# Qualitative research protocol

## Study title

Exploring adolescents’ and young adults’ experiences of seeking information about chronic pain using the internet and social media: a qualitative interview study

## Administrative details

Ethics number (ERGO): 56803

### Study team

Ms Anna Hurley-Wallace (primary researcher); A.Hurley-Wallace@soton.ac.uk

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### Patient and Public Involvement (PPI)

The PPI group consists of three individuals aged 16, 22, and 27 years, who are currently experiencing or have experienced (retrospective account) mixed chronic pain conditions throughout adolescence.

Mailing list: YA-chronicpain@groups.soton.ac.uk

### Patient partner

Hypermobility Syndromes Association (HMSA); <https://www.hypermobility.org/>

## Background

Chronic pain in adolescence is a globally recognised problem. In the UK 16-19% of adolescents experience multi-site chronic pain (Gobina et al., 2019), which is often associated with considerable functional disability with regard to physical, emotional, social and school functioning (Dick & Riddell, 2010; Forgeron et al., 2010). Interdisciplinary treatment, which is defined as multimodal treatment delivered by a multidisciplinary team working towards the same clinical and therapeutic outcomes (IASP, 2016) [add ref], reflects a biopsychosocial approach to chronic pain management and is recommended in clinical practice (Liossi & Howard, 2016). However, online self-management interventions for adolescents with chronic pain (Palermo et al., 2016; Grasaas et al., 2019), as well as online peer support platforms (Ahola Kohut et al., 2016) are increasingly implemented. Online interventions have shown relative efficacy in improving pain and quality of life outcomes, compared to usual care [refs].

To date, there has not been a multimodal, interdisciplinary online intervention developed for adolescent chronic pain in a UK context. The needs of adolescents in the UK may differ compared to adolescents in other western countries, such as the USA and Canada, based on their experiences of NHS healthcare and their experiences of chronic pain in different social contexts (Viner et al., 2012). Understanding this context is important when developing complex healthcare interventions, and conducting qualitative research can provide an insight into population-level factors that may impact whether an intervention in successful or not (Cathain et al., 2019).

The Medical Research Council (MRC) guidance for developing complex healthcare interventions stipulates that qualitative insights are important in intervention development from planning through to evaluation, however this can be supplemented with other more detailed approaches (Cathain et al., 2019) to ensure qualitative data collected is useful to developers. The Person-Based Approach (PBA) (Yardley, Morrison, Bradbury & Muller, 2015) provides a detailed overview of how qualitative feedback from intervention stakeholders (for example patients, patients’ families and healthcare professionals) can be integrated into online interventions in three stages; planning, optimisation and evaluation (Morrison, Muller, Yardley & Bradbury, 2018). The planning stage focuses on primarily qualitative, but also mixed-methods, research that can provide rich data on factors that impact engagement in potential users. Following the planning stage, guiding principles are formulated; these specify design objectives and key features that will help to achieve these objectives. Guiding principles outline the core design elements of the intervention which are intended to support engagement with content. The next stage of optimisation is where interventions are modified based on user-feedback, and finally implementation and evaluation employ mixed-methods research to conduct process evaluations and understand individuals’ experiences of a ‘full’ intervention.

Key to understanding the context in which adolescents with chronic pain will engage with novel interventions, at the planning stage, is gaining a better understanding of their use of the internet for seeking information about chronic pain management, particularly because adolescents are digital natives (Ofcom, 2017, 2019). Similar research investigating parent’s experiences of using the internet to seek information has been conducted at the planning stage of an intervention developed for about their childhood eczema, using the PBA (Santer et al., 2015). Additionally, in relation to adolescent pain, research has been conducted to explore healthy adolescents’ use of online resources for pain management (Henderson, Keogh & Eccleston, 2014). Qualitative findings from this study highlighted three main themes: drivers of internet use, barriers, and anxiety around use. One of the main barriers was website design, where participants mostly had negative experiences of navigating through content, and symptom checklists were viewed as unhelpful. Anxieties included a mistrust in the quality of online content and pain-related anxiety. Some adolescents linked pain severity to their decision of whether to consult the internet or seek help in person.

Further, mixed-methods survey-based research has identified social media platforms, such as Instagram and YouTube, as important resources of chronic pain management for adolescents in the UK (Hurley-Wallace, Schoth, Lilley, Williams & Liossi, 2020). However, a qualitative exploration of online chronic pain information-seeking in this population has not been pursued. Using qualitative interview methodology can help intervention developers in adolescent chronic pain by providing an in-depth insight into which internet-based resources are already being used, by whom, when, and why. It may also be the case that this research reveals certain elements of multimodal pain management are not sought out by this population or are already covered by existing apps or websites.

