Supporting Clinical Uses of Patient Self-Tracking Data in the Context of Rheumatic Diseases

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Abstract

Continued growth in the use of consumer self-tracking technology, such as health apps on smartphones and wearable activity trackers has attracted attention from healthcare and computer science researchers over recent years. Many have explored its use in medical research and patients' self-management of chronic conditions while others attempted to leverage its value for clinical decision-making and to improve patient-provider collaboration. Yet challenges such as workflow constraints, sensemaking difficulties and data quality concerns have hindered the effective inclusion and use of self-tracking data during clinical encounters.

Our research addresses this by investigating the many opportunities and challenges associated with the clinical use of self-tracking data in the context of axial spondyloarthritis - a typical rheumatic chronic condition. We carry out online and field studies using a combination of qualitative research methods to investigate how self-tracking data could fit into existing clinical workflow and benefit routine check-up appointments. Our approach also covers both patients' and healthcare providers' perspectives on a variety of subjects including determinants of users' self-tracking adherence as well as the expectations and concerns regarding collaborative use of data. We provide structural understanding of the healthcare context in which self-tracking data is shared and discussed which helps us identify practical applications of said data in real-life clinical scenarios.

Our findings show that the use and discussion of self-tracking data may improve existing activities associated with the clinical encounters between patients and providers by supporting the process of evidence gathering and decision-making regarding treatment and action plans, despite some challenges relating to tracking adherence, data-sharing and agenda setting as identified in this research. We provide practical design recommendations rooted in the field of Human-Computer Interaction, such as graphical user interfaces and data visualisation tools to overcome these issues, thus setting the course for future research and the design of self-tracking technologies.

Publications

The contribution of the work presented in this thesis has been recognised through the following peer-reviewed publications[1] :

The early summary of this work was presented at the following doctoral consortium: William Hue. Supporting collaborative use of self-tracking data in the context of healthcare and chronic conditions. In *Companion Publication of the 2019 on Designing Interactive Systems Conference 2019 Companion*, pages 93–96. ACM, 2019.

The work in Chapter 3 was published in: William Hue, Simon Jones, and Raj Sengupta. Exploring the future role of self-tracking data in the rheumatology clinic. *Studies in health technology and informatics*, 259:33–38, 2019.

Work from Chapter 4 contributed to the following publication: Simon L Jones, William Hue, Ryan M Kelly, Rosemarie Barnett, Violet Henderson, and Raj Sengupta. Determinants of longitudinal adherence in smartphone-based self-tracking for chronic health conditions: Evidence from axial spondyloarthritis. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies*, 5(1):1–24, 2021

[1]The researcher is professionally known as William Hue

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Chapter 1

Introduction

1.1 Thesis Overview

Over recent years, consumer-facing self-tracking technology such as health apps (e.g. MyFitnessPal [MyFitnessPal, 2022], Apple Health [Apple, 2022a]) and wearable activity trackers (e.g. Fitbit [Fitbit, 2022], Apple Watch [Apple, 2022b], Garmin [Garmin, 2022]) has seen rapid growth in its user base [Consumer Technology Association, 2016]. What was once a niche habit of gym-goers and fitness-conscious individuals has became a global phenomenon. According to the [Government Office for Science, 2021], the number of connected wearable devices worldwide is expected to exceed 1.1 billion in 2022. Market research companies estimated the growth rate of the wearable market to be around 13.8% to 23.3% per year until 2027/28 [Report Linker, 2022, Grand View Research, 2018]. The growing trend appears to be long-lasting and is likely upheld by the steady rate of innovation in the development of smart sensor technologies [Dehghani and Dangelico, 2017]. These sensor-rich devices allow users to capture their physical activity data in real time with relatively little effort (e.g. steps, exercise duration, heart rate, sleep). Smartphone apps on the other hand, support the collection of health data which can not be easily captured through electronic measurement, such as symptoms, medication and mood. Recent trends show that an increasing amount of people have begun to use self-tracking apps and wearable devices for the management and monitoring of their long-term health conditions [ORCHA, 2021]. Apps such as Chronic Pain Tracker [Chronic Stimulation, 2022], My Pain Diary [DamoLab, 2022] and Flaredown [Flaredown, 2022] can help patients collect and store data about their disease activities, medication and physical activities for later use.

With the vast amount of patient-generated health data constantly being produced through self-tracking technologies, healthcare and computer science researchers have begun to investigate the potential value of self-tracking data in the context of chronic conditions. A number of studies showed that analysis of data collected through self-tracking apps on the cohort-level may produce usable, generalisable insights which support health management and improve understanding of long-term health conditions [Sohda et al., 2017, Dixon et al., 2019]. In the domain of Human-Computer Interaction (HCI), researchers found that health data collected through wearable devices and smartphone apps may help patients who suffer from chronic conditions (e.g. chronic fatigue syndrome, irritable bowel syndrome) better understand, monitor and self-manage their conditions [Davies et al., 2019, Raj et al., 2017a, Ayobi et al., 2017]. However, sensemaking challenges such as information overload and lack of disease expertise were identified as major obstacles to patients' use and understanding of self-tracking data [Jones and Kelly, 2018]. On a similar note, healthcare providers who recognise the value of patient self-tracking data also face numerous difficulties with regard to analysing and using said data in the clinical context, e.g. unfamiliarity with the data, data quality concerns and situational constraints associated with the existing clinical workflow [West et al., 2018, Zhu et al., 2016]. Research has begun to explore potential solutions to challenges are associated with the use of self-tracking data in the broader context of chronic conditions. Use of data visualisation tools was shown to have helped some patients navigate complexity and extract actionable insights from their self-tracking data [Ayobi et al., 2018]. Studies show that collaborations around self-tracking data, such as the co-interpretation of data between patients and healthcare providers, may help address some of the aforementioned challenges related to the independent review of self-tracking data by individuals [West et al., 2016, Chung et al., 2016a]. Other potential benefits of the co-interpretation of self-tracking data include improved patient-provider relationship and self-management accountability [Chung et al., 2016a].

Nevertheless, research on the collaborative use of self-tracking data to date has produced mixed results as some patients reported feeling dissatisfied with the interactions they had with providers around said data [The Robert Wood Johnson Foundation, 2014, Murnane et al., 2018]. Issues such as conflicting priorities regarding the use and discussion of data [Raj et al., 2017a] as well as overall scepticism regarding data-using expertise and validity have halted progress on its inclusion in the clinical environment [West et al., 2018, Zhu et al., 2016, Chung et al., 2015]. Additionally, very little is known about the real-life clinical scenarios in which the use and discussion of self-tracking data could take place, therefore limiting the potential value they could bring to the patient care process. The overarching aim of our research is to **facilitate the**

clinical integration of patient self-tracking data by understanding the opportunities and challenges associated with its usage in the context of chronic conditions. This work places emphases on the collaborative aspects of the clinical use of health-related self-tracking data. We use axial spondyloarthritis (axSpA), a typifying chronic condition with regard to its treatment and patient care process, as research context to investigate a number of research questions synthesised through our review of recent literature (see section 1.4), concerning the potential roles self-tracking data could play in the clinics, factors which may influence patients' self-tracking adherence, patient perspectives on the collaborative use of self-tracking and the actual use and discussion of self-tracking data in real-life clinical encounters. Our methods include a combination of research techniques, including clinical shadowing, field-based observations, semi-structured interviews, online surveys and thematic analyses. We take a broad, unbiased approach to investigating issues related to the collaborative use of self-tracking data by examining both patient and provider perspectives on the matter.

This thesis first tackles the lack of understanding of the existing clinical context of axSpA patient care through an observation & interview study, producing a structural framework of the pre-established clinical workflow, alongside the activities involved during clinical encounters between patients and providers (i.e. clinicians). Based on our framework and the existing categories of data involved in the clinical activities which we identified, we propose potential roles which self-tracking data could play in rheumatology clinics. We then examine potential determinants of axSpA patients' self-tracking adherence through a qualitative survey study to understand how we could design self-tracking tools which encourages more adherent tracking behaviours, thus improving the clinical validity of self-tracking data. Next, we explore the expectations and concerns associated with the collaborative use of self-tracking data from axSpA patients' perspectives, highlighting potential obstacles to the sharing and discussion of data during clinical encounters. The final study investigates the actual use and discussion of self-tacking data in the real-life clinical scenario of routine axSpA check-up appointment. We discuss how the observed uses of self-tracking data during the check-ups align with the existing clinical workflow as well as their design implications on tools which support the clinical use of self-tracking data in the context of chronic conditions. We conclude this thesis by discussing the contributions our work makes to the wider self-tracking and HCI research community, while drawing attention to its limitations while outlining future research directions.

The remainder of this chapter is presented as follows: We define key terms that will be used throughout the thesis in section 1.2. We provide an overview of the research

context in section 1.3, covering the specific chronic condition which our investigation will be focusing on, an associated research project and an introduction of our collaborator in healthcare. We define our research scope at the end of this section. This is then followed by the introduction of the overall research aim and research questions in section 1.4. Next, we discuss the research methods which we use in our studies to tackle these research questions (section 1.5). Lastly, we outline the content of each chapter in section 1.6.

1.2 Definitions

In this section, we define key terms from the fields of Human-Computer Interaction (HCI) and healthcare research which are used throughout the thesis to ensure the clarity of language and help avoid misinterpretation. Many terms associated with personal informatics (PI) and self-tracking have been used liberally and interchangeably by researchers and other stakeholders. For example, the use of the term "personal informatics", depending on the context and audience, may refer to the *practice* of collecting personal data, the *analysis* of said data and its outcome, or the *tools/technology* used to enable and/or facilitate the collection or analysis of said data [Li et al., 2010]. We start by defining important terms from the field of PI and self-tracking research to avoid confusion and ambiguity. We explain the nuance of the terms commonly used to describe and emphasise different aspects of PI and self-tracking research, including relevant technology and data categories form this field. Since our research is intimately linked with patient care in the context of chronic conditions, some use of technical language from the healthcare domain is also inevitable. We therefore also define key stakeholders in the healthcare setting and data categories which exist within healthcare information systems to give readers context. In cases where no widely accepted definition exists for a term, we may provide our own definition based on our interpretation and rendition of the concept as well as how it's typically used in the research context.

1.2.1 Defining Personal Informatics and Self-Tracking

Personal informatics (PI), also known as "personal analytics", is the umbrella term commonly used by HCI and healthcare researchers to describe the collection of systems which aggregate and analyse personally relevant information for the purpose of self-reflection and the acquisition of self-knowledge [Li et al., 2010, Lupton, 2016a]. PI is commonly referred to as "quantified-self (QS)" and sometimes interchangeable with "self-tracking" (which we discuss below). QS is the recent incarnation of the practice of collecting personally relevant information for the purpose of gaining self-knowledge

through *quantitative* analysis of data, i.e. "self-knowledge through numbers" [Lupton, 2016b, Quantifiedself.com]. The QS movement represents the phenomenal rise of self-tracking culture fostered by the wide scale adoption of consumer-grade fitness trackers and health apps in recent years [Wolf, 2009], and is almost synonymous with the international *community* of self-tracking researchers and enthusiasts who are interested in exploring and developing technological tools which facilitate the acquisition of self-knowledge.

Self-tracking is largely synonymous with PI with a stronger focus on the practice and means of knowledge creation through the use of technology or manual tools of data-logging. Unlike PI, the term self-tracking implies that the practice of collecting personal data is the result of individuals' autonomous and voluntary decision to self-log [Lupton, 2014]. Self-tracking does not assume the analysis of data, as self-tracking individuals, i.e. self-trackers, may engage in the practice of the autonomous collection of personal information for reasons and purposes beyond self-reflection, e.g. documentation-style tracking and fetishised tracking [Rooksby et al., 2014]. The term "self-tracking data" highlights the active role data subjects played in the creation of the information while "personal data" is a much broader term which describes information which could to traced back and attributed to individuals (either directly or indirectly), including data which is passively collected by service providers, such as names, addresses, digital traces and transaction history. Both "self-tracking data" and "personal data" are used in this thesis to better characterise difference types of personal information depending on context. Other terms such as "self-logging", "life-logging" and "self-surveillance" are largely synonymous, variant forms of "self-tracking" which had been used sporadically in the research community [Lupton, 2016a]. We choose to avoid using them in this thesis for simplicity and consistency.

Though PI, QS and self-tracking are semantically similar and often interchangeable, each term has a slightly different focus on the broader notion of acquiring self-knowledge through the collection and analysis of personal data. While PI is characterised by its systematic approach to collecting and curating personal data, the term itself could be used to describe various aspects of the approach, such as its practice, results, or the technologies involved. Self-tracking, however, is more descriptive of the practice and means of collecting personally relevant information, albeit without the emphasis on the analytics of that information. QS on the other hand, serves the dual purpose of conveying the cultural significance of PI and broadcasting a sense of community among researchers and enthusiasts. Having said that, there is no distinct difference between the use of terms PI and self-tracking in the research context. Therefore, depending on

the context and emphases, we will use PI and self-tracking interchangeably or simultaneously throughout the thesis. PI and self-tracking are cross-domain topics, covering a wide range of data (e.g. health & fitness, personal finance, productivity) from a variety of sources (e.g. wearable devices, smartphone apps, website platforms, physical media). This thesis focuses on exploring these topics and their practical applications in the healthcare context. Therefore, the following definitions of PI, self-tracking and their derivatives are adopted to reflect the scope of the thesis (see section 1.3.3):

Personal Informatics System

We use the term personal informatics system (PIS) to refer to a computer information system (e.g. software, app, website) which either collects, stores or processes personally relevant information for the purpose of knowledge creation. Although some PISes may exist in a physical medium (e.g. hand-written disease diary, hand-drawn graphs), transcription and digitisation of data are often required before carrying out analysis of any scale. The use of the term PIS will therefore be limited to digital medium in the scope of this thesis. A PIS may acquire information directly and indirectly from users and a variety of other data sources such as healthcare providers (e.g. medical history, summary care records) and smartphone app/service providers (e.g. weather and GPS data).

Self-Tracking

We use the term self-tracking to refer to the practice of *voluntarily* and *consciously* engaging in the systematic collection of personally relevant information through the use of one or more PISes for the purposes of self-reflection or knowledge creation. A self-tracker, or self-tracking individual, is therefore someone who actively and consciously practices self-tracking on a routine basis. A self-tracking tool can be regarded as a PIS which enables or supports users in the voluntarily collection of personally relevant information.

Self-Tracking Data

The term self-tracking data refers to any personally relevant information collected through the use of a self-tracking tool, such as health-related personal data, personal finance data (e.g. weekly spending) and productivity-related data (e.g. screen time, tasks completed). Health-related self-tracking data can be further broken down into physical activity data (e.g. exercise, sleep), mental activity data (e.g. mood, stress), medication, symptoms (e.g. pain, fatigue) and food/water intake (e.g. calories intake,

caffeine intake). Self-tracking data does not refer to personally relevant information which does not change frequently over time, such as names, addresses, contact details as well as personal data that is collected via service providers (e.g. browser history, bank statements, utility bills).

1.2.2 Defining Self-Tracking Technology

The practice of systemically collecting personally relevant information for the purpose of self-reflection had been around long before the term "self-tracking" was introduced following the advent of digital self-logging tools and sensor-rich wearable devices. The arrival of digital/electronic self-tracking technologies has enabled consumers to track more information, more easily through automation of data collection. Nevertheless, it is still necessary to incorporate physical tools, such as paper diaries and journals when discussing self-tracking technologies in the context of healthcare, as their use remains vastly popular among patients [Ayobi et al., 2018]. We define self-tracking technology, or a self-tracking tool, as an instrument, either physical or digital, that facilitates or enables someone to engage in self-tracking behaviours. In addition, we define the types of self-tracking tools which are relevant to the context of this research based on their methods of data collection, namely *manual* and *automatic* data collection. We discuss the pros and cons of both methods in the next chapter (see section 2.4.2). It is worth noting that, some self-tracking tools use hybrid data collection or "semi-automated tracking"[Choe et al., 2017] to gather information about an individual by combining manual and automatic data collection. For example, MyFitnessPal allows users to input weight and diet data manually while collecting other health data such as steps and sleep and automatically.

Manual Data Collection

We use the term manual data collection to refer to the conscious and deliberate reporting or recording of personally relevant information by an individual through the use of a self-tracking tool (physical or digital). Manual data collection is often characterised by its requirement of user effort in regard to the input of data, including material efforts (e.g. time, body movement) and cognitive efforts (e.g. reminiscence and self-reflection). Examples of manual data collection include the use of physical or digital journal, blog, personal diary, symptom diary, rating scale and questionnaire.

Automatic Data Collection

Automatic data collection refers to the computerised, active and unobtrusive gathering of personally relevant information by a self-tracking tool, such as the collection of one's digital traces (e.g. screen time, browser history, transaction records) and the collection of data through sensor-embedded devices (e.g. wearables, smartphone, smart scales). Unlike manual data collection, tools which use automatic data collection are generally pre-programmed and self-operating, thus requiring minimal to no user effort with regard to the input of data, with the exception of using, wearing or carrying the device itself. Self-tracking tools which collect data automatically often require a certain degree of user effort in relation to upkeep and maintenance [Choe et al., 2017], e.g. activation/deactivation, charging, software updates, synchronisation. Examples of automatic data collection include the use of fitness trackers and smart watches (e.g. Fitbit [Fitbit, 2022], Garmin [Garmin, 2022], Apple Watch [Apple, 2022b], Samsung Galaxy Watch [Samsung, 2022]), health apps which use the embedded sensors (e.g. Apple Health [Apple, 2022a], StepsApp [StepsApp, 2022], Heart Rate Monitor [REPS, 2022]), productivity tools (e.g. StayFree [Sensor Tower, 2022], Forest [Seekrtech, 2022]), smart scales (e.g. Withing [Withings, 2022]) as well as personal fiance apps (e.g. Monzo [Monzo, 2022]).

1.2.3 Defining Healthcare Context

We will use and make reference to a number of relevant terms from the domains of healthcare and chronic conditions throughout the thesis. We provide definitions for key terms related to chronic conditions, healthcare stakeholders and common clinical data categories. There is a large degree of variation in the definition and use of the term "chronic condition" among healthcare institutions, professionals and researchers [Bernell and Howard, 2016], especially when it comes to disease duration, progression and causation. We adopted relevant definitions provided by NHS [2021] and CDC [2021] to better describe and characterise these terms in the context of the thesis. In addition, we define axial spondyloarthritis, a specific chronic condition which serves as the context of our investigations of the clinical use of self-tracking data (more about this in section 1.3.1).

Chronic Condition

A chronic condition, also known as chronic disease, chronic illness, broadly refers to any human health condition that is persistent in its effects and require ongoing treatment or medical attention. The course and duration of chronic conditions can be highly

varied, ranging from three months to lifetime. Examples of chronic conditions include long-term physical conditions such as rheumatic diseases (e.g. arthritis), cardiovascular diseases, cancer, diabetes, irritable bowel syndrome, chronic fatigue syndrome, Parkinson's disease, HIV, as well as psychological disorders such as depression, bipolar disorder and obsessive compulsive disorder. The majority of chronic conditions are also characterised by their debilitating impact on patients' activities of daily living.

Axial Spondyloarthritis

Axial spondyloarthritis (axSpA) is a type of debilitating, inflammatory chronic disease which primarily affects the spine and sacroiliac joints in the body, including ankylosing spondylitis (AS) and non-radiographic axSpA [NASS, 2018a]. It is a typifying chronic condition with regard to its healthcare pathway which consists of the following components: routine check-ups, physiotherapies, patient self-management (e.g. medication and exercise) and surgical operations [NHS, 2017]. Formal diagnoses of axSpA usually require conclusive radiographic evidence (e.g. x-ray, MRIs), which typically, slowly becomes available as the condition progresses. Common symptoms of axSpA include chronic back pain, fatigue, stiffness, night sweats, psoriasis and uveitis.

Healthcare Provider

We use the term "healthcare provider" (provider for short) to refer to a person or an institution that provides health services to individual who require medical attention or advice, such as the diagnosis and treatment of health conditions. Individuals who are qualified to provide health services are also known as *healthcare professionals* or *clinicians*, such as consultants, physicians, surgeons, clinical psychologists, physiotherapists, dietitians, general practitioners (GP), nurses, locums and midwives.

Outpatients and Inpatients

An outpatient in the context of a chronic condition refers to an individual who attends a healthcare facility (e.g. clinic, hospital) for diagnosis and/or treatment without staying overnight. We use the term inpatient to refer to an individual who is admitted into a healthcare facility for any duration of overnight stay in order to receive medical care or treatment.

1.2.4 Defining Clinical Data Categories

Healthcare providers often follow the principles of evidence-based medicine when making clinical decisions about individual patients (e.g. diagnosis, prognosis, treatment).

Evidence-based medicine combines providers' clinical expertise (e.g. professional judgement, medical proficiency) with rigorous external clinical evidence derived from research [Sackett et al., 1996, Sackett, 1997] to reduce the reliance on intuition when making clinical decisions. We use the term clinical evidence to refer to scientific findings which could be used as grounds for decision-making during the diagnosis, prognosis and treatment processes of a health condition, such as the effectiveness of medications and treatments or the impact of significant biomarkers. Providers often base their clinical decisions on a combination of clinical data, including use of clinical evidence, medical tests and a variety of clinical outcome assessments (COAs) or outcome measures. For example, a provider may prescribe treatment based on reasonable assumptions when a patient possesses a biomarker that is associated with high likelihood of a certain disease and exhibits relevant symptoms at the same time. An outcome measure will typically undergo a series of evaluations in regard to its reliability, accuracy and safety before receiving approval for use. In reality, validation studies on clinical outcome measures are constantly taking place in the field of medical research. In the meantime, healthcare providers use both validated outcome measures and the ones that have yet to be validated in their provision of patient care. Medical tests and COAs are important aspects of clinical information gathering. Historically, both medical tests and COAs are collected, archived and managed by health providers using in-house health record management systems or software. Since the popularisation of consumer self-tracking technologies, organisations such as and NHS Digital and Public Health England have advocated for patient-generated data [HSCIC, 2019, PHE, 2017], including self-tracking data to be integrated with electronic health record (EHR) management systems (EHRMS). We define medical test, common types of outcome measures and patient-generated data below based on taxonomies provided by FDA [2020], Walton et al. [2015], Abdolkhani et al. [2019] and ONC [2018].

Medical Test

We use the term medical test, or medical examination, to refer to any laboratory examination or sampling of the human bio-specimen using objective methods that are free from the influence of human judgement in its collection process. Examples of medical tests include laboratory analyses (e.g. biochemical analysis) of human tissues or biological samples (e.g. blood tests, urine tests, genetic sequencing) as well as medical imagining, also known as medical radiography and diagnostic radiology exams (e.g. CT, MRI, x-ray).

Clinical Outcome Assessment

A clinical outcome assessment (COA), or clinical outcome measure (outcome measure for short) refers to the measurement of patients' symptoms, mental state, Quality of Life (QoL) and bodily functions which is administered by a human actor, e.g. patient, carer, clinician. COA metrics are often based on the subjective observations of an individual, therefore can be influenced by human judgement and motivation. There are four common types of COAs: patient-reported outcome measures, observer-reported outcome measures, clinician-reported outcome measures and performance outcome measures.

Patient-Reported Outcome Measure

A patient-reported outcome (PRO) measure, or PROM, is a form of COA based on patients' direct reporting of their own health condition (e.g. symptoms, bodily functions, QoL, mental health) and experience of care without external amendment or interpretation by another person [Cella et al., 2015]. A PRO can be measured through self-reports, self-assessment forms, questionnaires and interviews with a provider. Examples of PRO measure include Margolis pain diagram [Margolis et al., 1986], The Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) [Garrett et al., 1994], Ankylosing Spondylitis Disease Activity Score (ASDAS) [Lukas et al., 2009] and Ankylosing Spondylitis Quality of Life (ASQoL) [Doward et al., 2003].

Observer-Reported Outcome Measure

An observer-reported outcome (ObsRO) measure is a form of COA based on the reporting of observable signs, events or behaviours related to a patient's health condition by an someone other than the patient or a provider, such as a caregiver or family member. An ObsRO does not require professional judgement or medical expertise in relation to the patient's health condition and is typically used when the patient is unable to report for themselves. Examples include the FLACC Behavioral Pain Assessment Scale [Voepel-Lewis et al., 1997] and Acute Otitis Media Severity of Symptoms scale (AOM-SOS) [Shaikh et al., 2009].

Clinician-Reported Outcome Measure

A clinician-reported outcome (ClinRO) measure is a form of COA based on the observation and reporting of a patient's health condition by a trained healthcare professional. Unlike PRO and ObsRO, the measurement of ClinRO require a certain level of professional judgement and medical expertise usually acquired through prolonged training

and experience. ClinRO measurement usually takes place during in-person interactions between patients and clinicians (i.e. clinical encounters). ClinRO may include symptoms or other manifestations of the health condition which are directly observable during the time of measurement. Examples of ClinRO measure include physical examinations during clinical consultations (e.g. red eyes, swollen joints) and the use of clinician-administered indices or rating scales such as the Psoriasis Area and Severity Index [Langley and Ellis, 2004] and the Hospital Anxiety and Depression Scale (HADS) [Snaith, 2003].

Performance Outcome Measure

A performance outcome (PerfO) measure is a form of COA which examines how well a patient is able to complete a set of standardised tasks according to instructions. Some PerfO measures can be administered independently by patients themselves, e.g. Bath Ankylosing Spondylitis Functional Index (BASFI) [van Riel, 1995] while others require the presence of health professionals, e.g. Bath AS Metrology Index (BASMI) [Jenkinson et al., 1994].

Patient-Generated Data

Patient-generated data (PGD), or patient-generated health data (PGHD) is a term which frequently appears in healthcare, PI and self-tracking literature and research [Abdolkhani et al., 2019]. There is a large degree of variation between the definition of PGD as provided by different research communities. It can be used to describe one or more of the following data categories: patient-reported outcome measures (e.g. completed BASDAI questionnaires), patient self-tracking data (e.g. symptoms, medication, lifestyle) and historic health data (e.g. biometric data). The Office of the National Coordinator for Health Information Technology (ONC) defined PGHD as "health-related data created, recorded, or gathered by or from patients (or family members or other caregivers) to help address a health concern" [ONC, 2018]. The ONC named two distinct characteristics of PGD that are different from data generated in clinical settings through encounters with providers, referring to the proactive role patients play in the collection and sharing of their data. Our use of the term PGD refers to any information that is created, recorded or collected by patients for health purposes, using either home health equipment (e.g. blood pressure monitor), or self-tracking tools (e.g. wearable devices, smartphone health apps).

1.3 Research Context

In this section, we describe the clinical context of the various online and field studies presented in this thesis, including why we choose axial spondyloarthritis as a typifying chronic condition to ground our research and the introduction of Project Nightingale, a self-tracking research initiative led by our healthcare collaborators. Deliberate delimitation of research scope is necessary to producing relevant and well-evidenced research outcome due to sheer number of chronic conditions which could serve as the clinical context of our investigation. Narrowing our scope of research down to a single condition enables us to focus on the use and discussion of self-tracking data in a specific clinical context, thus allowing us to explore the potential values self-tracking data could bring in regard to the various activities associated with the patient care process for that condition. This provides consistency with regard to the context of each study that targets a specific research question and ensures that findings can be carried over from one study to the next (more details in section 1.4).

1.3.1 Axial Spondyloarthritis

Axial spondyloarthritis (axSpA) is a typifying chronic condition that demands ongoing monitoring, treatment and self-management from patients and their healthcare providers. As mentioned in our definition of axSpA (section 1.2.3), it is a chronic inflammatory disease which predominantly affects the patient's spine and sacroiliac joints, therefore causing enduring pain and reduced spinal and joint mobility [NASS, 2018a, Siebert et al., 2016]. There are two classes of axSpA: ankylosing apondylitis (AS) and non-radiographic axial spondyloarthritis (nr-axSpA), together affecting approximately 1 in 200 adults globally [Siebert et al., 2016, Dean et al., 2014]. While AS is thought to be a disease which primarily affects men, emerging evidence suggest that nr-axSpA has roughly equal prevalence among men and women [Wright et al., 2020]. The provision of patient care in regard to axSpA include diagnosis, prognosis and treatment [Sieper and Poddubnyy, 2017, Strand and Singh, 2017, Robinson and Brown, 2014]. We discuss how patient self-tracking data may benefit different aspects of axSpA patient care, providing justification to our research context:

The clinical diagnosis of axSpA is often a complicated and time-consuming process which relies on long-term observations of symptoms and consistent measurement of clinical outcomes [Sieper and Poddubnyy, 2017]. The diagnostic usually begins when a patient notices the onset of early symptoms, such as morning stiffness, soreness, fatigue and pain, and will not become conclusive until radiographic medical examinations such as x-ray and magnetic resonance imaging (MRI) produces definitive evidence [Maksy-

mowych, 2019, Protopopov and Poddubnyy, 2018]. In result, formal diagnosis could take an extraordinarily long time, usually between 8-11 years from the time of onset of the earliest symptoms [Khan, 2002, Mau et al., 1988, Feldtkeller et al., 2003]. Furthermore, the diagnostic process is subject to delays based on factors such as gender [Slobodin et al., 2011] and presence of HLA-B27 bio-marker or lack thereof [Reveille, 2015]. So long as radiographic imaging remains inconclusive, diagnosis and prognosis depends on the collection of other types of clinical data, including PROs and ClinROs (e.g. BASMI, BASFI and ASQoL) as well as medical examinations (e.g. blood test). Data collection predominantly occurs during clinical check-up appointments which typically take place once or twice per year, though the frequency may vary depending on the severity and stage of the patient's condition. The longitudinal collection of these data forms an integral part of the prognosis and post-diagnosis treatment, allowing providers to understand how the disease progresses over time. However, since the frequency of data collection is dictated by frequency of patients' clinical visits, new data is often generated at a relatively very low frequency (i.e. once or twice a year), making certain disease patterns such as seasonal variations hard to identify. Additionally, infrequent measurement of PROs may subject patients' reporting of disease experience to recall bias [Schmier and Halpern, 2004, Shiffman et al., 2008]. The practice of self-tracking may help address this issue by providing additional patient-generated data that is useful to the diagnosis and prognosis of axSpA. To begin with, self-tracking technology such as wearable activity trackers (e.g. Fitbit [Fitbit, 2022], Garmin [Garmin, 2022]) and smartphone health apps (e.g. Chronic Pain Tracker [Chronic Stimulation, 2022], My Pain Diary [DamoLab, 2022]) can be used to capture health data related to axSpA, including exercise, sleep and pain on a highly frequent basis. In addition, a few self-tracking tools which specialise in axSpA (e.g. ASAS [ASAS, 2022], RheumaBuddy [Daman Digital, 2022], uMotif [uMotif, 2022], Talking AS [Carroll et al., 2014]) has been developed to allow closer and more precise monitoring of symptoms (e.g. types and areas of pain), physical activities and medication. Some apps have even been developed to allow patients to measure PROs at home, such as MySpA by [Barts Health NHS Trust, 2021].

Due to the debilitating and progressive nature of the disease, axSpA can severely impact patients' quality of life if left untreated, leading to reduced physical mobility, sleep quality and mental health issues. Since there is no known cure for axSpA, ongoing treatment is the key to reducing the frequency and severity of symptoms. The treatment of axSpA requires ongoing efforts from both patients and healthcare providers. It typically involves a treatment plan advised by providers during clinical visits, including the prescription of medication, recommendation of physiotherapies, rehabilitation courses,

and if necessary, surgical operations. Patients who undergo overnight rehabilitation courses and surgical operations are often considered inpatients before discharged. The vast majority of axSpA patients are outpatients who manage their conditions by engaging in self-management behaviours without the assistance of providers or caretakers. Self-management in the context of axSpA involves patients' adherence to the treatment plan by doing recommended exercises and medicating according to instructions. A number of recent studies have investigated the value of PI and self-tracking data in patients' self-management routines [Danve and Deodhar, 2019]. Our research focuses on the clinical and collaborative use of self-tracking data between axSpA patients and healthcare providers, instead of the independent review of the data by patients or providers. This thesis will contribute to the understanding of the value of self-tracking data in the processes of diagnosis, prognosis and treatment planning and evaluation.

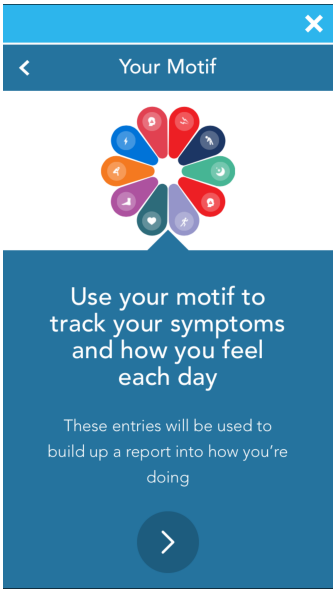
As we briefly mentioned in the overview (section 1.1), we focus on axSpA as a typifying example of chronic conditions and use it to define the scope of this research. We anticipate that findings regarding the use of self-tracking data in the context of axSpA are likely to generalise to other conditions, such as other chronic musculoskeletal conditions characterised by similar symptoms, e.g. rheumatoid arthritis, as well as other conditions with similar approach to ongoing treatment and management, e.g. irritable bowel syndrome, chronic fatigue syndrome, HIV. While other chronic conditions may serve as perfectly reasonable contexts of this thesis, factors such as the university's partnership with the Royal National Hospital for Rheumatic Diseases (RNHRD) and its ongoing patient self-tracking initiative position axSpA as the ideal candidate for the context of our research. We discuss this further in section 1.3.3.

1.3.2 Project Nightingale and uMotif

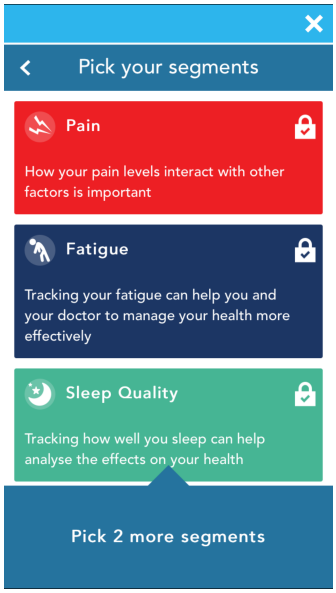
A significant portion of our research is conducted with the University of Bath's research partners in the healthcare sector, including the Royal National Hospital for Rheumatic Diseases (RNHRD) [NHS, 2022a], Royal United Hospitals (RUH) Bath NHS Foundation Trust [NHS, 2022b], the National Axial Spondyloarthritis Society [NASS, 2018b] and Bath Institute for Rheumatic Diseases [BIRD, 2019]. This allows us to: access patient record and health data, recruit patients through the healthcare system and public patient communities, carry out research in healthcare facilities and access patient self-tracking data collected through Project Nightingale [RNHRD, 2017, Project Nightingale, 2020] and the uMotif app [uMotif, 2022] with the appropriate ethical approvals (details provided in the respective chapters).

Project Nightingale is a research initiative led by Dr Raj Sengupta, a consultant

rheumatologist at RNHRD [RNHRD, 2020]. The project aims to explore the value of self-tracking technology, including smartphone health apps and wearable devices, in the context of patient care and axSpA research. The project involves a patient-facing smartphone health app, uMotif [uMotif, 2022] (developed by White Swan [Swan, 2018]). The app allows users to self-report data that could be useful to the diagnosis, prognosis and treatment of axSpA, including disease activities (e.g. pain, fatigue, flare status, eyesight, red eyes, hot flushes, psoriasis, blood in stool), medication (e.g. intake and adherence to prescription), physical activities (e.g. sleep, exercise), mental activities (e.g. stress level, mood, confidence in self-managing symptoms), food intake (e.g. alcohol, caffeine, water) and other health related data such as screen time and menstrual cycle. Patients are able to self-report these data using a petal-like rating system that is equivalent to a set of five-point scales (see Figure 1-1 and 1-2). In addition, the umotif app could also aggregates health data from other smartphone health apps and apps for wearables (e.g. Fitbit [Fitbit, 2022], Garmin [Garmin, 2022], MyFitnessPal [MyFitnessPal, 2022], Strava [Strava, 2022] and Apple Health [Apple, 2022a]) through back-end APIs, provided that the user authorises it [uMotif, 2022]. Project Nightingale also consists of a clinician-facing web platform which allows providers to view and download both unprocessed and visualised data (see Figure 1-4, 1-5 and 1-6). However, the current version of the clinician portal offers little data insight and analytical features beyond simplistic visualisations (e.g. time series). Nevertheless, the uMotif platform has been used in a number of studies investigating the use of self-tracking technology in the context of chronic conditions, e.g. [Barnett et al., 2019, Druce et al., 2017, Lakshminarayana et al., 2017, Reade et al., 2017].

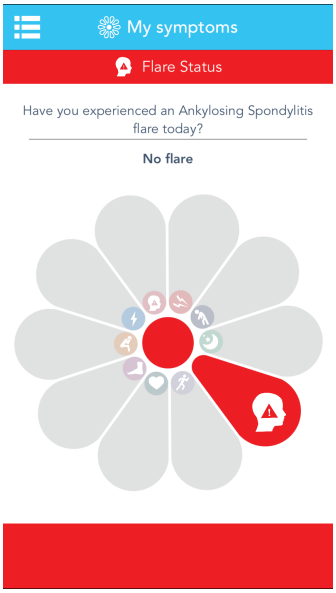


(a) Welcome page

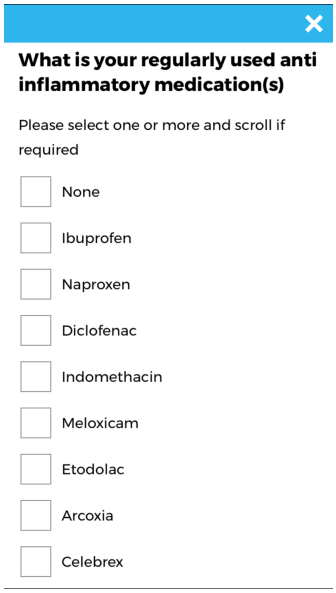


(b) Petal customisation

Figure 1-1: uMotif - welcome page and petal customisation

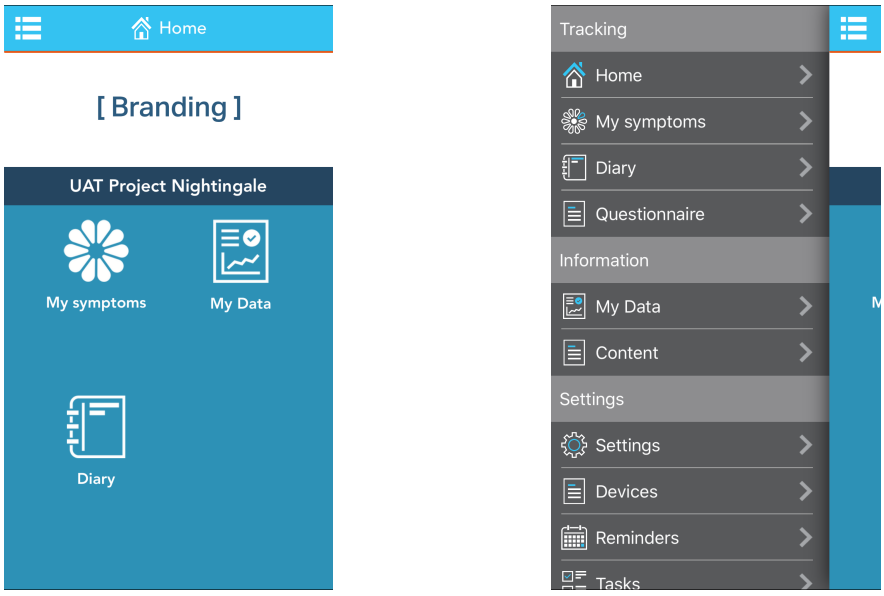


(a) Petal scale



(b) Daily questionnaire

Figure 1-2: uMotif - petal scale and daily questionnaire



(a) Main menu (b) Side menu

Figure 1-3: uMotif - main menu and side menu

The project was initially launched in Q1 2018, and by the end of the year, it had enrolled over 180 prospective and diagnosed axSpA patients. By Q1 2021, the number rose to 368, indicating a significant amount of patient interest and continued engagement. The project serves as an ideal platform for our exploration of the clinical use of patient self-tracking data. We investigate patient self-tracking adherence via the uMotif app to identify factors that may affect tracking engagement in Chapter 4, therefore determine whether apps like this could produce data that is adequate for clinical use. In Chapter 6, we investigate how self-tracking data produced by Project Nightingale participants contribute to the provision of patient care as well as the interactions between axSpA patients and providers.

