information, because it's often really hard to find that in terms of like what people's wait times, like, what's the accessibility like off where - like getting there? And things like that, because often you have to do a lot of that - finding out the information for yourself. You know, like calling up and stuff like that; because often that information isn't easily accessible, so that could be really helpful, too…" (P19_NB24)*

How a digital health solution could support young people's experiences with healthcare providers and healthcare services

Young people perceived that DHSs they could augment and support clinical encounters by helping with communication with healthcare providers by producing reports (e.g. symptom tracking) or tips to facilitate more helpful clinical encounters (e.g. checklists).

> *"But maybe it's also available for your health care professionals. They could see how you're tracking. But yeah, then also, like as your answers change, what's recommended to, you also can change. So, then it becomes more personalized as it moves on." (P13_W21)*

DHSs were also perceived as a mechanism that could support coordination between their healthcare providers by enabling interprofessional communication or monitoring and responding to young people's needs (e.g. tracking progress and personalizing care).

> *"I think it would be cool as a healthcare professional, if you could log in, like you could either log in as a client or, or log in as a healthcare professional, and then actually select your patients, and if they allow it, maybe be like, oh, 'this is the notes that their physio put down,' especially with Physios and GPS." (P13_W21)*

Young people also perceived that a DHS could help with health service navigation by generating information about resources that theycould access in their local setting, such as local support groups/organizations or condition-specific providers (specialists).

> *"I think a big thing like here is relevancy and like the relevancy of like resources and information that's provided. Because a lot of information and like resources that I've been able to access in the past have had some good like general information. And then all of this specific information has been relevant to the UK or to the US. Or or like other places around the world. And so finding specific, relevant information is pretty hard." (P20_W23)*

Theme 3. Young people's choices about their CMP care

Young people discussed a range of factors that influenced how they made choices about their CMP care, and these were intricately linked to their lived experiences of managing their CMP (Theme 1), and their healthcare experiences (Theme 2, Figure 1).

Young people typically chose care that minimized the burden of CMP, effort required to self-care, minimized risks of harm and were able to be used for a long time. In making choices about care options for their CMP, young people considered the balance between effort expenditure with conserving energy (subtheme 3.1), financial burden (subtheme 3.2), and potential gains in quality of life (subtheme 3.3). They expressed preferences for CMP care options that were energy efficient so they could continue to engage in other aspects of their life (i.e., consumes the minimum amount of energy required to get the desired benefit), affordable, aligned with their CMP care goals, and tailored to their personal goals and needs (i.e., their lived and care experiences). Finding a balance between these often competing priorities was difficult for young people because they did not know how effective a CMP care option was until they tried it.

Balancing effort with conserving energy

In choosing care options for CMP, young people considered how much effort was required to access or adopt it. Interventions or services requiring high effort or energy expenditure consumed young people's limited energy reserves, reducing their potential to participate in other activities they valued. Consequently, young people chose CMP care that consumed less energy, yet still provided them with benefits. For example, CMP care options such as those involving hours of travel time, were not preferred, whilst using sleep as a (self) care strategy was preferred due to its relative ease of access (anywhere, anytime).

> *"So kind of to summarize all those; I prefer my health care to be relatively minimal. I don't wanna be in different doctors and specialists every day of the week, and things like that. And it can feel almost a little bit obsessive and kind of taking over your life if there's a lot." (P11_W21)*

> *"So initially, it'll be due to, you know, inconvenience of the pain and and the impact on my work and social life, and then that will, that will determine how much intervention it requires. So if I need, like a low intervention pain option because you know, the pain is not too bad. I might take some paracetamol or something like that." (P3_M23)*

> *"It took him two hours just to get there. Like there's two hours there. And an hour there that and two hours back or something that, like, almost your entire day is just gone. I guess that sort of comes with the, maybe, level of engagement but I guess that's something people probably think about. Maybe me like not so much, but definitely if I was like really busy, I'd have that so in the back of my mind." (P2_M18)*

However, this preference was balanced against their perceived CMP care needs (e.g. need to address pain levels), where greater needs necessitated greater tolerance for options with higher energy demands.

