RESEARCH PROTOCOL

Full title of project
Understanding and improving endometriosis experiences: a qualitative study into patient and healthcare professionals' experiences of management, diagnosis and treatment
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Ethical approval
Objective 2: The study has been added by minor amendment to the study 'Narratives of health and illness for research, teaching and dissemination via www.hexi.ox.ac.uk' approved by Berkshire Ethics Committee REC Ref 12/SC/0495.

Objective 3: Separate ethics approval will be sought.

Version control

Version number	Author	Proposed change	Date
V1.0	Abigail McNiven	n/a	25/10/2024
V2.0	Abigail McNiven	Revision from scoping review to narrative syntheses review, as former deemed to duplicate existing work and of limited benefit	31/01/2025
V2.1	Abigail McNiven	Refinement of Objective 1 research question added	07/02/2025

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Research plan

Summary of research/abstract

Endometriosis is a long-term condition, involving the abnormal presence of endometrial tissue outside of the uterus, with prevalence estimates around 10% of women but likely higher. It is associated with symptoms such as pelvic pain and fertility problems, and detrimental impacts on quality of life. The average length of time between first seeing a healthcare professional about symptoms and getting a diagnosis is 8-10 years.

Endometriosis patients in the NHS have voiced their poor care experiences, including through the recent Women's Health Strategy for England. Recent efforts have sought to raise awareness amongst GPs in order to improve patients' experiences (e.g. RCGP Learning, 2019); yet many people continue to report poor experiences. More research is needed to better understand a wide range of patient experiences and healthcare professionals' perspectives to identify other improvements that can be made.

Our aim is to build a comprehensive understanding of UK patients' experiences of endometriosis healthcare, integrated with understandings from professionals in primary care and specialist services, to identify opportunities to use this learning for improvements in care journeys. To address this, our objectives are to: (1) Build on what is already known about patient and healthcare professional perspectives and experiences of endometriosis; (2) Explore diverse experiences of patients in the UK with endometriosis; (3) Explore the experiences and perspectives of healthcare professionals involved in endometriosis care; (4) Develop a comprehensive and integrated whole-system understanding of endometriosis healthcare journeys and experiences, and use the findings to develop resources for patients and healthcare professionals.

After undertaking a review of existing literature, we will interview up to 50 patients across the UK about having diagnosed, or suspected, endometriosis, seeing healthcare professionals, and experiencing treatments and diagnosis. We will hear from patients with different experiences, including from racially minoritised groups, with disability, and from different socioeconomic backgrounds including people living in poverty. We will also interview up to 30 specialist healthcare professionals (including specialist nurses) and up to 10 practice nurses and clinical pharmacists, and re-analyse interviews we have already collected with 42 GPs (ref: NIHR SPCR 403; Dixon *et al.*, 2021). We will analyse the datasets and bring the findings together.

Within and across the perspectives of patients and healthcare professionals, we will explore similarities and differences in what patients and healthcare professionals say, and look for examples of both good and poor healthcare as well as points where there is mismatch between the accounts of patients and healthcare professionals. The learning in our study will be used to co-design resources that will support patients, inform healthcare professionals, extend knowledge about endometriosis experiences, shape

health services, and guide policy to improve care journeys. This will include producing a resource developed from patient experiences on the HEXI website – a platform with the potential for use in education and training in medical schools in the UK. Throughout the study, we will be guided by a Public and Patient Involvement group and an Advisory Panel, in addition to a Study Steering Committee.

Background and rationale

Endometriosis is a long-term condition involving the abnormal presence of endometrial tissue outside of the uterus (Farquhar, 2000). Symptoms vary, but endometriosis is typically associated with chronic pelvic pain and subfertility. It affects approximately 10% of women (Zondervan *et al.*, 2020), though estimating the true rate can be challenging, in part because laparoscopic surgery is the 'gold standard' for definitive diagnosis (ESHRE, 2022).

For NHS patients, the route to diagnosis typically involves seeing a GP, referral to specialist care, and undergoing specialist imaging or laparoscopy. Navigating these healthcare journeys is complex and linked with delayed diagnoses (Ballard *et al.*, 2008; Pugsley and Ballard, 2007; Cea Soriano *et al.*, 2017; Burton *et al.*, 2017; Ghai *et al.*, 2020). The time lapse between first presenting with symptoms and receiving an endometriosis diagnosis averages 8-10 years, with little demonstrable improvement to this diagnostic delay despite campaigns and increased awareness. How to improve endometriosis care and reduce diagnostic delay was a top ten priority in the James Lind Alliance Priority Setting Partnership in 2017. Delayed endometriosis diagnoses are associated with healthcare dissatisfaction (Ballard *et al.*, 2008), with concerns that this extended window of time results in missed opportunities for better patient experiences and outcomes – including for those who experience fertility difficulties.

Studies have highlighted the quality-of-life impacts of endometriosis and suboptimal experiences with healthcare services, including around delayed diagnoses (Simoens *et al.,* 2012*)*. Qualitative studies have provided insights into the challenges of societal attitudes around symptom normalisation and menstrual etiquette (Seear, 2009) that patients (and healthcare professionals) have to navigate. However, most patient experience research has recruited women from specialist clinics and support networks (Simoens *et al.*, 2012), representing only a limited sub-set of healthcare experiences and journeys. Those who are not referred and/or choose different treatment pathways, for example those who prefer GP management for suspected endometriosis, or return their care solely or mostly back to GPs following diagnosis, have largely been absent. The demographic variety of experiences has also been limited in existing research, including in relation to ethnicity in endometriosis diagnostic journeys (Bougie *et al.,* 2019).

Explanations for dissatisfaction with healthcare for suspected endometriosis and diagnostic delays have largely focused on concerns that GPs do not take key symptoms seriously or refer to specialist services quickly enough. Thus, a GP 'knowledge deficit' explanation has underpinned efforts to raise awareness of endometriosis in primary care.

However, our National Institute for Health and Care Research (NIHR) School for Primary Care Research (SPCR) funded study highlighted the complexity of GP thought processes and decision-making, including around referral and (individual) trials of treatment (Dixon *et al.,* 2021). Whilst GP awareness is a pre-requisite for considering endometriosis, other important uncertainties and considerations underpin (retrospectively labelled) diagnostic delays (Dixon *et al.,* 2021).