Recent definitions of adolescence indicate than an inclusive definition of adolescence expands up to 24 years old, which is appropriate for modern role transitions and reflects later social development (Sawyer, Azzopardi, Wickremarathne & Patton, 2018). To reflect this, the current study includes participants up to 24 years old, with a lower age limit of 16 years old, which is when adolescents in the UK transition from paediatric to adult healthcare. This group shares a key similarity in that whilst they are considered adolescents, they are independent with regards to managing their health. Some participants’ chronic pain may have developed several years beforehand; talk surrounding these experiences in retrospect is welcomed in this study.

## Aims

This study primarily seeks to explore adolescents’ experiences of searching for information about chronic pain using the internet. This includes exploring experiences of searching the internet using search engines (e.g. Google), health information websites (e.g. the NHS website), and social media platforms (Facebook, YouTube, Instagram). Secondary aims include: (i) to explore adolescents’ experience of chronic pain management strategies, including pain management techniques and advice provided by healthcare professionals, and self-management strategies, and any internet resources that have helped facilitate this (ii) to explore which online resources adolescent’s believe have been the most helpful, and/or may have been potentially helpful for managing chronic pain, if available.

## Method

### Methodological Approach

This study will use semi-structured, individual interviews to collect qualitative data. An interview guide will be used to ensure topics explored during interviews are consistent with the aims of this research, however a semi-structured guide is flexible enough such that interviewees may direct the conversation to other related issues, which will also be explored. Semi-structured interviews are appropriate for this study because these interviews are intended to be steered by the research question (Willig, 2013b), to encourage talk about specific experiences of seeking chronic pain information online. Additionally, data from semi-structured interviews is compatible with reflexive thematic analysis (Braun & Clarke, 2019a), which will be used to analyse the data in this study.

Focus groups were also considered as a data collection method for this study, however the research question is around individual experiences of internet use, for a wide variety of pain conditions, the interaction among participants was not considered a data source of interest (Willig, 2013b). Focus group dynamics also have potential to cause distress in group members, which the research team were particularly aware of in relation to young participants with chronic pain and was additionally highlighted by the PPI group for this study.

Care will be taken when integrating interview context into the data analysis (Smith, Hollway & Mishler, 2005). These interviews are to be conducted online using Microsoft Teams, which some interviewees may be familiar with, where others will not. To level out this experience and address any participant worries about conducting the interview online, an initial online ‘screening’ interview will take place. A reflection on the whole interview process, set within the context of conducting remote interviews during the COVID-19 pandemic, will be included either within the main write-up of this study, or as supplementary material.

### Participants

Inclusion criteria: (i) 16 to 24 years old (Sawyer et al., 2018), (ii) bodily pain lasting 3-months or longer, (iii) chronic pain condition, including any on the ‘pain conditions list’ below, or any other chronic pain condition diagnosed by a healthcare professional, as listed in the ICD-11 (Treede et al., 2015), (iv) permanent residence in the UK.

Exclusion criteria: (i) <16 years old, (ii) >24 years old, (iii) bodily pain lasting less than 3-months total duration, (iv) residing outside of the UK, (iv) no access the internet for the online call, (v) unable to communicate in fluent, spoken English.

