s / themes	Quotations
1. Explore young people's experiences of	
g with persistent musculoskeletal pain	
Study*	"because I'm still at school I am challenged with trying to balance a lot of my school work with the
	rest that I need to recover from the pain and the fatigue that I get from the painIt's already
	stressful enough doing, like, Year 12, let alone having the extra pain on top that nobody else has to
	seem to worry about." (FG1)
Ability to engage in the workforce*	"I still do the stuff that I was, wellI suppose for me, which is not very good so I wouldn't recommend
	it to other people, but I do the jobs that I have to do in terms of the employed by other people sort
	of thing. So I would never cancel a shift at work" (IP07)
Fear of living a life in pain	"But when I really sort of sit down and think about it, I always sort of think of what's it going to – like,
	I'm 22 now. What's it going to be like when I'm 50? (IP16)
	"Like it's never going to get better. I just can't remember what it's like to have no pain anywhere I
	don't know what it's like anymore to just be able to sit down without pain on public transport or
	standing up or walking. It's just always there." (IPI2)
	"Um, well just where, you know, am I going to have this for the rest of my life? What do I $-$ surely
	there's something I can do to alleviate this pain because yeah, you know, I just don't think I should
	at 20, well not even 20 years old that I should have, you know, just constant pain even though it's a
	a very manageable level it's like it will get worseI presume and that's not something you really
	want to be thinking about." (IP10)
Sleep*	"Yeah, because it seems like, well, I'm really tired all the time but then when it comes to night I can't

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

Physical activity*

Despite the majority of participants acknowledging benefits of physical activity for pain management, juggling busy lifestyles whilst concurrently managing pain and fatigue often resulted in infrequent physical activity or protracted absences. Participants' self-esteem in relation to body image and weight management, their psychological wellbeing and social interactions were negatively impacted.

Simple daily tasks*
For several participants, their persistent

get to sleep. And even if I get to sleep now I'll just keep waking up, so it's a bit annoying, because you sort of – in the day you're like desperate to sleep but then when you're home then I'm wide awake..."(IP07)

- "...if I can get to sleep I'm good, but I do struggle to get sleep and I try to be in bed by 10.30 every night so that I can get enough sleep, but yeah, like, sometimes there are nights where I just can't get to sleep till 1 or 2 a.m. in the morning because I'm in too much pain..." (FG 1)
- "...it's hard when you want to get fit, you want to be healthy and stuff, and yet feeling good and being healthy don't always align, like exercise will make you wake up the next day not necessarily feeling as good...Or you're miserable so you want to eat yummy food, which contributes [to weight] you know? Yeah. It's making it hard for me to be healthy and do everything I want to do, I feel, and I feel that it's ... By stopping me exercising, I feel so much more tired than I felt last year, and that's been really frustrating" (IPO3)

I can't run, I mean like I can, but it does not work out well when I do. Usually it ends up with either my hips or my knees or my back or whatever just screwing up majorly. So um, although I haven't had to do sport in a long time, so that's not been too much of an issue. Yeah, I don't really do a lot of exercise. I do stretches every day and I walk to and from uni and I walk around the city and stuff like that, but I can't do it for too long; I need to take breaks and like I said, I get tired and pain comes on fairly easily with that. Also, one reason I'm really looking forward to seeing the physio is it's difficult for me to know what exercises - see I don't know a lot about it and a lot of normal exercises can put a lot of stress on my body, even things like doing sit ups." (IPI5)

"It makes it hard to do things that I used to take for granted a few years back...If I drop something, a few years ago in high school I'd just bend over and pick it up, no dramas, but now it's a big hassle,

pain experiences created difficulties in undertaking simple daily tasks such as standing up from a chair, taking a shower or brushing their teeth.

Overall lifestyle*

Participants strongly agreed that pain restricted their ability to lead their desired lifestyle. Whereas adolescents were particularly worried about the toll on their social life and lack of peer understanding, young adults appeared more pragmatic in acknowledging their limitations.

Invisibility of pain

you know? I have to get down slowly and sort of ease myself down and then pick it up, and it's a lot of effort and pain it takes, you know. It takes a lot longer to do simple things like that and getting up. Like getting in and out of chairs, in and out of bed, just things generally I notice, when I go down the stairs and get in the shower and that sort of thing. So fear of falling over and injuring myself even more. I worry a bit like that, yeah." (IPO2)