Current national and international guidance recommends that non-steroidal anti-inflammatories or hormonal therapies are tried first, with onward referral only where these are unsuccessful. However, where such treatment trials are not experienced as collaborative shared-decisions with routes for follow-up assessment, there are risks that patients feel dismissed in primary care and see these clinical steps as contributing to a perceived delay. There is also uncertainty about how best to support patients whose symptoms improve with empirical first-line treatment in line with guidance, or who do not want referral for diagnostic investigations. Additionally, little is known about how endometriosis specialists navigate uncertainties, including concerns that laparoscopies (investigative, concurrent with treatment) come with risks (Chapron *et al.,* 1998), and their perceptions of healthcare services and interfaces, including pre-referral or ongoing management in primary care.

Evidence explaining why this research is needed now

Compared to other long-term health conditions with similar incidence and impacts, endometriosis remains under-researched (Rogers *et al.,* 2009; Brady *et al.,* 2016). The James Lind Alliance Priority Setting Partnership on endometriosis (2017) identified many unanswered questions, uncertainties, and challenges for clinicians and patients alike, including around disease mechanisms (causes, progression), diagnosis, fertility management, and treatment options and outcomes (medical, surgical), as well as emotional and psychological support needs. Patients' experiences, their relationships with healthcare professionals, and the potential for more holistic healthcare were also represented (James Lind Alliance, 2017).

Dissatisfaction with endometriosis healthcare was highlighted in the recent National Confidential Enquiry into Patient Outcome and Death review on endometriosis (NCEPOD, 2024), and further underscored in the Call for Evidence (DHSC, 2021a), Our Vision (DHSC, 2021b), and Women's Health Strategy for England (DHSC, 2022). The Women's Health Strategy for England (2022) is a landmark strategy that lays out a 10-year ambition that "women and girls with severe endometriosis experience better care, where diagnosis time is reduced on the journey from initial GP appointment through to final diagnosis" and, directly citing our published work (Dixon *et al.,* 2021), that, "We will use the findings to inform our understanding of barriers to diagnosing endometriosis". More broadly, the need to listen to and learn from women's experiences and concerns in healthcare has been highlighted by the Cumberlege 'First Do No Harm' report (2020) and Ockenden Maternity Review (2022).

A whole-system approach to understanding endometriosis healthcare experiences offers opportunities to hear from patients themselves and explore these in the wider system context. This necessarily includes both primary and specialist healthcare professionals to help illuminate the complexities at play, and identify opportunities for improvements. We will also consider the role of ongoing and planned service re-configurations, such as the Women's Health Hubs which are recommended for expansion in the Women's Health Strategy for England (DHSC, 2022) and have been evaluated (Daniel, 2022, 2024). Further research is urgently needed to understand this process of navigating the initial routes to and through care, the role of diagnosis for patients, and implications for how professionals communicate with and treat endometriosis patients. To our knowledge, no study has looked at (or is currently looking at) healthcare professional and patient perspectives across all components of NHS healthcare services (primary, secondary, tertiary), in order to bring these cohesively and comprehensively together in constructive dialogue. Existing research on endometriosis experiences does not represent those who are not/do not wish to be referred, managed or treated in secondary care, including for formal diagnosis or specialist treatments, and critical reflection on whether, where and how calls for raised awareness have translated into improvements for patients.

Additionally, there has been a notable paucity of inclusion in research regarding those with lived experience of endometriosis who are from racially minoritised and lower socioeconomic backgrounds (Bougie *et al.,* 2019; Seear, 2016). Awareness raising and charity/support group outreach work has also been criticised for a lack of diverse representation, or perceived barriers about who support is intended for or able to resonate with. There is a recognised need for more information and support resources for people with endometriosis, including around sharing and learning from others' lived experiences, and particularly that which adopts an inclusive ethos with diverse representation. Understanding the experiences of a diverse range of patients, with varying diagnostic and care pathway trajectories, will help explore how calls for awareness-raising over recent years have translated (or not) into improvements in care – and how these impacts may have been disproportionate and potentially reinforced existing inequities. This study will identify areas for improvement, intervention, and transition, develop public-facing resources to address information and support needs for patients, and generate service improvement ideas for healthcare professionals and policy-makers. We envision our study contributing to these knowledge gaps, and being used to inform practice and policy guidance.

Aims and objectives

Our research aim is to build a comprehensive understanding of UK patients' experiences of endometriosis healthcare, integrated with understandings from professionals in primary care and specialist services, and to identify opportunities to use this learning for improvements in care journeys.

Our objectives are to:

(1) Build on what is already known about patient and healthcare professional perspectives and experiences of endometriosis;
(2) Explore diverse experiences of patients in the UK with endometriosis;
(3) Explore the experiences and perspectives of healthcare professionals involved in endometriosis care;
(4) Develop a comprehensive and integrated whole-system understanding of endometriosis healthcare journeys and experiences, and use the findings to develop resources for patients and healthcare professionals.

Research methods overview

Our study is a qualitative exploration of the different perspectives and experiences of managing endometriosis – from the points of view of various patients and healthcare professionals – with a view to identifying opportunities for improvements. It will entail a narrative synthesis review to build on existing knowledge, primary qualitative interviews and a secondary analysis of existing interviews, the development of a quality framework, and co-design activities – all supported by extensive PPI work and expertise from the research team and advisory groups.

The work proposed in this study will be undertaken by a highly experienced, multidisciplinary team with a strong track record of patient experience research with public-facing outputs and a range of methodological and topic-specific expertise, networks and connections for recruitment, data collection, co-design activities for improvement, and dissemination to ensure that findings are impactful with relevant groups.

Study set-up

We prepared a job description and advert for a suitably qualified and experienced post-doctoral qualitative researcher to be circulated on notification of application success.

For the study preparation, we will:

- Undertake a series of Patient and Public Involvement (PPI) discussion groups and one-to-one conversations focused on diversity in lived experiences of endometriosis, and expand our PPI Group (more details in the PPI section).
- Expand our Advisory Panel, which will include healthcare professionals, patients with lived experience, charity and voluntary organisations, researchers, and clinicians, to advise on study parameters.
- Add the patient experiences study component of this study to our existing over-arching ethics coverage: The qualitative methods for the interview study with patients have been approved by NRES Committee South Central – Berkshire (REC reference number 12/SC/0495) and HRA for all health conditions involving adult participants. Our interview studies do not require NHS sites to act as 'Research Sites' (under the National Research Ethics service guidelines), but only as

'Participant Identification Centres (PIC)'.

- Submit an ethics application for interviewing healthcare professionals: We will acquire and adhere to ethical approval to recruit and interview healthcare professionals (practice nurses, clinical pharmacists, specialists).

Objective 1: Build on what is already known about patient and healthcare professional perspectives and experiences of endometriosis

We will undertake a narrative synthesis and augmented review with a UK focus, building on our existing knowledge of patient and healthcare professional experiences of endometriosis. We anticipate that the majority of existing qualitative syntheses appropriate to our guiding question will focus on the patient experience. An augmented approach will entail us running additional searches for (1) publications focused on healthcare professional experiences that have not been included in previous syntheses, and (2) publications focused on patient experiences that have been published since the most recent syntheses.