1.3.3 Research Scope

In this section we refine the scope of the thesis by narrowing down our focus to issues related to the clinical use of patient self-tracking data and the design of personal informatics systems that support it. Since this research is set in the context of healthcare and chronic conditions, we limit our use of self-tracking technology and data to that which relate to a person's physiological condition and mental health, including apps and/or devices that track disease activities, i.e. symptoms (e.g. pain, fatigue, red eyes, psoriasis, blood in stool), physical activities (e.g. exercise duration, distance travelled, heart rate), mental well-being (e.g. diary, stress) and medication. This also includes less

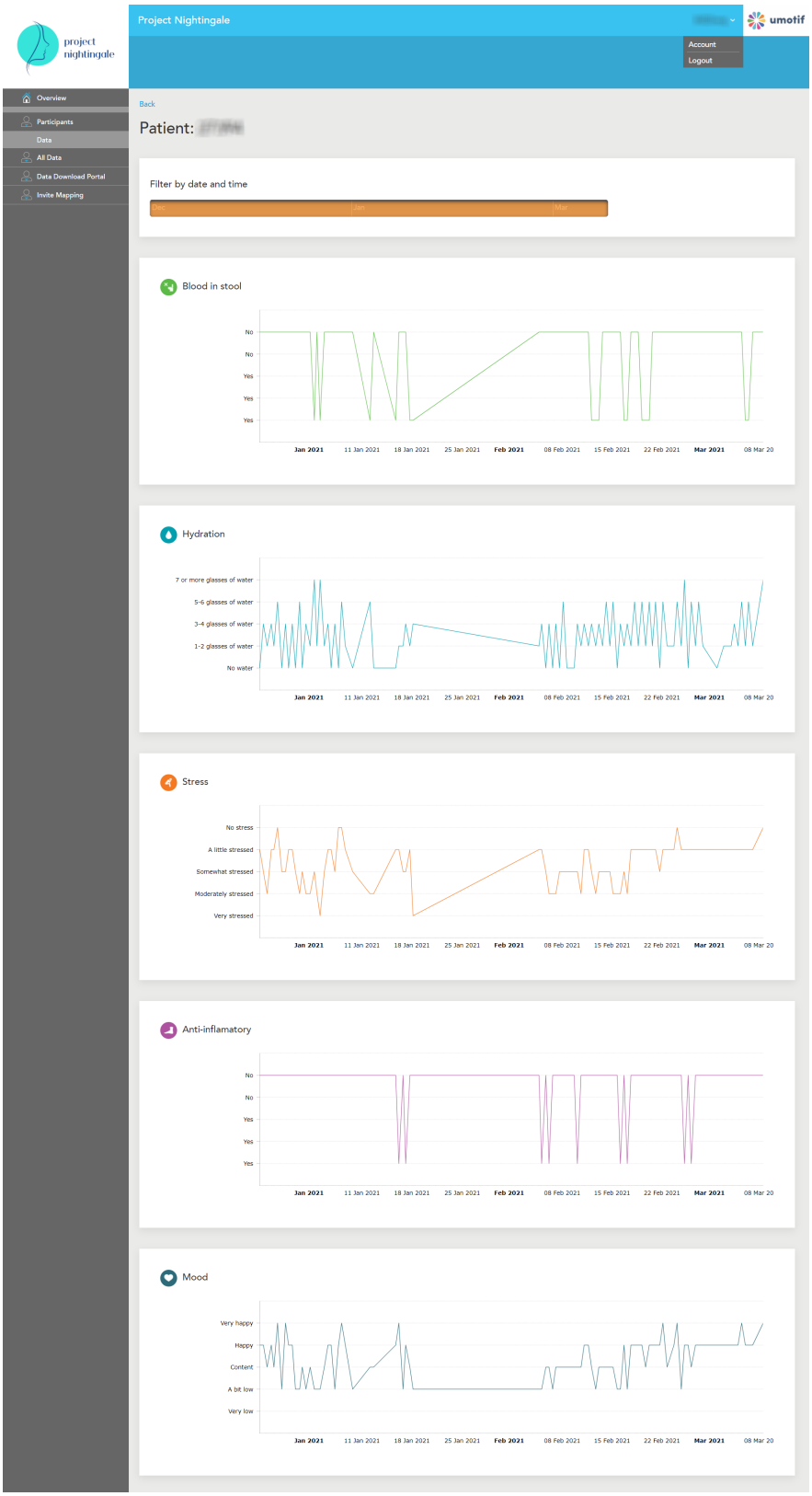


Figure 1-4: Visualisations of a patient's uMotif data: blood in stool, hydration, stress, anti-inflammatory intake and mood

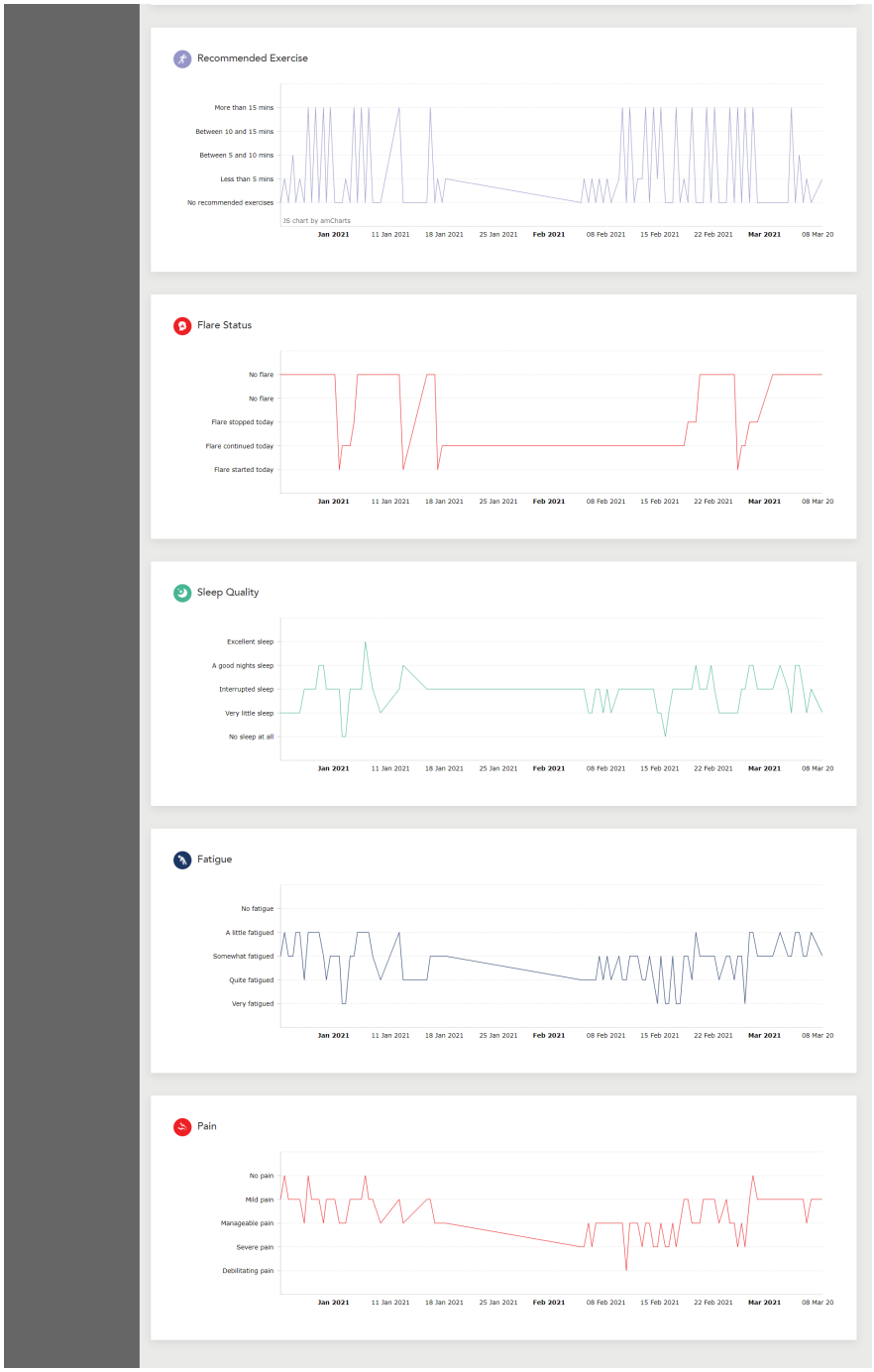


Figure 1-5: Visualisations of a patient's wearable data: recommended exercise, flare status, sleep quality, fatigue and pain

Figure 1-6: Visualisations of a patient's wearable data

relevant but potentially useful health data collected through fitness apps (e.g. fitness goals, body measurements, BMI, sleeping habits), weight loss apps (e.g. diet, water intake, caffeine intake, alcohol consumption), journaling apps (e.g. life events) and weather apps. Other types of PI and self-tracking research, including personal finance (e.g. bank statements, energy bills), productivity management (e.g. work activities, calendar events, browsing history), social communication (status updates, blog posts, messaging history) are not within the scope of this thesis.

As we pointed out in section 1.1, the rise of consumer self-tracking technology such as wearable fitness trackers and smartphone health apps led to the increase in research focused on the clinical use of patient self-tracking data, including medical research, patient self-management and the provision of patient care (e.g. diagnosis, prognosis and treatment). This thesis acknowledges the importance of medical research based on self-tracking data and the roles it may play in the clinical setting. Though we may carry out cohort analysis on self-tracking data to understand patients' self-tracking behaviours, the focus of this research is not to address long-standing health questions or create new clinical evidence through the statistical analysis of self-tracking data. Similarly, how patients use self-tracking data to manage their condition independently from healthcare providers and outside of the clinical setting is not within our research scope. Issues related to patient self-management will only be addressed and discussed when they are relevant to the clinical use of self-tracking data and the provision and

patient care. The primary focus of this thesis is on the clinical and collaborative uses of self-tracking data, as well as the design of PISes and self-tracking tools which facilitate and contribute to this process.

There are many clinical scenarios involved in the provision of axSpA patient care and that of similar chronic conditions, such as check-up appointments, medical exams, hospital ward rounds and psychotherapies. It is not currently well-understood whether or how patient self-tracking data could benefit each and every clinical scenario. Since it is not realistic for us to fully explore every clinical scenario in this thesis, further scoping decisions need to be made as our understanding of the care process of axSpA improves. Our research emphasises on clinical scenarios that involve both patients and providers, i.e. clinical encounters, as they are the primary settings where the collaborative use and interpretation of self-tracking data could realistically take place.

As mentioned in section 1.3.1, we choose axSpA as the primary setting of the research presented in this thesis due to the many opportunities self-tracking data provides in regard to the provision of axSpA patient care, including diagnosis, prognosis, treatment planning and evaluation. Nevertheless, since the processes involved in the provision of care for axSpA is very typical of chronic conditions of similar nature (e.g. rheumatoid arthritis [Lacaille et al., 2005, Bernatsky et al., 2006], irritable bowel syndrome [Grundmann and Yoon, 2010], Parkinson's disease [Rao et al., 2006]), the findings of this work likely contribute to the overall understanding of the value of PI and self-tracking technology in the context of healthcare and chronic conditions. Moreover, the types of data that would be useful to track in the context of axSpA, such as self-reported disease activities (e.g. pain, fatigue), medication, physical activities (e.g. exercise) and mental health (e.g. stress) are similar to that of many other chronic conditions, as evidenced by studies investigating the use of self-tracking technology in the context of multiple sclerosis [Ayobi et al., 2017], irritable bowel syndrome [Schroeder et al., 2017] and Parkinson's disease [Mishra et al., 2019] and endometriosis [McKillop et al., 2018]. This means the design implications that we produce for tools which support the clinical use of self-tracking data can be extrapolated and applied to other chronic conditions involving similar clinical data categories.

In addition, our research focuses on clinical scenarios which exist in the provision of outpatient care, rather than inpatient care (e.g. post-surgery recovery, residential rehabilitation courses). Though the use of wearable devices and health apps among inpatients has been observed (e.g. [Reed et al., 2021]), self-tracking remains a behavioural pattern which occurs most frequently outside of healthcare facilities. Last but not least, our research concerns primarily the use of patient self-tracking data between axSpA pa-

tients and their consultant rheumatologists. Although the provision of care for axSpA may involve many types of healthcare professionals such as physicians, dietitians and nurses, consultants are usually those who interact with patients most consistently and are responsible for making the most important clinical decisions including diagnosis, prognosis, treatment planning and evaluation. We discuss how future work in this area may expand on this and investigate the use of self-tracking technology and data at the hands of other healthcare professionals in Chapter 7.

The locations of the work carried out in this research are based in the United Kingdom, including NHS facilities such as the Royal National Hospital For Rheumatic Diseases (RNHRD) and the Royal United Hospitals (RUH). RNHRD, the subsidiary organisation of RUH as of 2015, employ of a team of ten consultant rheumatologist which cater to over 1,000 axSpA patients each year, not including its other specialist services such as pain services and biologics services [RNHRD, 2020, CQC, 2016]. The parent organisation RUH caters to a wider population of 500,000 around Bath, North East Somerset and Wiltshire [CQC, 2018].

1.4 Research Aims

As we stated in section 1.1, the practical use of patient self-tracking data in real-life clinical scenarios remains largely unexplored, as research to-date had primarily focused on artificial/simulated data use between patients and providers. As the result, limited evidence had been produced to demonstrate the value of self-tracking data in the provision of patient care in practice, such as prognosis, diagnosis and treatment. Fewer studies have been carried out to directly investigate the interactions between patients and providers around self-tracking data during clinical encounters, as well as the potential challenges associated with the clinical use of self-tracking data, such as limited resources, expertise and perceived data quality issues. A more in-depth investigation which directly targets the clinical use of patient self-tracking data will help determine the benefits, risks and viability associated with the inclusion and integration of PI technologies in the healthcare context.

The overall research aim of this thesis is therefore to **facilitate the clinical integration of patient self-tracking data by understanding the opportunities and challenges associated with its usage in the context of chronic conditions**. Our research will produce practical design implications which help HCI researchers and developers create software solutions and PIS features which facilitate the clinical use of self-tracking data and potentially improve the provision of patient care, laying

the groundwork for future research. The outcome of the thesis will provide the much-needed clarity for researchers and healthcare stakeholders (e.g. patients, providers, researchers, developers, investors, regulatory authorities) with regard to realistic way in which self-tracking data could be used in rheumatology clinics and similar clinical encounters.

To refine our research aim and make it more specific and measurable, we conducted a preliminary literature review on recent development in PI and self-tracking technology and its use in context of healthcare and chronic conditions, allowing us to identify major knowledge gaps in the research and synthesise them to form the following research questions (RQs):

RQ1: What roles could patient self-tracking data play in real-life clinical scenarios?

RQ2: What are the key factors which may influence patients' engagement with self-tracking?

RQ3: What are the patients' perspectives on the collaborative use of self-tracking data?

RQ4: What are the benefits and challenges associated with using patient self-tracking data in real-life clinical scenarios?

These research questions will be evidenced more thoroughly in Chapter 2 as we review recent publications from the fields of self-tracking and healthcare. These research questions will be tackled individually in Chapter 3, 4, 5 and 6, as we refine them and break them down into measurable secondary research questions at the beginning of the respective chapters.

The next section covers how we're going to address these RQs as we outline the research methods we will throughout this thesis.

1.5 Research Methodology

As previously mentioned, this thesis aims to facilitate the clinical integration of patient self-tracking data by understanding the opportunities and challenges associated with its usage in the context of chronic conditions, so that it can be used to inform the design of PISes and self-tracking tools. This means the studies we conduct to address the individual RQs should produce results which can be easily interpreted and understood by HCI researchers and designers of self-tracking technologies. To that

end, we will adopt standard research methods which are commonly used by PI and self-tracking researchers, as seen frequently in publications we reference throughout the literature review and the rest of the thesis. Our approach may involve a mixture of qualitative and quantified research methods, depending on the research objectives of each chapter and the availability of data. The rationale behind this is that both categories of research methods have their respective strengths and weaknesses with regard to the richness of information, and the speed of data collection, as neither is universally applicable to every research scenario. For example, in Chapter 3, we use qualitative methods such as clinical shadowing and field observations to model the clinical procedures involved in axSpA patient care due to the nuanced nature of the topic. For the qualitative explorations of subjects' beliefs and attitudes in Chapter 4, we use surveys and interviews consisting of rating scales and open-ended questions to gather data for analysis (e.g. thematic analysis [Braun and Clarke, 2006], breakdown analysis). We may analyse users' behavioural data (e.g. adherence) using quantitative methods (e.g. linear regression, cluster analysis) as they are generally more adequate for gaining statistical insights. Depending on the research question, we may use qualitative and quantitative methods conjointly to investigate topics such as patients' self-tracking adherence in order to capture the subjective reasoning behind statistical patterns. We give more detailed explanation of the research methods we use to tackle each research question within their respective chapters. Where alternative approaches are available, we provide justifications for the methods we use as we discuss their suitability alongside the availability of data.

While methods such as the longitudinal collection of quantitative data from a large sample adopted in cohort studies such as Dixon et al. [2019] and Sohda et al. [2017] benefits the acquisition of insights through statistical analysis, it usually comes at the cost of the level of detail and richness in relation to data which qualitative research methods could afford, such as contextual information which could help explain the correlations uncovered through statistical means. For example, Dixon et al. [2019] used a first-order hidden Markov model to uncover various self-tracking engagement patterns among participants (i.e., high, low, disengaged) but did not have the qualitative information needed to identify factors which could have contributed to the disparity in tracking behaviours. Overall, we elected to use qualitative research methods sparingly due to the level of nuance they could help capture over quantitative approaches. Methods such as affinity diagrams and thematic analyses are, generally speaking, better at extracting qualitative information inductively where no pre-defined metrics apply, allowing researchers to tackle problems which require extensive observation, e.g. contextualising the clinical workflow in which self-tracking data is likely used in. Additionally,

our work focuses on scenarios relating to the use of patient self-tracking data during and around clinical visits instead of individuals' self-tracking behaviours that are removed from the the clinical setting where quantitative methods may be better suited.

Due to the subject matter of our research and its focus on both patients and providers as users of self-tracking data, a significant portion of the research will be conducted in the healthcare environment (e.g. axSpA clinics, hospital wards, patient and public involvement events). This means that the methods we deem the most informative (e.g. workshops at moderate scale) may not always be practical and cost-effective, as research approvals which involve advanced and lengthy ethics reviews from regulatory authorities, e.g. NHS REC, would likely be required. Participant recruitment and sampling may also be limited due to highly rigorous prerequisites such as missing patient consent to be contacted for research purposes. We aim to ensure both the quality and validity of our research by taking a balanced approach in choosing research methods, weighing the time and resources required from seeking regulatory approval against the richness of information which we expect to obtain.

1.6 Thesis Outline

In this section we outline the structure of the thesis by chapter. Figure 1-7 maps out the research questions, how they are addressed in each chapter, and how they link to the overall research aim.

Chapter 1 - Introduction

In Chapter 1, we introduced the subject and scope of this work, provided clarity with regard to the use of key terms throughout the thesis, summarised our research background, delineated the overall research aim as well as methods we intend to use to address the main research questions.

Chapter 2 - Literature Review

In Chapter 2, we review and discuss relevant literature from the domains of HCI and healthcare research, thus providing context and justification for the research questions and work presented in this thesis. We review major theoretical developments in recent PI and self-tracking research as well as published work around the adoption of PI and self-tracking technology in the context of healthcare and chronic conditions to identify knowledge gaps in the literature.

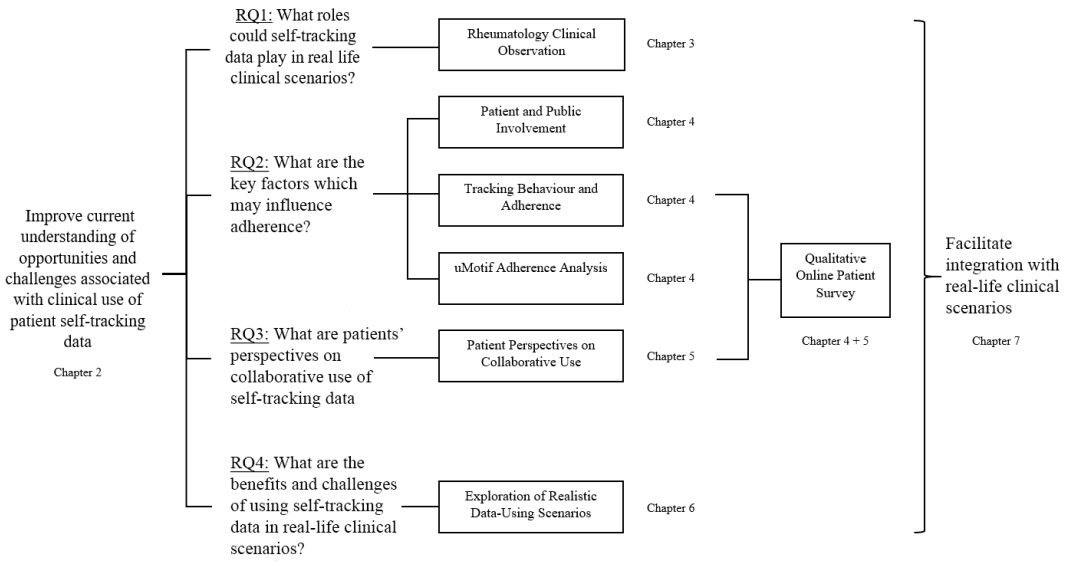


Figure 1-7: Thesis outline

Chapter 3 - The Role of Self-Tracking Data in the Clinical Context and Provider Perspectives

Chapter 3 addresses RQ1 through an observation & interview study (Study 1) which focuses on activities which take place during clinical encounters between axSpA patients and their providers. We observe 28 clinical sessions between axSpA patients and their consultants at the Royal National Hospital for Rheumatic Diseases (RNHRD), including routine check-up appointments and follow-ups of rehabilitation courses. We developed a stage-based model of activities based on field notes which captures the typical clinical workflow of rheumatology clinics, illustrating how these activities situate within the broader context of the healthcare pathway for rheumatic diseases. We also uncover major clinical data categories used by providers during the check-up appointments and how their usage relates to each clinical activity. We propose potential ways in which self-tracking data could benefit the consultation while acknowledging the existing clinical procedure. We discuss how this study informs research of subsequent chapters.

Chapter 4 - Patient Engagement and Adherence with Self-Tracking for Clinical Purposes

Chapter 4 provides a deeper understanding of axSpA patients' adherence to self-tracking through a combination of qualitative and quantitative studies. We first use

a patient and public involvement (PPI) event to gather information about axSpA patients' experience with uMotif, a self-tracking app which allows users to self-report data about their disease activities and self-management behaviours. We notice significant variations in users' self-tracking adherence, i.e. frequency of data collection through self-reporting. We use this information to refine RQ2 and design a qualitative survey study which investigate factors contributing to patients' self-tracking behaviours and engagement (i.e. Study 2). Through thematic analysis we identify potential determinants of axSpA patients' self-tracking adherence such as condition severity, relevance of data and routinisation. We discuss design implications in the context of another study which directly investigated axSpA patients' self-tracking adherence from a quantitative perspective. The work of this chapter helps delineate the reality of self-tracking data collection in the axSpA context, allowing us to determine its the practical value and viability in the context of patient care provision.

Chapter 5 - Patient Perspectives on the Collaborative Use of Self-Tracking Data

The chapter examines patient perspectives on the collaborative use of self-tracking data in the clinical context through a survey and interview study (Study 3), covering patient expectations, priorities and concerns with regard to using and discussing data with healthcare providers, therefore addressing RQ3. We conduct follow-up interviews with respondents who had experience in sharing or discussing data with providers to elaborate and contextualise topics identified through thematic analyses of survey responses. The study uncovers the motivations behind patients' decisions to share self-tracking data with providers, as well as reasons for withholding them. It also acknowledges and contextualises known issues associated with patient-provider collaboration around self-tracking data.

Chapter 6 - Collaborative Use of Self-Tracking Data in Realistic Clinical Scenarios: A Qualitative Exploration

In Chapter 6, we present the CoUs-axSpA study which investigates the collaborative use of self-tracking data during routine check-up appointments. We invite axSpA patients who self-track consistently via the uMotif app to discuss data in-person with their consultant rheumatologists. We evaluate value added to the provision of patient care from both patients' and providers' perspectives through questionnaires and interviews, addressing RQ4 in the process. The results see the value of discussion takes form in patients' improved understanding of their conditions and self-management practices.

Transcripts of post-study interview with the provider reveal several practical challenges associated with the discussion. We discuss how the use of self-tracking data align with existing clinical activities and its design implications.

Chapter 7 - Conclusion

In the final chapter, we discuss main findings of this thesis, its contributions to self-tracking research and its broader impact on the healthcare community as well as potential future work.

Chapter 2

Literature Review

2.1 Chapter Overview

In this chapter, we review and discuss relevant PI and self-tracking literature from the domains of HCI and healthcare research. The work reviewed in this chapter constitutes the theoretical foundation of the topics explored in this thesis and provides readers a fundamental understanding of PI and self-tracking technology, self-tracking motivation and behaviour which is relevant to our investigations of patient-provider collaboration surrounding self-tracking data in the clinical context. We identify knowledge gaps in the current literature regarding the clinical use of self-tracking technology and data on which underpin our research questions.

2.2 Modelling Personal Informatics

Reviewing the theoretical frameworks which laid the groundwork for recent investigations of the use of PI and self-tracking data in healthcare could help us understand the aims and processes of self-tracking, its general challenges as well the underlying technology which shapes the way users collect and consume data. As defined in section 1.2.1, PI broadly refers to a class of systems that collect and/or analyse personally relevant information for the purpose of self-reflection and the acquisition of self-knowledge. We believe the use of the word "system" could be interpreted in two ways, either as the *method* or the *process* of obtaining self-knowledge in an organised manner or *computer systems* which aggregate personal data to facilitate said processes. Modelling how PI works as a method of acquiring self-knowledge helps us understand the various activities involved, providing structure to what is otherwise a vaguely defined topic. This

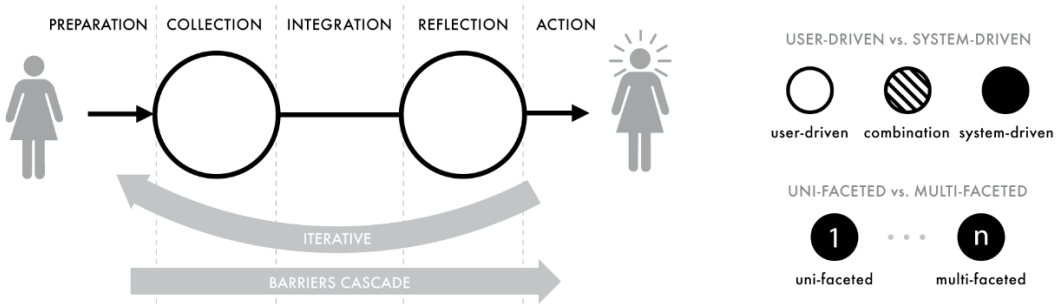


Figure 2-1: Stage-based personal informatics model [Li et al., 2010]

allows researchers to partition PI into smaller chunks or stages where in-depth research could be carried out to investigate the purpose, opportunities and challenges associated with each individual stage of activity.

2.2.1 Stage-Based PI Model

One of the best known PI model is the stage-based model devised by [Li et al., 2010], consisting of five stages of iterative activities: *preparation*, *collection*, *integration*, *reflection* and *action* (as shown in Figure 2-1).

The *Preparation* stage is the first stage of a data collection cycle. Users will determine the type of information to be collection based on their motivation (see section 2.3.1) as well as how the information will be recorded (see section 2.4.2.1), e.g. objectives, data categories and collection methods. General collection strategies will be considered at this stage, e.g. collection frequency and duration.

The *Collection* stage concerns the practical process of gathering and storing personal information as determine by the preparation stage.

The *Integration* stage is a transition stage where the collected information is prepared and transformed to into formats that are easier to understand, therefore helping users to make sense of the data. The degree of transformation could vary depending on the PIS. Examples of information transformation include: data aggregation, data cleansing and quality assurance, statistical analyses, data visualisation, natural language feedback generation etc.

The *Reflection* stage is where users review the transformed data and attempt to acquire data insights. This could refer to making sense of the knowledge prepared by the system during integration, i.e. summary, interesting statistical insights. Alternatively, users may extract new information from the transformed or unprocessed data by themselves

or with the help of the PIS, i.e. interactive features that facilitates sensemaking.

The last part of this iterative model is the *Action* stage, where users determine their actions in response to the insights they acquired from the reflection stage. Some PISes were designed to inform and help users to take actions, e.g. alerts, suggestions, notifications. If the user decides to continue self-tracking, the stages of activity will repeat itself as user starts with collection once again.

2.2.1.1 User Driven vs System Driven

Each stage or activity in the model can be led by users (i.e. user-driven), the computer system (i.e. system-driven) or a combination of both. The stage and magnitude in which the PIS contributes to may various depending on the design of the software. Li et al. [2010] argued that people who self-track using conventional data collection methods (e.g. paper journaling and disease diary) are more likely to engage in user-driven analysis of the data unless the data is digitised first. A great number of fitness trackers, especially smartphone health apps such as MyFitnessPal [MyFitnessPal, 2022], allow custom entries to be added to the default list of trackable data categories, blurring the line between user and system-drive data collection. This dichotomy between user-driven and system-driven designs opens up many new possibilities in the design space of PISes. Depending on the context of self-tracking (e.g. fitness, healthcare), designers of PISes needs to choose the degree in which computer systems guide PI activities in their respective stages, i.e. whether computer systems should take full responsibility of transforming data and producing insights. Meanwhile, arguments could be made that user-driven reflection may help self-trackers internalise and memorise new knowledge. Regardless, it is worth developing features which could potentially facilitate activities such as data collection, reflection and action by reducing users' mental burdens (e.g. sensemaking difficulties and memory-related issues).

2.2.1.2 Cascading Barriers

Li et al. [2010] pointed out that potential barriers and hindrances exist at each stage of the model and that such barriers will cascade onto the following stage if left unaddressed. These barriers may be associated to any activities including data collection (e.g. time commitment), integration (e.g. difficulties with data exporting and formatting), reflection (e.g. sensemaking challenges) and action (e.g. target-achieving challenges). Over time, unresolved barriers may accumulate and lead to user frustration, lapsing and even abandonment of self-tracking all together. Therefore, it is important that we evaluate the impact of potential barriers associated with PI activities in the

healthcare context, hence generating relevant design implications for PISes. We discuss known barriers associated with health-oriented self-tracking in section 2.6.3.

2.2.2 Lived Informatics Model

The stage-based activity model represents a major development in PI theory and laid the foundation for future PI modelling work. Soon after that, Li [2011] created a refined version of the model by breaking down the reflection stage into *maintenance* and *discovery* in order to better represent the tracking behaviour of different user types (e.g. goal-achieving, exploring the technology). Epstein [2015] later revisited the stage-based model, proposing many changes based on the behavioural paradigms of self-tracking individuals, suggesting that activities in the original stage-based model may occur concurrently and/or out of order. In addition, users may alter their choice of self-tracking tools, lapse and resume tracking due to a variety of reasons, e.g. usability issues, achieved targets, life events. Furthermore, Epstein [2015] highlights the importance of recognising the difference between instrumental users (i.e. people who self-track to achieve certain goals) and curiosity-driven users (i.e. people who are intrigued by self-tracking), as tracking habits and behaviours may vary drastically depending on users' tracking motivation. For example, curiosity-driven users may skip the action stage completely after reviewing their self-tracking data whereas instrumental users are more likely to produce action plans based on the insights acquired. Individuals may decide to engage in self-tracking behaviours for a variety of reasons. We discuss tracking motivations and their implication further in section 2.3.1. For the above reasons, Epstein [2015] proposes the lived informatics model which updates the stage-based activity model by incorporating the behaviours and lived experience of self-tracking individuals (e.g. lapsing and resuming).

The new model divides the preparation stage from the original into two activities: deciding to track and selecting tools. *Deciding to Track* - where an individual contemplates a self-tracking project in order to determine whether or when to start tracking. *Selecting Tools* - once the individual has decided to track, they need to select a self-tracking tool. This process may take more or less time depending on the individual's previous tracking experience and tracking motivation. For example, while a new self-tracker may struggle to decide on the tools they should use for the intended purpose of tracking, a former self-tracker who is resuming may spend significantly less time on that decision. While information needs play a major role in users' choice of self-tracking tools, other factors such as fashion aesthetics, price and convenience could also influence the decision [Epstein, 2015]. *Tracking & Acting* - the cycle of collection, reflection

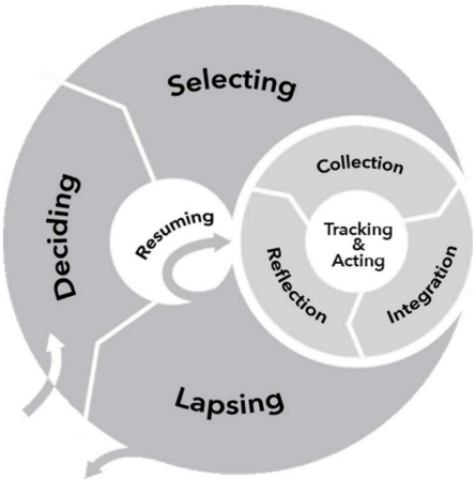


Figure 2-2: The lived informatics model [Epstein, 2015]

and action where activities are closely intertwined. Though it share the basic flow of as the original stage-based model (i.e. collection, integration, reflection and action), activities can and will happen concurrently and/or out-of-order. *Lapsing* occurs when a self-tracker temporarily or permanently stops using their self-tracking tool(s). Lapses may occur for a variety of reasons (e.g. forgetting, upkeep, skipping, suspending), linking back to the cascading barriers associated with the stage-based model. *Resuming*: a user may resume tracking after the barriers expire or are resolved. Depending on the duration of the lapse, users may have to revisit their decisions to track and tool selection.

The lived informatics model incorporates the everyday tracking habits of self-tracking individuals, adequately reflecting the average user's decision-making process regarding "when to track" and "how to track". The model provides context for further investigations of factors which may contribute to individuals' tracking adherence and engagement.

2.3 Self-Tracking Motivation

2.3.1 Tracking Motivation

People engage in self-tracking behaviours for many reasons as their tracking motivation may vary even among those who use the same devices to track similar data categories. The diversity in tracking motivation may contribute to different user expectations and tracking styles. By examining users' self-tracking motivations, we may

better understand factors which could determine tracking adherence and engagement, thereby addressing issues such as lapses and abandonment caused by negative tracking experiences. Rooksby et al. [2014] described five categories of self-trackers based their reasons for tracking, i.e. motivation:

Directive Tracking occurs when the user's main objective for self-tracking is to achieve certain targets, e.g. weight loss, step counts, screen time and sleep duration. These goals are often help promote behavioural changes in users as they keep tracking of their progress. Directive users are intrinsically motivated, although the targets they choose to focus on may be derived from external sources, such as clinician recommendations (i.e. pushed self-tracking [Lupton, 2014]) and reason related to social comparison (i.e. socially motivated self-tracking [Murnane et al., 2018]).

Documentary Tracking occurs when the user's self-tracking practice is driven by the self-documentation of activities and lifestyle, rather than personal goals. Individuals who engage in documentary tracking may be motivated by a variety of reasons, including the need for self-assertion, curiosity and interest in self-understanding, e.g. *"how much exercise do I usually do?"*, *"what puts me in a good mood?"*. The duration of documentary tracking depends on the user's perceived value in the continuation of self-tracking after their initial curiosity is satisfied.

Diagnostic Tracking describes a style of tracking where the user focuses on collecting and reflecting on personal health data to gain knowledge related to one's health status or conditions. This type of self-tracking focuses on finding and understanding underlying correlations and patterns (e.g. symptoms triggers) across several data categories, e.g. physical activity, disease activity and medication.

Rewards Collecting is another style of tracking where users engage in the practice of self-tracking to receive monetary or psychological rewards. Examples include participants who are financially motivated to take part in self-tracking studies as well as fitness trackers who enjoy the social recognition from peer self-trackers.

Fetishised Tracking is defined here as a type of tracking where the user self-track to make themselves feel or look good, due to pure interest in the appeal and functionality of the gadgets and technology [Ayobi et al., 2017].

Epstein [2015]'s work highlights how tracking motivation may contribute to users' self-tracking habits and behaviours, such as tracking frequency, duration, lapses and continuation. For example, people who are motivated by behaviour-changing goals may track more frequently than curiosity-driven users. In addition, users' tracking motiva-

tion may consists more than one of the tracking styles above, and may evolve and change over time. It's important to understand the underlying drivers of users' self-tracking behaviours when designing PIS features. Researchers have started to investigate how PISes could be designed to facilitate users in achieving self-tracking goals as dictated by on their tracking motivation or style. Niess and Wo [2018] suggest that users' self-tracking goals are manifestations of their hedonic & eudaimonic needs, which can be either quantitative or qualitative in nature. They argue that in order to keep users engaged in self-tracking, PISes need to facilitate users' reflection of their progress by showing how the achievement of quantitative targets contributes to qualitative goals over time. Recent work in the domain of healthcare and PI investigated the use of directive and goal-directed self-tracking in the context of chronic conditions, e.g. Migraine [Schroeder et al., 2019], revealing potential roles of PISes in supporting the achievement of self-management goals and evaluation of treatment. We investigate patients' tracking motivations in the context of chronic conditions and axSpA in Chapter 4 in order to understand the factors which may influence self-tracking engagement as well as how PISes could be designed to support patients in achieving their own self-tracking goals.

2.4 Multifaceted Self-Tracking and Tool Selection

Self-trackers' information needs are largely determined by their tracking motivations. For example, a diagnostic tracker needs to collect data that is specific to their health conditions. Their choice of self-tracking tool(s) therefore depends on whether it satisfies the information needs of the user [Li et al., 2010]. In the context of chronic conditions, the information needs of self-tracking patients are often complex and multifaceted [Chung et al., 2016b, Schroeder et al., 2017]. Furthermore, tools which don't meet the user's information needs alongside usability issues may reduce self-tracking engagement and lead to lapsing and abandonment [Li et al., 2010, Epstein, 2015]. In this section we review and discuss work related to the data ecosystem of PISes and factors which contribute to users' selection of self-tracking tools, so that we can better understand their self-tracking behaviours.

2.4.1 The Multifaceted Approach to Self-Tracking

The term "personally relevant information" which is commonly used to define PI and its related concepts, very vaguely describes the type of data that is of concern to PI and self-tracking research. The term may refer to a broad spectrum of data generated from multiple facets of people's lives such as physical and mental health, financial activities,

social status and life events. While most self-tracking tools on the market specialise in tracking singular facets of a person's life, e.g. physical activities [Li et al., 2010], some PISes are capable of aggregating and analysing multifaceted data from multiple data sources, e.g. wearables, smartphone apps and websites, e.g. Mobile Health Mashup [Tollmar et al., 2012], Apple Health (previously known as HealthKit) [Apple, 2022a], Exist [Code, 2018, Jones and Kelly, 2018] and BeWell+ [Lane et al., 2014].

These multifaceted PISes give users the ability to manage and analyse various types of personal information in one place, therefore painting a holistic picture of a person's activities [Dingler et al., 2014, Jones and Kelly, 2018]. Multifaceted self-tracking may add value to individuals' PI practices in a number of ways. Bentley et al. [2013a] and Haddadi and Brown [2014] found that the ability to see correlations between different categories of health data resulted in better user engagement. West et al. [2016] and Choe et al. [2014a] suggested that multifaceted self-tracking may also benefit sensemaking and facilitate patient-provider communication. For example, self-tracking data such as symptoms could be misinterpreted by patients and providers if taken out of context. By incorporating other facets of a person's life (e.g. employment status, life events) as data context during analysis, one can acquire a more well-rounded understanding of the data. This multifaceted approach to self-tracking closely resembles the information system which exist in the provision of healthcare, where various types of medical exams and outcome measures contribute to the overall clinical decision-making process. In fact, many patients with chronic conditions have already begun practising multifaceted self-tracking, including the monitoring of their symptoms, medication, body measurement and physical and mental activities [Chung et al., 2016b, Schroeder et al., 2017]. Although patients' tracking motivation may vary from person to person, the data categories that are being tracked can be studied and summarised to understand what is relevant to the patients and our research.

To that end, we briefly review and discuss the taxonomy of data which is commonly collected and used by PISes based on data facets. We produce a summary of common data facets that exist within the data ecosystems of most PISes (see Table 2.1). We focus on 13 data facets and the data categories contained within each facet, alongside their respective data sources. Our summary is aggregated based on the work done by Li et al. [2010], Jones and Kelly [2018], Epstein [2015] and Trace et al. [2017], as each of these studies cover a broad range of data categories which are representative of data collected by general users of wearables and self-tracking apps. Although some data categories such as symptoms, medication, physical and mental activities may seem more directly relevant to axSpA patient care more than others (e.g. finance,

productivity), studies such as Dixon et al. [2019] show that circumstantial data such as weather may still be relevant for discussion. We exclude data categories which are not updated frequently (e.g. name, age, gender, address) and data that is irrelevant (e.g. contact information, log-in detail). This does not include data which is collected and controlled by healthcare providers (e.g. patient health records, medical test results), although they may still be relevant to look at in conjunction with patient self-tracking data. This summary may help readers form a more concrete idea about the concept of "self-tracking data" and its underlying data categories. It also provides context for our efforts in understanding which data categories may be relevant to the treatment and management of axSpA as we investigate it further in Chapter 3.

2.4.2 Tool Selection

2.4.2.1 Categorising Self-Tracking Tools

As we mentioned previously in section 1.2.2, the method or technique of data collection can be broadly divided into two categories: *automatic* and *manual* data collection. [Li et al., 2010] found that automatically collected data, such as data recorded actively by computer devices and software (e.g. wearables, smartphones) and service providers (e.g. banks, utility companies, mobile carriers, social media companies) makes up the majority of data generated by self-trackers. On the other hand, manually or passively collected data which refers to data recorded via user input (e.g. writing by hand, completing rating scales), sometimes falls behind in terms of the rate of collection and ease of use, especially when it comes to integration and reflection. For example, it is difficult to carry out analysis on symptom and medication data recorded through physical medical journals at any scale without transcribing or digitising it first, not to mention the risks related to loss and physical damage. Despite its disadvantages, manual data collection usually offers users more freedom and flexibility regarding the format and detail of the data that can be be recorded, making it technologically accessible and suitable for the collection of qualitative data. There are other ways of categorising PI and self-tracking tools, for example, Trace et al. [2017] and Rapp and Cena [2016] propose a similar way of categorising self-tracking tools based on data-generating agency (e.g. users, computer systems, service providers). However, we focus on the distinction between automatic and manual data collection as discussions of other taxonomies is beyond the scope of this research.

Facet	Data Category	Source
Physical Activities	Steps, distance and duration (e.g. running, walking, cycling etc.), calorie burned, heart rate (during exercise), sleep	Wearable fitness trackers, smartphone health apps, pedometers, training records.
Self-Measurements	Weight, height, blood pressure, blood glucose, bust/waist/hip measurement, body mass index (BMI), mobility test etc.	Smart scales (e.g. Withings [Withings, 2022]), fitness/weight loss apps (e.g. MyFitnessPal [MyFitnessPal, 2022]), medical journals.
Mental Activities	Mood, mental state (e.g. stress), unhealthy thoughts and feelings.	Smartphone apps (e.g. Daylio [Habitics, 2022], MoodKit [Thriveport, 2022]), mood diary.
Symptoms	Pain, drowsiness, nausea, blurred vision, skin irritation, blood pressure hike, panic attacks etc.	Symptom tracking apps (e.g. uMotif [uMotif, 2022], symptom logs.
Medications	Drug/substance intake, adherence to prescription etc.	Medication logs, traceable pills, prescriptions.
Diet	Food/calorie intake, water intake, caffeine intake, alcohol intake, etc.	Web and smartphone applications (e.g. Bowelle [Bowelle AB, 2022]), food journal.
Women's Health	Menstrual cycle, pregnancy, etc.	Women's health apps (e.g. Flo [Flo Health, 2022]), journals
Social Activities	Text messages, phone call history, social media activities (e.g. posts, status updates, likes, shares and retweets)	Downloadable social media history (e.g. Facebook [Facebook, 2022], Twitter [Twitter, 2022]), digital archive, smartphone data (e.g. SMS, phone call history), email provider etc.
Life Events	Achievements, career changes, change in relationship/marital status, moving home, illness, accidents, traumatic events, public opinion, imprisonment etc.	Social media (e.g. Facebook timeline [Facebook, 2022]), diary, blog posts, photo books etc.
Location	Location tags, current location, location history, routes travelled, distance travelled etc.	Social media (e.g. posts, check-ins), navigation systems, smartphone apps (e.g. WhatsApp [WhatsApp, 2022], Google Maps [Google, 2022]), travel logs, journals etc.
Weather	Humidity, temperature, wind speed, precipitation, UV level etc.	Smartphone apps (e.g. WunderStation [The Weather Company, 2022]), weather diaries etc.
Finance	Income, expenditure, tax, transaction history, trading history etc.	Bank statements, utility bills, smartphone apps (e.g. Monzo [Monzo, 2022]), paper/electronic ledger etc.
Productivity	Internet browsing habit, calendar events, screen time, work activities, task completion rate etc.	Browser data (e.g. browser history, cookies, bookmarks), productivity websites/apps, to-do lists, journals.