- "... I worry about my friends want to make plans to go out for a party or something in, like, a week's time and I don't know if I'm going to be able to physically get out of bed and feel okay to do that kind of thing. So it takes a big toll on, like, my social life in that nobody understands it so it's quite difficult in that aspect." (FG1)
- "...you know, I've kind of aged out and you just watch other people's lives, you know, speed off. That's kind of the way it feels, just kind of catches up to that like oh wait, my life is going to be entirely different to all the people around me and ... no one's going to really understand that." (IPO4)
- "I guess when my friends invite me out and they want to go, you know, out to lunch and then out to dinner and go clubbing and whatnot and I'm in a bit of pain, I'm not as keen" (IP01)
- "I got a new job in December and I haven't actually even told them that I have the condition because I'm just hoping I don't get a flare up and that I can keep going to work, because there is that lack of understanding and that it is a casual position, so I didn't really want to start off on that foot with something so serious and risk sort of being let go. I'm sure they wouldn't label that as the reason, but there's that sort of niggle in the back of my mind that you know, if they weren't understanding of it and it caused problems, that they would let me go. I did actually lose my previous job over an argument about my back." (IP15)

"I find that my friends, they kind of just like, "Oh, you know, you're just in, like, a little bit of pain, and

The two-way relationship between pain and mental wellbeing

it's just like, off and on", but no, it's constant and they just don't understand. They think I'm just exaggerating or that I'm just, you know, being silly. So I find that quite frustrating". (FG5)

- "I think it go both ways because I find I'm in less pain when I'm with my friends and laughing or you know, I'm still in pain but it's off my mind, so in that aspect, yeah I think emotions definitely influence pain, but the pain definitely puts me in a bad mood" (IPI2)
- "Oh lots, an awful lot. Um, just feeling like you're in pain, especially when it's a pain that it stops you from doing so many things. Of course it impacts on your mental health and it makes you think that you're not doing as much as you should, which kind of leaves you feeling sad. If the feeling goes on for a while, then you develop depression and whatnot" (IPO1)
- "... I get quite upset sometimes just because it feels like my body's kind of failed at being a body if that makes sense, and so I find that emotionally I struggle with that...to just get over the fact that my body is never going to work the way that everyone else's does, and that's had a massive effect on my wellbeing. Like, I've gone from being, like, confident in what I can do and who I am to having no idea what I can do now or next week or tomorrow. Like, it's crazy how big of an effect just, like, one diagnosis can make." (FG1)

Aim 2. Explore needs for information, skills and support to better manage pain condition

Health professionals who understand persistent musculoskeletal pain

- I think it's just the fact that it's young people that they're dealing with and usually like pain, like thought to be more for like older people and like bone density's going down and stuff like that.

 (IP18)
- "I've sort of been very disheartened by the fact that there's, yeah, they don't really look into it and, you know, there's GPs out there who just seem to brush off every condition that you have but um,

yeah I think sort of I've got a very negative attitude about doctors now...just generally GPs don't seem to, the ones that I've been to, don't really seem that interested in actually getting you better, they just want to prescribe you antibiotics and painkillers and, you know, they're not actually treating it." (IP10)

"... even though if you say, "I've had this pain for the past five years on and off", they're not going, yeah, you know, it's just a sort of a perception I find that – like in my experience the GPs that I've been to haven't been very proactive about why do you have this pain, you know..."(IP10)

"They're absolutely not tailored for me. Doctors seem to have this one size fits all approach and a lot of them go - well, I actually had a supposed specialist tell me that I was probably just going to be one of those people that ends up in hospital every now and then and has to have pain management".

(FG1)

"I once went into a specialist and he assumed that I was elderly so he had set up all this stuff, like a walking stick and all a wheelchair... so that was pretty embarrassing." [FG4)

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

Aim 3: Explore preferred modes of service delivery with a focus on digital technologies.

"The Tumblr format, where you post little snippets of pictures and pictures and short bits – that could

Lack of integrated care

actually be really good...in, like, "Here's a strategy in mindfulness" ... and then at the bottom a link to more details" (IPO3)"

"Even if there was an app for people with pain, like a pain management app and you could rate maybe what you did and what you – what you did for the day, what you ate, you know, whatever, and then how you're feeling and what your energy levels are and maybe that could help them to map what their level of pain is or what makes them feel worse, what makes them feel better, and they could then make some correlations and then improve their lives by seeing what increases their moods and their energy and what decreases it.(I15)"

"I think [a] combination – the forums would be good for other people to find you know, sort of forum support groups, that sort of thing. Like videos could definitely implement as education and sometimes people have like different ways of learning. Some people can read the whole thing and totally get it, but other people need to have a more visual explanation, that sort of thing." (IP12) "I would say the basic things like television advertisements, hospital, newspapers, radio...and also having a social media presence. Like it's pretty easy to set up a Facebook page or you know something similar to spread the word these days. Like a Twitter account or something." (IP08)

Legend: * Summary description of theme not already shown in results; IP=individual participant; FG=focus group; GP=general practitioner