Our working question for the review is, “What is known about patient and healthcare professional perspectives and experiences of health care in managing endometriosis?” A narrative synthesis of existing syntheses on these topics – of which there are several high-quality examples identified in our initial searching – will build on and add to existing knowledge, and guide the rest of the study. We anticipate the literature will include experiences and accounts of decision-making around treatments, referral and diagnostic investigations, communication of knowledge about endometriosis, and experiences of navigating healthcare services. We are mindful that one of our key study objectives is consideration of whole journeys through complex systems, hence our interest in different contexts (specialist clinics, GP, community, fertility settings).

The review will map out the current knowledge about patient and healthcare professional perspectives and experiences, and transitions between settings/contexts – building on what is already known. We will look for examples where there might be disagreement or misalignment between groups (e.g. patients, different healthcare professionals). We anticipate this will include different accounts of why and how delayed diagnosis and poor healthcare experiences occur, and the implications for healthcare structure, services, professionals, practices and processes.

We will conduct the narrative synthesis in line with Toye’s mega-ethnography approach (Toye et al, 2017; a method drawing upon and extending meta-ethnography approaches (Noblit and Hare, 1988), and a new but growing area of inquiry with approximately 5 peer-reviewed mega-ethnographies published to date. We have access to an information specialist (Nia Roberts) through the Department and Dr Toye, who has extensive expertise in qualitative evidence synthesis including pioneering mega-ethnographies, has indicated willingness to offer guidance and support..

A narrative review approach will enable us to develop "an interpretive overview" (Greenhalgh et al, 2018) of our topic, endometriosis healthcare experiences. Our intention is also to use this review to attune us to gaps in the existing literature and the underpinning research that has been undertaken to date. We will extract this information during the review and will consult original publications where more information is needed. In addition but separately, we will consider the relevant grey/policy literature as potential insights relevant to our research aim reside in non-academic literature which are important to capture, for example the Women's Health Strategy for England (DHSC, 2022), the Women's Health Plan for Scotland (2021), and Women's Health Wales (2022), guideline changes (for example, NICE reviewed their 2017 endometriosis guidelines in 2022 and updated these in November 2024, including sections on 'diagnosing endometriosis', 'surgical management', and 'surgical management if fertility is a priority'), and other advocacy organisation work and reports.

Objective 2: Explore diverse experiences of patients in the UK with endometriosis

Informed by the review, a (newly appointed) post-doctoral qualitative researcher with experience in women's health and interviewing on sensitive topics, will conduct in-depth narrative interviews with a maximum variation sample (Coyne, 1997) of up to 50 patients with endometriosis living in the UK. We will include women and gender-diverse people from different ethnic groups, of different ages, and from across the life course (from menstruation to menopause and beyond, and including those with and without biological children), those with diagnosed endometriosis, and those with suspected endometriosis (without official diagnosis). We will seek experiences of consulting primary and/or secondary and tertiary care, different treatment experiences and outcomes, and those who describe their care in different ways.

Recruitment and inclusion-exclusion criteria

To achieve as diverse a sample of people with experience of endometriosis as practicable, we will use a range of recruitment strategies and sources across the UK: expert Advisory Panel members, NHS sites, local and national charities and support groups (e.g. Endometriosis UK, and broader gynaecology and reproductive health advocacy groups like Cysters, Medical Herstory), social media, and snowballing. Our diversity discussions and ongoing engagement from the established PPI group (see PPI section below) will also be valuable in ensuring we are engaged with non-traditional recruitment routes. Previous examples used successfully in PI MCNIVEN's studies include advertising about the research through attending mother-baby groups and Women's Institute meetings (for a study on urogynaecological conditions) and displaying recruitment posters at tattooist premises (for a study on common skin conditions).

Our sampling and recruitment approach will seek to ensure we include those with a range of lived experiences, especially people from minority and underserved communities. With recognition that 'underserved' is a contextual, rather than a universal definition, we note that much existing endometriosis patient research and representation in campaigns and

media reporting has tended to focus on White, middle-class, heterosexual, cis-gender women with fertility concerns. Whilst these experiences will be included, we will also actively seek to include people with lived experience from other types of backgrounds and with other considerations, for example, those with Black, South Asian, and Mixed Heritage backgrounds, those with language/interpreter needs, those from lower socioeconomic backgrounds, trans-men and non-binary people who have uteri, those for whom fertility is not a current or anticipated priority, and those for whom fertility is important who are not in heterosexual relationships (e.g. lesbian and bisexual sexual orientations, single people). This is in recognition that there may be other considerations, needs, and challenges faced by individuals from these groups in terms of their health, accessing and using health services, and their priorities for treatment and management of symptoms – including areas of inequities that may disproportionately impact or disadvantage these groups – that should be considered. Intersections mean that some of our participants will represent several of these characteristics, meaning that, guided by our experience in similar studies, we expect with careful sampling over the anticipated 10 months of recruitment to achieve an appropriate sample within 50 interviews. The only exclusion criterion in our recruitment for patient interviews is if the person does not identify themselves as having (diagnosed) or probably having (suspected) endometriosis.

To help achieve our aim of diverse recruitment, we will keep a spreadsheet of 'expressions of interest' based on reply slips (with optional demographic questions), which we will regularly review and use to inform further tailored recruitment, for example, if we are not hearing from individuals from a particular sociocultural background. In addition to the support organisations, groups and networks already identified to help achieve a diverse sample, and the input we anticipate from our PPI work, we will continue to identify and collaboratively work with groups focused on supporting underserved populations as the study progresses. Additional time has been built into recruitment and interviewing to support the inclusion of underserved individuals.

Information for participants, support to withdraw from the study, and consent

Individuals who express interest in the research will be sent an information leaflet by post and/or email (depending on preferences). The leaflet will include (amongst other information): an outline of the study and intended outputs; details on taking part in an interview; statements around information governance adherence, including data storage and management; and contact details of the researchers or alternative contacts if the individual wishes to make a complaint. Participants will be reminded that they can choose to stop their involvement at any point and that, if they wish to share their reasons why, we would be grateful for their feedback to help us identify opportunities where we might better support participation for everyone.

If an individual is interested in taking part in an interview, they will be encouraged to contact the researcher by telephone, email or post. They will have an opportunity to ask questions and will be asked to complete a 'reply slip' with some optional fields on their

background as well as their preferred contact details. The researcher and individual will discuss arrangements for an interview, led by the individual's preferences (e.g. whether the interview takes place in person, online or over the phone, and when the interview is scheduled).