Table 2.1: Summary of self-tracking data facets

2.4.2.2 User's Choice of Self-Tracking Tools

Self-tracking individuals' choice of tools can have significant impact on their tracking behaviours, effort and data accuracy [Rapp and Cena, 2016]. However, the decision may not always be clear to the users as the market of consumer self-tracking technology is overflowing with choices, ranging from wearables (e.g. Apple Watch [Apple, 2022b], Fitbit [Fitbit, 2022], Samsung Galaxy Watch [Samsung, 2022], Garmin [Garmin, 2022], Fitbug Fitbug [2022]) to smartphone health apps (e.g, Strava [Strava, 2022], MyFitnessPal[MyFitnessPal, 2022], MapMyRun [Under Armour, 2022]), not to mention traditional paper-based tools for tracking (e.g. journaling, exercise log, symptom diary). Furthermore, patients with chronic conditions who desire to engage in multifaceted tracking may find it difficult to have a product that "does it all", as many tools available on the market specialise in single-faceted tracking, such as body measurement and physical activity. Other apps which support multifaceted tracking, such as MyFitnessPal [MyFitnessPal, 2022], often rely on manual data collection as well as data-sharing with third party apps or wearables, raising questions about about their cost-effectiveness.

As previously mentioned, the information needs of self-tracking individuals play an important role in their selection of tools [Li et al., 2010], as tools that are unable to collect data from the facets and categories which users need are likely to be overlooked, abandoned or replaced [Epstein, 2015, Epstein et al., 2016, Li, 2011]. In addition to the collection of primary data, tools which do not provide the secondary data, i.e. data insights, that the users require (e.g. correlations, patterns) are also likely to be rejected [Trace et al., 2017]. Users may resort to using bespoke software and tools when they are unable to find suitable mass-market alternatives. According to Choe et al. [2014a], while most users prefer widely-available wearables and apps, around 21% of the self-trackers surveyed have used bespoke software that is tailored to their information need. In addition, 40% of users surveyed have used spreadsheet to record bespoke data categories.

Additionally, the usability of the self-tracking tool may also contribute to the users' decision. To begin with, the ease of access of the self-tracking device or software may affect users' data-tracking efficiency and readiness, e.g. access to a computer when disease flares up [Li et al., 2010]. Similarly, Vafeiadou et al. [2021] suggest that patients with Parkinson's disease choose their self-tracking tools based on three major criteria: accessibility, flexibility and familiarity. Secondly, the effort of data collection (e.g. time, number of clicks) may have tremendous impact on users' choice of tool [West et al., 2016]. For example, some patients found disease diaries time-consuming and

cumbersome to use [Chung et al., 2016b] despite the value certain clinicians see in the qualitative data that it provides [Chung et al., 2015]. The choice of self-tracking tool(s) sometimes involves a trade-off between information richness and ease of use, as qualitative data collection generally require more effort from the users. On the other hand, although digital self-tracking tools may require routine maintenance and upkeep, e.g. charging, synchronisation [Epstein, 2015, Rooksby et al., 2014], they are still relatively effortless compared to the likes of paper diaries and medical journals. Furthermore, quality of life features such as the ability to set/receive tracking prompts/reminders also contribute to users' choice of tool [Tollmar et al., 2012, Epstein, 2015]. Last but not the least, other factors such as fashion aesthetics and price may also influence users' choice of self-tracking tools [Epstein, 2015].

There is likely no one-size-fits-all solution to tracking health data in the context of chronic conditions. Depending on one's information needs, usability of the tool and other factors such as price and aesthetics, the selection may differ among individual patients. It is important to acknowledge the pros and cons of both physical and digital self-tracking tools. Physical or paper-based self-tracking tools such as spreadsheets, journals, diaries and drawings are widely used by patients and healthcare professionals alike, despite being susceptible to physical damage, theft, loss and degradation over time. As mentioned in section 2.4.2.1, physical self-tracking data can be difficult to store, manage, replicate and analyse. Nevertheless, the accessibility, flexibility, user familiarity of paper-based self-tracking helps it retain popularity among patients with chronic conditions [Vafeiadou et al., 2021, Schroeder et al., 2017].

When it comes to digital self-tracking tools, recent wearable technologies such as fitness trackers and smartwatches offer great portability and are, by and large, less intrusive than conventional heart rate monitors and pedometers. Activity bands like Fitbit [Fitbit, 2022] and Garmin [Garmin, 2022] are particularly good at the continuous tracking physical activities such as steps, pulse, temperature and location. Mobile health apps on the other hand, offer basic automatic tracking (e.g. steps) due to hardware limitations. However, applications may still utilise the processing power and I/O capabilities of smartphones to provide manual data collection features (e.g. e-journal, rating scales), multifaceted tracking and visualisations to support reflection, integration and action.

2.5 Self-Tracking Adherence

As mentioned in the previous section, automatic self-tracking technologies such as wearable devices and sensor-rich smart phones are capable of the autonomous monitoring of

users' physical activities (e.g. exercises, sleep, sedentary lifestyle) and health indicators (e.g. heart rate, blood pressure and glucose levels) [Sanders et al., 2016, Wang et al., 2018, Dohr et al., 2012]. Compared to manual data collection, the use of automatic self-tracking tools require minimal effort and user input, with the exception of the wearing and charging. While automatically collected health data can be useful in the context of chronic conditions (e.g. setting exercise target), the provision of patient care (e.g. diagnosis, prognosis, treatment) often involve data that is predominantly captured through manual input for the time being (e.g. self-reporting of symptoms, medication and lived disease experience). However, consistent manual self-tracking usually require considerable effort and commitment from users compared to the use of wearables devices. From healthcare providers' perspective, poor adherence to self-tracking may undermine the perceived validity of the data, therefore rendering it unsuitable for clinical use [West et al., 2017]. Therefore, it is vital for us to understand the factors which could potentially influence patients' self-tracking adherence in order to determine the value of self-tracking data in the context of axSpA, as well as improve the design self-tracking tools to facilitate consistent tracking.

2.5.1 Self-Tracking Adherence in the Clinical Context

As mentioned in section 2.6.2, self-tracking allows patients with chronic conditions to frequently and routinely monitor their symptoms, medications, physical and mental activities, thus painting a more complete picture of the management and treatment of their conditions. However, inconsistent tracking and poor adherence can lead to fragmentary and sporadic data, therefore undermining its value in the clinical context [West et al., 2017, Tang et al., 2018]. Moreover, users may lose interest in self-tracking over time due to a variety of reasons (e.g. fulfilled curiosity, accomplished goals, lack of useful insights) [Rooksby et al., 2014, Epstein et al., 2015a], resulting in lapses, and eventually abandonment or switching of tools [Clawson et al., 2015b, Cordeiro et al., 2015].

Previous work defines adherence as a measure of data completeness, reflecting how closely users follows a data collection protocol (e.g. recording data a certain number of times over a given time period) [Tang et al., 2018]. However, the threshold of tracking frequency which determines whether a user has been "adherent" over a period of time may vary depending on individuals' self-tracking objectives and information need [Turner-McGrievy et al., 2019, Rooksby et al., 2014]. The determination of adherence threshold will also likely affects the result of the examination of users' self-tracking adherence [Tang et al., 2018].

Previous literature on adherence discussed its importance in the accurate interpretation of longitudinal self-tracking data (e.g. incomplete data may hinder meaningful comparisons of patient health across different time periods) [Tang et al., 2016, 2018]. Poor adherence may undermine the quality and validity of self-tracking data [Trost et al., 2005], rendering it unsuitable as grounds for clinical decision-making [West et al., 2017]. Furthermore, irregular and infrequent tracking may produce data which does not accurately capture users' experience (e.g. missing data entries about symptoms caused by a flare-up of the disease) [Ward et al., 2005]. Moreover, self-tracking tools that fail to capture data which accurately reflects patients' disease experience may erode users' trust in self-tracking technologies [Bentley et al., 2013b].

Previous studies on adherence had focused primarily on the use of automatic self-tracking tools [Quisel et al., 2019, Xu et al., 2018, Doherty et al., 2017, Marin et al., 2019, Yingling et al., 2017, Murnane et al., 2020]. Fewer studies have investigated factors which may affect user adherence with manual self-tracking, such as the use of smartphone apps which allows the routine self-monitoring and self-reporting of symptoms (e.g. Chronic Pain Tracker [Chronic Stimulation, 2022], uMotif [uMotif, 2022]). Other studies highlighted the impact that users' selection of tools may have on tracking adherence, suggesting that wearable trackers foster better adherence in general than manual self-tracking tools which requires more time and effort [Tran and Nathan-Roberts, 2018]. Given that manual data collection (e.g. self-reporting) is still necessary in the context of chronic conditions, namely axSpA, it is vitally important for us to understand the impact of this additional effort on patients' tracking consistency and frequency.

2.5.2 Determinants of Self-Tracking Adherence

Previous studies have investigated factors which may affect users' self-tracking adherence. Doherty et al. [2017] analysed data from 100,000 users who were assigned with a physical activity tracker, revealing a number of predictive factors including age, sex, time of the day and season. However this study doesn't offer insights into factors which may affect adherence with manual tracking. Other studies also produced results which linked adherence to age [Ledger and McCaffrey, 2014, Shih et al., 2015], finding that older adults are much less likely to abandon use of self-tracking tool(s) than younger people [McMahon et al., 2016]. Potential determinants of tracking adherence have also been reported as secondary findings of other studies. For example, users' tendency to lapse or abandon in self-tracking could be influenced by their tracking motivations [Lazar et al., 2015], health goals, physical abilities and live events [Clawson et al.,

2015a]. Furthermore, adherence may also be determined by whether the effort required outweighs the perceived benefits of self-tracking, as well as the mismatch between user expectations and the capabilities of the technology [Epstein et al., 2015a, Clawson et al., 2015a]. In addition, issues related to the usability of the self-tracking tool (e.g. effort of data input, device maintenance and upkeep, comfort of wearing), design aesthetics as well as compatibility with the user's lifestyle or self-image have all been linked to adherence [Epstein et al., 2015a, Fadhil, 2019, Lazar et al., 2015].

Determinants of adherence have also been reported in research related to Ecological Momentary Assessment (EMA), a method for collecting data on subjects' current behaviours and experiences in real time and in their natural environments [Shiffman et al., 2008], such as activities, emotions or other elements of their daily life [Van Berkel et al., 2017, p.3]. Much like the use of manual self-tracking tools, EMA requires users to enter their data manually after receiving a prompt (e.g. reminder, push notification) [Van Berkel et al., 2017]. Moreover, poor adherence to the collection of EMA data also may undermine data analysis. Studies relating to EMA identified numerous factors which may affect adherence, including age [Rintala et al., 2019], gender [Sokolovsky et al., 2014], time of the day [Ramsey et al., 2016] and user's location [Boukhechba et al., 2018, Rintala et al., 2020]. Recent studies on the use of EMA in the monitoring of the lived experience of patients with chronic conditions found that patients had lower adherence than healthy control group [Gershon et al., 2019, Rintala et al., 2019]. Furthermore, Gershon et al. [2019] revealed a potential link between the debilitating influence of health conditions (e.g. condition severity, suicidal attempts) and adherence. EMA research to date revealed a range of potential factors which may influence adherence of self-tracking in similar ways. Yet direct investigations into users' manual self-tracking adherence is still lacking, especially in the context of chronic conditions and axSpA.

2.6 PI and Self-Tracking in the Context of Chronic Conditions

2.6.1 The Rise of PI and Self-Tracking Technology

As mentioned in section 1.2.1, self-tracking can be defined as the process of gathering information that is related to any aspects of a person's life, e.g. personal health, financial status and social activities etc. A personal informatics system builds on top of the practice of self-tracking by organising and curating the data collected, and transforming it into self-knowledge [Li et al., 2010]. Today, PI and self-tracking are often associated

with the use of wearable devices and mobile health technologies. Nevertheless, the practice of collecting personal information for the purpose of self-reflection had been around long before the invention of the first wearable computer in 1955 [Thorp, 1998]. Individuals have long been using bookkeeping tools (e.g. account books and ledgers) to record and manage their personal finance, such as setting budgets to control spending [Nissen et al., 1993]. Personal diaries have been used to facilitate reminiscence and self-reflection through the externalisation of one's thoughts and memories [McCarthy, 2000]. Daily planners and target-setting tools grew hugely in popularity in the 18th century following the industrial revolution, allowing people to manage their productivity [Franklin, 2010, McCarthy, 2013]. In healthcare, symptom diaries and medication journals are still widely used by providers and patients to monitor disease progression and management [Hodge, 2013]. For a very long time, people relied on the use of physical tools, such as paper based diaries, bullet journals and spreadsheets for the recording of personally relevant information and self-reflection. However, despite their flexibility and accessibility, physical self-tracking tools are highly limited with regard to the efficiency of data collection and ease of data analysis, not to mention that they are also susceptible to physical damage and loss.

Over the years, self-tracking tools have drastically improved in terms of their efficiency and accuracy with regard to data capturing. Notably, the arrival of digital technology have transformed the way self-tracking is practised in the modern context. First of all, personal computers, sensor-rich wearable devices and smartphones enabled the automatic and real-time collection of one's physical activity data (e.g. heart rate, steps, sleep, GPS location) as well as digital traces (e.g. browser history, transactions, screen time). Secondly, PISes such as smartphone health apps (e.g. Fitbit [Fitbit, 2022], Apple Health [Apple, 2022a]) featuring user-friendly interfaces has improved the efficiency of manual data collection, e.g. self-reporting of symptoms, recording of expenses. In addition, many PISes offer features such as data analytics and visualisations to facilitate users' self-reflection [Li et al., 2010]. Thanks to the global success of consumer wearable technology and smartphone apps, self-tracking transitioned from being a niche hobby of gym-goers [Feng et al., 2017], data-enthusiast [Boll et al., 2016] and quantified-selfers [Choe et al., 2014b] to the mainstream phenomenon that we see today [Consumer Technology Association, 2016, p.130].

Though PI and self-tracking may cover a wide variety of topics, ranging from personal finance to productivity, fitness and well-being has become arguably one of the most popular and well-known examples of self-tracking, as data produced by wearable devices often relate to personal health and medical issues. A recent report suggest that use of

digital health apps, such as symptom diaries and mood trackers drastically increased since the global COVID-19 pandemic in 2020 [ORCHA, 2021], indicating a shift of user focus from fitness to overall mental and physical health. Furthermore, adding to a wide range of sensor-rich self-tracking devices which collect data (e.g. exercise, sleep and weather), a great number of health apps have been developed for the purpose of the monitoring and management of chronic conditions, (e.g. Chronic Pain Tracker [Chronic Stimulation, 2022], My Pain Diary [DamoLab, 2022], uMotif [uMotif, 2022], Flaredown [Flaredown, 2022]), allowing the collection of patient-generated data such as symptoms and medications. This led to a massive boom in use of self-tracking technology amongst people who suffer from chronic health conditions, thus producing an enormously amount of health data that is potentially valuable to health research.

2.6.2 Self-Tracking Research in the Context of Chronic Conditions

Research on the use of PI and self-tracking technology in the context of healthcare and chronic conditions to-date has focused on three areas: *medical research* [Dixon et al., 2019, Sohda et al., 2017], *patient self-management* [Meyer et al., 2017, Davies et al., 2019, Raj et al., 2017b] and the *provision of patient care* (e.g. diagnosis, prognosis and treatment) [Murnane et al., 2018, Zhu et al., 2016]. First, the use of self-tracking technology by patients and the data it produces may be used in medical research. Studies have revealed that the analysis of patient self-tracking data on a cohort level could provide data insights which may help address long-standing questions regarding chronic conditions and develop new understandings around public health. For example, the Cloudy with a Chance of Pain study analysed 2658 patients' self-tracking data, revealing statistically significant relationships between pain and relative humidity, pressure and wind speed [Dixon et al., 2019]. Similarly, [Sohda et al., 2017] analysed 7043 females' menstrual and ovulation data recorded through a smartphone health app, revealing numerous statistically significant correlations related to the lengths of menstrual cycle, follicular phase and luteal phase which led to improved ovulation prediction. Both studies took a predominantly quantitative approach towards the analyses of patient self-tracking data on a cohort level, focusing on potential correlations between various data facets such as condition severity, stages of menstrual cycle and weather. In the context of axSpA, Barnett et al. [2020] identified various flare patterns among patients using self-reported symptom data though the uMotif self-tracking app. Despite the value of the statistical analysis of patient self-tracking data on the cohort level, this thesis will not directly investigate its usage in medical research. Nonetheless we will draw attention to the importance of relevance of medical research enabled by patient self-tracking in later chapters as part of the discussions of research findings.

The second area of research concerns patients' use of self-tracking technology and self-tracking data in the self-management aspects of their health conditions. The practice of self-tracking allows patients to closely and routinely monitor different aspects of their health conditions such as disease activity, medication and exercise, therefore providing grounds for self-reflection [Meyer et al., 2017]. Recent studies suggest that many patients have begun integrating self-tracking into their daily self-management routines. [Davies et al., 2019] found that use of smartphone health apps among chronic fatigue syndrome (CFS) patients can help them understand healthy physical limits, support the routinisation of self-management practices and cope with mental health problems. [Vafeiadou et al., 2021] found that patients with Parkinson's disease used self-tracking data to identify side effects of medications as well as capturing and verifying disease experience. The work done by [Raj et al., 2017b] showed that self-tracking allowed patients with type 1 diabetes to better evaluate the efficacy of various self-management practices (e.g. medication and exercise), addressing questions such as what actions would alleviate condition flare-ups more effectively, and what would cause the worsening of disease activities. Ayobi et al. [2017] investigated how multiple sclerosis (MS) patients use self-tracking technology to benefit self-care, achieving similar results which include: identifying and understanding symptom triggers, maintaining physical abilities, promoting healthy behaviours and coping with emotional impact of MS. Similarly, Swendeman et al. [2015] highlighted the therapeutic benefits of self-tracking for HIV patients, such as self-expression for catharsis, non-judgemental disclosure and in-the-moment support. Other studies examined the potentially negative impact of self-tracking on patients' self-care, such as being frequently reminded of one's health conditions as well as the burden of consistent self-tracking in terms of time and effort [Ancker et al., 2015, Vafeiadou et al., 2021, Swendeman et al., 2015].

This line of work also focuses the creation of patient mental models in regard to tracking behaviours (e.g. adherence [Jones et al., 2021]), motivation and goals [Schroeder et al., 2018] as well as use of self-tracking technology in various aspects of self-management, such as symptoms prioritisation [Davies et al., 2019], habituation and sensemaking [MacLeod et al., 2013, Mamykina et al., 2017]. Furthermore, research is being carried out to explore the value of self-tracking technology in the education of patients with rheumatic diseases, specifically during self-management intervention courses [Azevedo et al., 2015]. To sum up, this area of research helps us understand outpatients' perspectives on the use of self-tracking technology in the daily management of their conditions, providing necessary context for our investigation into the clinical use of self-tracking data.

The third area of PI and self-tracking research in context of chronic conditions relates to the clinical use of self-tracking data, specifically in the provision of patient care (e.g. diagnosis, prognosis, treatment). This is also sometimes known as *"clinical self-tracking"* [Piras and Miele, 2017] or *"diagnostic self-tracking"* [Karkar, 2018]. The clinical use of self-tracking data involves healthcare providers' examination of the data which typically occurs around or during clinical encounters with patients (e.g. check-up appointments and hospital ward rounds) [Gobat et al., 2015]. In result, discussions may take place between patients and providers who are both trying to make use of the self-tracking data. Recent research on the collaborative use of patient self-tracking data identified several benefits and challenges associated with the co-interpretation of self-tracking data, including but limited to the areas of diagnosis, treatment planning and self-management [Chung et al., 2015, 2016b, Mentis et al., 2016]. First, patients trying to analyse data independently often encounter sensemaking challenges such as information overload, unfamiliarity with data, lack of disease expertise and inadequate tools for analysis, therefore preventing patients from fully comprehending the data and acquiring actionable insights [Choe et al., 2014b, Jones and Kelly, 2018, Raj et al., 2017b]. Research suggests that the co-interpretation of self-tracking data between patients and health experts could help address some of these challenges [Chung et al., 2016a, West et al., 2016]. For example, while providers contribute to the interpretation of self-tracking data by offering their expert knowledge of the condition, patients are often able to provide contextual information about their lived experience and life events, thus leading to more accurate analysis and decision-making [Raj et al., 2017b]. Moreover, studies which directly observed the interactions between patients and providers revealed that discussions around self-tracking data may help reveal hidden problems in the management of the disease and therefore inform treatment decisions, whereby data insights are transformed into meaningful course of actions and targets [Mentis et al., 2017]. However, due to the limited time allowed for data interpretation, i.e. 10 minutes, participants of Mentis et al. [2017] were only able to analyse the data on the surface level, e.g. identifying outliers. Therefore, further study which allow more time for deeper analysis of patient self-tracking data is required for us to fully understand the clinical value of said data. Meanwhile, exploration of technologies which support patient-provider interactions around self-tracking data has revealed the promising potentials of tools, such as visualisations and visual highlights, in overcoming sensemaking challenges related to self-tracking data [Schroeder et al., 2017, Ayobi et al., 2017, 2018]. Additionally, studies have suggested that positive experiences in collaborations around self-tracking data may contribute to better patient-provider relationships and the development of mutual trust [Schroeder et al., 2017], thus improving patients' self-tracking

engagement and openness to future discussions. Further investigation into the clinical use of self-tracking data could help us improve the provision of individual patient care. However, many issues related to the real-life use of self-tracking data in the clinical setting have yet to be fully addressed. We discuss some of these issues in the section 2.6.3.

2.6.3 Challenges Surrounding Clinical Use of Self-Tracking Data

Despite the many potential benefits that patient-provider collaboration brings, investigations into the clinical use and discussion of self-tracking data thus far have produced mixed results. Some studies suggest that patients who shared self-tracking data with their providers reported feeling dissatisfied with the feedback they received, attributing it to the lack of engagement and dismissive attitudes [The Robert Wood Johnson Foundation, 2014, Murnane et al., 2018]. There are several potential explanations for this, ranging from providers' perception of patient self-tracking data to situational constraints such as the lack of training and limited consultation time. To begin with, studies which investigate provider perspectives on the clinical use of self-tracking data suggested that, despite the overall curiosity and optimism about the technology, providers hold widespread scepticism about the relevance, quality and integrity said data [West et al., 2016, Zhu et al., 2016, West et al., 2018]. More specifically, issues such as the use of non-standardised devices and adherence problems contribute to providers' lack of trust in self-tracking data [Chung et al., 2015, West et al., 2016, 2017]. Some providers also believe that patients may selectively disclose information for specific purposes, such as acquiring prescription drugs and access to physiotherapies, while others question the clinical rigour of patient self-tracking data compared to validated outcome measures such as blood tests, x-ray and MRIs [West et al., 2016, 2017].

Secondly, providers expressed worries about their unfamiliarity with patient self-tracking data as well as lack of training on how to use them, which discouraged them from using and discussing it with patients [Chung et al., 2015, Zhu et al., 2016]. Other studies suggest that pre-established clinical workflows can sometimes limit the opportunity for patient-provider collaborations, whereby providers struggle to fit the discussion about self-tracking data in with their usual clinical responsibilities [Chung et al., 2015, Zhu et al., 2016, West et al., 2016, Hue et al., 2019]. In addition, collaborative use and discussion of self-tracking data may suffer from differing priorities and interpretation criteria between patients and providers [Raj et al., 2017b, West et al., 2016, Zhu et al., 2016]. For example, some patients may have the tendency to ignore and rationalise data outliers (e.g. atypical blood glucose levels) which could be otherwise alarming in

the eyes of the providers, and instead focus on observations based on their subjective experiences. Such differences can be exacerbated by the knowledge gap between patients and providers with regard to disease expertise and data analysis as well as time limitations imposed by rushed appointments [Hue et al., 2019].

Furthermore, patient-provider dynamics during co-interpretation of self-tracking data may also have direct impact on the outcome of the discussion. Mentis et al. [2017] analysed the conversations between nine patients with Parkinson's disease and their neurologist at the end of a four-week study where patients wore smart sensors consistently. Their findings suggest that during the co-interpretation of self-tracking data in the context of Parkinson's disease, patients and providers engage in a "view-crafting" process where data in transformed into insights which are relevant to the provision of care, e.g. diagnosis, treatment planning. Mentis et al. [2017] suggest that during this process, providers often have more control over the interpretation of the data, using non-verbal cues to deliberately guide the attend of patients towards data points where they deem more relevant. Although the methodology used in Mentis et al. [2017] allowed researchers to observe patient-provider dynamics during co-interpretation of self-tracking data, the appointments for scheduled for the sole purpose of discussing said data, disregarding other activities which normally occur during clinical visits, (e.g. medical examinations and treatment planning), thus raising questions about the real-life applicability of the findings. Similar to [Mentis et al., 2017], past studies which investigate the collaborative use of self-tracking data were often set in artificial scenarios which exist outside of the standard healthcare procedure, where participants were usually given sufficient time to explore and discuss the data with minimal interference or the added pressure of existing clinical tasks (e.g. [Chung et al., 2016a, Schroeder et al., 2017]). Since most clinical encounters are typically led by providers who usually take a "checklist" approach to consultations [Crampton et al., 2016], the added task of interpreting and discussing self-tracking data may come at the cost of the patients' interest and data-using priorities, e.g. concerns, wishes, requests and goals patients may have during clinical encounters [Gobat et al., 2015]. It is important to understand patients' agenda with regard to the collaborative use of self-tracking data since failure to address it may demotivate patients who have shared their data, leaving them dissatisfied and therefore less likely to engage in the sharing and collaborative use of self-tracking data in future clinical encounters [Ospina et al., 2019]. In result, practical challenges associated with the clinical use of self-tracking data as mentioned above have scarcely been addressed in research. Furthermore, due to the lack of research set in real-life clinical environments, it is unclear what actual value the collaborative use of self-tracking data between patients and providers may bring to the provision of care

and patients' understanding of the condition as well as their data. This thesis aims to address this gap in the literature and investigate how patient self-tracking data could realistically be used in the clinical setting.

Another potential challenge surrounding the clinical use of self-tracking data is the lack of clarity in regard to patients' perspectives on the collaborative use of said data. Previous studies which investigated provider perspectives on patient self-tracking data revealed numerous expectations and concerns which providers may have with regard to using and discussing self-tracking data during clinical encounters [Zhu et al., 2016, Chung et al., 2015, West et al., 2016, 2017, 2018]. This includes the telemonitoring of patients' disease activities and self-management behaviours to support diagnosis and the evaluation of treatments, understanding patient preferences to provide treatment tailored to individual needs as well as promoting accountability with regard to patients' adherence to treatment plans [Chung et al., 2015]. For example, West et al. [2016] used a series of semi-structured interviews to capture the opinion of primary and secondary care providers in regard to the use and discussion of self-tracking data shared by fictional patients using written vignettes, rather than real patients. While studies like these allow researchers to focus one type of users at a time and are generally easier to set-up, patients' expectations and concerns regarding the use and discussion of self-tracking data have remained relatively vague in result. Previous research which investigated patient perspectives on the clinical use of self-tracking technology and self-tracking data focused largely on the self-management aspect and usability-related issues (e.g. [Schroeder et al., 2018, Fausset et al., 2013, McMahon et al., 2016]). Details about the patients' expectations for how self-tracking data should be used and discussed by providers during clinical encounters are still lacking, including patients' priorities, desired outcomes and concerns regarding the collaborative use of their data. Previous research suggested that one of the concerns patients had with regard to sharing and discussing self-tracking data with providers is linked to privacy and perceived relevance, whereby patients may withhold information from providers which they deem overly sensitive or unrelated depending on the goal of their clinical visit [Lim et al., 2016, Lavallee et al., 2020]. It is important that we understand the goals and expectations patients have with regard to the sharing of self-tracking data so that time and resources could be allocated more efficiently to satisfy the needs of both providers and patients during clinical visits.

Chapter 3

Potential Roles of Self-Tracking Data in the Clinical Context and Provider Perspectives

3.1 Chapter Overview

In this chapter, we investigate how patient self-tracking data could potentially be integrated into clinical scenarios to add value to the provision of care, with the aim of addressing **RQ1: What roles could patient self-tracking play in real-life clinical scenarios?**. We achieve this by conducting a two-part field study (Study 1) set in real-life clinical encounters between axSpA patients and providers, namely consultant rheumatologists. This include the observation of routine axSpA check-up appointments and post-study interviews with healthcare providers. The results from the study provide a structural model of the clinical processes involved in axSpA patient care, as well as a practical understanding of the data ecosystem which exists in the clinical environment. We propose potential ways in which patient self-tracking data could be used during clinical encounters to add value to the provision of care for axSpA patients: *supporting agenda setting*, *supplementing patient-reported evidence*, *providing a platform for collaborative decision-making*, and *facilitating realistic goal setting*, hence providing further validity to the topic of this research.

3.2 Refinement of Research Question

As we pointed out in Chapter 2 (section 2.6.3), research set in the domain of self-tracking and chronic conditions has frequently been carried out in artificial data-using scenarios which do not accurately reflect the standard provision of patient care (e.g. Mentis et al. [2016], West et al. [2016], Schroeder et al. [2018]). Consequently, practical obstacles to the clinical use of patient self-tracking data caused by time constraints and pre-established procedures could not be effectively addressed, due to the lack of structural understanding of the clinical workflow. However, patient-provider collaboration (e.g. co-interpretation and discussion) is crucial to the clinical use of self-tracking data due to reasons mentioned in section 2.6.2, e.g. providing data context, addressing sensemaking challenges. Nevertheless, research has yet to clearly identify suitable scenarios or opportunities for collaborative use of self-tracking data between patients and providers to take place. It is important for us to acquire structural understanding of process of axSpA care provision, so that we could identify suitable opportunities for the collaboration to take place in real-life clinical scenarios. Furthermore, to understand how self-tracking data could add value to axSpA patient care, we also need to understand the major data categories (e.g. medical exams and outcome measures) that is currently used by axSpA professionals. RQ1 is therefore broken down into two secondary research questions: **RQ1a: What processes/activities does the provision of care for axSpA involve?** and **RQ1b: What types of data are typically involved in axSpA patient care?**

3.3 Study 1 - Understanding the Clinical Context of axSpA Patient Care: Overview

Study 1 is a qualitative exploration of the clinical context of axSpA patient care which centres around routine check-up appointments between patients and their healthcare providers, consultant rheumatologists in most cases. The study consists of on-site observations of routine patient check-up appointments and semi-structured interviews with healthcare providers. Study 1 aims to address RQ1a and RQ1b by painting a high-level picture of the processes and activities involved during, before and after the check-up appointments as well as the data ecosystem which exists within the scope of axSpA patient care. This will help us identify potential roles patient self-tracking data could play in the clinical context as well as some of the challenges associated with them.

3.4 Method

We use a field study combining a series of on-site observations and semi-structured interviews with healthcare providers to investigate RQ1a and RQ1b, as this provides the flexibility and richness of information required for obtaining structural understanding of axSpA patient care. We received permission from the Royal National Hospital for Rheumatic Diseases (RNHRD) in Bath and the university to sit in and observe two major components of the axSpA care process, namely *routine outpatient check-up appointments* and *hospital ward rounds* (i.e. clinician reviews involving inpatients enrolled in an axSpA rehabilitation course). Check-up appointments and clinician reviews are crucial parts of the care provision process in the context of axSpA, typifying the healthcare pathway of most chronic diseases. It is also during these 15-20 minutes clinical encounters where most patient-provider communications take place.

The study took place over a 6-month period, including three observational sessions set during check-up appointments and one observational session set during clinician reviews following the rehabilitation course (Mean duration = 16.5 mins, range = 11-27 mins). These observational sessions were not audio-recorded due to ethical constraints regarding patient privacy. This was to ensure that both patient and provider participants feel comfortable during their discussions. Instead, we used field notes noted by the researcher [1] to capture the events of the clinical encounters as well as the topics and types of clinical data that were discussed (see Appendix A). We then created affinity diagrams to analyse the notes without a predetermined coding scheme. This helped us identify distinct activities which took place during and around check-up appointments and clinician reviews. Furthermore, we extracted the types of clinical data that was mentioned during these sessions and used affinity diagrams to group them together, thus identifying major data categories involved in the provision of care for axSpA patients. 28 axSpA patients (P) consisting of 20 outpatients and 8 inpatients took part in the study (i.e. P1-P28), including formally diagnosed patients as well as those who were experiencing symptoms of axSpA but had not received a formal diagnosis at the time of participation. Participants are demographically diverse, including 17 males and 11 females aged between 17 to 72 (Mean = 41.20). Participation of the study was entirely anonymous and voluntary as no financial incentives was given.

We carried out semi-structured interviews with the two consultant rheumatologists (CR) who took part in the observation sessions (1 male, 1 female, Mean duration = 33 minutes), i.e. CR1 and CR2, to investigate their views on the potential roles

[1] The term "the researcher" is used throughout this thesis to refer to its author, Weihua Zhang

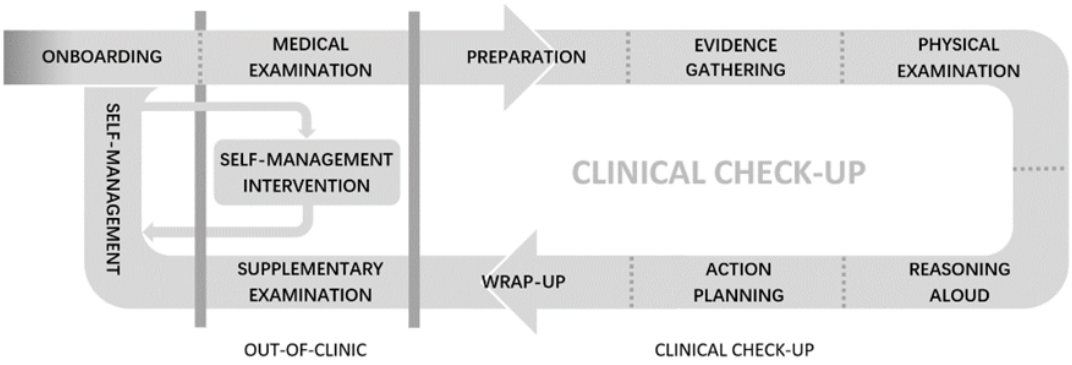


Figure 3-1: A stage-based model of the care provision process for axSpA

patient self-tracking data may play in relation to the provision of care. We audio-recorded the interviews with consent and transcribed them verbatim. We conducted reflexive thematic analysis [Braun and Clarke, 2006] on the interview transcripts, using an inductive approach where themes were developed from the content of the data.

3.5 Results

Study 1 has two major findings. First, it delineates a staged-based model of activities based on the clinical procedures involved in the routine patient check-up appointment in the axSpA clinic. Second, it paints a clear and complete picture of the types of clinical data which are used during axSpA patient care.

3.5.1 A Model of Activities in the axSpA Clinic

We analysed our field notes using affinity diagrams, identifying distinct activities and data categories involved in the care provision process. We also observed a clear pattern in the flow of activities during each clinical encounter. The activities which occurred during clinical reviews following the rehabilitation course were indistinguishable from routine check-up appointments, hence we refer to both clinical encounters as "clinical check-ups" from now on. Using these information, we produced a stage-based model of the care provision process for axSpA, which is split into two iterative phases: *out-of-clinic* phase and *clinical check-up phase* (see Figure 3-1). Our model focuses on the activities which patients and/or providers engage in during the diagnosis, prognosis and treatment of axSpA. We discuss the design implications of the model and how it relates to potential future roles of patient self-tracking data in section 3.6.

For axSpA patients, the typical care provision cycle begins when they are transferred

to secondary care (e.g. hospitals specialised in rheumatic diseases) in a process known as *patient onboarding*, usually through reference by a primary care provider (e.g. GPs). After taking the essential medical exams (e.g. MRI, urinalysis, blood test), patients would engage in consultation with a specialist (e.g. consultant rheumatologist), thereby commencing the *clinical check-up* phase. During the clinical check-up sessions, patients and providers engage in a variety of data-centric activities in a synchronous, co-located setting. These typically occur in the order of: *preparation*, *evidence gathering*, *physical examination*, *reasoning aloud*, *action planning* and *wrap-up*. We identify four distinct data categories which were used throughout these activities, they are: *summary care records*, *patient-reported outcomes*, *medical examination results* and *clinician-reported outcomes*. We discuss the relationships between clinical activities and their corresponding data types (see also in Table 3.1 below):

Preparation - prior to each consultation, the provider spends 3-5 minutes reviewing clinical data that is relevant to the consultation, including summary care records (e.g. medical history, biomarkers), medical examination results (e.g. medical imaging results, blood test) and clinician-reported outcomes (e.g. past diagnoses, consultation letters). This activity informs the provider's agenda for the conversations which will take place during the clinical encounter.

Evidence Gathering - is where the provider collect further information that is necessary for making clinical decisions about diagnosis, prognosis and treatment, including patient-reported outcome measures (e.g. disease activities, physical and mental activities, adherence to medication and exercise) and clinician-reported outcome measures (e.g. observation of posture and skin conditions). The collection of patient-reported outcome measures typically involve rapid-fire questions, e.g. *"Have you been experiencing morning stiffness?" (CR1)*, *"Have often do you take the medicine?"* (CR1) as well as self-reporting, e.g. *"I have been getting up at night 3-4 times for the last months or so"* (P3), *"The spine has been relatively pain-free, it's mainly the back of the neck"* (P17).

Physical Examination - is an additional data-gathering activity where providers physically examine patients' condition (e.g. swollen joints, numbness, range of motion). The provider may ask patients to perform certain tasks (e.g. lifting arms, bending legs) and observe their performance. The providers may also ask patients to give descriptions of what/how they feel during the examination (e.g. location of pain, type of pain). This activity allows the provider to collect performance outcome measures and information related to patients' physical conditions, therefore producing the necessary information for decision-making.

Reasoning Aloud - is a data-centric activity which combines sensemaking with the transference of knowledge. Following evidence gathering and physical examination, the provider evaluate data collected thus far in the session in combination with historic data (e.g. x-ray, MRI and BASMI results) about the patient to make decisions regarding diagnosis, prognosis and/or treatment. During this activity, providers may sub-vocalise their reasoning process, sharing their knowledge and expertise with patients to help them make sense.

Action Planning - is where the patient and provider discuss and evaluate treatment options that are available and suitable for them (e.g. medications, exercises, rehabilitative courses, surgeries), covering their effectiveness and potential risks such as side-effects, e.g. *"Are you planning on having children in the next 12 months? If so let's avoid this medicine"* (CR1). During this activity, patient and providers may collaboratively determine the best course of action and set actionable targets with regard to patients' self-management, e.g. *"Let's keep up with the stretch exercises and try to keep the BASMI score low"* (CR1).

Wrap-Up - once an action plan has been agreed upon, the provider would proceed to conclude the session by: summing up the outcome of the consultation, booking follow-up check-up appointments and supplementary medical examinations (e.g. medical imaging and blood tests), issuing questionnaires consisting of various patient-reported outcome measures, prescribing medications and creating a dictated letter.

Once patients had left the healthcare facility (e.g. hospital) following a check-up appointment, they enter the *out-of-clinic* phase of the care provision process, where the majority of them are required to self-manage their own condition (e.g. through medication and exercise). A range of self-management intervention programmes are made available through healthcare providers to improve patients' self-managements skills and understanding of the disease [Iversen et al., 2010]. In the context of axSpA, patients have the option enrol in residential or nonresidential courses where a range of rehabilitative activities (e.g. physiotherapies) and educational seminars would take place under the supervision of healthcare specialists (e.g. therapists, dietitians, counsellors, consultants).

3.5.2 Clinical Data Ecosystem

As previously mentioned, we used affinity diagram to analyse the data that was used during the clinical check-ups, identifying seven main data categories: summary care records, medical examinations, patient-reported outcome measures, clinician-reported

outcome measures, performance outcome measures, observer-reported outcome measures and lastly, patient-provider communication history. We assigned frequency ratings to each data category based on how frequently they were used (e.g. mentioned or discussed) during clinical check-up sessions: *High* - used in 2/3 (or more) of all check-ups observed, *Medium* - used more than 1/3 of all check-ups observed but less than 2/3, and *Low* - used in less than 1/3 of all check-ups observed (see Table 3.1). This helps us identify the potential use of patient self-tracking data in relation to the activities of the routine axSpA check-up appointment and gives readers a clear view of the mapping between data categories and each clinical activity.

Data Category	Description	Examples	Sources	Corresponding Activity
Summary Care Records (High)	Summary of patient data systematically collected and stored by healthcare providers, typically held digitally on a central database.	Name, age (date of birth), gender, NHS number, address, contact information, prescription and medication history, co-existing conditions, allergies, biomarkers, hospital admission history, check-up appointment history etc.	Electronic and physical patient records collected by hospitals, GPs and dental practices	Preparation
Medical Examinations	Historic records of medical exams and medical imaging results	Diagnostic radiographical imaging results (x-ray, MRI, CT scan), blood test, urine test	Electronic and physical patient records	Reasoning aloud and medical examination
Patient-Reported Outcome Measures (High)	This category refers to data collected through patients' self-assessment and self-reporting of health conditions	Disease activities (e.g. pain, fatigue, red eyes, skin irritation), adherence to medication, physical activities (e.g. exercise, step count), mental activities (e.g. stress, mood), lifestyle (e.g. screen time, diet) and life events (e.g. job change, accident, pregnancy, psychological trauma).	Symptom diary, quality of life questionnaires (ASQoL), disease activity indices (e.g. BASDAI), functionality indices (e.g. BASFI), pain diagram, wearable devices (e.g. Fitbit [Fitbit, 2022]), smartphone health apps (e.g. Chronic Pain Tracker [Chronic Stimulation, 2022]).	Preparation, evidence gathering and reasoning aloud
Clinician-Reported Outcome Measures (High)	Data about patients' health conditions that is observed and reported by qualified healthcare professionals (e.g. consultants, therapists, nurses)	Physical examination of patients' health (e.g. range of movement) and symptoms severity (e.g. degree of joint swelling)	Visual inspection, physical examination	Physical examination, treatment planning, wrap-up (e.g. dictation)
Performance Outcome Measures (High)	Summary of records and scores reflecting how well patients performed in certain tasks under the supervision of healthcare professionals	Supervised stretch exercise and walking exercise, metrology indices (e.g. BASMI)	Medical examination and supplementary examination	
Observer-Reported Outcomes (Low)	Information about patient health reported by an observer of the patient who is not a healthcare provider (e.g. family member, caretaker)	Flare episodes, sleep quality, family history of illness, life events	Consultation	Evidence gathering
Patient-Provider Communication History (Low)	Records of historic communications between patients and providers (e.g. patient letter, email)	Appointment booking confirmation, dictation letter, patient letter, information about medical trial, question from patient	Electronic patient records, email service providers	Treatment planning

Table 3.1: Information categories used during clinical consultations

3.6 Discussions: Future Roles of Self-Tracking Data

The stage-based model provides a structural understanding of the real-world context in which the use of self-tracking data can be explored. The results show that axSpA care provision is a cyclic process involving two iterative phases, i.e. *out-of-clinic* phase and *clinical check-up* phase. The identification of distinct phases can help determine when independent or co-located review of patient self-tracking data could take place within the clinical context, allowing researchers to better support the collaborative use of self-tracking data. Previous research on the use of self-tracking data in the context of chronic conditions placed limited emphasis on pre-established workflow and procedures. This may have undermined the value and feasibility of prior design recommendations and limited the understanding of the potential value of self-tracking data in supporting the existing clinical activities. The stage-based model identifies routine clinical activities in the check-up phase which support researchers in identifying practical benefits of self-tracking data from the perspective of the axSpA clinical workflow. This allows us to identify potential roles that self-tracking data could perform in the clinical setting and ways in which it could be integrated into current clinical practices. Furthermore, by identifying major data categories associated with the clinical check-up process and mapping them to individual activities, we provide much needed clarity in regard to the existing ecosystem of clinical data and support the inclusion and integration of self-tracking data in future research.