#### Pain Conditions list:

1. Chronic primary pain (including area-specific chronic pain of unknown aetiology e.g. [Low back pain](https://www.nhs.uk/conditions/back-pain/), chronic widespread pain, [Fibromyalgia](https://www.nhs.uk/conditions/fibromyalgia/), and [IBS](https://www.nhs.uk/conditions/irritable-bowel-syndrome-ibs/))
	1. Chronic primary pain is only appropriate where pain cannot be better explained by categories 2-7 and is associated with significant emotional distress or functional disability (Treede et al., 2015; Nicholas et al., 2019).
2. Chronic cancer pain (pain caused by cancer itself or by cancer treatments)
3. Chronic post-surgical or post-traumatic pain (pain that persists beyond normal healing time following a surgical procedure or tissue injury)
	1. Chronic post-surgical pain is often neuropathic in nature (Haroutiunian, Nikolajsen, Finnerup & Jensen, 2013) (see 4)
4. Chronic neuropathic pain (damage to the somatosensory nervous system)
	1. Demonstration using imaging, biopsy, neurophysiological, or laboratory tests, in addition to negative or positive sensory signs, must be present for definitive identification as neuropathic.
5. Chronic headache or orofacial pain (including primary and secondary headaches, and [Temporomandibular disorder (TMD)](https://www.nhs.uk/conditions/temporomandibular-disorder-tmd/),)
	1. Pain must be present on at least 50% of days to be classified as chronic within this category.
6. Chronic visceral pain (pain originating from internal organs of the head and neck region and the thoracic, abdominal, and pelvic cavities)
7. Chronic musculoskeletal pain (pain arising as part of a disease process that affects the bones, joints, muscles, or related soft tissues. This includes conditions of persistent inflammation, such as [Arthritis](https://www.nhs.uk/conditions/arthritis/), as well as pain resulting from structural osteoarticular changes, such as [Ehlers-Danlos syndromes](https://www.nhs.uk/conditions/ehlers-danlos-syndromes/), [Joint hypermobility syndrome](https://www.nhs.uk/conditions/joint-hypermobility-syndrome/))

### Sampling and sample size

This study will use opportunistic sampling.

Participant recruitment will continue until data is approaching saturation (analysis ongoing). Research on saturation indicates that code saturation may be achieved at approximately 9 interviews, whereas saturation of meaning approximates 16-24 interviews and represents an in-depth understanding of the issues and topics identified (Hennink, Kaiser & Marconi, 2016). Hence, the guide sample size for this study will be 16 individual interviews. Whilst research on saturation can serve as a guide for developing qualitative research protocols, the reflexive TA methodology used in this study calls for a more flexible, interpretive approach (Braun & Clarke, 2019b). It has been noted within academic discussions of reflexive TA that coding and analysis cannot reach a fixed end point, as new meanings are always theoretically possible (Low, 2019). Rather, the researcher makes an interpretative decision about when to stop coding and start generating themes, and when to move on to mapping thematic relationships (Braun & Clarke, 2019b). The sample for this study is likely to be mixed and complex, with a variety of different pain conditions and social contexts represented; the key issue will likely surround what parts of the data to explore, rather than when there is ‘no new’ data. Hence, there is no minimum sample size for this study, and the maximum sample size will be set at 50 participants (for insurance purposes). As ERGO requires specifying how many participants will be in the 16-17 years range versus the 18-24 range, 25 participants will be input for each group (although the separation of these groupings are not required for the purposes of this study).

### Recruitment

This is an incentivised study, where research participants (excepting University of Southampton psychology undergraduate students, who will be awarded 12 research participation credits) will be offered an incentive of £20 ‘Love to Shop’ e-vouchers for their time during the research interview. Participants will not receive an e-voucher for the screening interview, as they may be deemed ineligible at this stage. One research participation credit will be awarded as a token to students who participate in the screening and are deemed ineligible.

Community participants will be invited to the study online via relevant organisations, charities, using social media, and via contact with colleges and sixth forms.

Psychology students will see the study advert on eFolio, where participants will be provided with the study title, a brief overview, eligibility criteria, number of credits available, and asked to email AHW for more information.

Relevant organisations and charities that support young people with chronic pain will be identified through discussion with the PPI group, and by the primary researcher. The HMSA was identified prior to the start of the study and has agreed to advertise this research on their website, pending ethical approval. An application will also be made to Fibromyalgia Action UK (FMAUK) following ethical approval. With the exception of instances where the organisation has a specific contact form for advertising research (such as FMAUK does), contact with organisations and charities will begin with the gatekeeper email. This will be sent to the relevant organisation leader or administrative email (for example the ‘contact us’ email address) by AHW. Organisations and charities that agree to advertise the research will be provided with the lay summary, the PIS, and any other study documents they wish to review prior to advertising the study on their media streams.

Social media platforms that will be used for advertising the study include Facebook (including Facebook and Instagram paid advertisements), Twitter, and Reddit, as well as any other platforms identified by the research team throughout the study (advertising material appended as supplement). The research team may decide to use Call for Participants (<https://www.callforparticipants.com/>) to co-ordinate social media advertising. Call for Participants can be used to create a summary page for research studies (for a small fee), where participants can view the lay summary of the research, incentives and inclusion criteria, then express their interest by entering their email directly into a form on the webpage. Their email address is sent directly to the owner of the study page. Social media gatekeepers (if present), for example, group admins and moderators, will be asked for site-specific permission before using the platform to advertise.