At the interview, the researcher will check that the participant has read the information leaflet, is happy to sign the consent form, and proceed with an interview. We will remind them that they can pause or stop involvement in the interview (and study more broadly) at any time. A copy of the signed consent form and a copyright form (which assigns permission for the use of the interview data to the University of Oxford for analysis, teaching, secondary analysis, publication and websites) will be given to participants for their records.

Overview of methods (interviews)

In-depth qualitative interviews will use a narrative approach (Mishler, 1991; Sandelowski, 2007) to encourage participants to highlight their own concerns, meanings and priorities. Interviews will be conducted by the appointed post-doctoral researcher, supported by MCNIVEN who has an established track record of qualitative research about sensitive women's health and reproductive topics. In addition, there is a depth of experience on this topic in the team from DIXON and HINTON.

The interview guide will begin with an open-ended narrative question, inviting participants to begin describing their experiences in their own words and from whichever starting point (e.g. when they first suspected a problem) they would like. Supplementary follow-up questions, informed by the narrative syntheses review and discussions with PPI and the advisory panel, will prompt consideration of topics not yet covered and encourage reflection on specific areas. We anticipate these may include (mis)communication with healthcare professionals, diagnostic delays, uncertainty about investigations and treatments, quality-of-life impacts, and journeys through healthcare services (including specialist referrals and for mental health provision). We will consider areas of tension or controversy, including those identified in the scoping review (Objective 1), which will be sensitively and carefully broached in the interviews (as will topics highlighted earlier that may have additional cultural or broader sensitivity). The interview guide will be revised in line with PPI Group feedback (for example, on the language used and flow of content), and further nuanced and refined over time.

According to participants' preferences, the interviews will either be audio or video recorded for analysis. We will offer face-to-face, as well as online, interviews to mitigate against digital exclusion and maximise the potential geographical spread of participants. We have wifi dongles, tablets and headsets to courier to participants without ready access to the internet, and we have requested in our budget some childcare costs for those with these caring responsibilities. Interviews may take place in one session or across several shorter sessions, at times suited to the participant (e.g. evenings, weekends). We recognise that flexibility is vital, particularly in the context of potentially

debilitating endometriosis symptoms. To help engage individuals seldom heard in research for reasons of language exclusion, we will translate study information, work with relevant community groups, and offer bilingual researchers for those for whom English is not their first language.

We recognise that there may be cultural and other types of sensitivities for individuals and groups with regards to the interview topics around endometriosis – including, for example, menstruation, sex, genitals, fertility, and mental health challenges. These may be topics that some participants prefer not to speak about or describe through particular phrasing, and we will be respectful of participants' choices on how much they share and how they articulate their experiences. After the interview, we will offer participants a chance to verbally debrief. We will also provide an information leaflet of support organisations and, where appropriate, offer to follow-up with the participant again at a later date (for example, a few days after the interview). In addition to support from team members with skills in interviewing on sensitive health topics (MCNIVEN, HINTON, DIXON), the appointed post-doctoral researcher will attend cultural competence training before fieldwork.

Payment and ongoing communication

Interviewed participants will be given a one-off 'thank you' shopping voucher of £40. Travel and childcare costs incurred for the interview will be reimbursed. After the interview has been completed, transcribed verbatim, checked for accuracy against the recording, and de-identified, participants will be given the opportunity to see their transcript and a summary of their interview. Participants can review these documents and mark sections which they do not want to be used for any given purpose as specified in the copyright form. We will stay in touch with participants (if they would like us to and through their preferred medium, including by email and phone) to give updates on the study and key outputs.

Analysis

Analysis and data collection will proceed simultaneously and until the widest practical range of experiences have been included. Interview transcripts will be analysed by the appointed post-doctoral researcher in collaboration with PI MCNIVEN and a dedicated research buddy whose role is to add further rigour to the analyses and outputs such as the content of the HEXI.ox.ac.uk resource (see Objective 4 for further details).

The data will be entered into NVivo, a specialist software package, to organise and code for detailed analysis. We will follow the six stages of reflexive thematic analysis to organise data and distil them into themes: (1) Familiarisation with the transcripts (reading and re-reading); (2) Coding (allocating words or short phrases to segments of the interview transcript, which will be reviewed by other team members to consider consistency and different interpretations); (3) Generating initial themes from the coding (e.g. through research team discussions); (4) Developing and reviewing themes; (5)

Refining and naming themes; before (6) Presenting themes as findings (e.g. for outputs, for further use alongside findings from Objective 3 in the development of a quality framework) (Braun and Clarke, 2021). Attention will be paid to emergent (i.e. unexpected) themes as well as those anticipated (Pope *et al.,* 2020). Some of the conceptual lenses we may draw upon include theories of stigma, candidacy (access to healthcare), and views around what 'good' care looks like.

Analysis will use well-established qualitative thematic approaches, including constant comparison, further developed by MCNIVEN, DIXON and HINTON's research group and used for over 120 comparable studies since 2000 (Pope *et al.,* 2020; Ziebland and McPherson, 2006). We will compare women's accounts of their healthcare experiences to illuminate key aspects for unmet information and support needs, including for particular subgroups of patients, healthcare professionals, and other relevant groups (including policy-makers). Our analysis will be undertaken with a range of different outputs and audiences in mind, including a patient experience website (see Objective 4), publication in journals (aimed at healthcare professionals and/or social science researchers), and service improvement ideas through the development of a catalyst film.

Objective 3: Explore the experiences and perspectives of healthcare professionals involved in endometriosis care

Specialist healthcare professional interviews

We will interview around 30 specialist healthcare professionals providing endometriosis care in NHS secondary or tertiary settings. The sample will include geographical, career stage and role variation (including around 10 specialist nurses and advanced clinical practitioners). Sampling will be purposive, drawing on co-applicant networks and contacts, those of expert Advisory Panel members, and professional bodies. Clinical scenarios will be co-developed with our advisory groups, to create a neutral 'think-aloud' space for clinicians; this is an approach utilised in our previous work with GPs about endometriosis (DIXON, HINTON and MCNIVEN, with input from VINCENT). For the new interviews, the scenarios we develop will be based on the narrative syntheses review and considered alongside the interviews with women, and have input from the Advisory Panel and PPI Group, to explore different perspectives amongst clinicians involved in endometriosis care. Interviews with specialists will be over the phone, with in-person and online options available, and informed consent will be taken before the interview starts. Participants will be reminded that they can pause or stop the interview and involvement in the study. The interviews will be recorded and transcribed, and participants will be asked if they would like us to keep their contact details to inform them about study outputs. Participants will be offered a one-off 'thank you' payment of £40.