Financial burden

The cost of CMP care was described as an additional source of stress experienced by young people because of the concurrent high cost of living and private healthcare in Australia (e.g. provider costs, digital health solution costs), and young people's often limited financial resources, even if their parents offset the direct costs of care.

> *"Yeah, I think cost is massive, because at the end of the day it just creates more stress in a way, if I know, even if I know it's gonna work, But if it's gonna cost a lot of money, it's just adding stress in a different area of my life. So even though it works with pain management it's just, I can't keep going to all these appointments that cost a lot of money because they end up creating more stress. I'll have to work more which, Yeah, it kind of has a backwards effect, in a way." (P8_W22)*

In choosing a care option for their CMP, young people considered both the cost of an intervention or service itself and the cost of accessing the intervention, such as transport (e.g. taxi, public transport). In considering cost, young people were also mindful about indirect costs in their care choices, for example, income loss due to time off work to access care. In choosing an intervention, young people also considered what private health insurance and public health system subsidies were available to them (and, in some cases, to their families) to help offset the care costs.

> *"Do we have health insurance? Do we, like are we going through the public system? can we access things that mitigate the cost impact on us? I think that's; it's a big consideration." (P3_M23)*

> *"I think costs obviously, is a big thing. I think in the past I've used a pain app and before I was working, mum was okay, obviously with the less expensive pain apps. But I think a lot of them are quite expensive in general, so that that was a challenge. Mum would have done anything but obviously the cost was sometimes not accommodating." (P23_M19)*

Preference for chronic musculoskeletal pain interventions that improve my quality of life, minimize risk and can be used long-term

Young people sought and chose CMP care that helped them to control their pain so that they could live the life they wanted to and achieve their goals (e.g. to "*move and get outside and be active*").

> *"I want strategies that kind of align to my goals and lifestyle and let me live those out." (P11_W21)*

Care that provided rapid pain relief, a distraction from pain, experience of pleasant emotions, or prevented pain were preferred by young people. CMP care that supported their physical functioning was also valued (e.g. physiotherapy).

> *"I tend to prefer going to physiotherapists and things like that, and chiropractors rather than seeing GPs pretty regularly. But I think that's more kind of starting to align with that, I prefer the movement-based side of things and less of the medication." (P11_W21)*

Recognizing that their mood and pain were interrelated, young people were more likely to choose care that supported their mood and outlook for the future. Consequently, young people preferred CMP care that was tailored and responsive to their needs and preferences at the time. For example, young people valued care that targeted to personalized goals, that was aligned to what was important to them, and that helped them to stay engaged with their current CMP.

> *"I would say like having an individualized pain management plan would be good because like, sorry, I just stumbled across my words, just like going to the physio or going to chiro or whatever, and then doing whatever else they do on other people may not work for you. You might go back later feeling even worse or like even in a few hours be back to the same pain. So having things that, you know, work for you and making it individualized, I think is really important." (P6_W22)*

Young people also felt that non-personalized care, such as generic exercise, could be potentially harmful if it was not tailored to their situation, and so for this reason, they felt that personalized pain management plans were important in their care.

> *"I've been implementing that without really having having it called pacing to me. It's it's just a, a way of focusing on, on the the things that you value and the things that bring joy and kind of ease in your way back into those things. And I think that's important, because you yeah, like I said, your mind is focused on on things that bring you joy rather than dealing with pain and and and worrying whether what you're gonna do is - what you're doing - is gonna bring on additional pain." (P24_M23)*

Young people described balancing the benefits of CMP care interventions/services to their quality of life against their potential harms. For example, in choosing pharmacological treatments for their CMP care, young people carefully considered the short- and long-term risk of harms associated with medicines, including the risk of medicine interactions and "toxicity." Young people preferred CMP care with a low risk profile and that did not interfere with their lifestyle, such as university study. However, this was balanced against their immediate need to manage their pain, such as during a pain flare.