3.6.1 Role 1: Supporting agenda setting for Clinical Conversations

Our interviews highlighted the issue of conflicting agendas between patients and providers during check-up sessions: *"Time is really the challenge here... You have a list of things you need to get to, and patients also have a list of things they'd like to talk about"* (CR2). Conversation was primarily provider-driven throughout all observed sessions. Both providers reported being acutely aware of time constraints placed on their interactions with patients, and were conscious about the limited opportunities for patients to drive the conversation, e.g. to ask questions or raise concerns. Prior study have shown that failure to elicit patient agenda limits the orientation of the clinical consultation towards specific topics which are deemed important by the patient [Ospina et al., 2019]. Therefore, we believe that there is an opportunity for self-tracking data or data summary which conveys patients' lived experiences with the condition to be made available to providers at the appointment preparation stage, thus allowing providers to gain better understanding of patient priorities. One possible direction for future research could be to explore the design of software systems which allow patients to

review and "flag" data facets which they deem important to discuss as part of their clinical agenda. For example, better expression of patients' wishes to discuss certain aspect of their health (e.g. sleep, pain) through the sharing of self-tracking data may lead to more personalised and patient-centred conversations in the clinic.

3.6.2 Role 2: Supplementing Existing Patient-Reported Evidence

Our study revealed that providers gave significant consideration to patient-reported outcomes, such as subjective reports of symptoms, physical activity and medications. Providers dedicated 3-5 minutes of every clinical session to the gathering of patient-generated data in a rapid-fire manner: e.g. *"When did the symptoms start to show?"* (CR1), *"No rashes? ...dryness in the mouth? or eyes?"* (CR1). Providers relied solely on handwritten notes and dictated letters to record and store these outcome measures, making data relatively difficult to transcribe, share and analyse. CR1 expressed concerns over the ineffective use of questionnaires handed to patients at the end of each clinical check-up session, which consist of validated outcome measures such as pain diagrams, disease activity indices, and functional indices. This type of data is often subject to recall bias [Schmier and Halpern, 2004, Shiffman et al., 2008] as patients' answers rely heavily on memory. Meanwhile, collection frequency of said data is usually dictated by the scheduling and attendance of clinical check-ups, often resulting in sparse data sets which could be unsuitable for analysis. Both providers commented on the potential value of allowing patients to self-track their symptoms between clinical appointments and enabling them to their tracking data as supplementary evidence of their disease activities. Hence, designers should seek to develop provider-facing platforms which collect and summarise self-tracking data in a clinically useful format, as a potential way of giving providers richer pictures of patients' conditions while optimising time spent on evidence gathering during clinical consultations.

3.6.3 Role 3: Providing a Platform for Collaborative Decision-Making

The reasoning aloud stage played an essential role in establishing patient-provider consensus and enabling collaborative decision-making. From the perspective of providers, sharing data, information and knowledge was a potential way to address the disparity in disease expertise between patients and clinicians, e.g. providing justification for their diagnoses and treatments. We observed several uses of clinical evidences (e.g. medical imaging, blood results) by the providers during knowledge transferring activities: *"Do you see the whiteness there? That's inflammation forming in the bones"* (CR2). However, providers sometimes struggle to find tangible data or evidence as reference while

explaining their findings to patients: *"I would love to sit down with the previous scores and try to incorporate it into the conversation if I could"* (CR2). Some patients faced a similar issue where they struggle to provide evidence for their claims or theories: *"I can only tell from my experience, but it seems to me that the effect of it [rehabilitation course] is very short-term"* (P26), *"[flares] seem to be getting gradually worse since I got off the pills... a lot more frequent"* (P23).

We argue that self-tracking data, when summarised and presented appropriately, may support knowledge sharing and collaborative decision-making between patients and providers. CR1 expressed the interest in using cohort-level self-tracking data (i.e. from many patients) as evidence to help inform patients of the likely trajectories of the progression of their conditions, e.g. matching patients against those who share a similar disease phenotype to inform patients of likely outcomes and effective treatment pathways. Nevertheless, the use of cohort-level insights during axSpA clinics largely hinges on the development of technologies that enable efficient data navigation, manipulation and sharing.

3.6.4 Role 4: Facilitating Realistic Target-Setting and Progress Monitoring

During the action planning stage, providers frequently set targets for patients in order to measure the outcome of treatments and patient self-management, e.g. *"You had a BASMI (score) of 8 before the course, now it has dropped to 3. Let's try to keep it that way"* (CR1), *"Try to make stretches more regular, even 10 minutes a day makes a big difference"* (CR1). While goal setting plays an important role in patients' management or their own condition, they can often be demotivated when unrealistic goals are given [Playford et al., 2009]. Inexperienced and newly diagnosed patients, in particular, may require a degree of guidance in regard to the development of realistic and achievable goals. Self-tracking data which accurately reflects a patient's existing self-management behaviours and lifestyle could therefore support conversations around the setting of appropriate targets. Currently, patients have limited opportunities in obtaining outcome measures that reflect the progression of their disease (e.g. BASMI and x-ray occur only a few times per year). CR1 also stated that while reflection based on these measures are beneficial, they can often be difficult and costly to perform without the substantial disease-specific knowledge.

Although self-tracking data may lack the clinical rigour and reliability compared to validated outcome measures, access to data which reflect their condition provides patients with opportunities to reflect on their progress on a regular basis, thus allowing

them to make adjustments to their actions and set more achievable targets based on real-time self-monitoring. Nonetheless, providers and designers must be aware of the potential risk of overstating the significance of short-term targets, while losing sight of the long-term progression of the disease as indicated by traditional, validated measures.

3.7 Study 1 Summary & Chapter Conclusion

To reiterate, the contributions of this chapter include a stage-based model of activities which provides a structural understanding of the pre-established clinical workflow involved in axSpA patient care. Although it is likely that other rheumatic diseases share similar healthcare pathways as the one presented in our model, further investigation is required before the results could be generalised and applied to other conditions. Nevertheless, this study provides researchers the necessary knowledge to include and integrate self-tracking data with real-life scenarios such as routine clinical check-ups in the scope of axSpA. The model also supports the design of technologies which support existing clinical activities through patient self-tracking data, providing much-needed clarity in regard to the potential roles self-tracking data could play in the clinical context. We demonstrate this through our second contribution which is the proposition of potential roles self-tracking data could play in the axSpA clinics based on the existing clinical activities.

Although both providers in our study were interested in the use of self-tracking data during and around clinical consultations, our study highlights that there is unlikely to be a one-size-fits-all solution for incorporating data into the existing clinical workflow of axSpA patient care. Self-tracking data may fulfil various roles within clinical appointments, it is therefore important that tools for exploring, interacting with, and discussing data are designed to transform data so that it may cater to the demands of different activities. For example, where preparation necessitates the grasping of overview of patients' condition, reasoning aloud often focuses on identifying patterns and correlations within and between data facets. The use of self-tracking data should complement existing clinical activities, rather than replacing or disrupting them in an already time-constrained workflow. Our work provides a model of the clinical activities which take place in the rheumatology clinic and serves as a starting point for designing tools which leverage the value of self-tracking data in association with these activities. Future work should aim to assess the benefits of actual use and discussion of self-tracking data during clinical encounters and evaluate their impact on the clinical outcomes of axSpA patients as well as their satisfaction with the consultation.

The findings presented in this chapter shed a light on axSpA healthcare professionals' perspectives on the clinical use of self-tracking data. In the following chapter, we move our attention to patients' perspectives on the matter by investigating factors which contributes to axSpA patients' self-tracking adherence while taking a look at their self-tracking motivations, preferences and behaviours.

Chapter 4

Patient Engagement and Adherence with Self-Tracking for Clinical Purposes

4.1 Chapter Overview

In this chapter, we investigate axSpA patients' self-tracking behaviours and engagement with data-logging to understand the feasibility and value of self-tracking for clinical purposes, addressing **RQ2: What are the key factors which may influence patients' engagement with self-tracking?** in the process. The chapter comprises of three parts, each contributing to the understanding of patients' self-tracking behaviours and adherence from a unique perspective.

First, we use a public and patient involvement (PPI) event to learn about axSpA patients' experience with a self-tracking app (uMotif) designed for tracking health data related to the condition (e.g. disease activity, medication, exercise). The insights we obtained through this event shed a light on users' perspectives on the clinical use of self-tracking technologies as well as potential factors that may influence data-logging adherence, allowing us to further refine RQ2 and inform the design of Study 2.

Study 2 is the first part of a two-part qualitative online patient survey, investigating determinants of axSpA patients' data-logging adherence alongside their self-tracking motivation and preferences (e.g. tools used, data tracked, time of data input). The second part of the survey (Study 3) is discussed in more detail in Chapter 5. The

results from Study 2 paints a broad picture of axSpA patients' self-tracking behaviours and provides a qualitative understanding of factors which may affect users' data logging adherence. We discuss the results of Study 2 in the context of another study - uMotif adherence analysis, where Jones et al. [2021] analysed manually collected self-tracking data from 184 uMotif users over a period of 593 days, investigating axSpA patients' self-tracking adherence from a quantitative perspective, while identifying six statistically significant factors which correlates with users' data-logging adherence: age, device, preference regarding data facets, time of interaction with self-tracking tool and reported symptom severity. We compare and discusses the qualitative and quantitative findings about axSpA patients' self-tracking adherence from Study 2 and Jones et al. [2021], laying out implications for the design of PISes.

4.2 Chapter Background

4.2.1 Project Nightingale and uMotif

Some of the work presented in this chapter was associated with Project Nightingale (NHS REC Reference: 13/SW/0096), a research project created by the Royal National Hospital for Rheumatic Diseases (RNHRD) in Bath, United Kingdom, in partnership with the data science company White Swan [Swan, 2018]. As mentioned in section 1.3.2, the project uses uMotif, a smartphone self-tracking app to gather data about axSpA patients' disease activity, medication, physical activity and mental health, with the broad aim of understanding the value of self-tracking in axSpA care provision and research. The researcher was not involved in the conducting of Project Nightingale. Nonetheless, data collected through the project was shared with the researcher per agreement between the university and RNHRD. The project is referenced in relevant parts of this chapter, specifically in section 4.3 and section 4.5. The project also provides research context for [Jones et al., 2021] - a paper co-authored by the researcher, which investigates determinants of uMotif users' self-tracking adherence from a quantitative perspective. We hereby provide a summary description of Project Nightingale, what it involved and how it was conducted. The uMotif adherence analysis [Jones et al., 2021] is one of many studies that are associated with Project Nightingale (e.g. [Barnett et al., 2019]). Project Nightingale also serves as part of the research context for Study 4 in Chapter 6.

In section 1.3.2, we introduced the uMotif, a smartphone app which allows users to self-track health data related to a specific chronic condition through manual self-reporting (see Figure 1-1, 1-2, 1-3), and to upload physical activity data from wearable de-

vices such as Fitbit [Fitbit, 2022] and Samsung Galaxy Watch [Samsung, 2022]. As previously mentioned, Project Nightingale uses a bespoke version of the uMotif app which allows patient participants to self-report data daily from a total of 10 data facets/segments. 8 of them were predetermined by the provider: pain, fatigue, flare status, anti-inflammatory drug use, recommended exercise adherence, mood, stress and sleep quality. The remaining two facets were chosen by patients from a list of 13 options, including: caffeine intake, hydration, drug adherence, confidence in self-management, chest pain, eyesight, screen time, hot flushes/sweats, menstrual cycle, painful eyes, smoking, flare of psoriasis, and blood in the stool (see Figure 4-1).

The app collects data through an interactive graphical user interface (GUI) which appears as a flower-like visualisation (see Figure 4-2). The visualisation consists of 10 petal-like rating scales which users may interact with through a "drag-and-drop" action (e.g. by placing their finger tip at the centre of the flower and dragging it outwards towards the edge of the petal). This action allows users to change/determine the size (or fullness) of the petals, therefore assigning data values to the rating scales. Data value for each segment is recorded through either a 5-point scale (e.g. rating pain level from *"1 - Debilitating pain"* to *"5 - No pain"*) or a binary choice (e.g. answering *"Have you taken an anti-inflammatory drug today?"* with *"Yes"* or *"No"*). The interface resembles the "ubifit garden" interface which uses the health and growth of the flowers as a metaphor to symbolise users' health status [Consolvo et al., 2008]. For example, a full-looking flower by the end of data input in uMotif represents the user's reporting of overall good health (e.g. low levels of disease activity or flare-ups, low reliance on medications), whereas a small or incomplete looking flower represents poor health (e.g. severe pain and fatigue, lack of exercise) as reported by users.

Participants of Project Nightingale are encouraged by their healthcare providers (e.g. consultants, physicians) to fill in all segments on a daily basis. The app has a reminder feature which sends push notification to users at 8pm every day by default. Users may alter the time and/or frequency that they wish to be reminded to enter data at or disable the reminder all together. As previously mentioned (see section 1.3.2), the uMotif app allows users to upload data collected through their wearable devices (e.g. Fitbit [Fitbit, 2022], Apple Watch [Apple, 2022b], Garmin [Garmin, 2022]) and/or health data aggregators (e.g. MyFitnessPal [MyFitnessPal, 2022], HumanAPI [Human API, 2022], Apple Health [Apple, 2022a]) through uMotif if they wish to, supplementing symptom data collected through the flower-like interface with physical activity data (e.g. steps, heart rate, calories consumed) and lifestyle data (e.g. diet, screen time).

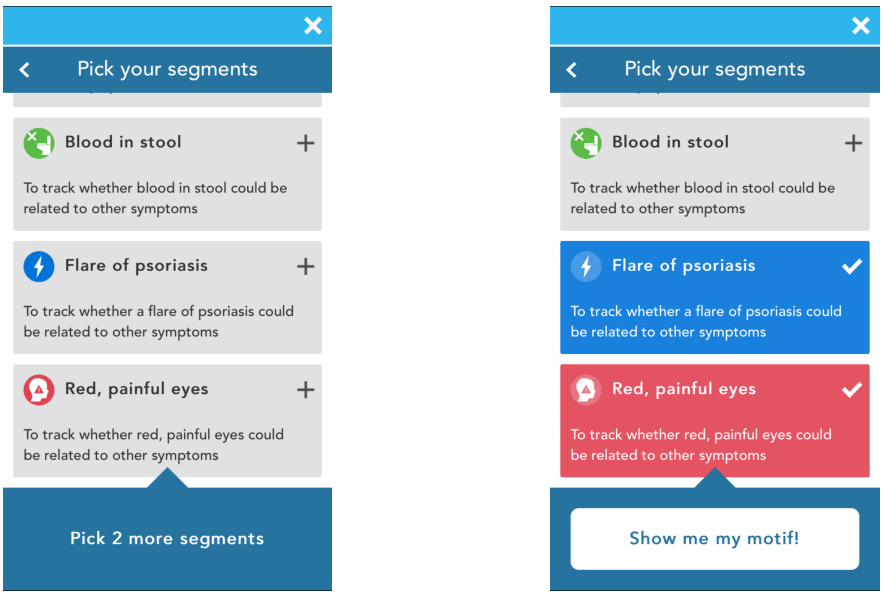


Figure 4-1: User selection of two optional data facets in addition to provider-determined data facets

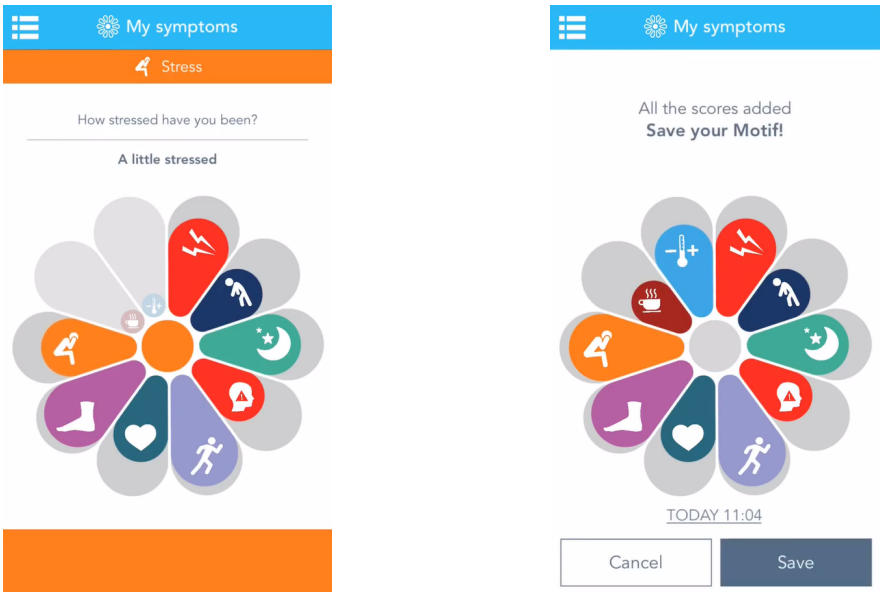


Figure 4-2: Using uMotif to record symptoms by dragging finger along each petal

4.2.1.1 Participant Recruitment & Research Procedure

Participants of Project Nightingale are registered patients of the RNHRD. Participants were recruited either by their healthcare professionals (e.g. consultant rheumatologists) during clinical encounters (e.g. check-up appointments) or through posters and flyers that were distributed at the hospital. The researcher did not take part in the recruitment process. All patients who had received full diagnosis of axSpA as well as those who were receiving axSpA care but had yet to receive a full diagnosis were eligible to participate. Interested participants were instructed to complete an online registration process before being directed to download and install the uMotif app on their iOS or Android devices. There are no difference between the iOS and Android versions of the app in terms of features and appearance. Recruitment of participants was carried out on a rolling and ongoing basis from 05/04/2018.

Participants of Project Nightingale were instructed to download the uMotif app and self-report axSpA-related data using the flower-like interface daily. A total of 184 patients finalised their consent and engaged in the use of the app, of which 126 identified as female and 58 identified as male. Participants' age range from 22 to 85 years (Mean = 52.33, SD = 13.59). Participants were instructed to track as consistently as possible (i.e. entering data once per day) and for as long as possible. In addition, participants were encouraged to resume tracking after potential period(s) of lapses or inactivity. They were also informed that data produced from continuous usage of the app could potentially support healthcare providers in the diagnosis and treatment of their conditions. Furthermore, participants were told that their data could be aggregated to support health research and improve understanding of axSpA on the cohort level. All participant data collected through the uMotif app were stored in a secure database that is accessible to researchers and providers associated with Project Nightingale.

4.3 Refinement of Research Question

In this section, we present a patient and public involvement (PPI) event conducted at RNHRD on 22/08/2019, 16 months after the initial launch of the project. The event was set up by the hospital (i.e. RNHRD), uMotif (i.e. White Swan) as well as researchers from the lead university (i.e. University of Bath) with the intention of gathering feedback and gauge user engagement with the self-tracking app. 16 participants of Project Nightingale took part in the event which lasted 1 hour 45 minutes. The event was structured in a way that is similar to a patient focus group study, where patients were able to express their opinions freely by raising their hands in a forum-like

environment. The PPI also involved other elements including an interim report on the research outcome (e.g. findings from the cohort analysis of patient' self-tracking data) presented by a researcher on behalf of the hospital and White Swan, as well as a Q&A session focused on addressing the technical difficulties users encountered when using the app.

We used the majority of the event (approximately 1 hour) to gather information about participants' experience with using the app, covering user experience, engagement (e.g. how frequent/consistent the users recorded data through the app), things that the app did well and the things which could be improved, as well as whether the user obtained useful data insights from the data they tracked. We used open-ended questions to explore patients' previous tracking experiences (e.g. *"Have you used any self-tracking apps or devices prior to Project Nightingale?"*, *"If so, do you find them useful in helping you manage your condition?"*) as well as their views on using the uMotif app (e.g. *"Did you find the data collected through the app useful in helping you manage your condition?"*), including potential factors associated with tracking adherence, e.g. *"How frequently did you track with the uMotif app?"*, *"How easy or difficult is it for you to track symptoms daily?"*, *"Did you encounter any difficulties when using the uMotif app?"*. We asked follow-up questions on a few occasions to invite participants to elaborate on their answers, e.g. *"Can you tell us more about what caused you to stop tracking?"*.

Due to the lack of formal approval from the NHS Research Ethics Committees at the time of the PPI event, we were unable to collect personal identifiable information from participating patients. Circumstances such as this were out of our control as the PPI session was scheduled and promoted before our involvement with Project Nightingale. Therefore, there was no time for researchers from the lead university to amend the existing ethics approval and acquire permission to use participants' quotes for reporting. However, we were permitted to audio-record the session with the explicit consent from all participants. In addition, due to the forum-like format of the PPI event, participants' voices could not be distinguished from one and another, thus limiting the options for data analysis. We transcribe the audio-recording verbatim and reviewed it in the fashion of reflexive inductive thematic analysis [Braun and Clarke, 2006]. However, the amount of data we collected through the event was insufficient for developing distint themes. Nevertheless, our analysis revealed issues relating to user experience and adherence, allowing us to refine **RQ2: What are the key factors which may influence patients' engagement with self-tracking?** and inform the design of our subsequent investigation into axSpA patients' self-tracking adherence (i.e. Study 2).

We observed some noticeable variance in users' tracking adherence, with some reporting frequent lapses (ranging from days to weeks) and difficulties with recording data daily while others were able to track consistently and daily. Some of the participants were able to attribute lapses to explicit reason such as usability issues (e.g. visibility of data points, lack of zooming options, complex synchronisation process), irrelevance of data due to absence of symptoms (e.g. blood in stool), difficult life circumstances as well as flare-up of conditions. Others weren't able to give specific reasons for their low engagement and adherence. In addition, patients who were consistent with their use of the app shared a few things which may have contributed to their high adherence, such as how the app helped them identify symptom triggers, achieve self-management targets, as well as their keenness to support medical research. Another participant suggested that the reminder feature of the app helped them track consistently until it was disabled unexpectedly. Based on our observations of Projecting Nightingale participants' experience with self-tracking through the uMotif app, we develop two secondary research questions which underpin RQ2: **RQ2a: What are the factors which may contribute to adherent self-tracking behaviours?** and **RQ2b: What data facets do patients find useful/relevant to track?** We use a qualitative online patient survey (Study 2) to investigate patient perspectives on self-tracking adherence, addressing these research questions in the process.

4.4 Study 2 - Online Survey: axSpA Patients' Tracking Adherence

4.4.1 Study Overview

In this section, we present a qualitative exploration of factors associated with axSpA patients' self-tracking adherence, using an online survey (Study 2) to identify factors contributing to users' self-tracking adherence from the perspectives of patients from the broader axSpA community. The design of survey questions are driven by RQ2 as well as its secondary research questions derived from the PPI event. Our thematic analysis identified four factors contributing to users' self-tracking adherence: *condition severity and emotional impacts*, *tracking individually relevant data*, *establishing routines and being reminded*, and *user experience issues*, reflecting patients' subjective experience with self-tracking tool(s).

4.4.2 Ethical Approval

This study received ethical approval from the lead university's Research Ethics Approval Committee for Health (REACH) (Reference: EP 1819/078). Since participants were not recruited through healthcare providers, no ethical approval was required from the NHS.

4.4.3 Method

We designed and distributed a two-part online patient survey study to collect data for Study 2 which investigate factors related to patients' self-tracking adherence as well as Study 3 which explores patient perspectives on the collaborative use of self-tracking data with providers. Given that both studies target the same patient cohort, i.e. online axSpA patient community, we design and promote the survey in the way that allowed us to reach the most patients and gather their opinions on both topics in one sitting. Considering we would be using the same methods and platforms to promote and distribute our surveys to reach the same audience, merging the two topics of investigation would be a more efficient use of resources and participants' time.

Study 2 used the first part of the survey to collect data about the existing use of self-tracking tools within the wider axSpA patient community. We discuss the second part of the survey (Study 3) in Chapter 5. We provide brief introduction to the concept of self-tracking and self-tracking data in the beginning section of the survey to help participants better understand the context of the study. We made sure to address any questions participants may have throughout the study. Part one of the survey covers axSpA patients' self-tracking motivations, behaviours and potential factors related to adherence. We used findings from the patient and public involvement event mentioned earlier to help us formulate the questions, focusing on factors that may influence tracking adherence (e.g. *"When are you most likely to use produce self-reports?"*, *"How much effort does it require to provide self-tracking data consistently? Please rate from 1 - effortless to 5 - too much effort"*). We collected data across four topics, with the first covering *patient demographics* (e.g. age, gender, occupation, date of symptom onset, diagnosis received). The second topic concerns patients' *attitudes towards self-tracking* (e.g. views on self-tracking and self-tracking technology, tracking motivation and goals), involving the use of questions such as *"What is your general attitude towards self-tracking and self-tracking technologies?"* and *"What motivated you to start self-tracking?"*. The third topic concerns patients' *tracking behaviours* (e.g. types of tools used, types of data collected, tracking frequency, tracking facilitators and hindrances, reasons for lapsing), involving questions such as *"What self-tracking tool(s) do you or*

have you used?", *"How frequently do you use it?"*, *"What makes you more/less likely to keep tracking?"*, *"When are you most likely to use produce self-reports?"* and *"Why did you stop tracking with this tool?"*. The final topic concerns patients' self-tracking *data usage* (e.g. perceived usefulness of data collected, relevance to the management of axSpA), involving the use of a combination of open-ended questions (e.g. *"Please briefly describe how you made use of the data you collected using self-tracking tools"*), Likert rating scales (e.g. *"How relevant do you find these data to be regarding your management and/or understanding of axSpA? Please rate from 1 - not at all relevant to 5 - extremely relevant"*) and multiple choices (e.g. *"Does your self-management routine involve the use of any data from the list?"*).

4.4.3.1 Participant Recruitment

Our survey was open to patients who had received full axSpA diagnosis from their rheumatologists, as well as those who were experiencing the characterising symptoms of axSpA and were undergoing diagnosis, but had not yet received a full diagnosis at the time of participation. The survey was primarily aimed at patient who took an interest in self-tracking, or had experience with self-tracking technologies. We hosted the survey on *onlinesurveys.ac.uk* [Jisc, 2021] and promoted it through online axSpA patient communities via Twitter (@Bath_HCI, @BathSparc, @NASSexercise, @ppe_bird), Facebook (@BathInstituteRheumaticDiseasesPPE) as well as the NASS members forum. Both Bath Institute for Rheumatic Diseases (BIRD)[BIRD, 2019] and National Axial Spondyloarthritis Society (NASS)[NASS, 2018b] are UK-based charities involved in providing support to axSpA patients nationwide. Participation was voluntary and no financial incentive was offered.

We received 112 survey responses from 44 male and 68 female participants, i.e P1-P112 (108 diagnosed, 4 without formal diagnosis [1]), aged between 22 to 77 (Mean = 49.20, SD = 13.34) over a period of 6 months. 57 participants reported having other pre-existing chronic conditions. 75 participants reported that they have used at least one self-tracking tool, of which 50 have engaged in manual self-tracking through the use of smartphone health apps (e.g. uMotif, MySpA [Barts Health NHS Trust, 2022], Chronic Pain Tracker [Chronic Stimulation, 2022], My Pain Diary [DamoLab, 2022], MyFitnessPal [MyFitnessPal, 2022]). 46 reported to have engaged in automatic tracking via wearable activity trackers (e.g. Fitbit [Fitbit, 2022], Apple Watch [Apple, 2022b], Samsung Galaxy Watch [Samsung, 2022]).

[1] Results reported in Jones et al. [2021] were based on responses from fully-diagnosed patients only. We include responses from the four participants who were, at point of the study, still awaiting full diagnosis. This difference isn't significant enough to alter the findings.

4.4.3.2 Data Analysis

We analysed free-text responses to questions in the survey using inductive thematic analysis, where themes were developed based around the content of the data [Braun and Clarke, 2006, 2019]. The first and second researcher (i.e. Weihua Zhang and Dr Simon Jones) familiarised themselves with the data before they independently reviewed and coded its content. Coded elements were clustered into eight initial themes: condition severity, types of data tracked, data collection routines (e.g. time of recording), usability, effort, maintenance, battery life and emotional impact. The first and second researcher refined and consolidated the eight initial themes into the final set of four high-level themes. The researchers rated their agreement with the mapping between data points and the final set of themes, resulting in an Kappa inter-rater reliability measure of 0.934 (95% confidence interval: from 0.861 to 1.00), indicating almost perfect agreement among the authors [Landis and Koch, 1977].

4.4.4 Results

Our thematic analysis identified four factors contributing to users' self-tracking adherence: *condition severity and emotional impacts*, *tracking individually relevant data*, *establishing routines and being reminded*, and *user experience issues*, reflecting participants' subjective experience with self-tracking tool(s). The first three themes overlap with the determinants identified in our quantitative uMotif adherence analysis [Jones et al., 2021]. Though user experience issues as a factor was not reflected by the statistical model we proposed in Jones et al. [2021], it remains a widespread concern among patients and a likely contributor to poor adherence and lapsing.

Our survey did not yield results which support other determinants of adherence such as age and use of operating system. This is expected as the survey was not designed to collected data which reflects users' longitudinal tracking experience (e.g. how adherence may change with age). With regard to operating systems, it is very unlikely that most users would have engaged in self-tracking using both iOS and Android devices, therefore no sufficient data could be collected using the survey. We discuss the four themes below:

4.4.4.1 Theme 1: Condition Severity and Emotional Impacts

Survey responses suggest that users' condition severity is potentially linked with their tracking adherence - a number of participants reported that they were more likely to log data when their condition was worsening: *"I tend to use it when I'm struggling"* (P58), *"[I track] when I am feeling overwhelmed by this disease"* (P64). Similarly, some participants suggested that tracking motivation may decrease when they have

been successful in managing their conditions: *"I have not really used [the MySpA tracking app] consistently because I have so many other things to do and my AS is under control and I know my blood test results and BASDAI are regularly reviewed by the Rheumatology Dept."* (P2).

Participants suggested that unexpected changes in their disease activities (e.g. sudden improvement/deterioration) also played a role in their decision to track, and *"If symptoms or changes are regular or expected, [there is] no need to keep tracking with the app"* (P12). This indicates that some patients may use self-tracking as a way of monitoring/recording irregularities or fluctuations in their health status that are problematic or difficult to understand/explain. For these people, condition severity was therefore a causal factor of adherence. However, this type of tracking behaviour may result in periods of inactivity (i.e. lapses), producing data which could not accurately represent patients' health status over time, due to the lack of data points reflecting healthy periods.

We asked participants with existing experience in tracking self-reported data (49/112) to self-identify scenarios where they are most likely to track (through manual data collection) in relation to their health conditions and self-management routines. Figure 4-3 shows their responses to the multiple choice question *"When are you most likely to use tracking tools to self-report data?"*. The results show that while most participants (53%) reported using self-tracking tools consistently as part of their daily routine, 45% reported that they were more inclined to produce self-reports when experiencing unusual disease activities. Meanwhile, 42% reported that worsening conditions contributed to increased tracking frequency. Responses to this question suggest that positive disease experiences (shown in green in Figure 4-3) are less likely to encourage adherent self-tracking. Instead, the results suggest that negative disease experiences, e.g. degrading health (shown in red in Figure 4-3), changes in condition, e.g. unusual disease activities (shown in orange in Figure 4-3) as well as factors unrelated to condition, e.g. reminders, routinisation (shown in grey in Figure 4-3) serve as stronger predictor for patients to record data.

Although more evidence suggest that the worsening of condition contributes to higher adherence levels, roughly 10% of respondents to the question suggested that they were more likely to produce self-reports when condition was improving. For example, P72 suggested that *"apathy, anxiety and the feeling my condition is deterioratin"* negatively affected their tracking adherence, stating that they preferred to record data when feeling healthy, as a way of *"continuing the belief my condition is under control"*. Furthermore, the link between condition severity and tracking adherence as suggested

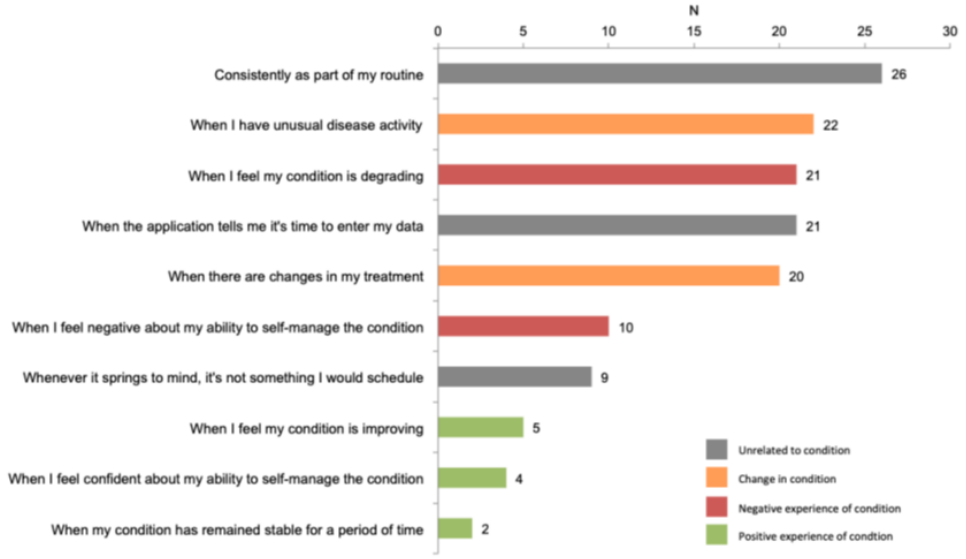


Figure 4-3: "When are you most likely to use tracking tools to self-report data?" (participants were able to select multiples answers) [Jones et al., 2021]

by Jones et al. [2021] may not always hold true as participants reported scenarios where their conditions hindered their ability to engage with the self-tracking tool, suggesting that tracking adherence could decrease drastically as their health deteriorates to an unmanageable level: *"[I'm less likely to track] when I have a flare up"* (P62), *"[I track] when I'm feeling well enough to use tools. If I'm feeling too unwell I will not have the energy to use [them]"* (P65), *"Sometimes I forget to log in my symptoms, especially if I'm fatigued"* (P106). These reports align with the findings of [Matthews et al., 2017], highlighting the effects of severe, debilitating symptom status on bipolar patients' tracking adherence.

The survey responses also revealed potential links between tracking adherence, condition severity and the emotional impact of self-tracking, as participants reported concerns that the practice of self-tracking may amplify or cause negative feelings about their own health and the condition, e.g. consistently reminded of being a sick person. For example, P8 stated that they *"stopped tracking as it was all very negative. I filled it out when I got up in the morning and it constantly made me focus on pain so I stopped it. It made me focus on the negative aspects of my condition on a daily basis which was soul destroying"*. Similarly, P58 stated that *"it becomes depressing to analyse how I'm feeling every day—prefer to just cope as best I can and log when I think to"*. P41 also reported the negative impact of self-tracking, stating: *"I believe strongly that to cope with the demands of a chronic painful condition one needs to operate in*

their here and now, rather than carrying a sense of the ongoing pattern of limitations pain and tiredness". Some participants who reported using automatic tracking devices (e.g. Fitbit [Fitbit, 2022]) suggested that condition severity had debilitating impact on their ability to achieve self-tracking target of staying active, stating: *"[I'm less likely to track] when I have a flare up. I feel guilty when I get reminders to try get my steps goal, and I can't because I'm in too much pain"* (P62). P38 mentioned the feeling of guilt when they fail to achieve exercise target: *"I feel guilty now if I don't reach my daily step target."* (P38).

For some patients, the practice of self-tracking helped them develop positive feelings about self-managing the condition, e.g. feeling active, confident in keeping symptoms under control, therefore making them feel motivated and keep tracking: *"It helps me feel that I am doing the right thing"* (P26). P31 said that it gave them *"Hope and encouragement"*. Another participant said they gained *"satisfaction at completing my daily targets and psychologically it feels like I am achieving something positive for my mental and physical health"* (P49). However, survey responses suggest that when patients fail to achieve targets or desired outcomes (e.g. keeping symptoms under control) despite their best efforts, they may feel discouraged therefore less likely to keep tracking, e.g. *"When you have done everything you need to do and AS still flares, it makes you think, what's the point?"* (P78). For P62, the reminder feature of their self-tracking app caused negative emotions such as guilt when they fail to meet targets due to high condition severity (*"When I have a flare up I feel guilty when I get reminders to try get my steps goal, and I can't because I'm in too much pain"*), making them less inclined to keep tracking. This aligns with previous work on the adverse effects of goal-directed self-tracking in the context of chronic conditions [Davies et al., 2019]. Similarly, P42 stated that *"the last thing I need is constant feedback regarding heart rate or blood pressure. The potential for fostering heightened levels of anxiety seem clear"* when asked of things that would make them less likely to keep tracking. In summary, although the use of self-tracking technology allows patients to monitor their health conditions and provide data for reflection, potential negative outcomes could be derived from the practice of reflection [Zhu et al., 2017, Cuttone et al., 2014, Leventhal et al., 1993], amplifying negative emotions that are often associated with the worsening of condition. Nevertheless, the desire to document worsening conditions for introspection and sharing may motivate more adherent tracking. For example, P78 said that *"admitting to myself I was struggling and being able to tell others I was struggling"* was a major facilitator to adherent tracking behaviours.

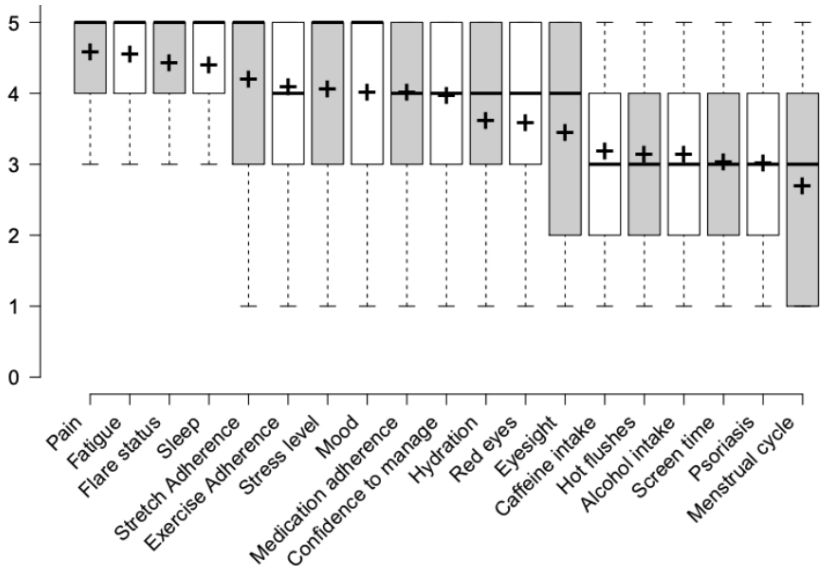


Figure 4-4: *"How useful/valuable is self-tracking of the following data types? (from 1 - not at all useful to 5 - extremely useful". "+"* indicates Mean. Boxes indicate Median and the Interquartile Range (IQR). Whiskers show lower and upper 1.5 * IQR. [Jones et al., 2021]

4.4.4.2 Theme 2: Tracking Individually Relevant Data

The second factor associated with patients' self-tracking adherence based on the survey responses is the type(s) of data being tracked. Participants reported that they were more likely to track frequently when the data being collected by self-tracking tool(s) was considered *"relevant"* (P14), *"useful"* (P50, P65, P86, P94) or having *"value"* (P76) in regard to the management of their conditions. Participants suggested that the ability to track relevant data or lack thereof had explicit impact on their willingness to track: *"The [self-report] questions don't always seem relevant so it's difficult to stay motivated. I'm putting in a lot of information that does not appear relevant, but [there is] no tracking of painkillers in my app"* (P45). Similarly, P14 suggested that having individual control over what types of data they could track will likely improve their adherence: *"[I want to] modify it [the tracking app] so I only have to answer questions that are relevant to me".*

Participants self-rated how useful/valuable they found each data type which they were able to track using self-tracking technologies on a Likert scale. Results show that the most highly rated data facet was pain, following closely by fatigue, flare status and sleep (see Figure 4-4). This was also reflected by participants' free-text responses, suggesting that managing disease activities was the primary objective for tracking for

many patients: *"It has pushed me to ask questions about the variation in pain level in one of the joints affected"* (P1), *"I was not understanding my constant fatigue and pain and not knowing what helped or made it worse"* (P99), *"[I started tracking] to understand my pain and fatigue, was there a correlation?"* (P85). Out of all disease-related data that can be tracked, pain was deemed most relevant and useful among patients (see Figure 4-4). Pain is also one of the most ubiquitous symptom of axSpA [NASS, 2018a, Siebert et al., 2016], directly reflecting the extend of disease activity and condition severity, therefore, patients may feel more inclined to report it as way of monitoring flares.

Some data facets were found to be highly integral to individuals' self-management routines. P21 stated that tracking hot flushes/night sweats was useful as it helped them identify oncoming flare-ups: *"Night sweats rather than hot flushes seem to signal a flare is coming"*. Overall, survey responses suggest that the perceived value of each data facet that is trackable via self-tracking technologies may vary depending on individuals' data-using priorities and needs. Participants reported feeling more engaged with self-tracking technology that was *"tailored to my need"* (P1), *"customisable"* (P14), allowed *"multiple tracking options"* (P59), and helped to *"track everything I need it to"* (P105). Similarly, P47 reported that the need for *"putting in a lot of information that does not appear relevant and having to input a lot of information"* made them *"difficult to stay motivated"* with regard to tracking.