Practice nurses and clinical pharmacists – interviews

We will undertake an additional 10 interviews with practice nurses and clinical pharmacists, following the same structure of data collection and analysis as above for

specialist healthcare professionals: clinical scenarios; interviews over the phone, in person or online; a one-off thank you payment of £40; interviews transcribed. These interviews will add to an existing dataset of GP interviews (see below), and resonates with a recent study we undertook (PI MCNIVEN, co-applicant DIXON) on primary care practitioners' perspectives on women's healthcare needs which embraced recognition of the changing team configurations working in primary care.

Analysis (for new interviews, and the secondary analysis)

Analysis and data collection will proceed simultaneously, providing opportunities to adjust interview schedules and clinical scenarios in order to ask about additional considerations raised by other groups (patients, healthcare professionals). Thematic analysis of the healthcare professional interviews will be undertaken as per the process outlined in Objective 2 for the patient interviews. The analyses for the different groups will be undertaken separately but concurrently (i.e. the specialist interviews will be analysed as one set, and the practice nurses and clinical pharmacists interviews will be analysed as another set). This approach will ensure we have constant familiarisation of content from different perspectives, whilst keeping them distinct in preparation for a combined analysis in Objective 4.

In addition, we will conduct a secondary analysis of our existing collection of 42 interviews with GPs about endometriosis management (ref: SPCR 403). The dataset was collected in 2019-2020 by DIXON, and originally analysed by DIXON, MCNIVEN and HINTON. This is a self-collected dataset to which we have access and a distinct analysis will be undertaken, guided by research questions underpinning this study (Heaton, 2008). This includes drawing on the findings of the narrative syntheses review (Objective 1), as well as the concurrent data collection of interviews with patients (Objective 2) and specialists (detailed above), to guide our approach to analysis. As the original researchers, we hold a detailed understanding of the original study in terms of design, context around the interviews, and how findings were developed and utilised to date, to enhance interpretation. We verify that the dataset is information-rich for a secondary analysis to explore topics from different angles, and with the whole-system approach at the forefront.

Objective 4: Develop a comprehensive and integrated whole-system understanding of endometriosis healthcare journeys and experiences, and use the findings to develop resources for patients and healthcare professionals

Combine analyses and sense-check

The findings from separate datasets (patient interviews; specialist interviews; practice nurse and clinical pharmacist interviews; secondary analysis of GP interviews) will then be brought together in a quality framework, as previously developed by HINTON (Hinton *et al.,* 2022). From the findings of each dataset, we will look for topics of interest that resonate (or might resonate) across the datasets in similar or different ways and develop a consistent/unified structure that can be explored across the groups. Dyadic analysis is

not suitable (because it is not anticipated that interviewed patients and healthcare professionals will be known to one another) and because we are particularly interested in an anticipated high degree of differences in interpretations and perspectives (Parkinson *et al.,* 2015) regarding the experiences of endometriosis healthcare . As such, our approach to developing a framework is not intended to merge and subsume differences from multiple participants; instead we will use qualitative meta-synthesis approaches to elicit the ways in which groups agree and differ, and to show their relationships (including juxtaposition) in the data (Hinton *et al.,* 2022). The developed quality framework will be populated as a table with distinct columns for different groups (which may further differentiate between subgroups of patients as well as subgroups of healthcare professionals) to highlight areas of divergence as well as overlap in perspectives and experiences. This is likely to be an iterative process: the framework will evolve initially from the findings from the thematic analysis of each dataset and we will cross-check the other datasets where additional considerations are raised or nuanced. Our approach of separate but concurrent analyses (as well as the narrative syntheses review), however, is intended to help reduce the need for this, as we will seek to develop simultaneous awareness of differences in the datasets, and to increase the richness of the framework approach we undertake.

The aim is to develop understanding about endometriosis experiences and journeys, including decisions to consult and access to appointments about symptoms suggestive of (or subsequently diagnosed as) endometriosis across the healthcare system. Particular attention intra- and inter- datasets will be paid to areas of contradiction, ambivalence, and uncertainties with regards to healthcare to identify, for example, points of miscommunication and misinterpretation that may be taking place in encounters, including around diagnosis, treatments, and the navigation of healthcare. For example, accounts of reasons to refer may differ between healthcare professionals as well as in women's accounts of why they thought they were (or were not) referred. Other areas we anticipate at the outset may include beliefs about the reasons for delayed diagnosis, communication challenges, and uncertainties in management and treatment options. We recognise this process may be challenging and therefore we have set aside dedicated time for this additional analytical process.

To sense-check our findings, we will consult the Advisory Panel and PPI Groups, and, if deemed necessary, undertake an additional discussion group with healthcare professionals identified as appropriate at this stage of the research. Traditional healthcare services are evolving and will continue to do so during the study, including with the recommended expansion of and forthcoming funding investment in Women's Health Hubs. We will take the opportunity to include any additional roles or experiences of healthcare professionals missing from our interview data, while recognising that many healthcare professionals are already working across interfaces between primary, secondary and tertiary care. The discussion group would therefore be an opportunity to take stock, ensure our findings are embedded within the current (and forthcoming) healthcare context and, if necessary, capture any additional perspectives to ensure our research remains relevant and current.

Develop a patient-facing online resource

Using the patient experiences interviews and analysis, we will develop a new section about endometriosis on HEXI.ox.ac.uk as a freely-available, online, **patient-facing information and support resource**. For the resource, we will write 20-25 analytic topic summaries in accessible language to reflect the most important themes and represent the full range of experiences, illustrated with written, audio, and video interview excerpts. To ensure quality and balance, each summary will be buddied and then reviewed by at least one suitably qualified Advisory Panel member before final editing. Strengthened, but not overshadowed, by the findings from healthcare professionals, the HEXI.ox.ac.uk resource will be nuanced and supportive, representing lived experiences and orientated towards optimising healthcare encounters and promoting a more balanced encounter between patients and healthcare professionals.

A **formative evaluation** will be carried out with potential users of the HEXI.ox.ac.uk resource, and changes made accordingly before final publication. We will invite women and gender diverse people who are potential users of the site to give feedback on a 'draft' version. The evaluation will identify strengths and limitations of the draft resource, through the use of focus groups. Amendments to the website will be agreed in discussion at meetings with the co-applicant team and advisory groups, before a shortlist of changes are made to the HEXI.ox.ac.uk resource. If we find that the study has missed some important perspectives, we will seek to add to the resource before it is published; we will make changes if any aspects are identified as helpful in enhancing accessibility. Changes will be implemented before the resource is officially launched and widely advertised (see section on Dissemination).