AHW may have the opportunity to advertise this study at some sixth form/ college open days and/or events. If such opportunities arise, AHW will email the appropriate gatekeeper (headteacher or head of sixth form/college/ department) ahead of the event, using the pre-written gatekeeper email. Potential participants who are interested in the study will be asked to provide their email address to AHW either in-person, online verbally, online via message (message platform will depend on platform being used by the college e.g. Google Classroom), or alternatively they may email directly.

### Consent

Consenting processes for this study have been discussed with University of Southampton Research Governance, reaching the conclusion that parental consent will not be necessary for the 16 to 17-year-olds who wish to participate in this study.

Participants that express interest in the study will be asked for their email address (if not already given), sent the participant information sheet (PIS) and the consent form by email and invited to a brief screening interview. The screening interview will not be arranged any sooner than the following day to allow participants extra time to decide if they would like to take part in the study.

If they have not already responded, they will be followed up three times by email, at 3-days, 7-days, and 10-days. If there is no response after the third prompt, no further contact regarding the study will be made.

At the beginning of the screening interview, participants will be asked if they have read and understood the PIS and consent form, and if they have any questions about the study. They will then be asked to provide verbal consent.

This study will use a verbal consent form, which will be recorded in MS Teams (at the beginning of the screening interview) and signed off individually for each participant by AHW (see verbal consent form in ERGO). This form uses questions from the Psychology Ethics Committee consent form template. The remainder of the screening interview will not be recorded.

At the beginning of the main interview (which will be recorded separately), participants will be asked if they have any further questions about the study, and if they are still happy to take part in the main interview.

### Materials

1. Microsoft Teams
2. Participant Information Sheet
3. Study advertisement
4. Lay summary
5. Gatekeeper email template
6. Follow-up/ prompt (3/7/10-days) email template
7. ‘Screening not passed’ email template
8. Chronic pain screening tool
9. Demographic form
10. Verbal consent form
11. Interview topic guide
12. Debrief

### Procedure

Respondents to the advert will be invited to an initial screening interview using Microsoft Teams (arranged via email). Microsoft Teams has functions available to conduct either an online video meeting or an online voice-only meeting. Potential participants may choose the option which best suits their circumstances and/or preferences, such that they feel comfortable in the interview setting. The PIS and consent form will be provided in the first email correspondence, and the screening arranged if they agree to take part. The screening interview will be conducted by AHW (recorded consent will be taken first), using the demographic questions and chronic pain screening tool developed for this study (the pain conditions list/ ICD-11 will be referred to as necessary). This will be an informal conversation in which layman’s terms will be used as much as possible to help clarify any questions about the study. At the end of the screening interview, AHW will arrange a suitable time to conduct the main research interview (additional email correspondence to arrange if necessary). Potential participants who do not pass screening will be followed-up with an email politely advising that they are ineligible to participate, thanking them for their time, and directing them to pain reduction resources on the NHS website (<https://www.nhs.uk/live-well/healthy-body/10-ways-to-ease-pain/>). Psychology students will additionally be advised in this email that they will receive 1 research credit for the screening.

For the research interview, participants will be invited to attend an online meeting via Microsoft Teams at the agreed time. Community participants (i.e. external to the University of Southampton) will be invited as a guest onto the Teams platform. The primary researcher will serve as the host, and gatekeeper to the meeting. When participants enter the online meeting as a guest, they will be asked to enter a screen name of their choosing; they may enter the meeting via the Microsoft Teams web platform or via the Microsoft Teams app. This initial meeting entry procedure will be explained clearly in the PIS.

When participants enter the meeting, AHW will greet them informally and check that they still wish to take part in the interview. The recording will then start, and the interview will last for approximately 1 hour. AHW will follow the interview guide developed for this study, and additionally take field notes. At the end of the interview, the recording will be stopped, and participants will be given an opportunity to ask any questions they may have, off the record. The debrief will be read verbally to the participants, and a copy will be sent to each participant via email after the end of the Teams meeting. The email containing the debrief will also contain the Love to Shop e-voucher, or for University of Southampton Psychology students, confirm that research participation credits have been awarded.

## Qualitative analysis

Qualitative data collected in this study will be initially reviewed by the primary researcher using the video/audio recording and base transcript, which is automatically generated in Microsoft Teams and uploaded to Microsoft Stream. Base transcripts will then be sent to an external provider to be fully transcribed and re-reviewed thoroughly by the primary researcher. Final transcriptions will be exported to Nvivo 12 (QSR International Pty Ltd, 2012) for analysis.