> *"I guess side-effects sometimes, if you're on meds for really long time, you just have a lot of side effects. but I mean, if it helps you manage it; like I'm on medications to help manage my pain. It's really good to help manage it, like if you have a flare up, extra medications might be needed. That's fine, too. I just. I think it's a good way to manage pain definitely. But like side effects, and you know you kind of go to weigh up pros and cons. So that's how I see it, I think." (P12_W17)*

Their choice of an intervention or service was also informed by how readily it could be reused over time (e.g. over years). Young people recognized that some interventions were limited in their repeatability over time (e.g. potential adverse effects of drug interventions when used long-term), whilst others could be safely repeated, such as self-care strategies like sleep. Young people recognized that they needed to take a long-term view to managing their CMP. Consequently, they preferred CMP options that could be repeated over a long period of time (years) with low risk of adverse events.

> *"What's kind of sustainable and what's not. So like, for example, like drugs. Like, I've taken a heap of anti-inflammatories before. Or like tramadol and what not. But it's not sustainable. Like, it's great if you need to get through the day, or you need to get through like, something. But at the end of day, like it does do a lot of damage. Like when I was seeing a rheumatologist, I had to get prescribed extra medication for my gut. Purely because it was, you know, the anti-inflammatory were so, like abrasive internally. So I don't believe they're sustainable. So usually, I just look for stuff that I can actually yeah, use long term…And it's one of those things where like, unless I was probably in my sixties and it was like, Oh, yeah, actually, like, I can't live at all – like, I can't at all - then I would probably consider it, but especially when you're young, there's there's just too much to risk, and they don't really, I think, tell you everything, either. It's it's just a quick fix, really." (P13_W21)*

How a digital health solution could support young people's choices about their chronic musculoskeletal pain care

Young people felt that a DHS could help them to make choices about their CMP care by helping them to prioritize CMP care options based on their values and preferences. For example, young people explained how they wanted a DHS that could capture their preferences for care recommendations and offer personalized strategies.

> *"So maybe like when at the start, when you're saying, um like in the 'get to know you' part, ., you could like say your preferred interventions, perhaps, and then so when you umm like, ask a question, and it says, oh you should do this, it can prioritize the ones that you would probably prefer, and would be better for you." (P05_W19)*

Discussion

While the extant literature provides insights into the lived and care experiences of young people living with chronic pain [4,15,16,27,52–56], to our knowledge, this is the first study to explore how young people's lived and care experiences influence their care choices for CMP, and *where* and *how* a DHS could optimally support their experiences and care choices. Understanding how young people make choices about CMP care is important; their choices can affect their current and future health and wellbeing and can inform how care and health services are planned and delivered, including digitally-supportive care. This is particularly relevant in contemporary healthcare where young people are digital natives and expect digitally supportive care [15,32], and where digitally-supportive care can mitigate care inequities [57].

Our visual display of findings (Figure 1) suggests that young people's lived and care experiences and their choices about CMP care are interrelated. Young people make choices about their CMP care by balancing their desire for a meaningful life (defined by their valued activities, e.g.; study, work, sport, socialization, relationships) against their self-care needs and responsibilities, and concurrently, aligning care choices with their preferences for interacting with healthcare providers and services. For example, young people may choose to abstain from accessing healthcare if the effort required precludes them from engaging in other valued aspects of their life. This balancing act requires young people to evaluate their CMP care options by gathering information about the potential benefits to their quality of life, financial cost, the energy required to adopt or use an intervention, and to what extent the care option is personalized to their context, values and preferences. These factors are all relevant to service and system-level planning for CMP care, highlighting that CMP care for young people is more likely to be accepted and adopted when these parameters are considered, for example, through co-creation efforts [12]. Further, our findings suggest that DHSs can support CMP care and self-care. Embedding DHSs within health services in a way that provides timely, integrative and personalized care could help young people who are often left "waiting in pain" [23,32,58–61], and better support them to navigate health services and systems; a barrier to care identified in our study and others [62]. For example, DHSs were perceived as supporting young people's confidence and capacity to self-care by helping to buffer the cognitive load involved in self-care; augmenting young people's interactions with healthcare providers and access to CMP services; or helping young people to make informed choices about CMP care options [63].