4.4.4.3 Theme 3: Establishing a Routine and Being Reminded

Participants' responses highlighted the importance of having an established self-tracking routine in the determination of adherence: *"You do need to discipline yourself to try to enter the data on a daily basis"* (P43), *"It is a conscious effort and needs to be incorporated into daily routines before it will become natural"* (P79). Survey identified memory-related issues such as forgetting to record data as a major obstacle to adherent tracking, with 9 participants reported instances where their forgetfulness negatively influenced adherence: *"Providing the data is relatively effortless but remembering to do it is more of an effort"* (P56), *"I don't remember to log every day... I log when I think to"* (P58). P55 also stated that they *"sometimes forget [to track]"* while P14 noted that *"it's very easy to do, just sometimes forget to do it"*.

One of the determinants of adherence as presented in Jones et al. [2021] was uMotif users' time of data input, with most people providing data during evening hours, overlapping with the app's reminder notification in default setting (i.e. 8pm). Participants of the survey also reported the role that alerts, alarms, reminders and push notifications

played in maintaining adherence tracking behaviours, e.g. *"Diaries require routine and habit. Apps however have reminders... that is helpful"* (P64), *"Alarm beeps on phone, I fill in the questionnaire"* (P104). Other participants suggested that their physical self-tracking devices served as a reminder in themselves: *"The watch itself is a reminder"* (P40). This coincides with results of the statistical analysis of uMotif data, where the use of automatic/wearable tracking devices was identified as a significant determinant of users' adherence with manual data collection (i.e. self-reporting).

4.4.4.4 Theme 4: User Experience Issues

In line with findings of previous research on users' tracking adherence [Epstein et al., 2015b], survey responses suggested that usability and user experience issues negatively affected participants' self-tracking adherence, highlighting a range of issues relating to the design of devices/apps, effort required for data collection and cost of maintenance. To begin with, usability issues associated with self-tracking apps and devices were reported as reasons for tracking lapses and discontinuation, with 19 participants explicitly stating that *"ease of use"* and *"simplicity"* were key features of the device/app which would keep them tracking. Similarly, poorly designed user interfaces, poorly phrased questions and *"difficult to use"* tools were reported to have negatively impacted adherence. For example, P32 suggested that *"complicatedly worded questions with lots of double negatives"* were annoying and off-putting.

In addition, the amount of effort required for data collection was also reported as a factor associated with adherence. Compared to sensor-rich self-tracking devices that utilise automatic collection (e.g. wearable trackers), tools that rely on manual data collection such as self-reporting require significantly more effort (e.g. time, reflection, recollection from memory) for data logging. In result, some participants found the practice of manual tracking tiresome and *"time consuming"* (P91), opting to track with wearable devices exclusively: *"I only collect data from my watch. I wear the watch daily, no real effort on my part"* (P40), "Some apps require a lot of self-entry which takes a lot of effort. Fitbit app is easy because it tracks it for you via the watch" (P86). Other users suggested that repetitive nature of self-reporting could lead to boredom and fatigue with manual self-tracking, expressing the need for a more engaging and interesting tracking experience [Murnane et al., 2020]. For example, P86 noted their frustration with *"having to enter in results all the time in order to see any useful data"*. P41 said *"If I had to manually record the data that would put me off. The watch and associated app collect all the data automatically"*. Similarly, P36 suggested that the effort required to set-up the device can be off-putting and that they would be

less inclined to track *"if a lot of effort is required to set it up each day"*. Another patient cited the repetitiveness of manual data collection as main contributor to abandonment: *"[I would be less likely to track] if it [the tracking app] is too complicated, asks repetitive questions and doesn't show me anything. I tried using a fibromyalgia tracker and it asked endless questions which were repetitive. I ended up stopping"* (P91). For some participants, the issue of repetitiveness was compounded by a lack of perceived benefits from tracking (e.g. improved health outcome, self-understanding, knowledge about the condition). For example, P75 mentioned *"constant data entry with no outcome or benefits"* as a factor which made them less likely to keep tracking.

In addition to data collection, the effort required by device maintenance was also suggested to be associated with adherence. 5 participants reported frustrations with the *"poor battery life"* of their self-tracking devices, linking it with lapsing and discontinuation of tracking. The issue of users forgetting to charge devices have been reported before in [Bielik et al., 2012], suggesting that forgetfulness or poor battery reserve could negatively affect adherence. Similarly, the constant need for checking if the device was correctly set-up was also reported as a source of frustration and reduced adherence, e.g. *"It's constant checking and making sure you have activate it"* (P62). Last but not the least, the inclusion of social features by self-tracking apps may affect adherence by altering users' motivation to track, e.g. peer comparison features and performance benchmarks. Our survey suggested that social recognition/comparison and benign competition between users may foster positive experience and better tracking adherence: *"I'm in competition with my 2 daughters so that encourages me to use it"* (P81). However, some participants reported that social comparison features may in fact reduce their willingness to track, by inciting negative emotions such as frustration and guilt: *"feeling like I've achieved less than other people"* (P31), *"feeling guilty if I don't reach my daily step target"* (P38).

4.5 Discussions and Design Implications

The aim of Study 2 was to explore factors which may affect axSpA patients' adherence with self-tracking, including both automatic and manual forms of self-tracking. We surveyed 112 patients who practised or were interested in self-tracking using a qualitative questionnaire, identifying four themes which describe potential determinants of adherence, namely: *condition severity and emotional impacts*, *tracking individually relevant data*, *establishing a routine and being reminded* and *user experience issues*. These themes provide qualitative understanding of factors which may affect axSpA patients' self-tracking adherence. While prior work focused on the investigation of fac-

tors associated with adherence in the use of automatic tracking devices, e.g. [Doherty et al., 2017], our approach took a global view on the subject by incorporating the use of manual tracking, identifying several potential adherence factors that are closely linked with axSpA, e.g. severity of conditions and types of data tracked.

The findings of Study 2 could help healthcare professionals and researchers better understand factors which may hinder or contribute to the collection of useful patient-generated health data. They may also help software developers and self-tracking researchers tackle user experience issues undermining user engagement with tracking technologies, hence addressing data quality issues surrounding the clinical use of patient self-tracking data caused by inconsistent tracking, lapsing and abandonment. Future work may wish to build upon our results and continue to investigate the adherence factors identified by the survey. For example, examining the impact of users' choice of data types to record as well as data collection routines using quantitative methods. In the following sections, we discuss how each theme may inform the design of PIS features with the aim of fostering user engagement and improving tracking adherence.

4.5.1 Discussion Context: uMotif Adherence Analysis

We discuss the results and implications of Study 2 in the context of Jones et al. [2021] [2], a peer-reviewed paper co-authored by the researcher which investigated factors associated with axSpA patients' manual self-tracking adherence through a quantitative approach. We may refer to this study as "uMotif adherence analysis" for the remainder of this chapter. While Study 2 investigated factors associated with axSpA patients' tracking adherence via a qualitative survey, the uMotif adherence analysis investigated the actual use of a smartphone app (uMotif) which allows axSpA patients to track health data related to the condition. The study identified several determinants of manual tracking adherence through quantitative analysis of patients' self-tracking data and demographic data. The uMotif adherence analysis study was conducted concurrently as Study 2, led by Dr Simon L Jones, first author of [Jones et al., 2021]. Much like the PPI event we discussed earlier, the uMotif adherence analysis study was conducted in association with RNHRD and Project Nightingale. All research activities have received approval from the lead university's ethical review board and the Research Ethics Committees (RECs) within the NHS (Reference: 13/SW/0096).

The uMotif adherence analysis produced a statistical model which has significant rel-

[2]Simon L Jones, William Hue, Ryan M Kelly, Rosemarie Barnett, Violet Henderson, and Raj Sengupta. Determinants of longitudinal adherence in smartphone-based self-tracking for chronic health conditions: Evidence from axial spondyloarthritis. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies*, 5(1):1–24, 2021

evance to the findings of Study 2, as the findings of the two studies complement each other by providing context and further insights into the factors identified through their respective research method. It is also important for us to understand how adherence factors identified through Study 2 overlap with the statistical model or how they may potentially differ from each other. Before we discuss the design implications of the findings of Study 2, we provide a brief summary of uMotif adherence analysis study, covering its method and results.

We examined Project Nightingale participants' adherence rate with regard to manual data logging using uMotif's flower-like interface, covering the period between 05/04/2018 (project launch) and 21/11/2019. The data set includes all 184 participants' uMotif data entries, their basic demographic information and health data provided by RNHRD with participants' consent, including age at enrolment, age at disease onset, age at diagnosis, sex at birth, and BASMI score which reflects patient's condition severity [Jenkinson et al., 1994]. The data set also includes information about the types of device used by the participants (e.g. operating system, use of wearable activity trackers). [Jones et al., 2021] disregard data recorded from automatic activity trackers for the analysis of user adherence as it doesn't indicate active and conscious usage of the uMotif app. Since patients were instructed by their providers to use the uMotif app daily (see 4.2.1), we defined the threshold for adherence as *"using the flower-like interface to manually record data at least once per day"*. Adherence or adherence rate was calculated by the percentage reflecting the number of days with at least one manually recorded data entry during the time period from the date at which participant entered data for the first time up until the cut-off date (i.e. 21/11/2019). [Jones et al., 2021] also conducted linear regression analysis on the aforementioned data to identify statistically significant determinants of adherence rate for each participant.

The results of the uMotif adherence analysis suggest that the average adherence rate of participants' data-logging via the flower-like interface was 26.4% (SD = 29.9%). The statistical model suggests that 27% of the variance in adherence among patients could be explained by six factors: *age*, *device used for tracking* (e.g. Android/iOS, concurrent use of wearable device), *condition severity* (pain), *choice of optional data categories* (hot flushes/night sweat) and the *time of the day* at which users provide data. Age was found to be the most significant predictor of adherence, accounting for 7.2% of the variance. In summary, participants were more likely to have had higher adherence if: they were older; they were using an Android device; they were using an wearable activity tracker (e.g. Fitbit [Fitbit, 2022], Apple Watch [Apple, 2022b]) concurrently with the uMotif app; they were entering data in the evening

(8pm); have higher condition severity (i.e. worse average pain score); chose to track hot flushes/night sweats as discretionary data facets. We use findings of Study 2 to explain and provider context for the correlations identified by the uMotif adherence analysis, linking users' lived experience to the determinants while discussing additional factors that may influence adherence.

Condition Severity and Emotional Impacts

Our thematic analysis of the qualitative survey identified axSpA patients' condition severity as a potential predictor of self-tracking adherence. Specifically, worsening condition or severe disease activity appear to have to contributed to better tracking adherence for a number of participants. Similarly, several participants linked reduced tracking motivation to stable health or being able to keep symptoms under control for a period of time. This is somewhat line with the findings of Jones et al. [2021] which suggests that worse disease experience leads to better adherence, with pain levels as the main predictor - contributing to 4.3% of the variance in adherence rate. It also co-aligns with the findings of Seppen et al. [2020] where high pain levels were identified as motivator for tracking among rheumatoid arthritis patients. However, Study 2 suggests that worsening conditions may not always increase adherence, as when patients' health status degraded past a certain threshold (e.g. due to a flare-up of symptoms), the debilitating impact of the condition would make self-tracking very difficult, therefore reducing adherence instead. We theorise that the lack of data entries reflecting extremely high condition severity due to patients' incapability to track may have caused this omission from the statistical model presented in Jones et al. [2021]. From a design perspective, potential inactivity and lapsing due to good health status over prolonged period of time could be addressed through pop-up questions, e.g. asking patients to give a rough description of their condition over the period of inactivity when they resume tracking. This could help PISes gather information about periods of inactivity and missing data.

In addition adherence, we found that the practice of self-tracking may create or amplify negative emotions regarding patients' health conditions (e.g. being reminded as sick person, anxiety, lack of positive self-management outcome, failure to achieve goals), therefore placing psychological burdens on axSpA patients. This led to reduced tendency to track and lower adherence among several participants, co-aligning with the findings of previous work highlighting adverse effects of goal-directed self-tracking in the context of chronic conditions (e.g. Davies et al. [2019]), potential negative outcomes of self-reflection (e.g. Zhu et al. [2017], Cuttone et al. [2014], Leventhal et al. [1993])

as well as the emotional burden of self-tracking (e.g. Ancker et al. [2015]). We also found the opposite to be true, whereby patients reported feeling positive emotions (e.g. feeling active, hopeful, confident and in control) as the result of tracking when they were healthy, making them more likely to track. We theorise that the risk of self-tracking amplifying negative emotions felt by patients could be associated condition severity, whereby worsening conditions increase the risk of tracking-induced anxiety. Ancker et al. [2015] also suggest that self-tracking technologies could serve as unwanted reminders of sickness, making patients suffering severe symptoms feel agitate and de-motivated. One potential design solution could be to reduce the frequency of tracking reminders (e.g. push notifications) when the patient's health has been degrading for a period of time based on the insights provided by the data.

In summary, patients are generally less likely to track when their condition is in control. Worsening of conditions such as flare-ups and irregular changes in disease activities are likely to lead to more adherent tracking behaviours, provided that they are not so debilitating that patients are deprived of the motivation and ability to track. Nevertheless, none of the predictors we found are universally applicable for all patients. PISes developers may wish to accommodate these behavioural patterns when designing features for improving adherence, such as altering the frequency of reminders around a flare-up.

Tracking Individually Relevant Data

Our analysis of the survey results identified the ability to track individually relevant data facets using self-tracking technologies as an important factor in users' tracking adherence. Participants suggested that they were more likely to track if they deemed the available data facets useful to the self-management of axSpA. In general, pain was identified as the most useful/valuable data facet, followed closely by fatigue, flare status and sleep. This is inline with the results of Jones et al. [2021], where high adherence was found to be associated with increased pain. Moreover, patients may view certain data facets as more useful than others depending on their individual conditions and data-using needs. The uMotif adherence analysis suggests that users' decision to track "hot flushes/night sweats" within the uMotif app correlates with higher adherence. Though limited survey responses offered some qualitative insights into this determinant, where users who did track this facet stated that tracking "hot flushes/night sweats" was extremely useful in helping them identify oncoming flare-ups. Since the usefulness of data facets may vary from person to person, it is essential for PISes to provide certain flexibility with regard to the data facets which can be tracked based on patients' individual needs, e.g. by giving users the ability to customise (add/remove) data facets,

allowing users to stop tracking data that is irrelevant to them.

Establishing a Routine and Being Reminded

Study 2 identified new users' unfamiliarity with tools and memory-related issues as major hindrances to adherent self-tracking behaviours. Our findings also suggest that forming a self-tracking routine as well as being reminded to track can positively contribute to adherence. This co-aligns with previous work on users' tracking behaviour with regard to the use of smartphone apps, e.g. Stawarz et al. [2015] which highlighted the importance of habit formation in determining long-term user engagement. The uMotif adherence analysis also revealed that the timing of data collection (e.g. time when patients enter data manually) was a significant predictor of adherence which constituted 11.5% of the variance in uMotif users' adherence [Jones et al., 2021], highlighting the importance of routines in consistent tracking behaviours.

Furthermore, software features which serve as tracking reminders (e.g. push notifications, alarm beeps) can improve adherence by addressing forgetfulness and fostering habit formation. The study also show that the use and awareness of physical tracking devices could sometimes remind users to engage in manual forms of tracking, such as self-reporting. This result is in line with that of the uMotif adherence analysis which suggests that high manual tracking adherence could be associated with the use of physical activity trackers, e.g. Fitbit [Fitbit, 2022], Apple Watch [Apple, 2022b], Garmin [Garmin, 2022]. We theorise that the presence of a tracking routine based on the use of wearable devices may help users adhere to manual self-tracking, as patients who actively engage in self-tracking through wearable devices may be predisposed to have positive views on self-tracking. For PIS designers, time-based reminders remain an effective way of improving users' adherence. Previous research has laid the theoretical groundwork for designing reminder features for PISes, including the effect of time of the day on users' willingness to track [Ramsey et al., 2016], effect of contextual cues (e.g. routine events/task, locations, and meaningful objects) on adherence [Boukhechba et al., 2018, Rintala et al., 2020], as well as their effects on habit formation [Stawarz et al., 2016]. Developers may wish to look into these factors when designing features to help users establish self-tracking routines for long-term engagement, therefore reducing the reliance on reminders. For example, to encourage users to record data in conjunction with daily tasks (e.g. before going to bed, after exercise) or in association with locations, (e.g. reminding users to track when at home). Meanwhile, highly frequent reminders may cause users to experience negative emotions such as annoyance and anger, especially when users are experience severe flare-ups, as pointed out in section

4.5.1. Designers may wish to avoid this by reducing the frequency of reminders when disease activities become significant.

User Experience Issues

Our study highlighted several user experience issues which participant identified as hindrances to their engagement with self-tracking technology, covering the design of the device/apps, effort required for collecting data as well as the cost of maintenance. Participants reported the desire for their self-tracking tools to be easy-to-use and the questions (used by the app to manually collect data) easy-to-understand. Participants also showed strong preference for self-tracking technologies that collect data automatically (e.g. wearable devices), suggesting that requiring users to enter data through manual means only could lead to frustration, especially when no obvious benefits are shown after prolonged periods of tracking. This is somewhat understandable since users of consumer-driven automatic tracking technologies such as Fitbit [Fitbit, 2022] and Apple Watch [Apple, 2022b] are often provided with data summaries and visualisations via synchronised apps on smartphones, where as manually collected data are generally much harder to analyse. To tackle this, developers may wish to explore design solutions which aim to address the repetitiveness of manual data collection as well as the lack of useful feedback showcasing the value of manually collected data, e.g. period progress reports, feedback on what the patients did right to manage their condition, what actions had positive impact on disease activities. Furthermore, a number of participants reported the desire for additional social features to be added to their self-tracking apps/devices, such as data-sharing and peer-comparison features which allow users to compare and evaluate their self-management efficacy against others. This could potentially help users see the value of their data produced through consistent tracking. Nevertheless, designers need to be aware of the potential negative impact of the social sharing and comparison of self-tracking data, e.g. reduced exercise/tracking motivation as the result bench-marking performance against high-performing individuals [Zhou et al., 2016, Bailis and Chipperfield, 2006], when designing social features for PISes. Furthermore, the cost of maintenance may also play a role in users' tracking adherence as issues such as poor battery life [Bielik et al., 2012], lack of feedback regarding the state of device (e.g. activated/deactivated) and synchronisation difficulties will likely reduce users' willingness to track.

4.6 Study 2 Summary & Chapter Conclusion

In summary, Study 2 investigated axSpA patients' perspectives on their engagement with self-tracking technologies through an online survey, providing qualitative insights into patients' tracking behaviours and identifying four main themes which contribute to adherence: *condition severity and emotional impacts*, *tracking individually relevant data*, *establishing a routine and being reminded* and *user experience issues*. We found that although patients may record data under any circumstances during their self-management of the condition, certain scenarios such as variations in condition severity and irregular disease activity are more prominent causes for tracking than others. This finding addressed **RQ2a: What are the factors which may contribute to adherent self-tracking behaviours?** In addition, the practice of self-tracking may amplify the negative emotions patients experience when they struggle to keep disease activities under control, therefore making them less likely to track. Secondly, patients suggested that having the ability to track data facets which they deem useful or relevant could positively contribute to tracking adherence, with pain and fatigue being the most high-rated symptoms in that regard, therefore addressing **RQ2b: What data facets do patients find useful/relevant to track?** Additionally, having established self-tracking routine could and reminder features could also lead to higher adherence. Last but not the least, user experience issues such as high effort required for data collection, high maintenance cost and poor usability contribute negatively to patients' willingness to track. We compare our findings with a quantitative study (i.e. uMotif adherence analysis) which investigated factors contributing to Project Nightingale participants' manual tracking adherence using the uMotif app, providing qualitative insights into a number of the determinants identified through linear regression analysis of users self-tracking data. We then provide practical recommendations for designing future PISes to foster better user engagement and adherence.

The discussions and design recommendations we provide do not offer a one-size-fits-all solution to highlighted issues associated with axSpA users' self-tracking adherence. When discussing factors related to adherence and users' engagement with self-tracking apps/devices, it is necessary to take individuals' tracking motivations into consideration. As previous work suggested [Epstein et al., 2015b, Rooksby et al., 2014], individuals' tracking motivation and style can have considerable impact on their short-term and long-term commitment towards self-tracking. Our survey suggested that some patients showed more commitment to self-tracking than others. P43 stated that the *"sheer determination to find ways of improving my management of AS"* was the driving force behind their high adherence rate. Similarly, P78 emphasised the role willpower

and determination played in help them record data consistently. On the flip side, P16 attributed their low adherence rate to *"laziness"*. Therefore, while the four themes as well as determinants revealed by Jones et al. [2021] improved our understanding of factors associated with axSpA patients' self-tracking adherence, individuals' commitment to self-tracking may still play a significant role in the determination of adherence rate. Future research may wish to further investigate how tracking motivation and personal variance such as personality types may affect one's commitment to self-tracking and adherence rate. This study suggest that people may record data under various circumstances when engaging in the self-management of their conditions, e.g. when condition severity and disease activity vary, prior to check-up appointment, after beginning new medical treatment etc. Though certain scenarios may trigger data collection more often than others from a general perspective, it is unclear what the most predictive factor might be on an patient/individual level. Certain types of self-tracking behaviours related to adherence may also exist within the wider patient community, subject to factors such as data consistency, lapsing frequency, duration and abandonment rate. Cluster analysis may be help identify archetypes of patients' self-tracking behaviours which may be influenced by hidden variables such as patients' personality types and vocation. This is considered out-of-scope for our work on axSpA patients' adherence and further ethical approval is likely needed for addressing these potential research questions.

Chapter 5

Patient Perspectives on the Collaborative Use of Self-Tracking Data

5.1 Chapter Overview

In this chapter, we examine patient perspectives on the collaborative use of self-tracking data in the clinical context through a survey and interview study (i.e. Study 3), therefore directly addressing **RQ3: What are the patients' perspectives on the collaborative use of self-tracking data?** We analysed survey responses from 112 axSpA patients and 8 semi-structured follow-up interviews, revealing themes relating to patient expectations, priorities and concerns with regard to using and discussing their self-tracking data with providers during clinical encounters. The results highlight the gap between patient expectations and the reality of self-tracking data usage in clinics, contextualising known issues related to the collaborative use of self-tracking data in the clinical setting (e.g. time constraints, dismissive attitudes) as introduced in section 2.6.3. The study also provides a deeper understanding of the motivations behind patients' decisions to share and discuss data with healthcare providers, as well as the potential reasons for withholding them. We discuss the implications of our findings for designing and developing technology that supports collaboration around self-tracking data in axSpA clinics.

5.2 Study 3 - Patient Perspectives on Collaborative Use: Overview

Study 3 is a remote qualitative study which tackles RQ3 by examining axSpA patients' perspectives on the collaborative use of self-tracking data in the clinical setting. It consists of an online survey and optional telephone follow-up interviews. The findings of this study paints a clear picture of axSpA patients' expectations, priorities and concerns with regard to using and discussing their self-tracking data with providers during clinical encounters.

5.3 Method

We design and use the second half of the online survey from Study 2 (see section 4.4.3) to investigate axSpA patients' perspective on the collaborative use of self-tracking data with providers (e.g. consultant rheumatologists, physiotherapists, dietitians). We refer to the second half of the survey (i.e. Study 3) as "the survey" for the remainder of this chapter. All 112 participants of Study 2 (i.e. P1-P112) completed the survey, hence the participant demographics remain unchanged from Chapter 4. As mentioned in the previous chapter (see section 4.4.3), the study received ethical approval from the lead university's Research Ethics Approval Committee for Health (REACH) (Reference: EP 18/19078). We recruited participants through two UK charities involved in providing support to axSpA patients nationwide, namely the National Axial Spondyloarthritis Society (NASS)[NASS, 2018b] and Bath Institute for Rheumatic Diseases (BIRD)[BIRD, 2019].

The survey collected information using a combination of methods, including open-ended questions and Likert rating scales, across the following topics: attitudes and experiences with regard to sharing and discussing self-tracking data with providers (e.g. *"Has your self-tracking experience highlighted any questions, topics or issues that you may wish to discuss with the provider?"*), expectations for providers and their use of self-tracking data (e.g. *"How would you expect your self-tracking data to be used by the provider?"*) and concerns about sharing and using self-tracking data (e.g. *"How comfortable do you feel about sharing the following types of self-tracking data with the provider? Please rate from 1 - very uncomfortable to 5 - very comfortable"*). Some questions asked were deliberately broad so that patients could express their opinions freely and unguided. We elaborated on the types of self-tracking data which are relevant to our survey, including: disease activity (e.g. pain, fatigue), medication, physical activity/exercise, lifestyle (e.g. sleep, screen time), mental health and well-being (e.g. stress, mood) and

diary entries, where most patients record their disease experience and thoughts about self-management.

Following preliminary analysis of the survey data, participants who reported having past experience in sharing (and discussing) self-tracking data with providers during clinical appointments were invited to a 30-minute follow-up interview, consisting of semi-structured questions such as *"What was your reason for sharing your self-tracking data with the provider?"* and *"Have you encountered any difficulties when discussing your data with the provider?"*. These interviews were conducted via either telephone or Microsoft Teams audio call.

5.3.1 Analysis

We conducted reflexive thematic analysis on the survey data, using an inductive approach where themes were developed based around the content of the data [Braun and Clarke, 2006, 2019]. The first and second researcher (i.e. Weihua Zhang and Dr Simon Jones) familiarised themselves with the data before they independently reviewed and coded its content. Coded elements were clustered into initial themes around patient expectations and concerns relating to the collaborative use of self-tracking data. These were developed into candidate themes before the review and refinement of the final themes. Transcripts of the follow-up interviews were not included in the thematic analysis due to the fact that interview questions were formulated around the themes. Inclusion would risk compromising the inductive nature of the analysis, instead we use quotes from the interviews to elaborate and contextualise the final set of themes we have developed.

5.4 Results

Participants rated the importance of having conversations about self-tracking data with the provider during check-up appointments on a Likert rating scale (from 1 - not at all important to 5 - extremely important). The majority of participants believed that it is *"extremely important"* (53.1%) or *"very important"* (29.7%) to discuss self-tracking data. We identified seven major themes in total, theme 1 to 3 reflect patient expectations for providers and their use of self-tracking data: *assist clinical activities to improve treatment provision*, *understand lived experience to provide timely support* and *collate patient data to generate cohort insights*. These themes reflect axSpA patients' views on the roles providers should play when using and discussing self-tracking data during clinical appointments, when and how providers should use and analyse the

data, what aspects of the data providers should focus on as well as the desired outcome of the collaboration. Theme 4 to 7 relate to patients' concerns about sharing and discussing self-tracking data: *selective disclosure and lack of control over data-sharing*, *rushed appointments and engagement issues*, *scepticism around provider's data-using expertise* and *lack of rapport and feedback loop around self-tracking data*.

5.4.1 Theme 1: Assist Clinical Activities to Improve Treatment Provision

Participants reported three main expected uses of self-tracking data by providers during clinical appointments, relating to evidence gathering, disease status/intervention monitoring, and treatment planning. Each type of use overlaps with clinical activities typically found in axSpA check-up appointments, such as preparation, where providers monitor and review patient's disease history; evidence gathering, where providers collect data about the latest disease activity and intervention, as well as treatment planning, where providers review and decide on the course of action [Hue et al., 2019]. These expected uses appear to be interconnected in a cascading manner and which reflects the typical flow of axSpA check-up appointments.

Improve Practice of Evidence Gathering

Currently, providers use rapid-fire questions to collect information about recent disease activity (e.g. *"how was your sleep?"*, *"have you recently experienced any flares?"*) [Hue et al., 2019]. Several participants pointed out the limitations of this method of evidence gathering relate to the conveying the bigger picture with regard to disease activity: *"I'm often asked 'so how is your condition?' - it's a very binary question when the truth is that it's a profile of responses"* (P25). Others reported memory-related issues such as recall bias and forgetting, believing it could lead to the reporting of inaccurate data. P33 stated that recalling symptoms during clinical appointments *"is a snapshot of how a patient has been in the last week and may not be accurate as the individual doesn't necessarily remember how they have been feeling"*. Similarly, P61 who stated that *"I am not at all objective with symptoms at appointments"*, commented further during the follow-up interview: *"if you haven't seen anybody for a very long time, when you go in, everything's dreadful and probably there has been light and shade in the last year or so"* (P61).

Many participants suggested that, instead of relying on on-the-fly recollection of symptoms, use of self-tracking data would provide more accurate information about disease activity: *"[self-tracking] symptoms before appointments to give clinicians accurate in-*

formation" (P112). P47 and P91 similarly stated: *"Daily data from tracking is accurate information to work from. Trying to remember your circumstances over 6 months does not produce accurate information"* (P47), *"[self-tracking data provides] reliable info about pain, fatigue, exercise is more useful than biased memory"* (P91), *"[to report] how axSpA has been between consultations rather than the day they see you"* (P70). Some participants even suggested that providers should leverage self-tracking data to keep themselves up-to-date with regard to patients' health conditions prior to the clinical appointment: *"I would expect them to at least review them before an appointment"* (P82), *"To pre-brief themselves before I arrive for a check-up"* (P25). However, some participants were sceptical about using certain self-tracking data to facilitate evidence gathering due to its subjective nature: *"[I] can put today I feel really horrible, I think I'm a 6 out of 10, but then in two weeks time I'm feeling horrible again, I feel 6 out of 10, but is that the same as the feeling I had two weeks ago?"*, *"I use it more for myself [rather] than to present to doctors how I'm doing"* (P65).

Monitor Disease Status and Interventions

Some participants believed that providers' close monitoring of disease status was a crucial element in the treatment of their conditions: *"treating my condition is a two-way process. The consultant monitoring and myself doing a lot of what I am asked to do"* (P47). However, some were frustrated with providers' current disease monitoring practices: *"nowadays they rarely take a history so this would force them to do so"* (P67), *"They can't help me if they don't have all the historical trends"* (P99). Many participants reported an expectation for providers to leverage self-tracking data for the monitoring of disease status: *"for monitoring progression of disease"* (P77), *"as part of monitoring the disease and my progress or otherwise"* (P104), *"to monitor the situation"* (P106). Others suggested the use of self-tracking data in the monitoring of self-management efficacy: *"keep professionals up to date when you are currently on track with your health"* (P100), *"[to know] how well the patient is managing their condition"* (P33), *"so that my physician can hold me accountable"* (P78).

We also found that there was an expectation for providers to monitor the effectiveness of interventions (e.g. medication, stretch exercises) through self-tracking data: *"to check the value of interventions"* (P97), *"they can see what's working and what's not"* (P78). Specifically, responses focused on the monitoring and evaluation of the impact and effectiveness of medical interventions: *"to monitor the impact of changes in medication"* (P25), *"hopefully to help educate them about side effects"* (P84). Similarly, P6 stated *"if there has been a change in medications, or other management it's important to*

evaluate changes to disease activity". P8 who recorded disease activity data said they would *"relay this information to my healthcare team and to help me track progress when put on new meds"*, hoping it would be used by providers to *"identify what does and does not work for me in relation to medication and lifestyle"*. P98 stated *"It should be used to determine the efficacy of the medication I'm on, and to suggest any courses of action"*, linking monitoring to the development of action plans.

Inform Treatment Decisions and Action Plan

The third expectation participants reported is for providers to use self-tracking data to inform decisions related to treatment: *"To assist in treatment plan, changes in medication or physical therapy as needed"* (P53), *"Help inform treatment and advice given at appointments"* (P66). Many suggested that providers should use self-tracking data to plan, adjust and personalise treatment which addresses patient needs: *"I would like them to review/adjust levels of medication, identify triggers and alternative treatments specific to me"*. Others reported the expectation for providers to offer self-management advice and action plans based on their data: *"To provide advice on what I can do to optimise management of my condition"* (P25), *"This is to show how it's progressed or regressed. It will help assist with a plan of action"* (P32). One participant reported the desire for providers to offer treatment options based on their data: *"For advice on management, and modification of medications and access to other services such as hydrotherapy, physiotherapy"* (P6). P29 reported that they would also like to see artificial intelligence used to help treatment planning based on self-tracking data: *"ideally would feed into AI with the best treatment plan (e.g. exercises, medication, tapering advice)"*.

Additionally, participants demonstrated good tacit understanding of the clinical activities involved in axSpA check-up appointments. Many pointed out the links between evidence gathering, disease status monitoring and treatment planning: *"...to be able to monitor more effectively my treatment and alter accordingly"* (P69), *"My doctor can use this information to see how controlled my symptoms are and therefore whether to recommend and change in medication or lifestyle"* (P4). P46 emphasised on the connection between disease monitoring and medicating, suggesting that providers should use self-tracking data *"to assess my fitness level and therefore manage my axSpA in conjunction with prescribed medication which also stops pain and enables exercise"* (P46). P11 believed that better evidence gathering will lead to better decisions regarding treatment, stating: *"The more they know about my personal condition, the better treatment and medication control can be administered"*.

5.4.2 Theme 2: Understand Lived Experience to Provide Timely Support

The second theme describes the expectation for providers to pay attention to and understand the lived experience of patients through the collaborative use of self-tracking data. Lived experience in the context of axSpA refers to its impact on patients' physical and mental well-being as well as how patients cope with it on a daily basis. Many participants wished to convey such experience to their providers through self-tracking data: *"[to] convey the lived experience"* (P101), *"for them to understand how these diseases affect daily life and how patients cope"* (P65), *"I certainly hope they will find it helpful to know how the patient is coping and living with the condition"* (P31), *"for them to understand the struggles that I have"* (P89). Many participants expected better support and encouragement from providers with regard to their mental health through sharing and discussing self-tracking data: *"to discuss emotional health"* (P107), *"just wish to discuss the emotional/mental side of the condition and the effect it has"*, *"encourage more for emotional support"* (P106).

However, participants reported difficulties with regard to documenting and conveying their lived experience and personal struggles. P28 stated that *"there is a real feeling of nobody understanding and as a result, an unwillingness to discuss with anyone"*, and that self-tracking provided *"a good mapping tool to see how I am feeling mentally"*, hence it was *"very important"* to discuss it with providers. Similarly, P105 also considered self-tracking to be an effective tool for documenting lived experience: *"otherwise how can they know how you're doing physically and emotionally"* (P105). Others suggested there was a lack of focus on patients' mental health during clinical appointments: *"There is not enough focus on AS affecting your mental health, I like them to be using the data to see how they can improve ways to support their patients in ALL aspects of their care"* (P60).

Many participants believed providers should offer support and advice on an as-needed basis, and that self-tracking data which reflects patients' lived experience could be used to determine when support and advice are most needed. P43 expressed the concern that patients' lived experience may not be communicated frequently enough, due to the low frequency of clinical appointments: *"Professionals need to understand how we patients deal with our condition more often than, say, a twice yearly consultation with a consultant"*. Similarly, P76 and P102 stated that: *"I would hope that they might be able to monitor patients and offer advice and support as required rather than the current yearly appointment"* (P76) and *"...to offer support or treatments at the appropriate time"* (P102). P66 stated that self-tracking data should be used by providers to *"help*

advice given at appointments or when I contact them if I'm unwell".

5.4.3 Theme 3: Collate Patient Data to Generate Cohort Insights

Participants reported the expectation for providers to collect and analyse the self-tracking data which they have shared alongside data from other patients. P73 and P36 suggested that cohort insights derived from self-tracking data should be fed back to the care given to individuals with the disease: *"If providers can see the data collected, there may be something new or different that could be applied to an individual's disease"* (P73), *"for research conclusions to be fed back"* (P36). Participants expected the analysis of collated self-tracking data to inform specific areas of the treatment, such as lifestyle choices: *"would be good if they could support us with healthy lifestyle choices that are proven good by self-tracking data"* (P44), *"I would imagine it would be collated with that of other axSpA sufferers to form a study to try and find helpful and unhelpful lifestyle choices"* (P4). Other participants expressed interest in managing their disease activities, such as pain and flares, using data insights that were fed back: *"It's a HUGELY important data source that we should be tapping into, especially for managing axSpA"* (P25), *"[to be used] for research and help with control and management of condition and flares"* (P5), *"...anything that will help me and others understand how to react to pain levels, fatigue and stress"* (P78).

Additionally, many participants expected their providers to collate and compare their self-tracking data with other patients who belonged to a similar or different patient group: *"To be used by comparing with other participants"* (P36). P43 expressed the desire for providers to compare their data with patients from similar demographic background and disease status: *"maybe they will compare my data with others of a similar age and degree of axSpA"* (P43). On the other hand, P73 appeared to be interested in understanding the disparity between patient groups: *"To see the difference between people, male, female, activity, same job types"* (P73). P102 believed that making comparisons between patients' self-tracking data could provide potentially valuable information for providers and their decision-making related to treatment.

Many participants reported the expectation for providers to gather and use patient self-tracking data for the benefit of the wider axSpA community, rather than just the individual subject of the data: *"To improve services and treatment for all with the disease"* (P88), *"The more that can be tracked the better possible outcome for me and others"* (P73). There was a general assumption amongst participants that data shared with providers would be used to aid research: *"with a live stream of data from thousands of users, research could be massively sped up and enhanced"* (P25). Several

participants expected the outcome of said research to be useful to other patients: *"To aid research and benefit everyone in a similar situation to myself"* (P28), *"To inform others in relevant areas and generally support other AS patients"* (P34). These expectations appeared to be based on the collation and analysis of self-tracking data on the cohort-level. P58 commented on a specific patient community which could benefit from cohort-level insights: *"could help with understanding impacts for women greater, better understanding of monthly cycle to pain management"*.

5.4.4 Theme 4: Selective Disclosure and Lack of Control over Data-Sharing

The survey revealed patient concerns with regard to the lack of control over the sharing of self-tracking data, characterised by selective disclosure, whereby patients choose what aspects of the data they wish to share with providers based on perceived usefulness and sensitivity. We asked participants to rate how comfortable they felt about sharing the following categories of self-tracking data: disease activity, adherence to medication and exercise, lifestyle, mental health/mood and diary entries on a Likert scale (from 1 - very uncomfortable to 5 - very comfortable). The results (see Figure 5-1) suggested that the vast majority of participants felt relatively comfortable with sharing and discussing self-tracking data with providers across all categories: *"My consultant already discusses my case with other consultants for advice or confirmation. Having tracking data being shared would be no different"* (P60), *"No worries about discussion"* (P21), *"I would not track if I was concerned"* (P104).

However, several participants expressed concerns about sharing and discussing certain categories of self-tracking data with providers. Many participants reported having neutral or negative feelings about sharing subjective data which could be susceptible to fluctuations. P93 expressed scepticism about the usefulness of their mental health data: *"my mental health data fluctuates through a day. In good [health] overall but may not be a useful data point"*. Similarly, P78 believed that their fluctuating perception of disease activities could undermine the validity of reporting: *"I think my notes are stupid, you feel really bad one day so write how bad the pain is, then when you go it sounds silly if you are having a better day"*. The responses also highlighted how perceived data sensitivity could influence patients' willingness to share and discuss certain categories of self-tracking data. P6 suggested that sharing information about one's lifestyle would feel intrusive. Many participants reported the reluctance to share and discuss diary entries which contains private thoughts and feelings with providers: *"Personal diary entries could contain private thoughts I do not want to share"* (P91),

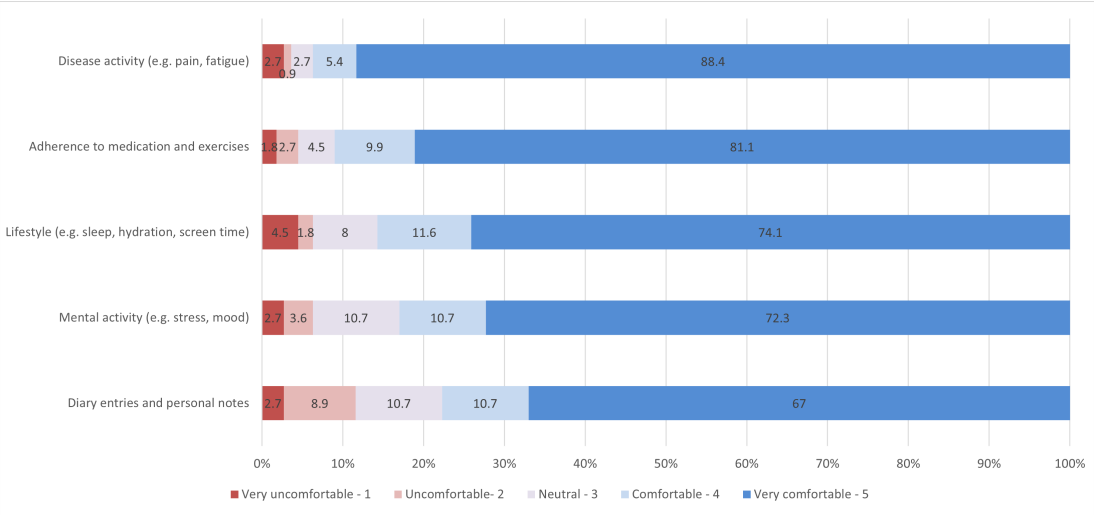


Figure 5-1: *"How comfortable do you feel about sharing the following types of self-tracking data with your healthcare professionals? Please rate from 1 - very uncomfortable to 5 - very comfortable"* (numbers show percentage of participants who gave specific ratings, N=112).

"Might be too personal" (P57), *"The diary is for me"* (P97). Overall, fewer participants reported feeling *"very comfortable"* with sharing diary entries (67.0%) compared to data categories which focus less on personal feelings such as disease activity (88.4%) and adherence (81.1%). P112 felt the need to keep providers satisfied through consistent self-tracking and was hesitant about having discussions due to the fear of being judged over poor adhesion: *"If the information is not kept up to date it may look as if you are not interested in successfully managing your symptoms"*.

In addition, we noticed a distinction between the reluctance to share the data and the reluctance to discuss the data, as they are not always equivalent to one another. P4, who felt *"comfortable"* sharing diary entries found it difficult to discuss it in person: *"I find it much more personal and more difficult to discuss thoughts and feelings than to discuss empirical external facts about my life"*. Similarly, P21 who reported feeling *"comfortable"* with sharing adherence data expressed concerns over having in-person discussions: *"I adhere to my medication, but don't adhere to my exercise and stretches as much as I should"*. One participant who found in-person discussions difficult suggested that they might feel more comfortable discussing mental health/mood data with providers if they had taken time to familiarise themselves with the data prior to the clinical appointment: *"it might make it easier to talk about stress and mood if they have seen the stress levels"* (P78).