Co-design and further resource development

To lay the groundwork for further co-design work (Locock *et al.,* 2014), we will work with our advisory groups to prepare a short 'catalyst' film using video and audio clips from the patient interviews and informed by findings from the healthcare professional datasets. Catalyst films are intended to identify and present 'touchpoints' (when patients come into contact with NHS healthcare services and professionals and there is scope for improvement), with a view to stimulating conversations about service improvements. This is in line with an accelerated experience-based co-design (AEBCD) approach, using existing research material (in this case, interview excerpts with permission) (Locock *et al.,* 2014). The selection of themes for the catalyst film will be based on a presentation of findings to our advisory groups, to help identify the key issues to highlight in the film. The catalyst film will be shared at the first of **three workshops** with patients, healthcare professionals, service managers, and policy makers (n=10-15, online). After this meeting, it will then be made freely available on HEXI.ox.ac.uk, alongside guidance for further use in service improvement (e.g. as part of a facilitated quality improvement process).

Our **first workshop** will aim to stimulate conversations and ideas, explore the resonance and relevance of findings, and scope the potential for resources and training, service improvement, and public-facing outputs. At the **second workshop**, we will present initial ideas and resources we have drafted or planned for feedback and refinement, and to generate any further suggestions for resource production. The focus of the **third workshop** will be to refine and expand improvement recommendations, and discuss ways to ensuring reach and impact of the resources and recommendations produced. Co-design activities will likely be ongoing in between these three meetings, with input from interested individuals or subgroups (e.g. of patients, healthcare professionals); the organisation of this input will, necessarily, be dependent on the resource to be developed, but may include attending additional meetings, feeding back on prototypes of resources, and co-writing aspects of the resources. It is anticipated at this stage that the same group of individuals will attend all three main meetings, and this will be encouraged, though there is flexibility to adjust arrangements for the workshops and attendees as appropriate. Drawing on HINTON's experience (Woodward *et al.,* 2024), the workshops will be held online for geographical spread of attendees and at convenient times, including potentially evenings or weekends, to ensure that those with lived experience are able to participate around other commitments. As with the interviews, to mitigate against digital bias, we can courier wifi dongles, tablets and headsets to those without access, and will work with individuals to develop solutions to support them (teaching or signposting to training on digital skills and online confidence). Additionally, we will undertake targeted discussion groups and/or one-to-one meetings with individuals for whom the online co-design workshops might not be a suitable or preferable environment, including the need for a translated conversation.

Though we note that the types of resources we develop will depend necessarily on the findings of the research and the co-design process itself, some examples of the topics we anticipate include shared decision-making resources about endometriosis investigation and/or treatments, and communication resources aiming to bridge between potential misunderstanding and disconnect between patients and health care professionals. These resources may be written documents, events like webinars, videos/animations, infographics, or podcasts.

Patient and Public Involvement (PPI)

Four women with lived experience of endometriosis were consulted in the design of this study – all of whom have expressed willingness to be part of the PPI advisory group and/or to be involved in other PPI activities planned at various stages if the application is successful. They attuned us to a diversity of experiences and considerations (including peri- and post- menopausal experiences and support needs), shaped our interview approach, and indicated support for a patient experience resource.

In addition, co-applicants COX and HEERA-SHERGILL, who will co-lead our PPI work, represent large communities of people with lived experience of endometriosis through their organisations (Endometriosis UK and Cysters, respectively). Their input has helped

shape and guide the research, and drawn attention to the need for sufficient resources to undertake this extensive PPI work in a meaningful way – which we have costed into the study.

With commitment to engaging with people who have been underserved in current endometriosis healthcare, research and support services, our planned PPI work includes:

Group and one-to-one discussions at the outset of the study with people with lived experience of endometriosis, focused on underserved communities and inclusivity in the research

These discussions will be facilitated by PI MCNIVEN, the post-doctoral researcher, and co-applicants COX and HEERA-SHERGILL (charity representatives who do not themselves have lived experience of endometriosis but are deeply embedded in networks and communities of individuals who do). COX (CEO of Endometriosis UK) has previously worked with a consultancy company to better understand the experiences of people who have not previously been involved with the charity. A key principle of Cysters, founded and run by HEERA-SHERGILL, is to support those who typically have been marginalised in their experiences of reproductive health (for example, by race and/or sexuality); both individuals and their respective organisations recognise and are continually striving towards furthering inclusivity in their charitable work – a key aim shared in this research too.

We recognise that seeking engagement with individuals who are not (for a host of reasons) currently networked with support groups or research, or have previously felt overlooked or poorly listened to, is inherently challenging; drawing on and expanding existing trusted networks of support and wider communities who are actively seeking to improve this problem, ensuring we have adequate resources and time to undertake the PPI work, and that these discussions have an avenue through which to then inform the entirety of a study (with co-design outputs) are crucial to giving us the best chance of meaningful and successful engagement. Hence we have planned and resourced for this work to take place at the study outset, and not before or long after the study begins. Whilst no ongoing commitment is required, those we speak to will be given the opportunity to continue their involvement (for example, as members of the PPI group, in evaluating the HEXI.ox.ac.uk resource developed or in co-design workshops later in the study), and all will be invited to a follow-up (in a group or one-to-one) in month 28 of the study to hear about the project and outcomes (and, crucially, how their input has shaped the research and outputs produced).

These discussions will lay the groundwork for a number of the next PPI activities planned, as well as informing the patient interviews.

Establishing a PPI group and lived experience representation on the Advisory Panel

Building on PPI undertaken in the design of this study and based on the above discussions, we will expand a PPI group to around 8 members, which will be co-led by co-applicants COX and HEERA-SHERGILL (with additional dedicated administrative time to help arrange meetings and support their work). Additional PPI members will be sought from underserved groups, including those from racially minoritised and lower socio-economic backgrounds, as well as any other considerations identified in the discussions highlighted above. The PPI group will be encouraged and supported to set their own plans for meetings (with costs set aside for up to six 1-2 hour meetings across the project, available to be used flexibly).

We will ask the PPI group to select two or three individuals to represent them at Advisory Panel meetings (i.e. alongside healthcare professionals, co-applicants, researchers, and other relevant individuals or organisation representatives). The Advisory Panel will meet a minimum of four times, with ongoing email correspondence for updates and queries. The Advisory Panel meetings will be scheduled around key stages in the study when input is expected to be most helpful, including: when we have conducted the first 5-10 interviews each with patients and specialists, with recruitment ongoing; as we begin the development of a quality framework; and for feedback on draft material for the patient experience HEXI.ox.ac.uk resource. The inclusion on the Advisory Panel of individuals with lived experience individuals (alongside COX and HEERA-SHERGILL) will help ensure a channel of communication exists between the advisory groups throughout the study.