Lived experiences were characterized by CMP interfering with daily life, valued life activities, and mental wellbeing, consistent with other reports of young people experiencing CMP [4,15,27,52–54]. Our findings highlight that young people's lived experiences and their care choices influence each other bidirectionally (Figure 1). For example, young people described how their desire to return to valued life activities, such as sport, drove care-seeking options that could help them achieve this goal. Similarly, care choices also impacted their lived experience (e.g. the improvement in mental wellbeing when CMP care choices supported returning to sport), highlighting the value of holistic and integrative pain care for young people [4]. The central role of pain self-care to lived experience emerged as a prominent theme. Specifically, pain self-care was identified as a responsibility that people with CMP carry to live well. Skills, experiences and preferences in young people's self-care behaviors influenced their choices about CMP self-care and broader pain care. For example, young people described the cognitive burden associated with finding and making sense of credible tailored CMP self-care information. Young people's choices about CMP care options were also informed by factors representing the overall value of care options (e.g. effort involved, cost, impact on quality of life), in accordance with other studies describing young people's desire for greater information support including knowledge about pain, how to manage pain and who to contact for help and support [52,64–68].

Healthcare experiences also influenced how young people made choices about their CMP care. Young people expressed their values and preferences are not routinely considered in healthcare and they often experience conflicting information and care advice, consistent with existing evidence [4,15,16,52,54–56]. Young people valued empowering and validating therapeutic relationships, being listened to, believed, and respected [55,56,68,69]. While similar care priorities have been expressed by adults living with chronic pain [56], these therapeutic skills are not routinely taught in an interprofessional model [70,71], or consistently advocated for in clinical practice guidelines [72], particularly with relevance to young people. Nonetheless, the importance of this approach is highlighted in the recent Canadian Pediatric Pain Management Standards [73]. Young people described how their negative healthcare provider experiences, such as feeling invalidated, having to "prove" themselves to receive care or repeat their clinical journey, led to an increased burden in self-care responsibilities and dwindling energy reserves. In this respect, young people described using DHSs for support (e.g. social media, websites, apps) but were at times frustrated by them, such as when apps were not interoperable with their care providers' systems. In this respect, young people identified that a DHS could fill this gap. Here, young people identified that DHSs could address their healthcare needs by supporting improved care coordination (e.g. through being able to share information with and between health professionals) and enabling access to accurate and time-sensitive information about their local services (e.g. cost, wait time, parking, healthcare provider expertise). These findings characterize how young people perceive value from digitally-supportive CMP healthcare and offer an entry point for service co-creation initiatives with young people, for example, using a youth council model [14].

Access to Australian pain care services typically involves protracted wait times [23], out-of-pocket costs and young people's engagement with CMP care providers may not reflect their preferences [25]. Therefore, considering how pain care services and self-care strategies can be augmented is critical to addressing inequities and young people's preferences for CMP care and choices in a timely and personalized manner [4,15,16,52,74]. In this respect, young people articulated how a person-centered, high-value CMP service could be supported using DHSs. Using El-Osta's self-care framework, self-care can be described using four cardinal dimensions [75]: 1) self-care activities (micro-level, person-centered), 2) self-care behaviors (meso-level, principles and actions that support, motivate and sustain positive self-care behaviors), 3) self-care context (meso-level, patient-centered, health system focused) and 4) self-care environment (macro-level, policy-driven, health system focused). This study highlights how a DHS can reach across three of these dimensions, adding value to CMP care for young people. This is important for health service designers to inform *where* and *how* a DHS can support young people to build confidence in their ability to make well-informed choices about their self-care, while also supporting the delivery of person-centered care [49]. For example, in the first dimension, young people described how a DHS could support tailored and timely mood support, credible education about *what* and *how* to utilize pain care options. In the second dimension, it was perceived that a DHS could help to motivate behavioral change by helping to remember what to do (e.g. exercises, managing pain flares). In the third dimension, young people described how a DHS could help with care coordination and access to affordable and convenient CMP services and communicate their care needs and history.