Data collected in this study will be analysed using a reflexive thematic analysis (TA) (Braun & Clarke, 2006, 2019a). Analysis will be based on the primary researcher’s interpretation of the data (Braun, Clarke, Hayfield & Terry, 2019) from a critical realist standpoint. A critical realist approach suits the exploratory nature of the main research question in this study. Participant experiences will be considered as approximations of reality, which are underpinned by social and psychological factors (Willig, 2013a). As such, the focus of analyses will be on the interpretation of meaning in context.

Braun and Clarke (2006) outline six phases of TA. The first stage phase includes familiarizing yourself with the data: transcribing audio data, reading, and re-reading. The second phase is code generation, which involves systematically coding interesting features of the data that are noticed across the data set. The third phase is searching for themes. To do this, codes are grouped together to form potential themes; Braun and Clarke (2006) state: *“A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set.”*

The fourth phase involves reviewing themes and checking if they fit the initial coded extracts, as well as whether they fit the entire data set. At this stage, a thematic map of the analysis can be created – this is like a mind map. In the fifth phase, the specifics and names of extracted themes are finalised. The sixth is the production of the report. A selection of compelling quotes from the data can be included in the report to provide an example of each theme. Selected extracts from the data may be analysed further for the purpose of the report, and the analysis will be related back to the research question and wider literature.

This study will also adhere to the 15-point checklist of criteria outlined for good thematic analysis (Braun & Clarke, 2006), which covers the transcription, coding, analysis, overall quality, and final report.

## Data protection and confidentiality

All research must comply with the requirements of the General Data Protection Regulation (GDPR) and the Data Protection Act 2018.

All data for this study will be electronic only. Compliant with University of Southampton guidelines, consent and interviews will be conducted and recorded securely via Microsoft Teams.

Consent recordings from Microsoft Teams are uploaded automatically to Microsoft Stream. These recordings can only be seen by individuals who were present in the online meeting and will thus remain stored in AHW’s University of Southampton account, and not shared anywhere else. Consent recordings will also be kept in a password-protected folder on OneDrive, that only the research team may access.

Interview data (video and audio) will be recorded and saved to Microsoft Stream, which will automatically generate a base transcript. This transcript will be checked by AHW initially, and video recording will be used to help clarify and finalise field notes. The audio recording will be extracted from the video recording (using VLC), and the audio-only recording will be sent to an external provider to be professionally transcribed.

Professionally transcribed recordings will be checked by AHW against the base transcript and original recording. Transcripts will be pseudonymised as much as possible at this point i.e. names replaced with fake names. The finalised transcriptions then will be saved as separate files in OneDrive, then exported to Nvivo 12 for qualitative analysis using the pseudonymised participant IDs.

Pseudonyms and other personal data will be kept in a password protected data key file, on the University of Southampton OneDrive, that only the research team may access. Each participant’s data will be labelled with their pseudonym, so that if they wish to withdraw their data, this may be done using the data key file. Participants can withdraw their data within 2-weeks of the interview if they wish. After 2-weeks, participants may not withdraw their data from the study.

Screening forms (chronic pain screening and demographic form) will be labelled with the participant’s pseudonym and saved as separate files in AHW’s University of Southampton OneDrive.

All interview recordings and base transcripts will be destroyed/ permanently deleted from Microsoft Stream once the professional transcription has been completed and checked, and all field notes have been finalised.

This study will be prepared as a manuscript and submitted to a relevant academic journal and deposited in the University of Southampton’s repository, Pure. Data from this study (pseudonymised transcriptions) will be stored by the University of Southampton for 10-years in-line with university policy. Data from this study (pseudonymised transcriptions) will be stored by the University of Southampton for 10-years in-line with university policy.

## Dissemination

The University of Southampton owns the data arising from this study. This study will be prepared as a manuscript and submitted to a relevant academic journal and deposited in the University of Southampton’s repository, Pure. This research will be also be presented as a complete paper in AHW’s PhD thesis.

Lay summaries of the research findings will be provided to any collaborating charities and organisations, as well as to study participants on request. Details of who to contact for further information about the study are provided in the study information sheet and debrief.

The published journal version of the report will only be made publicly available where the journal’s open access fee is covered by the university or collaborating organisations.

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