In addition to the selective disclosure of self-tracking data, participants also reported the need for more control over the sharing of data with providers, specifically, how to share and who to share it with. Many participants suggested that sharing of self-tracking data should be autonomous and a personal choice: *"I would want to choose whether I share or not"* (P112), *"I think it should be a consumer driven process that gives clients back some autonomy"* (P64). P12 reported that informed consent with regard to what to share should be acquired from patients prior to sharing: *"Fine to share, but would want to consent to specific data points being shared rather than doing so as norm"*. P64 wished to control how data is being shared, stating *"I'd prefer to show them the data myself or be able to email it to them"*. P64 also suggested that sharing of self-tracking data should remain private between patient and the professional unless otherwise agreed upon: *"patients should have the option to opt in or out of medical record sharing across providers"*. P86 made a similar statement: *"I would like to choose when and how I share my data with others"*. Furthermore, transparency regarding the collection and handling may provide peace-of-mind for those who have hesitations about sharing: *"Supportive, provided I know what is being tracked, who can access the data and that adequate confidentiality arrangements are in place"* (P42). P25 made a similar remark about the lack of transparency during the follow-up interview: *"I don't have any clarity around how my data is being managed. In fact, it just seems to be emailed across"*.

5.4.5 Theme 5: Rushed Appointments and Engagement Issues

A further theme in our data reflects how rushed schedule and provider disengagement could impact participants' desire and ability to share and discuss self-tracking data. Participants expressed concerns over the time limitation associated with clinical appointments and its impact on the collaborative use of self-tracking data: *"I don't have worries about discussion, but not sure where they would find the time to discuss it"* (P21), *"Generally, the time will not be available during clinical appointments"* (P71), *"...time with consultant are limited"* (P100). Patients who have infrequent interactions with providers found it even more difficult to discuss self-tracking data during these clinical visits: *"It's hard to discuss all of the symptoms, how much pain it causes, the fatigue, side effects and mental health... the list is too big when appointments are months apart"* (P80). Consequently, this limits the amount of information which could be shared with providers during clinical appointments: *"when you only see specialists periodically, it can be stressful to give all the information you want into a short period of time, even with notes. This leaves little time for questions"* (P96). Furthermore, the additional pressure associated with rushed appointments may limit participants'

ability to formulate questions related to their self-tracking data and priorities topics for discussion: *"Clinic appointments are rushed, you forget to ask questions and focus on what is actually the main concern... the time was not constructive at all"* (P61). Some participants expressed sympathy towards the stress and added pressure providers face with regard to using and discussing patient self-tracking data during clinical appointments. However, this did not make them more willing to share their data: *"You also have to have total trust in your health care professional which can sometimes be very difficult if they are short of time and stressed themselves"* (P112), *"The professional I saw was overworked, short in patience"* (P110). The perceived time constraints associated with clinical appointments had discouraged some participants from sharing their self-tracking data: *"Didn't think they would have time to do something like that so have always just viewed it as a thing that helps me remember and not as something they would use"* (P14).

Some participants who had shared, or attempted to share and discuss their self-tracking data reported a lack of engagement and interest from their providers: *"lack of apparent interest by GP/others besides myself in results"* (P39), *"I wish they would be more receptive to it (self-tracking data)"* (P7). P67 attempted to share and discuss their fatigue data with their provider but was met with little attention: *"Yes... [but] fatigue levels are something clinicians don't seem interested in"*. Likewise, P25 who shared their self-tracking data with the provider through email received no feedback or response: *"I sent it to my assigned medical professional who doesn't appear to be using it"*. The participant elaborated during the follow-up interview, stating: *"[There was] very little use of the data in these sessions which therefore means the data is not valuable or they don't care about it"* (P25). P98 suggested that their provider held a potentially dismissive attitude towards patients' first-hand experience: *"I often feel that professionals, especially consultants, tend not to listen to my first-hand experiences and just decide what is best somehow alone... I believe they think patients have a tendency to exaggerate"*. P99 also believed that providers held bias against patient self-tracking data in favour of validated outcome measures: *"There hasn't been much interest in discussing my tracking. They use only the blood tests and tests made in clinic"*. One participant theorised that the lack of treatment options may have contributed to providers' lack of interest in using self-tracking data: *"The actual interventions are quite limited and therefore don't need rich patient-centred data, NSAIDs or not, TNAs or not, a bit of physio, and a photocopy of exercises"* (P97). One participant reported that the provider who instructed them to begin self-tracking had in fact never made apparent use of the data: *"I presume they want to discuss it - I was asked to use the thing. Have not had an appointment yet where this has been referred to"* (P104). P2 suggested that they would

be more engaged with self-tracking had their providers made better use of the data: *"I would happily do more self-monitoring if my rheumatology appointments asked about this. They have not discussed this with me and the appointments are rushed/they are very busy"* (P2).

5.4.6 Theme 6: Scepticism around Provider's Data-Using Expertise

Many participants reported feeling sceptical about providers' knowledge and expertise in regard to using and analysing patient self-tracking data. Some participants expressed concerns over providers' lack of training regarding the use of patient self-tracking data: *"even if it is collected I would be concerned they wouldn't do anything with it due to lack of education"* (P29), *"[I'm not sure] how much value would it really give above my 'gut instinct"'* (P21). Issues caused by the lack of experience in handling patient self-tracking data could be exacerbated by rushed appointments: *"They are surprised with my data, and they try to find the data, and they can't find it and we spent the last... cause you only get a 15 minute windows essentially... it's not high on the priority list for me to educate them on the use of the data"* (P25). Participants' perception of the provider's ability to use and analyse self-tracking data appears to be also connected to the position held by the health professional. Many participants considered specialised providers (e.g. consultants, psychotherapists) to be more qualified than GPs and locums when it comes making use of patient self-tracking data: *"I do not trust all providers because axSpA is a very specific disease GPs aren't very confident about"* (P86), *"I don't mind necessarily, to share with physiotherapists or someone who's more involved in the exercise"* (P65). Similarly, P39 suggested that although they were willing to share self-tracking data with GPs as a *"reporting tool"*, they would rather have discussions about the data with a consultant rheumatologist.

Participants also reported concerns about the potential misuses of patient self-tracking data in the hands of unqualified or inexperienced providers. P101 pointed out the possibility of correlations which may exist in self-tracking data leading to false assumptions during the diagnostic process: *"Given how poor diagnosis is for axSpA (Occam's razor), I think there is too much risk of correlation being mistaken for causation"*. P67 raised a similar point: *"I don't mind [sharing] but am sceptical about 'evidence-based' findings, e.g. 'The grass is green therefore writing that green is grass' type of science"*, while highlighting the limitation of self-tracking data with regard to accuracy: *"They are useful as long as they are not relied upon as definitive evidence"*. One participant expressed concern that providers may become overly reliant on patient self-tracking data when it comes to decision-making: *"[for providers to only] look at data instead of*

taking a holistic approach to this disease as not everyone follows the same path" (P96). P65 suggested that self-tracking data could be misinterpreted by providers without understanding the relevant context, *"It's very hard to share the whole picture, to make them understand what was going on for the whole time"*. The participant gave a detailed example during the interview: *"if you look at my watch and my phone, it says I rode over an hour, I did 10 miles on my bike... It was really painful and it was very, very difficult to do. But if I shared that information with the doctor, all they'll see is that I've done 10 miles, and to them, 'Oh my god, you can do that. You're perfectly healthy. You don't need anything from us"'* (P65).

5.4.7 Theme 7: Lack of Rapport and Feedback Loop around Self-Tracking Data

Our survey highlighted the importance of good patient-provider relationships and feedback loops in the use and discussion of patient self-tracking data in the clinics. Participants suggested that having long-term professional relationships with their providers is necessary for treating and managing their chronic conditions, that collaborations around self-tracking data should reflect it: *"[to] emphasise that it's a long-term condition which is managed in partnership between patients and clinicians"* (P66), *"I have always found discussion with my rheumatologist and physiotherapist an important part of my ongoing treatment"* (P34). However, the absence of established patient-provider relationships can be a hindrance to the discussions around self-tracking data, as many participants reported feeling uneasy about discussing self-tracking data with unfamiliar professionals: *"[I] want to have a long-term professional relationship with my specialist. [It is] uneasy to have new specialists pretend to know me from my data"* (P13). Similarly, P61 reported feeling less comfortable about discussing mental health data with unacquainted professionals: *"I wasn't necessarily seeing anyone very regularly. Maybe once a year, I just didn't feel it. It wasn't the right environment to talk to them about it"*. P61 elaborated on this during the follow-up interview, stating that *"I hadn't before because I didn't feel I was able to, but I think the consultant that I have now... I definitely would speak to her"*. Poor existing patient-provider relationships could also prevent from sharing and discussing their self-tracking data. For example, a patient reported having negative professional relationship with their providers, describing them as *"dismissive"* and *"short in patience"* suggested that it has made her reluctant to discuss self-tracking data with said individual: *"If the same attitude was taken to myself tracking data I wouldn't want to discuss it, yet it should be an important tool, in the right hands"* (P110).

Participants also reported a lack of feedback loops around self-tracking data, whereby data shared with providers was not reciprocated with relevant insights or feedback. Some participants have reported feeling frustrated with the lack of feedback after sharing their self-tracking data: *"I never saw any data come back and no tracking or analysis of data occurred apart from a comparison with my most recent score"* (P25). During the follow-up interview, P25 suggested that it was vital for patients and providers to establish a *"data cycle"* around self-tracking data, stating: *"It shouldn't be a data black hole. It should be there to enable conversations"* and *"enable the user to value the data being collected and take positive action as a result of what they are presented with"*. Similarly, P65 linked low self-tracking engagement to the lack of feedback received from providers: *"I haven't used it enough. Because my providers, my consultants were not looking at the information, I haven't spent the time using the application"*. Contrarily, several participant reported positive experience in the use and discussion of their self-tracking data where providers offer data insights and feedback: *"[It] showed worsening symptoms which correlated with growing antibodies to drugs" (P66), "we can bounce ideas off of each other"* (P81), "[It] led to a useful discussion around walking aids and podiatry" (P91).

5.5 Discussions and Design Implications

The study found three major themes delineating patient expectations for providers and their use of self-tracking data in axSpA clinics, alongside four themes related to patient concerns regarding the collaborative use of self-tracking data. While previous research focused on the observation of collaborative behaviours between patients and providers when using and discussing self-tracking data (e.g. [West et al., 2016]), our study provides a deeper understanding of patient priorities when it comes to using and discussing self-tracking data during clinical appointments. This study also highlights the gaps between patient expectations and the reality of healthcare providers' current use of self-tacking data, which is often limited by the lack of resources and understanding of patient needs. Future research on the collaborative use of self-tracking data should acknowledge patient expectations and concerns so that design recommendations could be steered in the direction which benefits both patients and healthcare providers. We discuss potential implications of each theme identified in the study with regard to the design and development of future technology which support the collaborative use of self-tracking data in the clinics.

Assist Clinical Activities to Improve Treatment Provision

Our study showed that axSpA patients have good tacit understanding of the clinical activities typically involved in a check-up appointment in general, as evidenced by their reported expectations for providers and their use of self-tracking data. Instead of shifting the focus of the appointments towards the discussion of self-tracking data, patients reported the expectation for providers to use their data to assist and supplement existing clinical activities, such as evidence gathering and treatment planning, coinciding with provider perspectives on the clinical use of self-tracking data [Hue et al., 2019, Zhu et al., 2016]. However, it is possible for patient expectations to be influenced by perceived constraints related to the clinical routine, e.g. rushed appointments, thus limiting the use of self-tracking data beyond the current scope of existing clinical activities. We discuss the impact of rushed appointments in later sections. In the meantime, designers of tools which support the clinical use of self-tracking data may wish to develop features which target specific individual clinical activities (e.g. action planning), allowing easy navigation from one activity to the next through the design of a data dashboard interface layout (e.g. panels and sections) and use of interactive visual components (e.g. tabs, menus). To reduce visual complexity and combat the potential issues related to information overload, each area of the interface could have their own set of visualisations and statistics that are most relevant to its respective clinical activity, such as the use of line chart for showing the variation of condition severity while highlighting the efficacy of medications during action planning stage of the check-up appointment.

Many patients advocated for self-tracking data to be used at increased capacity during the evidence gathering phase of the consultation, suggesting that recorded data about disease activity and self-management behaviours would be more reliable than memory, therefore addressing issues such as recall bias [Schmier and Halpern, 2004, Shiffman et al., 2008]. While this was a prevalent view among participants, some were sceptical about relying solely on the use of self-tracking data for evidence gathering, echoing providers' concerns about data quality and the lack standardisation [West et al., 2017]. Consequently, no participants suggested that self-tracking data should be considered a replacement for validated clinical outcome measures, such as blood tests, x-ray and MRIs. However, self-tracking data in its current state could still serve as a memory-aid which helps patients recall data about their conditions since the previous clinical visit. Designers may wish to experiment with tools which integrate self-tracking data with existing clinical data categories (as outlined in Hue et al. [2019]) to improve the speed of evidence gathering.

Furthermore, patients expected providers to monitor certain aspects of their conditions (e.g. disease status, self-management behaviours) more closely through the disclosing and sharing of self-tracking data. The findings also reflect patients' desire for providers to keep better records of the progression of their diseases so that the information could be brought forth and utilised during clinical appointments. Additionally, some patients demanded more accountability and positive reinforcement with regard to their self-management practices whereby good behaviours are recognised and acknowledged by the provider. This offers designers the opportunity to explore features which facilitate the use and representation of historic self-tracking data (e.g. graphs showcasing how the patient's outcome measures changed over the years) as well as evaluation of the patient's self-management behaviours (e.g. highlighting good self-management behaviours such as increased exercise frequency from the previous year using a dual bar chart).

Understand Patients' Lived Experience to Provide Timely Support

Our study revealed that, despite providers' growing interest in self-tracking data which captures patients' subjective experience in living and coping with the disease, discussions rarely took place during real-life clinical appointments. Many participants reported feeling dissatisfied with providers' lack of attention to patients' struggles and emotional well-being during check-ups while others expressed the desire to share their lived experience more frequently and routinely. Nonetheless, participants reported feeling somewhat optimistic about the potential role self-tracking data could play in conveying their disease experience to providers and bringing attention to their mental and emotional needs. For those who seek support and encouragement from providers, bringing up their lived experience and emotional well-being during clinical discussions could sometimes be a challenge due to the sensitive nature of these issues. The sharing of self-tracking data provides a new way for patients to communicate their lived experience without the pressure of having to express it verbally. It also gives providers the opportunity to play a more active role in eliciting and attending to patient needs with regard to psychological and emotional support. For example, consistent low mood scores may be highlighted to draw attention from providers and allow them to notice issues regarding the patient's mental well-being, thus leading to relevant discussions during the appointment. Designers may wish to develop features which help identify and highlight irregular mental activities based on patients' self-tracking data (e.g. flagging, push notifications) and allow providers to view them prior to an appointment. Healthcare institutions may also wish to invest in digital platforms which enable more frequent sharing of patient self-tracking data so that professionals could be notified when patients experience mental distress caused by flare-ups or worsening conditions

and offer timely support.

Collate Patient Data to Generate Cohort Insights

Our study showed that axSpA participants expect providers to analyse their self-tracking data and acquire useful data insights, thus informing decisions with regard to the treatment of individual patients. Additionally, there was also the expectation for healthcare providers to collect and collate patient self-tracking data on the wider cohort level. Previous studies suggested that when aggregated and analysed on a cohort level, patient self-tracking data could provide valuable insights which help address long standing questions regarding chronic conditions and develop new understandings around public health [Dixon et al., 2019, Sohda et al., 2017]. For example, cohort analysis of axSpA patients' self-tracking data may reveal the impact demographic factors (e.g. age, gender, occupation) have on the efficacy of certain treatments (e.g. medication, physiotherapies) or lack thereof, hence inform clinical decision-making. Participants expected providers to leverage such insights from said analysis to improve and personalise their own treatment. Moreover, many participants expressed the desire for providers to make peer comparisons based on their self-tracking data, e.g. comparing exercise level with patients from similar disease and demographic backgrounds.

Despite patient enthusiasm for supporting cohort analysis through the sharing of self-tracking data, the current reality of health research and providers' handling of patient-generated data poses real challenges to this proposition. To ensure the validity and rigour of research, studies which involve cohort analysis of patient self-tracking data need to have strict criteria regarding data collection (e.g. devices used, patient demographics). Since the manners in which patients share their self-tracking data with providers can be spontaneous and varied (e.g. sending unprocessed data through email, bringing printed copies of data to clinical appointments), providers are often given data of unknown quality which may fail to meet the minimal standards of quality for statistical analyses [Zhu et al., 2016, West et al., 2017]. Compounded by the lack of expertise and tools that are necessary for aggregating and analysing self-tracking data, providers are likely to struggle with meeting such expectations from patients. Health providers should aim to increase transparency with regard to current limitations in the analysis of self-tracking data through better communications with patients who wish to share their data, therefore prevent patients from having unrealistic expectations. Meanwhile, existing self-tracking apps which specialise in chronic conditions may wish to experiment with features that allow patients to compare data with others who are using the app, e.g. showing percentile in activity level. Nevertheless, unsupervised and

unguided use of peer comparison features may lead to cause stress or other negative emotions among patients (e.g. when patient scores lower than the average). Designers may wish to work with providers to develop systems which enable the shared use of individual-cohort comparison features during clinical discussions so that providers may better address any concerns patients may have.

Selective Disclosure and Lack of Control over Data-Sharing

We found that while most participants reported feeling comfortable with sharing and discussing self-tracking data such as disease activities and physical activities, concerns were raised about the sharing of sensitive information reflecting patients' lived experience and emotional well-being, such as mental health data (e.g. stress, mood), personal diary and lifestyle data. Some participants questioned the rigour, usefulness and relevance of these types of subjective data which are susceptible to personal biases and inaccuracies in its measurement and collection. In addition, patients' selective disclosure of data could be attributed to the fear of being judged by providers on the basis of their adherence to self-tracking and self-management. Furthermore, patients who shared mental health data may find it difficult to have face-to-face conversations about their stress level and personal struggles with regard to the management of the condition. We found that patients' willingness to discuss data regarding mental health could be determined by provider's review and familiarisation with said data prior to clinical appointments. This warrants investigations into designs which allow providers to view patients' mental health data prior to clinical encounters, enabling them to take a proactive approach to addressing patient concerns and issues related to self-management. However, this will be predicated on the development of a platform which supports the remote, asynchronous sharing of patient self-tracking data prior and after clinical encounters.

Due to the aforementioned issues related to the selective disclosure of data and concerns about discussions, patients wished for better transparency and control over the sharing of self-tracking data with providers. Although most patients seemed to have a high degree of trust in providers' ability to safeguard their personal data, some raised concerns about the lack of security features and encryption which protect the sharing of data, as emailing remained as the primary option for patients who wish to share their self-tracking data [Zhu et al., 2016]. Providers may wish to explore technological solutions which facilitate data-sharing between patients and providers in a secure and organised way, such as licensed health apps which enable data upload directly to providers' server in a secure and encrypted manner, e.g. MySpA [Barts Health NHS

Trust, 2021] and Talking AS [Carroll et al., 2014]. In response to patients' desire to control which provider(s) are able to access and view their self-tracking data, privacy options should be made available to those who may wish to share, such as substituting broad consent with dynamic consent which allows patients to customise sharing preferences with regard to providers' and third-party access to the data [Spencer et al., 2016, Kaye et al., 2015, Steinsbekk et al., 2013].

Rushed Appointments and Engagement Issues

Although situational constraints such as limited consultation time and rigid clinical routine were identified as major obstacles to the clinical use of patient self-tracking data from a provider perspective [West et al., 2016, Hue et al., 2019], little is known about the impact they may have on patients who wish to share and discuss their data. Our findings suggest that perceived limitations regarding consultation time could negatively influence patients' desire and decision to share and discuss self-tracking data before and during appointments. Participants reportedly experienced difficulties regarding the use and discussion of self-tracking data due to rushed appointments (e.g. low rate of information exchange, failure to address important topics, limited opportunity to ask questions), which in some cases led to patients' reluctance towards sharing. While the inclusion of self-tracking data by may speed up the process of evidence gathering and improve the overall efficiency of clinical appointments, it is only made possible by patients who feel encouraged to share their data. Designers of tools which support the clinical use and discussion of self-tracking data may wish to develop interactive features which facilitate the elicitation of patient agenda, such as enabling patients to highlight important topics for discussion and assign them priority ratings, thus motivate patients to share their data with providers.

Moreover, patients' perceived lack of interest from providers and dismissive attitudes towards self-tracking data could further dissuade them from sharing and discussing said data during appointments. Many participants suggested that providers saw patient self-tracking data as irrelevant and unreliable information, resulting in reluctance to use and discuss it during appointments. Though it may be true to some extent, other factors such as time limitations and lack of training with regard to the use of self-tracking data may also contribute to providers' lack of willingness to engage in conversations with patients about the data. Healthcare providers should improve their communication with patients in order to establish realistic expectations regarding the use of consultation time for discussions about self-tracking data and address misconceptions surrounding their attitudes toward the clinical use of said data.

Scepticism around Provider's Data-Using Expertise

This study revealed numerous concerns which axSpA patients had about providers' expertise in using self-tracking data during clinical appointments. Overall, patients expect their providers to be equipped with the appropriate level of skills in regard to accessing and using patient data on a routine basis. However, participants reported that some providers lack proficiency in accessing patient self-tracking data during check-up appointments. Additionally, some patients were more willing to share data with certain types of providers than others, namely those who were more specialised in condition, such as consultants and physiotherapists. Furthermore, participants reported concerns about the potential misuse of self-tracking data in the hands of inexperienced providers who are perceived as ill-equipped to analyse the data, particularly during the processes of decision-making, e.g. mistaking correlation for causation, missing the bigger picture due to over-reliance on self-tracking data. Similarly, actionable insights derived from self-tracking data, e.g. exercise targets, may not be the best or most practical/attainable suggestion in terms of improving patients' overall disease experience. Designers may wish to develop features which allow patients to highlight the impact action targets may have on their lived experience to facilitate the setting of realistic targets, e.g. exhaustion from exercise, side effects of medications etc. Overall, patients expected providers to possess the expertise needed for correctly using self-tracking data while avoiding its misuses. Healthcare institutions may consider introducing training programmes for providers whom patients may wish share self-tracking with (e.g. consultants, physiotherapist, dietitians) in response to concerns related to data-using expertise.

Lack of Rapport and Feedback Loop around Self-Tracking Data

Many participants believed that the rapport and mutual understanding between patients and providers play an important role in the ongoing treatment and management of their conditions. Therefore, the lack of collaborative relationship between patients and providers may negatively affect patients' desire to share and discuss self-tracking data during clinical encounters. Participants preferred sharing and discussing self-tracking data with individuals whom they have an established professional relationship with (as opposed to unacquainted providers), since they're more likely to trust the providers who are familiar with their disease history and past treatments. Through rapport-building, providers may reduce the unease patients feel when discussing sensitive data which reflect patients' psychological well-being and personal struggles in regard to the management of the disease. In reality, however, patients may not always have the option to speak with their assigned/preferred consultants during clinical

appointments. Providers and developers could potentially mitigate this issue by developing online platforms which allow patients to share and discuss their data with providers who they feel comfortable with through either synchronous or asynchronous communication, e.g. remote consultation, discussion board [Kim et al., 2009, De Jong et al., 2014]. The study also suggested that the establishment of effective feedback loop between patients and providers is essential to the fostering of better patient engagement with regard to the ongoing collaborations around self-tracking data. We found that patients who had shared self-tracking data through the use of provider-endorsed health apps (e.g. MySpA [Barts Health NHS Trust, 2021]) had the expectation of receiving useful data insights, but in reality, individual feedback was rarely given. Providers should aim to improve transparency in regard to the expected outcomes of using these apps to avoid unrealistic patient expectations. Meanwhile, designers have the opportunity to develop features which support the establishment of feedback loops between clinical appointment whereby the sharing of self-tracking data is followed by actionable insights.

5.6 Limitations and Future Work

This study has several limitations. We focused on axSpA as a typifying example of chronic conditions while investigating patient views on the collaborative use of self-tracking data in its clinical context. Although the types of patient-generated data we investigated were mostly related to axSpA, the expectations and obstacles we identified around the collaborative use of self-tracking data are not unique in the domain of axSpA. We expect that most themes identified in this study can be extrapolated and applied to other musculoskeletal conditions (e.g. rheumatoid arthritis) as well as other chronic conditions (e.g. irritable bowel syndrome, Parkinson's disease) which involve routine check-ups and patient self-management in their respective healthcare pathways.

A broad range of commercially available self-tracking tools such as wearable devices and smartphone apps are capable of capturing data that is relevant to the treatment and management of axSpA, such as disease activity, medication and exercise. However, other types of chronic conditions (e.g. neurological disorders) may have a stronger focus on information which is difficult to capture via current self-tracking technology, such as attention and mood swings commonly seen in attention deficit hyperactivity disorder (ADHD) and bipolar disorder. In these cases, the value of discussing self-tracking data during clinical appointments may be limited with regard to the treatment of individual patients. Nonetheless, sharing of self-tracking data may still aid research and provide cohort-level data insights which could then be fed back to individual patients. Future

work may also wish to explore patient perspectives in the context of other chronic conditions which will likely have their own, unique set of additional expectations and challenges with regard to the collaborative use of patient self-tracking data.

Our study focused on routine axSpA check-up appointments where most of the interaction between patients and their providers take place. We did not attempt to uncover and account for all clinical encounters and data-using scenarios in this research. There are other opportunities within the healthcare setting for patients to collaborate with their healthcare team outside of the clinical appointments, such as rehabilitation courses and physiotherapies. We anticipate different sets of clinical activities to be involved in these sessions as well as various types of providers other than patients' consultant rheumatologists, such as nurses, dietitians and therapists. In result, design of systems which aim to support the collaborative use of data between patients and their providers in other settings needs to account for a variety of data-using goals and accommodate different types of users. For example, physiotherapists may prioritise the use of data related to exercise and physical functions of patients over the discussion of mental health issues and use of medications. Future work is needed to explore further data-using scenarios in different clinical settings.

Our thematic analysis was limited to the qualitative exploration of common beliefs and recurring motifs amongst patients based on the survey responses. There will likely be individuals who hold alternative views on topics covered in this study and those which were not captured by the themes. The findings also did not account for individual differences (e.g. views on technology and data sharing, personality traits) which were not captured in our survey. In addition, most responses reflect patients' existing views and expectations regarding the collaborative use of self-tracking data in the clinics rather than actual experiences in regard to sharing and discussing data with providers which remained a relatively rare phenomena. Future work may expand the sample size to uncover and thematise other expectations and concerns patients may have regarding collaborative use and collect information which may elicit and explain individual differences among patient groups.

5.7 Study 3 Summary & Chapter Conclusion

In this study, we explored patient perspectives on the collaborative use of self-tracking data, i.e. joined use and discussion of self-tracking data between patients and healthcare providers in the context of axSpA. We focused on a realistic data-using scenario where collaborative use could naturally occur should patients share their self-tracking

data with providers, i.e. routine check-up appointments. We used an online survey and interview study to examine axSpA patients' perspectives on collaborative use. In doing so, we identified three themes regarding patients' expectations for providers and their use of self-tracking data, concerning different aspects of the treatment: *assist clinical activities to improve treatment provision*, *understand lived experience to provide timely support* and *collate patient data to generate cohort insights*. Four further themes in relation to patient concerns around collaborative use were identified, they are: *selective disclosure and lack of control over data-sharing*, *rushed appointments and engagement issues*, *scepticism around provider's data-using expertise* and *lack of rapport and feedback loop around self-tracking data*. Our findings highlighted the commonality between concerns patients and providers share in regard the clinical use of self-tracking data. Moreover, this study revealed the gap between patient expectations regarding providers' use of self-tracking data and the reality of its clinical use, highlighting a variety of issues concerning data quality, sensitivity, lack of expertise in data analysis an transparency issues surrounding providers' handling of patient self-tracking data.

This study contributes to the overall understanding of patient perspectives on the collaborative use of self-tracking data in the following ways. First, while previous studies focused on artificial data-using scenarios which allow patients and providers to freely explore and discuss self-tracking data, our study ground its setting in real-life clinical encounters, reflecting practical challenges such as time constraints and the added pressure of clinical activities. This allowed us to make more useful and realistic recommendations on potential ways to improve and facilitate the collaborative use of self-tracking data while acknowledging situational barriers related to the clinical encounters. Secondly, we directly investigated axSpA patients' expectations for providers and their use of self-tracking data during clinical appointments, providing a thorough and structured understanding of patient priorities, beliefs and concerns in regard to the use and discussion of said data. Finally, we offer practical recommendations regarding how to tackle issues identified in relation to each theme, using examples to illustrate and guide future design and development of technological tools to support the collaborative use of self-tracking data.

Chapter 6

Collaborative Use of Self-Tracking Data in Realistic Clinical Scenarios: A Qualitative Exploration

6.1 Chapter Overview

In previous chapters, we explored the potential roles patient self-tracking data could play during and around clinical check-up appointments, covering both healthcare professionals' and patients' perspectives. In this chapter, we investigate the use and discussion of patient self-tracking data in a realistic clinical scenario, namely the routine axSpA check-up appointment between patients and their consultant rheumatologist. This chapter aims to address the final high-level research question - **RQ4: What are the benefits and challenges associated with using patient self-tracking data in real-life clinical scenarios?** We address RQ4 via the CoUs-axSpA study (Study 4), a three-part qualitative field study which investigates axSpA patients' and clinicians' opinions and behaviours relating to the collaborative use and discussion of self-tracking data within the context of routine clinical check-ups. The findings of this study provide the much-needed clarity regarding the value of using and discussing self-tracking data in real-life clinical scenarios. We discuss their implications on the design of PI systems and self-tracking tools at the end.

6.2 Refinement of Research Question

As pointed out in our review of self-tracking and healthcare literature in Chapter 2, the clinical use of self-tracking data stands to benefit from the collaboration between patients and clinicians during the interpretation process [Chung et al., 2015, Mentis et al., 2016]. Nevertheless, numerous obstables exist when it comes to using and discussing patient self-tracking data in real-life clinical scenarios. Previous studies on healthcare providers' attitudes towards self-tracking data highlighted several practical issues regarding the clinical environment in which the data is to be analysed and used for the provision of patient care, such as data relevance [The Robert Wood Johnson Foundation, 2014, Murnane et al., 2018] and time constraints [Chung et al., 2015, West et al., 2016, Zhu et al., 2016, Hue et al., 2019]. Findings from Chapter 5 also shed a light on patients' reservations with regard to sharing and discussing self-tracking data in the clinical environment. Nevertheless, studies which aim to investigate the collaborative use of patient self-tracking data in the context of chronic conditions are often limited to fictional scenarios where the use of self-tracking data is examined outside of regular clinical activities such as the ones identified in the stage-based model of axSpA [Hue et al., 2019].

It is therefore highly important that we address this gap in the literature and examine the value as well as the feasibility of incorporating self-tracking data into the established clinical workflow, i.e. **RQ4: What are the benefits and challenges associated with using patient self-tracking data in real-life clinical scenarios?** Doing so will help us identify and address issues associated with the realistic use of self-tracking data in the clinics through the design of PISes. Currently, the use and discussion of this data have not become a natural and integral part of the clinical consultation due to concerns presented in Chapter 5. Our goal in this chapter is to investigate how conversations about patient self-tracking data could fit into routine check-up activities and understand the potential benefits and challenges associated with it. We therefore divide RQ4 into the following secondary research questions: **RQ4a: What existing clinical activities may benefit from having conversations about patient self-tracking data?**, **RQ4b: What value does having conversations about self-tracking data during check-ups provide for clinicians and patients?** and **RQ4c: What are the challenges associated with using and discussing self-tracking data during check-ups?**

6.3 Study 4 - CoUs-axSpA: Overview

CoUs-axSpA is a qualitative study which examines the use and discussion of patient self-tracking data a real-life clinical scenario - routine axSpA check-up appointment. The study combines various research methods such as online questionnaire, clinical observation and semi-structured interview to examine the independent review and joint review of self-tracking data before and during the check-up appointment. The aim of the study is to help us understand how the use of self-tacking data could fit into existing clinical workflow, how it adds value to the consultation as well as the practical challenges involved with regard to its clinical integration.

6.4 Ethical Approval

This CoUs-axSpA study is backed by the Royal United Hospitals (RUH) Bath NHS Foundation. It received ethical approval from the NHS Research Ethics Committee (REC) (see Appendix D.10) and Health Research Authority (HRA) (see Appendix D.11) (reference: 20/SC/0140, IRAS project ID: 271239) and the Research Ethics Approval Committee for Health (University of Bath) (reference: EP 19/20 045). The researcher received access approval from RUH/RNHRD and the necessary training for conducting qualitative research with NHS patients and health professionals prior to any remote and on-site research activities, including the Good Clinical Practice training (see Appendix D.12).

6.5 Method

The CoUs-axSpA study is a three-part qualitative study which consists of a pre-study questionnaire, clinical observation and a post-study questionnaire. The aim of the study is to help us understand how discussions and collaborations between axSpA patients and health professionals around patient self-tracking data would take place in a realistic clinical setting, specifically, the routine check-up appointments between patients who are diagnosed with axSpA and their consultant rheumatologists at RNHRD. These check-up appointments follow the clinical procedure outlined in Study 1 (see section 3.5), i.e. *preparation*, *evidence gathering*, *physical examination*, *reasoning aloud*, *action planning* and *wrap-up*.

6.5.1 Phase 1: Pre-Study Patient Questionnaire

Once the participating patients completed the consent forms (see Appendix D.6) and confirmed the date and time of the appointment, they will receive anonymised Project Nightingale data they have collected during the last 12-month period from the researcher via NHS email (see Appendix D.1.3). Patients' data is provided in various formats including raw datasheets, interactive visualisations and large still images (see Appendix D.2) to accommodate a potentially large range of data/technology literacy among participants. This is accompanied by a brief guide on how to make use of the data in preparation for the check-up appointment, alongside the link to an online pre-study questionnaire (see Appendix D.8) which focuses on patients' views on the use of their Project Nightingale data, e.g. *"Please describe how you have made use of the data that was sent to you"*, *"Has the review of data highlighted any issues you would like to discuss with your clinician?"*, *"What topics would you like to discuss with your clinician during the upcoming check-up?"*. The pre-study questionnaire would be filled in by patients prior to attending their check-up appointment, allowing them to review their self-tracking data and think about their upcoming conversation with the consultant rheumatologist. Patients are encouraged to write down any findings related to their analysis of the data as well as topics and issues that may be worth addressing during the check-up appointment. It was made apparent to them that the information would not be shared with their clinicians.

6.5.2 Phase 2: Clinical Observation - Joint Review of Patient Self-Tracking Data

Participating patients will attend their routine axSpA check-up appointment as per usual, either in-person or remotely depending on their preference. Participants are encouraged to discuss or reference their Project Nightingale data at any point during the appointment for as long as they need before the end of the consultation. The session will be concluded if it exceeds 45 minutes, although we expect most discussions to come to a natural conclusion in significantly less time. The patient's Project Nightingale data will be made available to the participating clinician prior to the appointment. In addition, the researcher will arrive in the clinician's office 10 minutes prior to the check-up and provide them with a printout of the patient's datasheet (to be used as part of the check-up process should either the clinician or the patient wants to use it). The researcher will audio-record the entire check-up appointment (including preparation and wrap-up) using a Dictaphone and will not interrupt throughout the appointment. Two 30-minute semi-structured interviews are scheduled with the clinician 3 and 6

months after the beginning of the study. The clinician will be asked to reflect on their experience with regard to the conversations they've had with patients about their self-tracking data up until this point, and share their thoughts on what went well, what could have been better as well as any highlights or surprises regarding the discussions patients. The researcher will ask questions like: *"Have the conversations about self-tracking data influenced your decision-making process?"*, *"Did you learn anything new from the patient's self-tracking data as the result of the conversation?"*. The researcher may ask the clinician to elaborate and expand on their answers.

6.5.3 Phase 3: Post-Study Questionnaire

After the check-up appointment, patients will receive an email (see Appendix D.1.4) containing the link to a post-study online questionnaire (see Appendix D.9). Patients are invited to share their experiences with the check-appointment and reflect on the conversations they had with the clinician regarding their self-tracking data. The questionnaire includes questions like: *"Do you think that reviewing your data prior to the conversation was helpful?"*, *"Did you encounter any difficulties or issues discussing your data with the clinician?"*, *"Were you able to discuss all of the things about the data that you wanted to?"*, *"Has the discussion about your data changed your thoughts or opinions about the value of collecting self-tracking data?"*.

All questionnaire and consent forms are hosted through *onlinesurveys.ac.uk* [Jisc, 2021], a secure, GDPR approved survey website endorsed by the University of Bath. All participants' data is to be anonymised and no sensitive data such as personal details, medical records or self-tracking data is hosted through this service.

6.5.4 Participants Recruitment

Participating clinicians are consultant rheumatologists working at the RNHRD whose routine responsibilities include attending axSpA patient check-ups. Potential clinician participants were contacted by the researcher via email and in-person. Clinician Information Sheet (see Appendix D.5) which contains all the necessary information about the study and what taking part involves was sent to interested clinicians via email. Participation was then finalised through consent forms where clinicians agrees to take part in the study (see Appendix D.7).

We identify potential patient participants through their involvement with Project Nightingale and consistent use of the uMotif app. The CoUs-axSpA study was open to patients who were registered at RNHRD and had received an axSpA diagnosis from

their rheumatologists who were also participating in Project Nightingale and had consistently used the uMotif app (i.e. users who have generated 30 data entries within a three-month window) within the last 12 months (i.e. prior to 24/02/2021). Participation was voluntary and no financial incentive was offered. Potential patient participants were contacted by the researcher via NHS mail (see Appendix D.1.1) and are given a brief summary of the study, alongside Patient Information Sheet (see Appendix D.4) which contain all study details including research rationale, format, commitment required, incentives and selection criteria. Participation was confirmed via an online consent form given that the patient had no unaddressed questions about the study (see Appendix D.1.2 and D.6). All participants are able to withdraw their consent to participate at any time without a reason.

The CoUs-axSpA study began on 24/02/2021 with recruitment emails sent to over 40 eligible patient participants. One male consultant rheumatoglist (CR) from RNHRD agreed to take part and 8 patient completed the consent form with one patient dropping off after 3 weeks (data was excluded from analysis), totalling 7 male patient participants (P1-P7) age between 26 to 69 (Mean = 59.71, SD = 14.04). The average time spent on Phase 2 activities (including the clinician's preparation) was 21.4 minutes (range = 12 - 29 mins). The study took place over the duration of 6 months.

6.5.5 Analysis

We conducted reflexive thematic analyses on data gathered from the data preview and joint review phases of the study, including the pre-study questionnaire as well as verbatim transcripts of audio recordings from the joint data review phase. These analyses were carried out independently despite potential overlaps in the uses of self-tracking data prior to the check-ups. We summarise our findings from the post-study phase at the end of section 6.6. Since the amount of data collected through the post-study questionnaire and the interviews are inadequate for the purpose of thematic analysis, we instead use them to provide context for the themes identified from the prior phases. The themes were developed based around the content of the data using an inductive approach [Braun and Clarke, 2006, 2019]. The first and second researcher (i.e. Weihua Zhang and Dr Simon Jones) familiarised themselves with the data before they independently reviewed and coded its content. Initial clusters of themes were refined and developed into the final themes that were agreed upon. We use quotes from the questionnaire responses and interviews to elaborate and contextualise the final set of themes we have developed.

6.6 Results

6.6.1 Patient Data Preview Phase

Participating patients reported to have spent between 10 minutes and 1 hour reviewing their Projecting Nightingale data. Most participants reported feeling completely comfortable with discussing the data with their consultant: *"I look forward to further analysis of the data with my clinician, in the hope of recognising further trends"* (P3). Only one participant reported concern before deciding to proceed with the study: *"I believe it will be useful but challenging as I struggle talking about my symptoms as I can sometimes find it a little overwhelming. Talking to a professional could also be useful as they may be able to provide help and support with manage my condition or just to reassure me that everything I am experiencing is 'normal' "* (P7). The researcher reassured the participant that they could choose to withdraw at any time without consequences.

Thematic analysis on patients' reflections upon reviewing their Project Nightingale data collected through the pre-study questionnaire revealed three themes, they are: *facilitate reminiscence of disease experience through data snapshots*, *reveal interesting data patterns in disease activity and self-management behaviours* and *identify key issues and support formulation of discussion topics*. These themes delineate the major roles self-tracking data played in preparation for the check-up appointment from patients' perspectives.

6.6.1.1 Theme 1-1: Facilitate Reminiscence of Disease Experience through Data Snapshots

Several participants commented on how reviewing their self-tracking data prior to the check-up aided their recollection of recent disease activities and self-management behaviours and helped combat forgetfulness: *"Helpful because as time moves forward it is not always easy to remember how the disease has progressed and how you felt previously"* (P1), *"Reviewing the data prior to the conversation refreshed my thoughts and interpretations of the data prior to the conversation"* (P3). Several participants reported finding the Project Nightingale datasheet provided to them helpful and easy to use: *"I could see when I had done too much, or when I was feeling good"* (P2), *"Taking this regular 'snapshot' of my condition, my health and my behaviour is useful"* (P6). Furthermore, having a tangible, quantitative record of recent health conditions also appeared to help patients "reinforce what I felt to be case" (P1). Instead of having to rely on memory and patients' recollection of events, *"it [self-tracking data] helps by giving a quantitative measure rather than just my own feelings"* (P6), therefore help combat

recall bias during data gathering: *"the data is accurate on a daily basis, it is far more accurate than just having to remember what has been happening to me over the last year... this means that you will be getting an accurate diagnosis"* (P5). In addition, P5 also mentioned that reviewing their self-tracking data helped them fill in the BASDAI form prior to the check-up appointment: *"I have always had a problem remembering how my condition has been over a period of time. Having this data helps me fill in the forms I have to do about my condition prior to the meeting with the clinician by way of making it much more accurate"*. On a similar note, P1 thinks reviewing self-tracking data prior to the check-up complements traditional methods of data-gathering: *"I think that along with other information collected (e.g. BASFI/BASDAI etc.), it gave a good picture of disease progression and highlighted my own management of the condition"* (P1).