Co-design activities (producing a 'catalyst' film and identifying further resources to develop)

In all our co-design activities, we will involve people with lived experience, alongside others as relevant e.g. healthcare professionals, charity representatives, professional body representatives, teachers/educators, service managers, and policymakers.

Nearing the end of study discussions

The individuals with lived experience who we speak to in the group and one-to-one discussions at the study outset will also be invited to meet with us again at the end of the study. We think it is crucial that their input is bookended with at least these two meetings: at the very beginning of the study, when their input can shape next steps, and towards the end of the study, when we will be accountable for sharing with them how their input has been used and the ways we have sought to make the findings actionable and impactful. We anticipate that some of these individuals may also have been involved in other aspects of the PPI work during the study, including joining the PPI group and in the co-design work.

In recognition and gratitude of the time contributed to informing the study, individuals engaged with each and every PPI activity will be offered payment, as based on INVOLVE benchmark guidance (NIHR, 2022) and inclusive of an internet connectivity charge. For individuals involved in the PPI work (as well as for our patient interviews), we also request costs to reimburse those who incur childcare costs.

Additionally, we wish to acknowledge that the premise and design of our study draws on the PPI contributions to all of our earlier work in this field. This includes our academic studies (on endometriosis, urogynaecology, and women's healthcare needs) and charity engagement (by Endometriosis UK and Cysters, including in seeking to extend diversity and inclusion in reach). In addition are the endometriosis James Lind Alliance Priority Setting Partnership (2017) and Women's Health Strategy for England (DHSC, 2022) which was underpinned by public responses to a call for evidence which highlighted endometriosis as an area for improvement (DHSC, 2021a and 2021b).

Equality, diversity and inclusion for study participants

A commitment to equality, diversity and inclusion (EDI) will be a focus of the study, as we seek to include diverse experiences in our research recruitment and participation as well as our PPI work. In our patient experiences interviews, we will include those who have been underserved by existing endometriosis care, research and support work, as we seek a maximum variation sample to include a wide range of experiences across the UK. This includes those from Black, South Asian, and Mixed Heritage backgrounds, those with language/interpreter needs, those from lower socioeconomic backgrounds, trans-men and non-binary people who have uteri, and those for whom fertility is important who are not in heterosexual relationships (e.g. lesbian and bisexual sexual orientations, single/not in a relationship). We will carefully monitor expressions of interest and participation in the research to ensure we are hearing from a diverse range of people and with various clinical and personal experiences, and, where relevant, tailor recruitment approaches to include those we recognise as missing. This information will be collected through reply slips (indicating an expression of interest in participation) and a participant details form (completed at the time of the interview) – with all details optional and at the discretion of participants to answer or decline. Likewise for the healthcare professional interviews, we will seek to include a range of participants in terms of their personal as well as professional backgrounds, with no exclusions made on the basis of (for example) their age, disability, gender identity, relationship status, pregnancy and maternity experience, ethnicity, religion, sexual orientation, or socioeconomic status.

We will draw on a wide breadth of recruitment avenues to extend our reach when seeking study participants, including NHS sites across the UK, local and national charities and support groups, social media, and snowballing, as well as non-traditional and novel recruitment avenues we identify as having potential. To support inclusive research participation, we will offer various types of support and options, such as:

- Translating research materials and interpreter facilitation of interviews;

- Provision (via courier) of wifi dongles, tablets and headsets to mitigate against the digital exclusion of those without access;
- Flexibility of interview format (e.g. online, in person) and timings (including evenings, weekends), dependent on preference. This includes consideration of participants' other commitments, including work and childcare (e.g. flexibility around childcare arrangements and reimbursement of childcare costs incurred for the interview);
- Supportive recognition of the challenges in terms of the impact of endometriosis on quality-of-life, including that interviews may need to be rescheduled owing to symptoms;
- Recognition of personal and cultural sensitivities around the topic, reaffirming that it is the participant's choice on pausing/stopping their participation at any point, deciding what they do (or do not) wish to discuss in relation to their experiences, and offering follow-up support and signposting to sources of further support.

We will draw upon our PPI activities (with input from COX and HEERA-SHERGILL) in helping us to continually reflect and expand on our commitment to EDI in the research.

Dissemination, outputs and anticipated impact

Recent and ongoing policy and PPI work demonstrates an appetite for this research and the outputs we propose. We will draw on patient and healthcare professional perspectives to identify areas for improvement, intervention, and transition, and develop resources to address information and support needs for patients, healthcare professionals, policy-makers, and researchers. Producing a range of quality outputs is also a key consideration in ensuring the study is impactful and good value for money. We will produce and disseminate the following outputs for a range of audiences who are involved in endometriosis healthcare in the UK.

A new patient experiences resource about endometriosis on HEXI.ox.ac.uk – for patients, the public, healthcare professionals, and policy-makers.

A considerable strength and added value of this proposal is that the study findings will be assembled for publication as a new section on the university run platform HEXI.ox.ac.uk. The resource will summarise findings from the study and be illustrated by video, audio and written excerpts from the interviews; the consent will be based on diverse patient experiences, including those hitherto overlooked, supplemented but not overshadowed by the perspectives of healthcare professionals. The development of this online resource on endometriosis will help address an information and support need for reliable resources that people with lived experience can use. HEXI.ox.ac.uk can also be used by the families of people with endometriosis and others in their wider networks (including to inform employers with regards to workplace policies), as well as educating doctors, nurses and other health professionals across the health service about what it is like for patients. It is also a means of providing a patient-centred perspective to policy-makers, and those involved in commissioning and managing services.

The HEXI.ox.ac.uk website covers a wide range of health conditions and events, with currently more than 120 distinct subsections; the platform has a 'Women's Health' grouping to aid navigation, which includes existing resources on cancers and screening (breast, cervical, ovarian), urogynaecological conditions (prolapse, urinary incontinence), menopause, infertility, pregnancy, late miscarriage, pregnancy and birth complications, and breastfeeding, amongst others.

Our endometriosis resource on HEXI.ox.ac.uk will be advertised through our networks, affiliated professional social media accounts and by patient support/charity organisations. We will have regular updates on visitor numbers and other statistics on usage, and liaise with relevant charities and professional bodies on an ongoing basis to ensure the resource is widely advertised. We will also draw on our co-applicants, advisory groups, recruitment contacts, and PPI networks, amongst others, to ensure breadth of reach. We will seek for our endometriosis resource to be signposted on the NHS website for patients.