Our analytical approach is a strength of this study because it enables practical application of the findings in the context of creating meaningful and acceptable DHSs and health services for young people with CMP. Our findings support co-creation of innovative models of service delivery harnessing DHSs to support young people across their pain care continuum with personalized and timely support [10], consistent with experiences from services in mental healthcare [76,77]. Our approach and findings, aligned to global best-practice co-creation frameworks underpinned by universal design principles [13,78], also inform creation of an equitable and inclusive digital health ecosystem for young people. Co-design and reporting of the research with a young person partner ensured the research questions, design and outcomes reporting were meaningful and respectful from a young person's perspective. Focus groups were facilitated to minimize perceived power imbalance between researchers and young people and to promote rich discussion between participants about how they make choices about their CMP care. It is possible that individual interviews may have enabled greater depth of conversation than afforded with focus groups. Although we achieved heterogeneity in classification of pain conditions (see Table 3), young people are still developing their identity, values and preferences. This represents a potentially large variation in population preferences for CMP care that may not be fully reflected in our thematic findings. Exploration of this variability in future studies through purposive sampling and analysis within narrower age bands, by pain phenotype and/or by other service characteristics (e.g. healthcare provider experience), may elucidate this variation further and help consolidate the depth and transferability of the study findings. Further, the transferability of our findings could be strengthened by seeking greater representation from men and people living in areas of higher deprivation and rural settings, and diversity in sociocultural backgrounds.

Acknowledgements

The authors thank the young people who participated and shared their lived experience of chronic musculoskeletal pain in this study. The authors confirm that the data supporting the findings of this study are available within the article and its supplementary materials.

Authors' contributions statement

CRediT: **Jason Chua**: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing; **Helen Slater**: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Writing – original draft, Writing – review &

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Disclosure statement

The authors report no conflict of interest. SML reports that as a clinician and member of government and non-government organizations across Australia, she was involved in dissemination of information about the study in the recruitment phase.

Financial disclosure

HS declares research grant income, unrelated to the current submission, paid to her institution in the 36 months prior to submission of the current paper, from the following agencies: Commonwealth of Australia (Health Professional Pain Education; Health Professional Arthritis Education; Endometriosis), AO Alliance, Asia Pacific League of Associations for Rheumatology, Australian Rheumatology Association, Pan American League of Associations for Rheumatology, World Federation of Chiropractic, Western Australian Government Department of Health Grant. HS also declares travel and accommodation support from the International Association for the Study of Pain, Australian Pain Society, and Australian and New Zealand College of Anesthetists (Faculty of Pain Medicine) for invited presentations at scientific meetings and technical meetings.

PBO receives speaker's fees for conducting multi-disciplinary clinical workshops on person-centered care for people with musculoskeletal pain.

AMB declares research grant income, unrelated to the current submission, paid to his institution in the 36 months prior to submission of the current paper, from the following agencies: AO Alliance, Asia Pacific League of Associations for Rheumatology, Australian Rheumatology Association, Pan American League of Associations for Rheumatology, World Federation of Chiropractic, Western Australian Government Department of Health Grant, and Arthritis and Osteoporosis Western Australia. AMB also declares consulting fees paid by the World Health Organization, an honorarium paid by the American College of Rheumatology, and travel support to attend technical and scientific meetings from World Health Organization, the University of Otago, and World Federation of Chiropractic. AMB is an unpaid and voluntary member of the International Coordinating Council of the Global Alliance for Musculoskeletal Health.

Institutional review board

Statement of institutional review board or ethics committee approval of the study protocol

The research was approved by Curtin University's Human Research Ethics Committee (HRE2022-0588).

Funding

This research is funded by the Australian Government Medical Research Future Fund (MRFF) (APP2016567) with co-funding from the Government of Western Australia, Department of Health (WA Health). The MRFF provides funding to support health and medical research and innovation, with the objective of improving the health and wellbeing of Australians. Further information on the MRFF is available at www.health.gov.au/mrff. The contents of this published material are solely the responsibility of the individual authors and do not reflect the views of the Government of Australia or the Government of Western Australia. H.S., N.R.K., S.R. and A.M.B. were supported, in part, by MRFF funding. J.C. and B.T. were supported, in part, by funding from the Government of Western Australia, Department of Health (WA Health).

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