6.6.1.2 Theme 1-2: Reveal Interesting Data Patterns in Disease Activity and Self-Management Behaviours

Reviewing self-tracking data prior to check-up appointments supports patients' recollection and confirms what they already knew about their health conditions: *"supports what I already know in that pain levels have increased over several years and sleep continues to be major issue"*, *"It confirmed my feeling that AS was having an increasingly detrimental effect on daily life"* (P1). In addition, the reviewing process itself may reveal data insights which are previously unknown to patients through the highlighting of data patterns such as trends and correlations. For example, reviewing exercise data made P1 realise that they were not hitting their self-management goals: *"historical info from the app showed I wasn't doing as much daily exercise (such as walking/running) as I had thought before examining the data"*. P6 made a similar remark on how self-tracking data revealed insufficient exercise: *"It highlights that my recommended exercises are less frequent than they used to be, and my weight training has virtually stopped. This is largely due to an injury unrelated to axSpA that I need to get sorted when I can"*, *"uMotif was logging my steps so seeing the long-term overview is interesting, my new lifestyle habits have improved my step count, although I am a runner, I do feel that my 'walking endurance' has improved"* (P6).

Reviewing self-tracking data prior to the check-up appointment highlighted trends which suggest improvement and deterioration of patients' health conditions: *"Pain levels have increased over several years and sleep continues to be major issue"* (P1), *"It highlighted the following improvements: a reduction in stress, sleeping was much better, less fatigue, pain was reduced"* (P5), *"Flare frequency may have dropped, showing my*

healthy diet and lifestyle is diminishing the effects of axSpA" (P6). Furthermore, data review seems to facilitate the identification of potential correlations between various aspects of disease activity and self-management behaviours. Even without conducting rigorous statistical analysis, patients were able to notice links spotlighted via simple data visualisations *"[reviewing data helped me see] the close link between flare status, sleep quality and stress"* (P7), *"Reviewing the data revealed links between peaks of stress, mood, fatigue and exercise. When one peak occurred, it usually corresponded with peaks in the other parameters"* (P3). Furthermore, P3 was able to spot seasonal variations in stress episodes as well as the duration of spikes in disease activities: *"I also felt that there were seasonal trends, I found that peaks of stress occurred more frequently during the period February to April. Also, parameter peaks were literally spikes, and did not generally last more than one day"*. For P5, reviewing self-tracking data helped them identify the change in diet and the use of grounding sleeping mat as major causes for their improved conditions: *"I knew that I had improved but I did not know by how much and what caused it. I had tried different alternative methods and have been able to, through the data, establish which alternative methods had caused these improvements"*. Lastly, reviewing self-tracking data prior to the check-up help P7 understand their usual flare patterns: *"It's interesting to look at the timeframe to see which started first and the knock-on effects. Usually it starts with a flare, effects my sleep which then in turn effects my stress or my ability to handle stress"* (P7). Reviewing the data help P3 understand a significant pattern in their self-management behaviours, where *"good moods or high levels of energy and low pain result in me doing excessive things that cause me to then have a dramatic swing to the other extreme"*.

6.6.1.3 Theme 1-3: Identify Key Issues and Support Formulation of Discussion Topics

Reviewing self-tracking data prior to check-up appointments may help patients identify patterns in their disease activity and self-management practices. This in turn helps formulate topics or issues which need to be highlighted or discussed with the clinician: *"It helped to focus me into thinking about issues I might want to discuss and what answers I was looking for"* (P1), *"By doing this it enabled me to know what I was going to talk about. Often you would go to the consultant and just answer the questions they give, and when they ask 'have I got any questions', I usually can't think of any. Only when I have left, I think 'well I should have asked something I never thought of at the time' "* (P5). These discussion topics cover all aspects of the management of axSpA, including disease activities, self-management behaviours as well as lifestyle choices. For example, increased pain levels as illustrated by the data prompted P1 to discuss pain

management with the clinician: *"Data would have shown marked increase in severe pain if current trend continues. I need to find a way to manage the pain as it is beginning to have major effect on my life"* (P1). Sleep quality was revealed as another prevalent issue among participants: *"[I would like to discuss] sleep management – possible aids to better sleep"* (P1), *"Poor sleep quality seems to have an effect on other things, e.g. stress. How can I improve my sleep quality?"* (P7), *"I recognise that sleep is hugely beneficial to me. Continence issues make excessively long sleep periods unmanageable"* (P3), *"The sleep between the data points was excellent but has slipped a bit since. What could be the reasons?"* (P5). Issues relating to self-management behaviours were also raised, such as exercise intensity and medication: *"Have been walking 3 miles a day during [COVID-19] pandemic plus 20 minutes exercises. Is this too much? How will this level of exercise affect my condition positive or negative?"* (P6), *"In 2018 when my sleep pattern was the best, I was taking Amitriptyline, but [I] stopped. Do I consider taking Amitriptyline again?"* (P2). Other issues include the impact of lifestyle choices on patients' health, e.g. high caffeine consumption: *"When I'm well I feel I can justify drinking more and when I'm unwell I justify it as a rewarding compensation. Over the whole period, I actually feel more uniformly stable when I have minimal caffeine... I have never totally eliminated caffeine, but it may be of significant benefit if I totally eliminate it?"* (P3)

6.6.2 Clinical Observation Phase

Four further themes emerged from our analysis of the transcripts of the audio recording from the clinical observation phase where clinician and patient participants engaged in the collaborative use and discussion of self-tracking data, they are: *expedite and automate evidence gathering through holistic data preview*, *identify discussion topics and help set clinical agenda*, *explain and contextualise data patterns through discussion* and *support treatment planning and optimise self-tracking practice*. These themes were inductively produced despite the fact some activities naturally align with the stage-based model of the axSpA clinical workflow.

6.6.2.1 Theme 2-1: Expedite and Automate Evidence Gathering through Holistic Data Preview

Clinician reviewed patients' Project Nightingale data during preparation for the check-up appointments, using the datasheets provided to rapidly form a holistic view of the patient health in a rapid-fire manner, usually taking 5-10 minutes: *"Mood, quite a few low bits. Recommended exercise, so they don't do exercises most days... Sleep again, re-*

ally fluctuates, between interrupted and good. Fatigue, very few days where he's not fatigued" (CR stated while reviewing P2's data). When reviewing the data, clinician paid attention to fluctuations in patients' disease activities and self-management behaviours, or lack thereof: *"Stress fluctuates massively, short flares in duration. Overall, just ballparking, quite a fluctuating picture"* (CR stated while reviewing P2's data), *"This one is 'regular exercise', and highly variable so that's one thing that I spot here... fatigue again, all over the place, really variable fatigue patterns"* (CR stated while reviewing P1's data), *"Um, pain is highly variable – goes from episodes of no pain to severe pain to debilitating pain on one occasion. When we're talking about stress, again widely variable, goes through 'no stress', 'a little stressed', 'quite stressed', 'very stressed' "* (CR stated while reviewing P7's data), *"OK sleep is again quite hit and mess, fatigue is also quite hit and miss"* (CR stated while reviewing P3's data), *"His mood is always good... His sleep is fairly consistent and reviewing his Project Nightingale data, this is clearly evident... and pain wise, he's always in mild pain, okay"* (CR stated while reviewing P6's data), *"Next one is mood, most of the time very happy or content"* (CR stated while reviewing P1's data).

Clinician also paid attention to noticeable patterns in patients' disease activities and self-management behaviours, such as frequency, duration and consistency: *"Most days over 10,000 steps, which is very impressive and we're looking at the last three months here"* (CR stated while reviewing P6's data), *"They have nicely plotted their flares, they seemed to be lasting 2-3 days [each time]... They've also recorded hydration... usually sits between one and four glasses of water... They're quite an exercising person, there is really a lot of episodes where they've had more than 15 minutes of exercise so that's very good"* (CR prior to check-up appointment with P7), *"Then there is an [recommended] exercise adherence chart and what it appears he's very good being adherent to exercises"* (CR stated prior to P1), *"Very good with exercise, there has only very few occasions where he doesn't do recommended exercise. Only 5 flares over the last 2-3 years and the flares were very short lived"* (CR stated while reviewing P5's data). In addition to fluctuations, stable periods, frequency, duration and consistency, clinician occasionally highlight outliers in data, such as spikes in symptoms or medication use: *"Maybe 10 spikes where he said he's a little bit low [in mood], and one spike where he said he's very low"* (CR stated while reviewing P1's data), *"Debilitating pain on one occasion"* (CR stated while reviewing P7's data), *"Interestingly, he records anti-inflammatories in December only"* (CR stated while reviewing P6's data).

6.6.2.2 Theme 2-2: Identify Discussion Topics and Help Set Clinical Agenda

Although a quick data scan may help clinicians paint the overall picture of the patient's health over the past 6-12 months, further and more in-depth examination is required to determine relevant topics for clinical discussion and treatment planning. During the data preview sessions, clinician singled out various data patterns and data points in order to investigate them further with the patient, usually relating to potential causes for concern and ambiguity in the data. First, prolonged periods of unstable or severe disease activities raise concerns as they indicate ineffective self-management of the condition: *"Fatigue is not a major problem. Pain, not a major problem. Better fatigue but more interrupted sleep... it could be an issue"* (CR noting sleep down as a topic for discussion while reviewing P5's data). Suboptimal management of disease activities as illustrated by self-tracking data raises questions regarding its causes and broader impact in patients' health: *"Very mixed sleep, some nights' good sleep, quite often interrupted sleep, quite a lot of very little sleep. So that's very interesting, why? What's driving that and how is that poor sleep having an impact on his disease"* (CR stated while reviewing P1's data). In addition, the symptoms which patients prioritise in tracking may also be of relevance to the discussion, especially when they're suboptimal: *"Reviewing his Project Nightingale data, now this is interesting because he's elected to measure his 'blood in the stool' as he is getting infrequent episodes of blood in the stool, that is something we've got to ask him... so that's a top one"* (CR stated while reviewing P7's data)

Noticeable changes in disease activity in either direction usually get noted down as topics for discussion, as investigating the root cause is of importance to the clinician. For example, CR commented that P5 reported a period of *"really poor sleep"* throughout 2019, followed by *"a very good phase of sleep in 2020"*. However, concerns were raised by the clinician upon noticing recent decline in P5's sleep quality as appeared on the datasheet: *"We're heading back that way now. So sleep is something we need to talk to him about"*. On the flip side, notable improvement in P1's disease activities prompted clinician to mark it down as a topic of further discussion: *"Pain's been interesting and that's changed, so in 2018, 2019, quite a few episodes of mild pain, mostly manageable pain, few episodes of severe pain. But when we look at 2020, a lot less severe pain, most of it was quite manageable. So again, is this a COVID phenomenon? What's going on?"*, *"He reports quite a few days of little stress and then there are some spikes of moderate to very stressed. They have tailed off as of late. So less of those days in 2020 and I wonder if this is a COVID phenomenon, that maybe work made him stressed, he's working home and maybe there's been less stress? That'll be interesting to find*

out" (CR stated while reviewing P1's data). On a similar note, noticeable changes in patients' self-management behaviours are often selected as discussion topics: *"They've changed things quite a bit here, so they were really hitting between 5,000 and 10,000 [steps], and from the 3rd of November last year, he's become much more consistent in doing at least 10,000 steps a day, so that's important for us to ask"* (CR stated while reviewing P6's data), *"Wow, the daily steps. There's been quite a change, so up until 2020, He was fluctuating quite a lot between 5,000 and 20,000 steps. And now he's come to a much more regular 10,000 step routine and I think what's interesting is - You wonder whether this is why he's reporting less pain"* (CR stated while reviewing P5's data).

Frequently, clinician would notice vague data patterns that are relevant to the clinical discussion but require clarification from the patients, providing additional topics for discussion: *"I'd like to have known how they're managing their anti-inflammatory use with their flares – there seems to be a link where flare comes and they'll take anti-inflammatory... so I'm wondering if that is what they do, when they have a flare, they take an anti-inflammatory"* (CR stated while reviewing P7's data). Similarly, CR highlighted the ambiguity in observed data patterns which may benefit from further evidence provided by patients during the consultation: *"I can see he's not really using very much anti-inflammatory, so I wonder if their spondylitis isn't bad enough to require regular anti-inflammatory. In fact, maybe we're seeing their AS is quite well-controlled, because they're not requiring those anti-inflammatories"* (CR stated while reviewing P1's data), *"And then his daily steps ...well, I'd say it's highly variable, but I suspect it's a bit like mine where he does a lot of steps over the weekend, but the average is around 5,000 steps [per day] during the week"* (CR stated while reviewing P7's data).

6.6.2.3 Theme 2-3: Explain and Contextualise Data Patterns through Discussion

Reviewing self-tracking data prior to the consultation may provide a snapshot of patients' health conditions and help inform clinical agenda. Co-located discussions, on the other hand, may reveal key information required for the adequate interpretation and analysis of patient's self-tracking data. First, discussing self-tracking data during the consultation may help reveal underlying causes of positive or negative changes in disease activities and self-management behaviours. For example, CR enquired P7 about their blood in stool episodes, referencing the datasheet: *"The next was the blood in stool. What happened there? Because I was looking at your Project Nightingale's data..."*, prompting P7 to disclose the perceived link between the use of anti-inflammatory drug

and the symptom: *"What I was finding was taking the tablet was causing me stomach issues and off the back of that it was then causing, however it was linked, it was then causing the blood"*. Similarly, when ask about the *"ranging amount of [recommended] exercise, that can fluctuate a bit"* (CR), P4 attributed neck pain to reduced exercise frequency: *"I haven't been doing the neck one because, because of the pain with the muscle there when I turn left. So I stopped doing it because it was quite painful to do, at the moment it's getting better"* (P4). When asked about the fluctuations in the amount of recommended exercise they did, P6 attributed it a life event: *"I've probably been more erratic with it since retirement since I haven't consistently done my daily exercise, which was part of the going to work routine in the morning. In a 14 days [period], I would say, during work time, we were doing 12 to 13 mornings. Now in retirement out of 14 days I guess, we'll be lucky to get into double figures... it's something that I want to work on"*. When asked about their persistent yet *"albeit short-lived"* (CR) flare pattern, P2 identified laborious farm work as a direct cause of flares: *"I live on a farm but sometimes have to do jobs that are a bit laborious, like I've just cut the front hedge of our road. In the past when I, looking back, like 2019, I had quite a few flares and that's because I was doing some groundwork"*.

Discussing self-tracking data may also help identify factors which contributed to positive changes in disease activities and/or self-management behaviours: *"My fatigue is gone, and I feel I've got a lot of energy, and I put that down to the grounding"* (P5 attributing reduced fatigue to the use of grounding sleep mat). To give another example, when asked about improved exercise volume and consistency, P5 attributed it to the impact the COVID-19 pandemic had on their lifestyle and self-management: *"Since February, March 2020. You've got into much more consistent 10,000 steps a day"* (CR), *"What's happened [was], when the COVID started last March, we found the circuit to do three miles a day. And every single day over the past year, we've walked three miles. Very rarely that I miss the exercises, I did in this morning before coming here"* (P5). This in turn explained P5's improved symptoms: *"Since you've got a much more regular step pattern, your pain seems more stable, you're having less of the 'very severe' pain episodes"* (CR said to P5). When CR asked P2 if they observed any underlying causes which led to fluctuation in their symptoms, the patient suggested that the variation in pain was the result of taking part in the axSpA rehabilitation course and subsequent travels: *"What I did find fascinating on the [Project] Nightingale [app], looking back... when I came in here for the two-week course. That was marked 'no pain'. But when I went on holiday, you know I went to the Swiss Alps, again it was highlighted"*.

Additionally, discussing self-tracking data may help provide context to data patterns found during initial examination, thus enabling more accurate depiction of patient's health conditions. When asked about their recent sleep patterns, both P2 and P6 suggested that the interruptions to sleep was predominantly caused by factors that are unrelated to AS: *"I must admit at the moment, the summer doesn't help situations because you know, we're fortunate to have birds, but we also have a campsite. So I get woken up by that sort of noise... may have made a difference this time of the year"* (P2), *"it's not necessarily to do with my condition, it's to do with having two cats, and the lighter morning... and it's also to do with... there is a bit of family turmoil going on at the moment, which is a bit of, keeping me thinking at night. And, if I do wake up to pop to the loo, it gets you thinking again"* (P6). Similarly, P3 suggested that their elevated stress level was caused by productivity issues instead of axSpA: *"It's all about not being able to do things and finish. I'm terrible at focusing on anything. I go and do something and one the way there I'd do something else, it's constant, all the time, it's so annoying"*.

Discussing self-tracking data allowed clinician to get clarification on potential correlations illustrated by the data or lack thereof. During the consultation, P6 reported significant improvements to their condition following retirement, referencing the Project Nightingale datasheet in the meantime: *"Things have changed radically for me because I'm delighted to tell you that I retired. Did you see, have you look at my [uMotif] graph?"*. Using the datasheet, CR was able to identify the time window for when P6's retirement started: *"Would it have been some time around October by any chance?"*. Discussion with P6 also affirmed CR's speculation in that the patient's improved exercise adherence correlates to the beginning of the COVID-19 pandemic: *"I've been much better at keeping the right amount of running going, if we don't run then we make sure that we still walk and get our 10,000 [steps]"* (P6). To give another example, CR speculated that improved stress level could potentially related the beginning of the COVID-19 pandemic: *"Mostly you're a little stressed but you have the spikes of moderate stress or very stressed. It's almost... if I put COVID around there, the moderate or severe stress episodes have disappeared. Would you see [the connection] or is that just coincidence?"*. P1 denied that there was a link between the COVID-19 pandemic and the reduction in severe stress episodes: *"I think it's probably just sort of a coincidence. I think it may be a different solution to that, I've had two grandchildren in January and December 2020, and that's provided a welcome boost for me to be honest"*. Furthermore, discussing self-tracking data can also provide nuance in how patients perceive the severity of their pain and flares, as they typically vary among individuals: *"Most of the time I'm putting down 'manageable pain' because I would*

describe it as being manageable. I didn't really know where my 10 is but I thought it would be unbearable, you would be screaming" (P1), "I don't think I have distinct flares, I've put down on the odd occasions where I felt particularly uncomfortable, perhaps but I wouldn't know if it would be defined as sort of an AS flare" (P1), *"When you say flares... it's only one bad day, as a rule for me. Two days' the worst, and then I just pop back up"* (P3).

6.6.2.4 Theme 2-4: Support Treatment Planning and Optimise Self-Tracking Practice

Discussions about patient self-tracking data may support decision-making regarding ongoing treatment of axSpA. P6 reported that reviewing self-tracking data helped them understand their flare patterns: *"You can kind of see [from Project Nightingale data] that there are occasional flares and sometimes they just go within a day before I've taken anything. If you line it up with the medication, I haven't always got round to taking it and it's gone"*. P6 and the clinician concluded that based on the varying duration of the flares, delaying intake of anti-inflammatory drugs by 24 hours or so would be the most sensible way to manage the onset of flare symptoms. Discussions about self-tracking data may also reveal issues related to current treatment plans help clinician and patients devise new action plans. The spiking disease activities as highlighted through P7's self-tracking data, specifically blood in stool, led to a discussion about the severe side effects the patient was experiencing in result: *"I'm on them [anti-inflammatory] rigidly, but that was then causing these other issues which would then... you know, stomach aches and stuff were causing me to feel sick and just discomfort, so it's got to the point where I'm not taking them now because I was thinking the side effects were going to come... flip side of that is I'm never on anything and I'm in pain"* (P7). CR stated that actions need to be taken to reduce patient's dependency on anti-inflammatory drugs: *"We need to get ourselves out of this cycle of 'pain, anti-inflammatory, blood [in stool]'... and your Project Nightingale charts showed that beautifully. So, if we're gonna get away from that, we need to move away from anti-inflammatories and try something else"*, meanwhile suggesting that exercise may benefit the management of flares. Reviewing self-tracking data may also help patients and clinicians determine whether their axSpA treatment plans should include frequent clinical visit. In the case of P4, both clinician and patient agreed the condition was under control and well-managed upon reviewing their self-tracking data: *"I looked at your scores and things, and again your charts and your Project Nightingale data shows really quite stable symptoms overtime. You know, not getting huge amount of flares"* (CR), *"You see, there is no much wrong with me. I don't take any drugs or anything, not for my AS. Mood is always very good. Exercise,*

I do 22 minutes on an excellent regime", "I don't get any, I don't get fatigued, I'm not getting any pain" (P4 replied).

Reviewing and discussing self-tracking data may help inform future self-tracking practice and focus which would generate data that can be used for subsequent analysis. For example, upon finding out about the link between blood in stool and anti-inflammatory use, P7 wishes to stop tracking the symptom and focus on other potential links: *"I've seen the link with the blood [in the stool], it was useful, but I was just wondering if there is something that was better [to track]"*. In response, the clinician encouraged P7 to continue tracking blood in stool to determine whether the new drug prescribe has the same side effect: *"Yes, but at the same time I would like to see what happens to it [blood in stool] with this drug"* (CR). To give another example, after discussing the possibility that high exercise volume may be negatively associated with sleep quality, P7 was unsure about its implications on self-management and suggested that more data is needed to establish the link: *"I'm trying to work out why there's been some changes [with sleep] but as you say, is it to do with more exercise? Meaning that I don't need as much sleep, I don't know. That's why I'm trying to get the data on that"*. In result, CR suggested periodically varying the step counts to examine its connection to sleep quality or lack thereof: *"I suppose the other thing to potentially try is to vary the steps, but do it for sort of a two-to-four-week period and see what that does to the sleep, that will show us the link, wouldn't it?"*.

6.6.3 Post-Study Reflections

6.6.3.1 Patient Perspectives

Despite the fact that all participants completed the post-study questionnaire after the joint review of their Project Nightingale data with their consultant rheumatologist, the amount of information obtained was not adequate for a thematic analysis. Nevertheless, data collected through the questionnaire helped gauge participants' opinion on the discussion they had with the clinician about their self-tracking data. All participant reported feeling satisfied about the discussion they had with the clinician: *"I found it [the discussion with clinician] useful as it reinforced and clarified how I felt about the data and the trends that it showed"* (P3), *"I found discussing the data with the clinician very useful. The data also enables both the clinician and myself to establish patterns which you could not do without this data"* (P4), *"The clinician noticed that there might be a correlation between sleep and the number of steps I am doing. This has enabled me to look further into this as I am trying to understand why these changes in my sleep pattern are taking place"* (P5).

While all participants found the discussion they had with the clinician self-tracking data useful, only P1, P2 and P7 were able to discuss everything they wanted to discuss about the data. Forgetfulness appeared to be a main contributing factor in addition to time constraints: *"We did not get round to talking about the points raised in the first questionnaire because I forgot!"* (P6), *"Unfortunately, I forgot to bring a copy of the questions I was going to ask with me but I felt I had covered most... I never got to discuss ways I could reduce my stress levels further"* (P5). In addition, P3 and P5 shared their opinions on how the joint review process could be improved: *"If the clinician and myself could have shared viewing the data on screen together it would have been more pertinent if feel, and enabled more questions to arise on my part"* (P3), *"If this is done on a regular basis, both the clinician and myself would become used to this and more prepared. This in turn would provide improved outcomes. But for a first attempt, I thought it went well"* (P5).

6.6.3.2 Clinician Perspectives

Post-studies interviews suggest that the clinician's attitude towards the discussions was largely positive. The clinician stated that while data preview did provide useful information for the discussion, the regular preparation time was not enough for them to analyse the data fully: *"I think the data would be more helpful if I logged in before and had a look, and tried to digest the flares or not, but even doing it when I did it, it was still helpful to know accurately how many flares he's had and what he did at the time of the flares"*. This was compounded by the fact that there wasn't a dedicated user interface that supports the interactive exploration of the data beyond simple visualisations: *"the issue would be time. So if I'm trying to measure out every detail here with the on a piece of paper, it's not gonna happen in 15 minutes, because it's so hard to do it [by] eyeballing"*. The clinician suggested that there needs to be a certain degree of pre-processing prior to the review in order to reduce the complexity of data analysis: *"you could set the computer to do some [analysis of] correlations, then you have to go through an iterative process of me looking at these correlations"*, emphasising that human judgement is irreplaceable when comes to final decision-making. The clinician emphasised that the data insights produced by computer analysis prior to the check-ups don't necessarily have to be statistically significant, instead, possible correlations and causal relationships are well-worth investigating: *"doesn't have to be significant, I'm not looking to publish it"*. Clinician gave an example of the type of insight they were looking for when asked to elaborate: *"they've had two flares, these sorts of data at the time of flare, these were the symptoms he reported at the time of flare. [Then] they did this, took anti-inflammatories, did more exercise... 90% of the time he'd start some*

exercise, and the flares' gone. Those are the insights I'm looking for, on the individual patient level", emphasising the focus is finding effective ways of treating and managing the condition on an individual level.

Furthermore, clinician suggested that cohort-level analysis would allow direct comparison between patients and those who are similar to them: *"if there is a way of picking out all of the patients that are similar to him, so you could group them by how long have they had disease, what do their x-rays look like, what drugs they're on. So you can say for another 30 people who are of the exact same phenotype as this man. What are the equivalent patterns so we compare them to a comparative cohort, I think will be very interesting"*. Clinician hoped that cohort analysis of self-tracking data would reveal best practices and effective treatment options for patients based on their demographic and medical characteristics: *"[Let's say] I've looked at the data of another 500 patients and, this was what worked best for them"*, *"what is the best way to get rid of a flare [for people which shorter flare duration]?"*.

6.7 Discussions and Design Implications

We discuss the findings of Study 4 and how they address the low-level research questions that was raised at the end of section 6.2. First, the themes which emerged from our analysis of the pre-study questionnaire as well as transcripts of the joint review made clear how the use of self-tracking data could fit into and benefit the existing clinical workflow [Hue et al., 2019], therefore answering **RQ4a: What existing clinical activities may benefit from having conversations about patient self-tracking data?** While the themes don't completely overlap with the existing clinical workflow [Hue et al., 2019], they do offer valuable insights into how self-tracking data related activities and discussions may be integrated into future axSpA check-up appointments. We discuss this in more detail in the order of the themes identified.

The first set of themes (Theme 1-1, 1-2 and 1-3) relate to how reviewing self-tracking data prior to the check-up appointment could benefit axSpA patients in their discussion with the clinician during the check-up. Specifically, self-tracking data in its visualised form serves as data snapshots which could help patients recollect their disease experience, allowing them to provide more accurate information during the data-gathering phase of the check-up. In addition, reviewing self-tracking data may reveal interesting data patterns which help patients gain a holistic understanding of their condition as well as the efficacy of their self-management behaviours. This could potentially support the setting and self-monitoring of self-management goals if data is reviewed

periodically. Furthermore, reviewing self-tracking data prior to check-ups help patients identify key issues that need to be addressed (e.g. worsening symptoms, adverse effects of medications) as well as curate questions which could potentially be answered by the clinician (e.g. asking about potential correlations between self-tracking data facets, getting feedback on self-management behaviours).

While the themes above (Theme 1-1, 1-2 and 1-3) focus primarily on patient perspectives on the review of self-tracking data prior to the check-ups appointments, themes derived from the joint review phase of the study cover both patient and clinician perspectives on the matter, with Theme 2-1 and 2-2 emphasising clinician perspectives on data preview whereas Theme 2-3 and 2-4 focus on the collaborative review and discussion of the data. The uses of self-tracking data exemplified in Theme 2-1 could be applied to the preparation and data gathering stages of the clinical workflow [Hue et al., 2019], as they may help clinicians quickly grasp the patient's recent disease status and automate the process of information gathering traditionally performed through the use of rapid-fire questions about disease activities and self-management behaviours: *"Cause you're not relying on the patients remembering the last six months to the last year, you've got data that relatively accurately tells you how they last six months have been for the patient, the patient perspective"* (CR stated during the first post-study interview session). Despite that both axSpA patients and clinicians generally regard self-tracking data as more a accurate source of disease experience compared to the on-the-spot recollection of said information, the independent review of said data should not replace the evidence gathering stage in its entirety, as more information may be disclosed by patients during this activity. Compared to Study 2, the average time spent between preparation and consultation went up only by about 5 minutes (i.e. from 16.5 minutes to 21.4 minutes), potentially indicating the positive effect self-tracking data may have on the speed of evidence gathering.

Theme 2-2 bridges the gap between the evidence gathering and reasoning aloud stages of the stage-based model [Hue et al., 2019], in a way that allows the information collected about patient's health to be refined and pre-processed before engaging in conversations. This allows patients and clinicians to formulate a mutually agreed-upon agenda for discussion by focusing on key issues identified through the independent review of self-tracking data. Data perceived as lacking relevance could be assigned low priority or be filtered out all together to alleviate time pressure associated with the check-up appointment. For example, if the patient is shown to have consistent and healthy sleep patterns over a long period of time, it is then less likely that any changes in the disease activity is caused by sleep. As highlighted by the examples, the clinician tend to focus

on fluctuations and changes in patients' conditions (e.g. symptoms, medication and exercise) and low scoring areas which warrant concerns. In addition, the clinician pay close attention to potential correlations between data facets in order to better address patient problems or identify effective treatments. However, since ambiguities in the data may lead to inaccurate interpretation and assumption of correlations, further discussion with patients will be required. Supportive technology that uses self-tracking data should facilitate patients and clinicians in the identification and prioritisation of potential problems and ambiguities associated with patients' disease activities and self-management behaviours so that they can be investigated and addressed through discussion.

While Theme 1-1, 1-2 and 1-3 focus on patient perspectives on data preview, Theme 2-1 and 2-2 covers the clinician perspectives. There is considerable overlap between the two sets of themes relating to the preview of self-tracking data, with theme 1-1 highlighting the additional benefit to reminiscence that is more unique to patients, e.g. confirm what they felt subjectively about the condition with data evidence. Supportive technology could be designed in a way that allows the sharing of discussion topics formulated by both or either patients and/or clinicians prior to the check-appointment, making features such as computer assisted agenda setting possible.

Theme 2-3 closely relates to the reasoning aloud stage of the axSpA clinical workflow, in which the clinician examines key issues highlighted through prior clinical activities while investigating their root causes and potential remedies. The review and discussion of patient self-tracking data may reveal and clarify potential links between disease activities and self-management behaviours which could help inform the investigation. Our findings show that discussions between patients and the clinician is necessary for gathering contextual information which enables accurate interpretation and analysis of self-tracking data in regard to potential correlations. For example, P1 believes that self-tracking data should not be used in isolation without discussion with the patient: *"as a basis for discussion it could help, however the data is not a complete picture in my case"* (P1 reported in the post-study questionnaire).

Theme 2-4 relates to the treatment planning stage of the clinical workflow, in which the clinician advises the patient of the course of action to be taken in light of the clinical information gathered during the check-up (e.g. exercise, medication, rehabilitation course, medical examinations). Reviewing and discussing self-tracking data revealed a wide range of information related to treatment, from the correct timing of medication, side effect of drugs prescribed to the appropriate frequency of clinical visits: *"can Project Nightingale actually help you fine-tune when patients are seen or spoken to on*

the phone or video consultation without there being any detriment to their long-term outcomes?" (CR stated during the second post-study interview session). In short, the use of self-tracking data may help tailor treatment planning to better suit the needs of individual patients: *"If someone was showing lots of flares, I think I would be, doing more than I did for them, they came in quite well, and their data reflects that"* (CR stated during the first post-study interview while reflecting on their discussion with P4). Furthermore, our findings highlighted the future potential of incorporating discussions about self-tracking strategy into the treatment planning process. This could help patients and clinicians decide which data facets would be most valuable and informative come the next appointment. However it should be stated that, given the current stage of the technology, clinicians who decide to incorporate self-tracking data as part of the clinical evidence on which treatment is based would need to take full responsibility of the decision-making: *"What I strongly believe we're not doing is replacing me, we're making my 15 minutes with the patient much more of an informed consultation, and that's where the things like the apps come into play"* (CR stated during the second post-study interview session).

The findings of Study 4 address RQ4b, as each of the themes discussed above illustrates how reviewing and discussing self-tracking data may add value to the treatment and management of axSpA. The data preview process helps both patients and clinicians quickly grasp the overall picture of the condition and supports agenda setting based on quantitative information. The joint review process is mutually beneficial in that it helps address patients' questions about their self-tracking data while providing clinicians valuable information which supplements traditional methods of evidence gathering.

Our study highlighted several challenges with regard to the use and discussion of self-tracking data prior to and during the routine axSpA check-up appointment. First, there is a lack of tools supporting data preview. As per our findings, clinicians pay particular attention to changes and fluctuations in the data as well as low-scoring areas in order to identify potential issues or improvements in the patient's condition. Pre-processing of data could involve visually highlighting these data patterns to make them easier to spot. Secondly, supportive technology could make flares easier to spot by visually highlighting them while providing information which contextualises the flare, such as potential triggers and flare management practices, e.g. use of anti-inflammatory drugs during and after a flare episode.

Moreover, there is a lack of tools supporting the prioritisation of discussion topics once they have been identified and formulated by the user, i.e. either the patient or the clinician. Moreover, discussion topics can be easily omitted or forgotten about without

proper documentation or use of reminders which aids the user's memory, as demonstrated in section 6.6.3.1. In the meantime, clinicians who wish to spend more time with the preview of patient data would need tools to help them record topics for discussion and prompt them when needed during the consultation, especially when data preview is not immediately succeeded by the discussion where reliance on memory is further amplified (see section 6.6.3.2). Design of supportive technology should consider including features which allow users to add and edit discussion topics as well as the ability to assign priorities, similar to productivity tools such as to-do lists or the use of whiteboard with sticky notes for task prioritisation. The interface should serve as a physical reminder of the issues and discussion topics identified prior to the check-up appointment during the consultation. Since there is significant overlap between the manner in which patients and clinicians preview data prior to the appointment, additional features could be to incorporated to allow the sharing, merging and shuffling of discussion topics based on their priority rating (i.e. how important each user deems it is to discuss said data). This could potentially be a viable way to actively involve patients in the agenda setting process, thus allowing patient concerns to be acknowledged and addressed more effectively, as it was revealed as an obstacle to collaborative use in Chapter 5.

Additionally, there appears to be a lack of tools which support the shared viewing of patients' self-tracking data in the clinic. The inclusion of an adjustable display which could be rotated to face either or both patient and clinician would optimise viewing angle and aid discussions about self-tracking data by allowing users to visually reference the data points and/or data patterns being addressed.

6.7.1 Limitations

The findings of our CoUs-axSpA study offered valuable insights into the collaborative use of self-tracking data in a real-life clinical scenario. However, this study has several limitations, with the first one being the smaller sample size (1 consultant rherumatologist and 7 patients). Although the clinical workflow we drew reference to is representative of the typical axSpA check-up appointment, the order in which events occur may be influenced by clinician's personal consultation styles. Although this does not invalidate our findings, follow-up study may wish to feature a bigger sample size of clinicians to cover a wider range of opinions. The sample size of 7 diagnosed axSpA patients gave us just enough diversity to illustrate how individual patients may use and discuss their self-tracking data in ways which reflect their needs. However, a larger sample size would allow us to investigate the influence medical and demographic factors

(e.g. condition severity, age, gender and occupation) could have on the data preview and consultation processes. The increased randomised sample size should also allow us to cover the perspectives of female clinicians and patients. The smaller sample size is also due to a combination of external factors, reflecting the impact the COVID-19 pandemic had on the study design, ethical approval, participant recruitment process and access to NHS facilities.

Moreover, the additional time required for previewing and discussing self-tracking data around routine axSpA consultations may cause concerns among healthcare providers from an operational point of view. However, this could improve over time as patients and healthcare professionals familiarise themselves with the use of self-tracking data. On a different note, social distancing practices may have reduced the use of printed copies of the Project Nightingale datasheet during the consultations. The data visualisations we provided to both patient and clinician participants were uncomplicated and may be limiting to those who may wish to gain deeper data insights such as correlations. Combined with the lack of rotating screen which allows shared viewing of the data, we were unable to study how patients and clinicians may interact around data visualisations and graphs during the check-up appointment. Future studies may wish to address the lack of physical interactivity around datasheets and data visualisations through the use of multiple tablet displays which support concurrent viewing of the data while minimising physical contact.

6.8 Study 4 Summary & Chapter Conclusion

Study 4 addressed RQ4 by investigating the use and discussion of self-tracking data between healthcare professionals and patients in a real-life clinical scenario - axSpA check-ups. We addressed the gaps in the literature with regard to the co-located, synchronous use of self-tracking data between actual clinicians and patients with chronic conditions. We designed our study to integrate the use and discussion of self-tracking data into the existing clinical workflow of routine axSpA check-up appointments. The study provided valuable insights into how self-tracking data could fit into established clinical scenarios, what value it provides to both patients and clinicians as well as some of the practical challenges regarding the integration of self-tracking data into clinical check-up appointments. Our findings suggest that independent data preview may help both patients and clinicians identify useful insights worth discussing during the check-up even without in-depth analysis of the data. We also found that self-tacking data may be invoked to support numerous clinical activities from the stage-based model of axSpA check-ups as we proposed in Chapter 3, namely preparation, evidence gathering,

reasoning aloud and action planning. Our study revealed a general lack of tools which could support data preview, agenda setting and shared viewing of self-tracking data prior and during the appointment.

While previous chapters investigated clinicians' and patients' perspectives on the clinical use and discussion of self-tracking data separately, this study covered both angles as well as the interactions between data users in a co-located setting. This provides tangible evidence of the values collaboration may bring to the interpretation and use of self-tracking data in the clinical context. The aforementioned findings could be extrapolated to inform the designs of technology supporting the use of self-tracking data in support of chronic conditions with similar healthcare pathway and clinical workflow. We provide examples of design implications based on our findings and suggested potential solutions to some of the practical challenges raised. Future work may wish to experiment with the designs we proposed or expand the scope of this study to incorporate a wider variety of healthcare professionals and larger sample sizes.

Chapter 7

Conclusion

7.1 Thesis Summary

The purpose and drive of this thesis is to **facilitate the clinical integration of patient self-tracking data by understanding the opportunities and challenges associated with its usage in the context of chronic conditions**. As stated in section 1.3.3, the type of self-tracking we focus on in this work is health-oriented, which is to be distinguished from finance-related self-tracking and productivity-related self-tracking.

We first conducted a literature review (Chapter 2) which provided the necessary theoretical understanding of relevant topics in recent PI and self-tracking research and its healthcare context. This helped us delineate the potential values PI and self-tracking technology could provide for the self-management and treatment of chronic conditions as well as identify specific problems and challenges associated with its use in the clinical context. We learned that growing interest in the use of consumer self-tracking technology incentivised recent explorations of the use of self-tracking data in regard to the management and treatment of chronic conditions, specifically in areas such as medical research, patient self-management and the provision of patient care. However, despite its many potentials, users of self-tracking data, i.e. patients with chronic conditions and their healthcare professionals, frequently face challenges when applying said data to the treatment and management of the condition, such as sensemaking difficulties, concerns regarding the integrity and relevance of the data as well as limitations associated with existing clinical procedures. We also recognised the important role patient-provider collaboration plays in addressing the aforementioned difficulties and

obtaining actionable data insights. We identified knowledge gaps within existing research on the co-interpretation of patient self-tracking data, such as factors which may influence patient engagement with tracking as well as patient perspectives on the clinical use of the data. The literature review allowed us to narrow the focus of the thesis down to four key research questions to be tackled in each of the respective chapters that follow.

Our first observation & interview study (Chapter 3 - Study 1) explored the clinical context of axSpA patient care, providing us the necessary insights into how self-tracking data could potentially fit into the existing clinical workflow. We followed up the clinical observation with a series of semi-structured interviews with clinicians to understand their perspectives on the clinical use of patient self-tracking data. The study helped us develop a structural framework of the clinical activities involved in the provision of patient care in the context of axSpA routine check-ups, alongside a practical understanding of categories of clinical data which underpin the activities. This allowed us to address **RQ1: What roles could patient self-tracking data play in real-life clinical scenarios?**, by proposing four potential roles self-tracking data could play during axSpA check-up appointments, they're: *supporting agenda setting*, *supplementing patient-reported evidence*, *providing a platform for collaborative decision-making* and *facilitating realistic goal setting*. This study focus primarily on healthcare providers' perspectives on the clinical procedure and use of self-tracking data.

The following two chapters (Chapter 4 and 5) offer more insights into patients' perspectives on the clinical use of self-tracking data. We first followed up Study 1 with a public and patient involvement (PPI) event to learn about axSpA patients' experience with the use of a self-tracking app (uMotif) which allowed user to track data related to axSpA, such as symptoms, medication and exercise. The feedback we received prompted us to investigate factors which may influence patients' data-logging adherence since it is the key to understanding how feasible it is to use self-tracking data for clinical purposes, as poor adherence negatively impacts data completeness and therefore its clinical validity. In Study 2, we used a qualitative online survey to examine determinants of axSpA patients' self-tracking adherence, alongside their tracking motivation and preferences, hence addressing **RQ2: What are the key factors which may influence patients' engagement with self-tracking?** We identified four factors contributing to tracking adherence through thematic analysis, they are: *condition severity and emotional impacts*, *tracking individually relevant data*, *establishing routines and being reminded* and *user experience issues*. Our qualitative findings partly coincide with the results of a tie-in study which investigated axSpA patients'

self-tracking adherence using a quantitative approach [Jones et al., 2021]. We found that although patients may record data under any circumstances, worsening and fluctuating disease activities are more likely to prompt tracking than other reasons. The ability to track relevant data, the existence of tracking routine and good usability are likely to predict higher adherence.

In Chapter 5, we carried out a survey and interview study (Study 3) to investigate **RQ3: What are the patients' perspectives on the collaborative use of self-tracking data?** Although several studies have investigated healthcare providers' perspectives on the use of self-tracking data in the clinical setting, information regarding patient perspectives on the matter remained scarce. This study addresses this by revealing themes related to patient expectations, priorities and concerns with regard to using and discussing self-tracking data in the presence of healthcare providers during clinical encounters. We found that most participants believed that it is important to share and discuss self-tracking data with clinicians, with the main expected benefits/outcomes being *assist clinical activities to improve treatment provision*, *understand lived experience to provide timely support* and collate patient data to generate cohort insights. The survey also highlighted the gap between patient expectations and the reality of self-tracking data usage in axSpA clinics, revealing several issues and concerns regarding the sharing and discussion of self-tracking data, including: *selective disclosure and lack of control over data-sharing*, *rushed appointments and engagement issues*, *scepticism around provider's data-using expertise* and *lack of rapport and feedback loop around self-tracking data*. This study offered a deeper look into the motivations behind axSpA patients' decisions to share and discuss data with healthcare providers as well as the reasons for withholding them.

Previous research on the use of self-tracking data in the context of chronic conditions had not been situated around and during clinical encounters where time constraints and pre-established clinical activities apply. In Chapter 6, we set out to investigate the use and discussion of self-tracking data in the real-life scenario of axSpA routine check-up appointment, where patients and clinicians have one-on-one, face-to-face conversations about the management and ongoing treatment of the condition using a combination of qualitative research methods such as online surveys, field observations and semi-structure interview sessions. The findings of this study addressed **RQ4: What are the benefits and challenges associated with using patient self-tracking data in real-life clinical scenarios?**, as we identified multiple ways in which the use and discussion of self-tracking data benefited existing clinical activities. We found that reviewing self-tracking data prior to the consultation aided the recollection of disease

experience, evidence gathering and the formulation of discussion topics. Meanwhile, discussing self-tracking data was shown to help contextualise data patterns and reveal hidden factors associated with symptoms, medication and exercise. In addition, discussions of self-tracking data may aid treatment planning and help optimise self-tracking practice to support data collection for hypothesis testing purposes and more targeted disease monitoring, e.g. to examine the effect of new medication. We also showed that there is a lack of existing technology which could support data preview, formulation of discussion topics and the shared viewing of self-tracking data between axSpA patients and clinicians.