A catalyst film – for healthcare professionals and those involved in service design and management

We will co-design a short film with input from our advisory groups (which include people with lived experience and healthcare professionals) illustrating key themes, based on content from the patient interviews. The catalyst film will be shared at a co-design workshop with patients, healthcare professionals and other relevant individuals or organisation representatives to stimulate discussion, explore the relevance of findings, and identify other potential resources. The catalyst film will then be made freely available, alongside guidance for use in service improvement (e.g. as part of a facilitative quality improvement process).

Co-designed resources identified, developed and refined via workshops with attendees – for varied audiences such as patients, healthcare professionals, researchers, employers, policy-makers, and those involved in service improvement

Whilst the types of resources to come from our study on endometriosis experiences will necessarily be determined at the workshops, fitting to the target audiences and intended purposes, we anticipate these may include the production of resources and recommendations such as: leaflets, checklists, webpages, infographics, podcasts, training, events like webinars, and/or videos/animations. Some examples of the topics we anticipate developing resources on include shared decision-making resources about endometriosis investigation and/or treatments, and communication resources aiming to bridge between potential misunderstanding and disconnect between patients and health care professionals.

Conference presentations and peer-reviewed articles – for healthcare professionals, researchers, policymakers, and the public

The findings of the study will be presented at conferences, such as the World Congress on Endometriosis, the Society for Academic Primary Care, the Royal College of Obstetrician and Gynaecologists World Congress, and the British Sociological Association Medical Sociology Conference. Tailored to the specific audiences of each conference, the presentations will highlight the key findings of the study, the online resource for training/education for healthcare professionals and as a resource which endometriosis patients might be signposted to, and the catalyst film for use in service development.

We will publish at least two articles in high-quality peer-reviewed journals, targeting different audiences (including primary and specialist care, and those with a general interest in the topic as well as those with a specific interest in gynaecology and/or pain studies). Advisory Panel and PPI Group members will be invited to co-author alongside the research team.

We will also produce non-academic publications, for example a piece in *The Conversation*, podcasts, and social media (including through key charities).

Archived interviews, available for secondary analysis – for researchers

To maximise best use of the interviews, subject to the participant's approval, the de-identified transcripts will also form part of a University of Oxford archive. To support further research, the deposited transcripts will then be available to other bona fide researchers on reasonable request for data sharing and secondary analysis (Ziebland and Hunt, 2014).

Project / research timetable

Noting that some objectives of the study will be undertaken simultaneously, a summary of the project plan is outlined below with key milestones highlighted:

MONTH(S)	***ACTIVITY***	***MILESTONE/ COMPLETION***
Preparatory work		
1-4	Appoint main researcher	
1-4	Expand PPI group and Advisory Panel	
1-4	Submit additional ethics approvals for HCP interviews, and add patient interviews to existing ethics coverage	By end of month 4
1-4	Undertake PPI discussions (groups, one to ones)	
Objective 1		
2-4	Undertake narrative syntheses review	By end of month 6
Objective 2		

2-4	Establish recruitment avenues (for patient interviews)	
4	Develop interview guide (with advisory groups input)	
5-6	Undertake first ~10 interviews with patient participants	
5-14	Undertake all (~50) interviews with patient participants	By end of month 14
5-14	Undertake transcription, translation, data preparation, and preliminary analysis for patient interviews	
14-18	Undertake full analysis of patient interviews	
Objective 3		
4-5	Establish recruitment avenues (for HCP interviews)	
5	Develop interview guides and clinical scenarios	
6-7	Undertake first 5-10 interviews with HCP participants	
6-14	Undertake all (~40) interviews with HCP participants	By end of month 14
6-14	Undertake transcription, translation, data preparation, and preliminary analysis for HCP interviews	
14-18	Undertake full analysis of HCP interviews	
14-18	Undertake secondary analysis of GP interviews	By end of month 18
Objective 4		
19-21	Undertake combined analyses of the datasets	By end of month 21
22	Sense-checking and discussion group	
21-27	Development and production of a HEXI.ox.ac.uk resource	
25-26	Co-design of a catalyst film	
27-29	Evaluation and finalisation of HEXI.ox.ac.uk resource	By end of month 29
27-30	Co-design workshops (x3) and resource development	By end of month 30

Project management

The full co-applicant team will meet (virtually) every two months, although more frequent meetings with some or all of co-applicants will be scheduled when needed. Opportunities to speak one-to-one will be encouraged, for example, if queries arise about any issues in the team. Email and telephone communication will keep co-applicants involved throughout the study and facilitate feedback or further discussion.

The appointed post-doctoral researcher and MCNIVEN will meet at least weekly. The meetings will be opportunities to share emerging findings, ensure we closely monitor study progress, discuss challenges, learn from one another, and make collaboratively informed adjustments to enhance the study. MCNIVEN will be the main contact point for all aspects of the project and responsible for monitoring project outputs and deliverables.

Two advisory groups – a Patient and Public Involvement group, and an Advisory Panel (which will include people with lived experience, healthcare professionals, charity representatives, and others identified as relevant) – will be been established. COX and HEERA-SHERGILL will co-lead the PPI group. We have already had interest from individuals to join the groups if the application is successful, and both groups will be

further expanded with additional members recruited and invited to join in the early weeks of the study commencing. The advisory groups will provide guidance throughout the study, with plans for the Advisory Panel to meet (virtually) four times around key points in the study (see the Flow Diagram and PPI section), alongside email updates and correspondence.

A study steering committee will meet every 6 months of the study (months 4, 10, 16, 22, 28).

Ethics / regulatory approvals

The qualitative methods for the patient interviews have been approved by NRES Committee South Central – Berkshire (REC reference 12/SC/0495) and HRA for all health conditions involving adult participants, with approval for NHS sites to be 'Participant Identification Centres'. An ethics application for the interviews with non-GP Primary Care Practitioners (practice nurses, clinical pharmacists) and specialists (including consultants, specialist nurses and advanced clinical practitioners) will be submitted shortly after the study has started, and secured before Objective 3 begins.

Data protection and patient confidentiality

All investigators, research staff, PPI and steering group members will comply with the requirements of the Data Protection Act 2018 and General Data Protection Regulation (GDPR) 2016/679 with regards to the collection, storage, processing and disclosure of data including any personal information. The Principal Investigator (MCNIVEN) is the data custodian. University of Oxford is the data controller. Patient data collected during the study will be retained under HEXI Ethics for 100 years after the end of the parent study. Data from healthcare professionals will be retained for 10 years after the end of the study in accordance with University of Oxford policy. At the end of the retention period, data will be destroyed using the appropriate procedure advised at that time by the University of Oxford research data team.

Conflict of interest statement

There are no conflicts of interest to declare.

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