In this final chapter, we draw the thesis to a conclusion by recapping and discussing the key findings of our work alongside their limitations and contributions to the research community.

7.2 Discussion of Findings and Contributions

The findings of the studies presented in this thesis and their implications have been discussed in-depth within their respective chapters. In this section, we summarise and consolidate the findings to explain how they address our key research questions and outline the contributions of our research.

7.2.1 RQ1: What roles could patient self-tracking data play in real-life clinical scenarios?

Contribution 1: Providing structural understanding of the clinical activities involved in axSpA consultations

This first contribution of this thesis is a stage-based model of typical activities involved in axSpA clinics, providing a practical and structural understanding of the context in which the use of self-tracking data is to be explored. The model divides the care provision process for axSpA into two iterative phases, i.e. *out-of-clinic* phase and *check-up phase*, allowing researchers to better focus their effort on supporting the individual or collaborative use of self-tracking data. Previous work on the use of self-tracking data in the context of chronic conditions rarely acknowledged pre-established clinical workflow and the activities which are involved. This may have undermined the real-life feasibility of prior design recommendations and limited the role self-tracking data could play in supporting existing clinical activities. The identification of regular activities involved in the check-up phase support researchers in identifying practical benefits that self-tracking data could bring to the consultation. Furthermore, we identified main data

categories associated with the clinical check-up process and mapped them to individual activities according to relevance and frequency. This provides researchers the necessary understanding of the existing clinical data ecosystem within axSpA clinics and hence supports the clinical inclusion and integration of self-tracking data.

Contribution 2: Proposing realistic roles self-tracking data could play in axSpA clinics

A second contribution of this study is the proposition of potential roles self-tracking data could play in support of the clinical activities such as *preparation*, *evidence gathering*, *reasoning aloud* and *action planning*. First, self-tracking data which conveys patients' lived experience could be shared with providers to support the elicitation of patient agenda prior to and during the consultation. We showed that the types and nature of self-tracking data which is frequently collected by patients closely resembles existing forms of patient-reported evidence which informs clinical decision-making. This revelation raises the possibility that patient self-tracking data and the practice of self-tracking could be leveraged to automate and supplement the process of evidence gathering. The findings also show that the sharing of self-tracking data insights such as trend and duration of disease activities may support knowledge transfer and collaborative decision-making. Lastly, self-tracking data which quantifies patients' disease activities and self-management behaviours could be leveraged to support realistic target-setting and closer monitoring of the course of the disease. This work represents a substantial step towards further understanding of the value of self-tracking data in the context of axSpA and chronic conditions in general.

7.2.2 RQ2: What are the key factors which may influence patients' engagement with self-tracking?

Contribution 3: Identifying determinants of axSpA patients' self-tracking adherence

A major concern regarding the clinical use of patient self-tracking data among healthcare providers is clinical validity of the data or lack thereof, with data completeness being a specific concern. Self-tracking adherence which is driven by user engagement could determine whether the data is suitable for use in regard to clinical decision-making. A major contribution of this thesis is the qualitative exploration of axSpA patients' engagement with self-tracking, revealing *condition severity*, *data relevance*, *tracking routine* and *user experience* as major factors in determining tracking adherence. We found changing condition severity as indicated by elevated levels disease activities (e.g. pain) to be the most significant and common prompt for tracking. In

addition, negative emotions associated with worsening conditions and mental struggles to keep disease activities under control were identified as obstacles to adherent tracking. The ability to track relevant data, routinisation/habituation as well as quality of life features (e.g. reminders) may help improve tracking adherence among axSpA patients. The findings partly co-align with the determinants identified in an adjacent study which took a quantitative approach in examining axSpA patients' self-tracking adherence through linear regression analysis of patients' self-tracking data collected via a smartphone app Jones et al. [2021]. The practical recommendations we made could help designers of future PISes and self-tracking technologies incorporate features which could foster better user engagement and adherence. Our work highlighted that users' tracking motivation play a significant role in determining adherence, reaffirming findings of previous research [Epstein, 2015, Rooksby et al., 2014]. Although it is close to impossible to account for every factor which could influence adherence on an individual level (e.g. users' determination, life events), our work revealed some significant predictive elements in axSpA patients' engagement with self-tracking tracking, therefore helping us understand how to design for better adherence and make patient self-tracking data more suitable for clinical use.

7.2.3 RQ3: What are the patients' perspectives on the collaborative use of self-tracking data?

Contribution 4: Revealing patients' expectations and concerns regarding the collaborative use of self-tracking data

Another contribution of this thesis is the investigation of patient perspectives on the collaborative use of self-tracking data in the context of axSpA. Several studies have investigated healthcare providers' attitudes towards the clinical use and discussion of patient self-tracking data [The Robert Wood Johnson Foundation, 2014, Murnane et al., 2016, Zhu et al., 2016], yet patients' attitudes and expectations regarding the sharing and discussion of said data have remained largely unexplored. Our work addresses this knowledge gap by eliciting axSpA patients' expectation, priorities and concerns regarding using and discussing self-tracking data with providers during clinical encounters through a qualitative survey study. The results show that a significant part of the expected outcome of sharing and discussing self-tracking data for patients is to support existing clinical activities, such as to improve evidence gathering by reducing reliance on memory, enable closer monitoring of disease status and to leverage self-tracking data to inform treatment decisions and action planning. In addition, patients wish to con-

vey lived experience and express their need for empathy and timely emotional support through the sharing of self-tracking data. The findings show that there is considerable gap between what the expected outcome would be for patients and the reality of discussion or lack thereof upon the sharing of self-tracking data. Lack of autonomy and control over data-sharing, rush appointment and lack of engagement from providers, scepticism regarding providers' data-using expertise, lack of feedback and unrealistic hope for in-depth analysis from clinicians all contributed to the unmet expectations and unfulfilled potential of the collaborative use of self-tracking data. The identification of patient expectations and practical challenges associated with the use and discussion of self-tracking data in axSpA clinics calls for better communication between patients and providers in regard to areas of improvement and what is practically achievable in the current state of data use. While previous research focused on artificial data-using scenarios, our study was placed in the setting of real-life clinical encounters, reflecting practical challenges such as time constraints and the added pressure of clinical activities. We contribute further by making practical and realistic recommendations on how to improve and facilitate the collaborative use of self-tracking data.

7.2.4 RQ4: What are the benefits and challenges associated with using patient self-tracking data in real-life clinical scenarios?

Contribution 5: Investigating how self-tracking data could fit into existing clinical workflow add value to consultation

Our work on the use and discussion of self-tracking data in the real-life clinical scenario of axSpA check-ups represents a significant step forward in the direction of wide-scale adaptation of self-tracking data in the provision of care for patients with chronic conditions. There was limited information on how self-tracking data could fit into existing clinical workflow and the associated activities prior to our research. This work contributes by illustrating ways in which the use and discussion of self-tracking data could support and improve existing clinical activities as outlined in our stage-based model presented in Chapter 3. Our findings show that the review of self-tracking data prior to the appointment (i.e. data preview) supports activities in the preparation stage by allowing both patients and clinicians to obtain a holistic overview of patients' recent health status and digest self-tracking data in a time-efficient way to focus on changes and links among disease activities and self-management behaviours. A common concern among patients and providers regarding the inclusion of self-tracking data during clinical encounters is the added time pressure associated with data discussion [Zhu et al., 2016, West et al., 2016, Hue et al., 2019]. Our work shows that self-tracking data in itself may alleviate or provide solution to this known issue, in that it could be lever-

aged to improve and automate the process of evidence gathering. However, designers of self-tracking tools will need to work with healthcare providers to standardise the process and format of data collection if the evidence gathering is to be fully automated this way.

Moreover, data preview bridges the gap between the evidence gathering and reasoning aloud stages of the stage-based activity model by allowing information collected about patient's health to be refined and pre-processed before engaging in conversations. Our works show that reviewing self-tracking data prior to the check-up or during preparation could help both patients and providers identify noteworthy topics for discussion, such as concerning data patterns or data insights (e.g. trend, fluctuation, link). Our study illustrates the value self-tracking data has in supporting the formulation of clinical agenda and informs researchers about the design of technology which may facilitate the formulation and identification of discussion topics which reflect the needs of both patients and providers. However, we found that patients and clinicians often have to memorise these topics in order to bring them up during the consultation as there is a lack of tools supporting its documentation and management. This gives researchers the opportunity and justification to explore the design of tools which could support the formulation and management of discussion topics based on self-tracking data.

Our findings further reinforce the idea that co-interpretation of patient self-tracking data could help produce more accurate and usable data insights, as discussions about the data may contextualise and reveal key information relating to the data pattern observed by the clinician, such as triggers of elevated disease activities (e.g. physical exertion), suspected links between symptoms and self-management behaviours as well as life events which may affect patients' overall health and self-management routines. Such discussions occur mostly during the reasoning aloud stage which is made more engaging for patients thanks to the inclusion of self-tracking data. Designers may wish to further investigate the impact self-tracking discussions have on patients' attitudes towards data sharing and tracking adherence. We also found that joint review of self-tracking data may produce insights which help inform action and treatment planning as data patterns regarding medication and side effects have direct impact on decision-making in relation to treatment. Furthermore, having conversations about self-tracking data may help patients and clinicians optimise self-tracking strategy to support data collection for the purpose of hypothesis testing and more targeted disease monitoring, thus providing ground for future data analysis, e.g. continued tracking of blood in stool to examine potential side-effects of new medication.

Positive feedback was received from axSpA patients and their clinician regarding the

use and discussion of self-tracking data during and before the check-up session. However, the lack of tools supporting the shared viewing of self-tracking data limited the interactions between patients and the clinician. There are opportunities for researchers to investigate how tools such as rotating screens and tablet devices which support screen sharing may impact how data is used during the discussion, e.g. how users reference specific data patterns or data points and direct the attention the other user. Our findings also highlighted the common desire for cohort-level data insights which allows for the direct comparison of disease status and self-management behaviours between individual patients and others of the same medical and demographic phenotype. Future research may wish to explore how this information could be best presented to users without causing information overload and how discussion might fit into the existing clinical workflow. Overall, our work represents a major development in the exploration of the use and discussion of self-tracking data in real-life clinical scenarios, showing that the inclusion of self-tracking data in the check-ups is not only feasible but recommended despite the challenges.

7.2.5 General Contributions

Overall, the work presented in this thesis accomplishes the goal of facilitating the clinical integration of patient self-tracking data as it clearly demonstrated the value of patient self-tracking data in the context of axSpA patient care. By examining the clinical environment in which axSpA care is provided within the healthcare setting, we identify the routine check-up appointment to be the most conducive scenario in which patient self-tracking data could potentially add value. The similarity between common patient self-tracking data categories (e.g. symptoms, medication, physical activities) and existing types of clinical data involved in routine axSpA check-ups suggest that the practice of self-tracking could be leveraged to automate and supplement the process of evidence gathering. This is further evidenced by the results of Study 4 where both patients and healthcare providers were seen using patient self-tracking data to enhance evidence gathering. We propose feasible ways in which self-tracking data could be utilised in service of existing clinical activities which constitute the majority of interactions between patients and their providers. These proposed roles of self-tracking data in the axSpA clinics guided our subsequent research efforts as we introduce the element of patient self-tracking data into real clinical discussions. Our investigation of the collaborative use of uMotif data demonstrated ways in which self-tracking data could be realistically integrated with the existing process of axSpA patient care, while showcasing potential benefits it could bring to the existing form of consultation.

The output of our research have profound implications for healthcare providers and self-tracking/PI researchers alike. One of the major hesitations from a healthcare provider's perspective regarding the adoption of patient self-tracking data as an element of clinical discussions has been time limitations associated with established clinical workflow. Our research show that patient-reported data about disease activities and self-management behaviours may in fact improve the efficiency of evidence gathering, thus allowing patients and providers to focus on the interpretation of data with the limited time of consultation. From the perspectives of axSpA patients, the use of self-tracking data as supporting evidence could help address memory-related issues relating to conventional way of reporting past disease activities and self-management behaviours. In addition, inclusion of self-tracking data in discussions may highlight the impact certain life-events had on patients' condition, allowing more accurate interpretation of disease status by prompting conversation about data outliers or noteworthy patterns. The CoUs-axSpA study in particular shows that the information exchange between patients and providers surrounding self-tracking data often benefit the interpretation of said data, therefore negating certain sensemaking difficulties associated with individuals' lack of expertise or contextual information.

The benefits of discussing self-tracking data also extends to the development of ongoing collaborative relationship between axSpA patients and their providers. Our research show that a significant amount of patients feel positive about sharing and discussing self-tracking data as a way of conveying their lived disease experience and voicing their needs for support (Study 3). In addition, continued fostering of good patient-provider relationship may improve trust and encourage more open sharing of data and better engagement with self-tracking. This enables the continuous monitoring of disease activities (Study 2, 3, 4) and provide data needed to help set actionable targets (Study 1) and determine medication efficacy between clinical visits (Study 4), potentially resulting in improved decision-making and clinical outcome for individual patients. Good adherence also improves the completeness of self-tracking data used in cohort analyses, potentially resulting in more reliable data insights which could then be leveraged to improve clinical decision-making for the wider patient community.

Therefore, healthcare provider and institutions may wish to incentivise more open sharing of self-tracking data between patients and their health professionals. One of the major implications for healthcare providers relating to the clinical integration of self-tracking data is the slowing down of patient check-up turnover due to prolonged consultation. This issue may be more prominent during in the early stages of the adaptation due to clinicians' unfamiliarity with the data and may improve over time.

Our research suggest that the potential value self-tracking data may bring to axSpA patient care outweigh its downsides. For example, effective use of patient self-tracking data as supporting evidence of disease activity and medication use could make evidence gathering more effective, allowing professionals to prioritise patients who are most in-need through telemonitoring and hence optimising the use of healthcare resources. Therefore, provider buy-in is the key to unlocking the full potential of self-tracking data in the context of axSpA patient care. Furthermore, our research suggest that better communication between providers and patients is required to avoid setting false expectations regarding the provision of individual feedback in the early stages of wide-scale clinical integration of self-tracking data. Additionally, healthcare providers may wish to work with developers to standardise the way self-tracking data is shared and managed, improve transparency over its usage and provide patients with more control over privacy (e.g. what data is being shared and who's able to access it).

This work represents a substantial step forward in the direction of future clinical integration of self-tracking data in the context of axSpA patient care. Moreover, certain findings presented in this research can inform design of future studies which relate to the clinical use of self-tracking data in the context of other chronic conditions. For example, factors contributing to the self-tracking adherence of axSpA patients which we identified (e.g. condition severity, routinisation) could inform adherence studies regarding other musculoskeletal diseases from the perspective of data collection, enabling the use of deductive approach in the investigation of adherence factors due to the overlapping symptoms between axSpA and conditions such as osteoarthritis, rheumatoid arthritis and lupus [Bruce, 2021]. While similar contributing factors may apply to other chronic conditions such as cardiac disease, Parkinson's disease and irritable bowel syndrome, researcher may wish to examine them inductively as an initial approach in order to help uncover other potentially significant contributors which are unique to each condition. On a different note, patients' needs and concerns regarding sharing and discussing self-tracking data in during clinical encounters with providers, such as the need for feedback and privacy concerns, can likely be extrapolated and apply to chronic conditions of various categories, given that their healthcare pathway involves routine health check-ups.

Additionally, research methodologies we used in our work could be adopted by other researchers for conducting studies of similar nature in the context of other chronic conditions. For example, the approach we took in understanding the clinical context of axSpA could be adapted for the investigation of existing pathways regarding the patient care of other chronic conditions which involve routine check-up appointments

and outpatient self-management. The global approach we took in examining the value of self-tracking data in the context of patient care set in real-life clinical scenarios focus on feasibility, patient expectations and the observation of real-life clinical integration on a small scale. This approach could be replicated by researchers who wish leverage the clinical value of self-tracking data in the context of another chronic condition. Although the work in our thesis demonstrate significant values in leveraging self-tracking data in the clinical setting, a reasonably substantial body of work is likely required for healthcare providers to invest in large-scale integration of self-tracking data into the routine provision of patient care, e.g. provision of training for professionals who wish to include patient self-tracking data in their decision-making, guidelines regarding best practice and clarity regarding accountability. We discuss potential future work in the next section.

7.2.6 Limitations and Future Work

In Chapter 1, we discussed how we scoped our research problem to focus on issues related to the clinical use of patient self-tracking data and the design of personal informatics systems and self-tracking tools which support it (see section 1.3.3) following the review of literature in section 2.6.2. To that end, we investigated the healthcare context in which self-tracking data is expected be used for clinical purposes, adherence factors which could influence the completeness and the clinical validity of self-tracking data, patient attitudes towards collaboration around data as well as the real-life use and discussion of data in axSpA clinics. Other aspects such as the use of self-tracking data in medical research and the day-to-day self-management of the disease have not been examined as they're not within our research scope. We also have discussed some study-specific limitations in their respective chapters. This section focuses on overall limitations associated with the work presented in this thesis alongside potential future follow-ups.

7.2.6.1 Sample Size and Sampling Techniques

A main limitation of this research is the smaller sample size for each study relative to the larger population of the axSpA patient community. No prior research directly investigated the clinical context of axSpA patient care through the lens of PI and self-tracking research and limited information is available on its existing clinical workflow. The research required us to collect first-hand information about the procedure and activities involved in the clinical encounters between patients and clinicians. This was a time-consuming process involving lengthy clinical shadowing and observation within

healthcare facilities which was subject to limited availability of clinicians and patients with regard to the scheduling of check-up appointments. Although the final sample size of Study 1 (i.e. 28 patients and 2 clinicians) was demographically diverse, certain precautions must be taken before generalising and applying the findings to a larger patient cohort. Depending on the clinician's personal consultation style and factors related to the patient's condition such as severity, changes in disease activity or lack thereof, the activities which take place during the check-up appointment may vary. Future research may wish to expand the sample size and include multiple providers of various types (e.g. consultant, physiotherapist, dietitian) to capture a wider range of perspectives and clinical practices. The impact the COVID-19 pandemic had on the researcher's access to healthcare facilities and recruitment of patients significantly limited the scope of the Study 4, where the drawbacks of a smaller sample size was made clearer as the demographics of patient participants (e.g. age and gender) were not totally reflective of the population of axSpA patients. Future follow-up studies should consider expanding the sample size to include female clinicians' and patients' perspectives. Both field studies which involved clinical shadowing and observations were limited in regard to sample size due to the limited time the researcher could spend on site with patients and clinicians. Future work should consider the possibility of automated data gathering such as voice recording of in-person and telephone consultations to increase sample size provided that the appropriate ethical approval could be obtained.

In addition to sample sizes, sampling techniques adopted in this work also have their limitations. Patients recruited through Twitter, Facebook and online patient forums actively followed axSpA-related social media accounts and/or engaged in self-management discussions in online axSpA communities. Although efforts were made to include non-users of self-tracking apps and wearables, participants of our online survey studies arguably held more favourable attitudes towards self-tracking and therefore were more likely to engage in self-tracking behaviours for self-management and documentation purposes. One could argue that our findings could not accurately predict tracking adherence among the larger axSpA patient cohort as those who view self-tracking negatively may have opted out of the study. While that is a valid criticism, the determinants identified still provided usable insights into the design of self-tracking technology which could foster better user engagement and adherence. Future work may wish to broaden its recruitment of participants to include patients with more varied exposure, experience and attitude with regard to the practice of self-tracking.

Similarly, Study 4 recruited patients who were participants of Project Nightingale which used a non-random sampling technique where only those who were registered

at RNHRD and had smartphones which support the uMotif app were invited to participate. Very few studies prior to Project Nightingale recruited axSpA patients at scale for self-tracking research, with the Cloudy with a Chance of Pain study being a close example [Dixon et al., 2019]. Since the aim of the study was to investigate the clinical use and discussion of self-tracking data in the context of axSpA check-ups, it would make little sense to carry out another study which would produce the data we need for the observation. In addition to the inherent limitation of Project Nightingale, additional inclusion criteria were put in place for the CoUs-axSpA study where we limited eligible patients to those who had consistently used the uMotif app (i.e. users who have generated 30 data entries or more within a three-month window) within the last 12 months and had an upcoming check-up within 6 months. This delimitation was necessary for us to identify those who had actively used the app and produced enough data for clinical use and discussion. Future work may wish to expand its recruitment window to 12 months and above to include more participants given enough resource is in place (e.g. time required to conduct the study).

7.2.6.2 Generalisability of Findings

In this research, we focused on axSpA as an example of chronic health conditions as the result of deliberate scoping of the research problem of investigating the clinical use of patient self-tracking data in the context of chronic conditions. We anticipate that the majority of our findings could be extrapolated and applied to self-tracking research and the design of self-tracking technology for other chronic condition such as rheumatoid arthritis, diabetes and irritable bowel syndrome. The work on the clinical workflow of axSpA patient care gives structural understanding of the procedure and activities involved in the typical clinical encounter between patients and their consultant rheumatologists. The model also highlights the iterative processes axSpA patient care involves after initial onboarding, such as medical examinations, self-management of outpatients, self-management interventions and routine check-ups. Although the stage-based model informed our subsequent investigations of self-tracking data use in the axSpA clinics, it is not a one-size-fits-all representation of the patient care process of chronic conditions in general. Healthcare pathways and clinical processes are often vague, complicated and subject to change, sometimes involving the transition of care between primary and secondary facilities [Grover and Joshi, 2015]. Further work is required for the development of frameworks that capture individual clinical process for other chronic conditions, although moderate overlap of activities and workflow should be expected.

Furthermore, Study 1 focused on identifying the activies associated with the check-up process where the collaborative use and discussion of self-tracking data is most likely to take place before outlining potential ways in which data could support them. This work did not explore the use and benefits self-tracking data in regard to other processes involved such as the self-management of the condition outside of clinics as this would be considered out-of-scope (see section 1.3.3). Future work may also wish to investigate the use of self-tracking data within other types of clinical encounters which are complementary to patient care processes captured in our model, such as physiotherapies, residential rehabilitation courses, dietitian appointments and primary care appointments (e.g. GP appointments). Providers involved in these scenarios may have different information needs and possess different levels of expertise in regard to axSpA and/or other conditions. For example, a dietitian may focus on food and caffeine intake whereas a physiotherapist are more likely to pay attention to data relating to activity and posture (e.g. screen time, exercise duration).

The determinants of adherence with regard to axSpA patients' self-tracking practice that we identified through qualitative analysis of the online survey, such as condition severity, data relevance, routinisation and user experience are likely to be universal factors in the context of other chronic diseases, as supported by previous studies [Seppen et al., 2020, Epstein et al., 2015a, Lazar et al., 2016]. For example, the ebb and flow of disease activities are likely tracking prompts to patients of other rheumatic diseases such as rheumatoid arthritis and fibromylagia as they are characterised by similar symptoms such as pain, sleep problems and fatigue. The completeness of self-tracking data driven by adherence is therefore key to identifying flare triggers and effects of medications. Researchers may wish to expand upon the determinants identified in this work by carrying out similar studies in the context of other chronic conditions in order to identify unique factors which may influence adherence.

7.2.6.3 Integration with Other Domains of Self-Tracking Research

The work presented in this thesis primarily focuses on the clinical use and discussion of patient self-tracking data in the context of axSpA clinics. Although we achieved what we set out to do with the thesis having furthered our understanding of the clinical use of self-tracking data, we have not examined the other two major domains of self-tracking research in the context of chronic condition as outlined in section 2.6.2, i.e. self-management and medical research. The findings of this work suggest that there are many overlaps between the clinical use of self-tracking data and the other domains of research. For example, our investigation provided the necessary understanding of

the clinical workflow associated with axSpA check-ups, which enabled us to propose potential roles in which self-tracking data could play in future rheumatology clinics. This led to the suggestion of the use of self-tracking data for supporting realistic target-setting, which may in turn benefit outpatients' self-monitoring and self-management practice. The findings of Study 4 show that the joint review of self-tracking data could produce data insights which help optimise strategy with regard to ongoing self-tracking and self-management. This gives the researcher opportunity to explore how directives from clinicians may impact self-tracking adherence, i.e. whether patients are more likely to track per clinician's request for data collection.

The determinants of axSpA patients' self-tracking adherence we identified may help inform the design of self-tracking technology which promotes consistent tracking, which could in turn lead to better data completeness and credibility in regard to its use in medical research based on cohort data. Our work shows that both patients and providers desire features which allow them to make comparisons between individual patients' data and that of the larger patient cohort. Therefore, future research may wish to examine the links between self-tracking adherence and available features based on the fulfilment of users' information needs. In summary, our research highlighted the unique design space between the clinical use of self-tracking data and other domains of self-tracking research in the context of axSpA. Though it would not be realistic to further explore this considering the scope of the thesis.

7.2.7 Conclusion

The continuous growth in the popularity of consumer PI and self-tracking technology in recent years has given rise to research which aims to exploit the clinical value of self-tracking data in the context of healthcare. Although promising steps have been taken to leverage the benefits of patient self-tracking data in the management and treatment of chronic conditions, much of its practical application in real-life clinical scenarios was left unexplored. Our research used a series of qualitative studies involving field observations, surveys and interviews to examine the feasibility of the inclusion of self-tracking data in the provision of axSpA patient care, and understand the opportunities and challenges associated with the collaborative use of data between patients and providers. Our work shows that self-tracking data can be used to improve the consultation process and the ongoing treatment of chronic conditions similar to axSpA.

The work presented in this thesis advanced the field of research by improving the understanding of the opportunities and challenges associated with the clinical use of patient self-tracking data in the context of rheumatic conditions, specifically axial spondy-

loarthritis. Our research involved the identification of potential roles self-tracking data could play in the provision of axSpA patient care based on the existing clinical workflow, a qualitative look at the determinants of axSpA patients' self-tracking adherence as well their expectations and concerns regarding the collaborative use of self-tracking data. A qualitative exploration of the use and discussion of self-tracking data in a real-life clinical scenario reaffirmed the feasibility and benefits of the inclusion of self-tracking data in the provision of axSpA patient care. Furthermore, we provided practical recommendations for designing tools which support the clinical use of self-tracking data. We discuss how our findings and design recommendations can be generalised and applied to other musculoskeletal conditions characterised by similar symptoms, e.g. rheumatoid arthritis, as well as other chronic conditions with similar care provision process, e.g. irritable bowel syndrome, chronic fatigue syndrome.

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Appendix A

Study 1 - Example of Field Notes

A.1 Flow of Events

Date: 29/11/2017
Location: Royal National Hospital for Rheumatic Diseases

1.05pm Researcher arrives at the hospital

1.10pm Researcher meets up with clinician in the hospital lobby

1.15pm Researcher and clinician enters the office

1.15pm Researcher and clinician discusses patient demographics for the afternoon session and talks about the open-source testing of Project Nightingale

1.35pm Clinician starts preparing for the first patient visit in the afternoon

1.37pm Patient no.1 enters office

1.52pm Patient no.1 leaves office

1.52pm Clinician records dictation

2.22pm Clinician starts preparing for the second patient visit

2.25pm Patient no.2 enters office

2.37pm Patient no.2 leaves office

2.38pm Clinician records dictation

2.42pm Clinician starts preparing

2.44pm Patient no.3 enters office

2.57pm Patient no.3 leaves office

2.58pm Clinician starts dictation

3.01pm Clinician finds out Patient no.4 did not attend

3.01pm Researcher and clinician starts discussion

3.27pm Clinician finds out Patient no.5 did not attend

3.31pm Clinician and assistant engage in conversation

3.58pm Clinician starts preparing for the visit of Patient no.6

4.02pm Patient no.6 enters office

4.18pm Patient no.6 leaves office

4.19pm Clinician starts dictation

4.27pm Clinician starts preparing for the visit of Patient no.7

4.30pm Patient no.7 enters office

4.55pm Patient no.7 leaves the office

5.02pm Research leaves the hospital

Note 1: Dictation normally takes less than 3 minutes
Note 2: Conversations would take place briefly between researcher and clinician between events

A.2 Conversation Transcript

Patient Number: 1
Session Start Time: 1.37pm
Session End Time: 1.52pm (15min)
Patient Gender: Female
Age: 17
Existing Condition(s): Irritable bowel syndrome

Additional Information: New patient; family history of rheumatological disease

1. Clinician checks Cerner Millennium to see if patient has arrived)
2. Clinician opens door and invite patient and accompanying person in)
3. Started with patient's brief description of symptoms
4. Clinician gather information for diagnosis
   C: When did the symptoms start to show?
   P: About a year ago. I started experiencing aching around my neck, knees and ankles.
   C: When do you experience the most pain?
   P: When I take walk or...
   C: So it worsens with activity.
   P: Yes.
   C: At what time of the day do you experience the most pain?
   P: Ankles in the morning, afternoon and evening
   C: No swirling?
   P: No.
   C: Any tiredness?
   P: Constantly.
   C: No rashes? dryness in the mouth? dry eyes?
   P: No.
   C: Do your fingers change colour during winters?
   P: Yes, the tips will go white.
   C: Any family history of arthritis? Ankylosing Spondylitis?
   PF: Grandfather has arthritis.
   P: I might have irritable bowel syndrome.
   C: Any weight changes?
   P: Nothing drastic.
   C: Chest pain?
   P: Yes, sometimes. But not persistent.
   C: Do you feel pins and needles in any places?
   P: Numbness at times.
   C: Have you had any operations (in the past)?
   P: No.
   C: Medication?

P: Only taking some pain-killers (no anti-inflammatory etc.)
C: Do you smoke?
P: I used to.
C: Alcohol consumption?
P: Sometimes.
C: When did you take your last blood test? was it a month ago?
P: Yes (I've been taking some iron tablet).

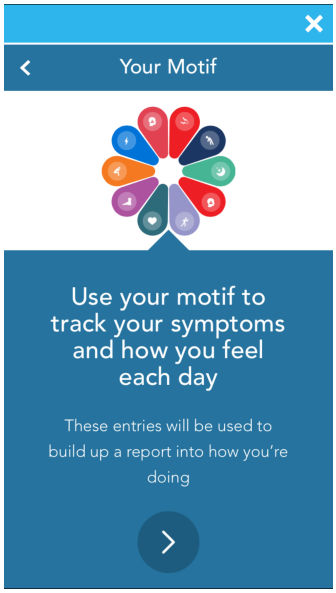
5. Clinician checks patient reported outcome, especially on medication and use of drugs
6. Clinician raises hypothesis
7. Patient's mother gave additional information
8. Clinician invite patient to an adjacent room for physical examination
   (a) Clinician gives instruction
   (b) Patient makes movement accordingly
   (c) Clinician ask for feedback (e.g. limitation of movement, pain etc.)
   (d) Patient gives feedback
   (e) Clinician perform supplementary/refined examination
   (f) Patient gives context information
9. Clinician lead patient back to seats
10. Clinician reflect result of examination
    C: I can't see a lot of symptoms (of rheumatological disease). But we're going to need to do more examinations (MRI and blood test).
11. Clinician gives patient suggestion
    C: You can take Paracetamol regularly. Yoga and/or Pilates will also help.
    P: Ok.
    C: Do you have any other questions?
    P: No.
    C: Ok then I'll see you in a few months.
12. Clinician sees the patient out
13. Clinician return to seat. Initiate dictation through interaction with Millennium

14. Clinician record and send (audio) dictation letter to assistant for transcription
15. Conclusion of a patient visit

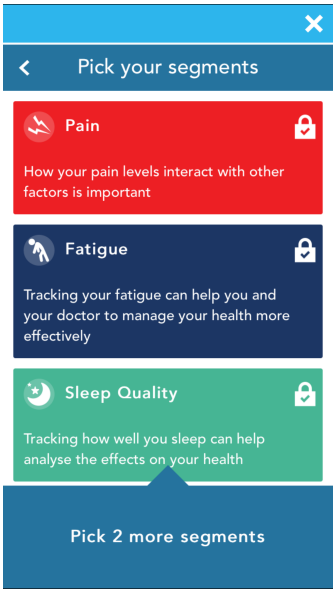
Clinical procedures and diagnostic process: Yes
Guiding of diagnosis/conversation: Yes, Clinician-driven
Decision-making dynamics: Clinician-driven
Use and PI and PGD N/A
Self-diagnosis No

Appendix B

uMotif Screenshots

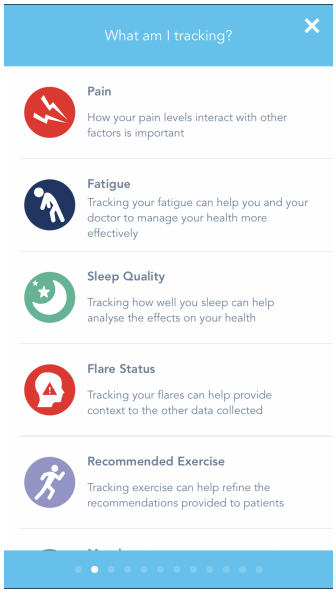


(a) welcome page

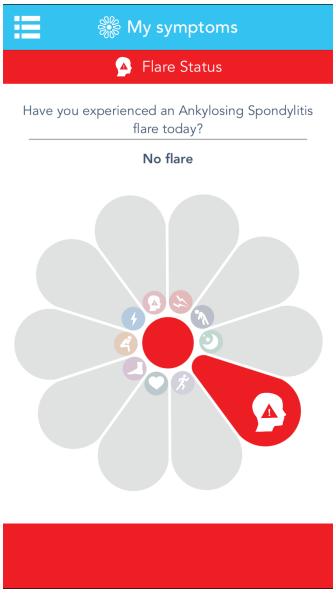


(b) petal customisation

Figure B-1: uMotif - screenshots 1

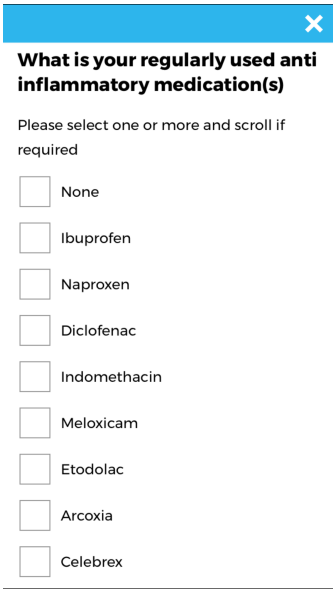


(a) data facets

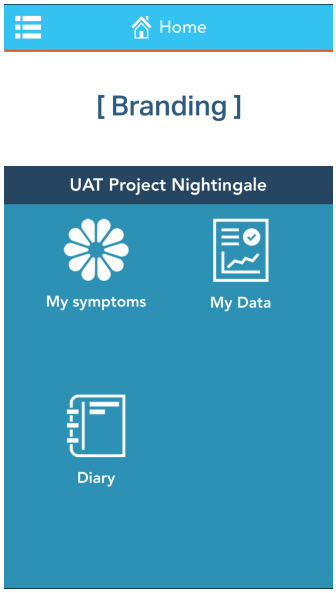


(b) petal scale

Figure B-2: uMotif - screenshots 2

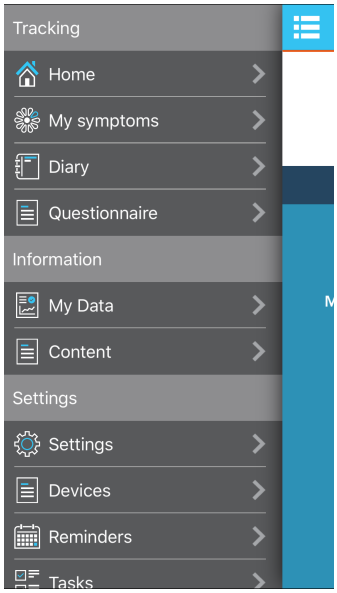


(a) daily questionnaire



(b) main menu

Figure B-3: uMotif - screenshots 3



(a) side menu

Figure B-4: A figure with two subfigures

Appendix C

Patient Questionnaire

Project Nightingale / uMotif Questionnaire

Patient Information

You are invited to take part in a study about how patients with axial spondyloarthritis/ankylosing spondylitis (AS) use and interact with self-tracking technologies for the management of the condition. Please read this form carefully and feel free to ask any questions you may have before starting the survey.

What is the study about

'Self-tracking' refers to the collection of personally relevant information for the purpose of self-reflection and self-understanding. Project Nightingale is a study designed to empower AS patients to take control of their symptoms and improve their quality of life with a technological solution based on self-tracking. Patients are able to join the study via the uMotif application which is designed to track daily AS symptoms and activities. We hope to hear your opinion of the application. The purpose of the study is to understand how AS patients use and get value out of self-tracking technology and how this could fit with established AS treatment approaches adopted by most healthcare professionals. The result of the study will be used to improve the design and usability of the self-tracking application as well as the sharing and use of its data.

This study is conducted jointly by the University of Bath and the Royal National Hospital For Rheumatic Diseases. If you have any other questions, please feel free to contact us via email: wz331@bath.ac.uk

What we will ask you to do

We would like you to complete a questionnaire that consists of open-ended questions, multiple choice questions and ratings regarding information about your AS condition, self-tracking history, experiences with Project Nightingale and your opinions on sharing data with healthcare professionals. You may decline to answer any questions that you feel uncomfortable with and you may withdraw at any time during the questionnaire. You will be asked to hand in the questionnaire after you've completed it.

This questionnaire will normally take 25-30 minutes to complete.

Risks and benefits

There are no anticipated risks with the participation in the study. Your participation in this study is entirely voluntary. There will be no financial rewards with the completion of the study. The data gathered from the study will be used to improve the usefulness of self-tracking tools in the management of AS.

Confidentiality and data handling

This study is conducted on an anonymous basis and does not require the collection of information that is identifiable to an individual, i.e., names, address, contact details and NHS number etc. Access to all data collected will be restricted to research staff and relevant healthcare professionals. Data collected during the study will be retained and archived for research purposes.

Participant's consent

By completing this survey you agree to the following statements:

1. I have read and understood all the information above
2. I am taking part in the study voluntarily and I understand that I am able to withdraw from the study at any time
3. I understand that the study is conducted on a strict anonymous basis
4. I understand that the data I provide during the study will be retained and archived for research purposes
5. I understand that my answers may be quoted (anonymously) for publications, reports and other research outputs

Section 1: Basic Information

We'd like to begin the survey by collecting some basic information about you.

1. Please tell us about yourself

1. Age

2. Gender

3. Occupation

4. Have you been diagnosed with Ankylosing Spondylitis (AS)?

- Yes
- No

4.a. If YES, when did you receive the diagnosis?

5. When did you first notice your AS symptoms?

6. Do you have any other chronic conditions?

- ○ Yes
- ○ No

6.a. If YES, please specify

2. Participation in Project Nightingale

7. Have you already signed up for the uMotif project/Project Nightingale?

- ○ Yes
- ○ No

7.a. If NO, what's the reason?

7.a.i. Will you consider joining the project in the future?

- ○ Yes
- ○ No
- ○ Not sure

8. What was your motivation for signing-up for Project Nightingale?

Section 2: Self-Tracking

In this part of the questionnaire, we will collect information about your previous experiences with ‘self-tracking’.

‘Self-tracking’ refers to the collection of personally relevant information for the purpose of self-understanding. Examples include the use of fitness-tracking applications (e.g., Myfitnesspal, Strava, Cardio), wearables (e.g., Fitbit, Apple Watch, Garmin) and paper diaries (e.g., disease activity journal, mood diary). We need your help in understanding how ‘self-tracking’ could benefit the treatment and self-management of AS.

9. Have you ever used any self-tracking tools other than the uMotif application?

- (•) Yes
- ( ) No

If you selected 'No', please scroll down to the bottom of this page and click 'Next'.

10. Have you ever used any self-tracking tools (other than uMotif) to understand or manage your AS? Please list them below and describe the type of data that you were collecting.

11. What was your motivation for self-tracking? What kept you going?

12. What value did self-tracking provide for you?

13. How did you make use of the data that you collected?

14. If you are no longer using the above self-tracking tools or apps, what was your reason for discontinuing use?

Section 3: uMotif Application - Page 1

The uMotif application allows you to track daily symptoms, exercises, medications and mood. It also gives you visual summaries of these data facets by graphs.

In this section, we will ask you questions about your recent experience with using the uMotif application and its data.

15. Have you used the uMotif application?

- (•) Yes
- ( ) No, I haven't signed up for the project yet
- ( ) No, but I did sign up for the project

15.a. If you did sign up for the project but have yet to use the application, why?

If you selected 'No', please scroll down to the bottom of this page and click 'Next'.

16. Are you still tracking with the uMotif application?

- ( ) Yes
- ( ) No

17. What motivates you to continue tracking with the uMotif application?

18. What makes you less likely to continue tracking with the uMotif application?

19. How much effort does it require to provide uMotif with data on a daily basis? Please rate it from 1 (Effortless) to 5 (Too much effort).

	1	2	3	4	5	
Effortless	☐	☐	☐	☐	☐	Too much effort

19.a. Please explain the choice you made.

20. How useful do you think your uMotif data could be for improving **your own** understanding and management of AS? Please rate from 1 (Not at all useful) to 5 (Extremely useful).

Please don't select more than 1 answer(s) per row.

	1	2	3	4	5	
Not at all useful	☐	☐	☐	☐	☐	Extremely useful

20.a. Please explain the choice you made.

20.b. Do you have any suggestions about how the data could be made more useful?

Section 3: uMotif Application - Page 2

21. Please rate how useful you think it is to collect the following data using uMotif? Please rate from 1 (Not at all useful) to 5 (Extremely useful).

Please don't select more than 1 answer(s) per row.

	1	2	3	4	5
Pain Intensity	☐	☐	☐	☐	☐
Pain Location	☐	☐	☐	☐	☐
Type of Pain (e.g. throbbing, burning)	☐	☐	☐	☐	☐
Eyesight	☐	☐	☐	☐	☐
Fatigue	☐	☐	☐	☐	☐
Flare Status	☐	☐	☐	☐	☐
Psoriasis	☐	☐	☐	☐	☐
Hot Flushes	☐	☐	☐	☐	☐
Red, Painful Eyes	☐	☐	☐	☐	☐
Stress Level	☐	☐	☐	☐	☐
Mood	☐	☐	☐	☐	☐
Confidence with AS	☐	☐	☐	☐	☐
Adherence to Prescription	☐	☐	☐	☐	☐
Adherence to Strech Exercises	☐	☐	☐	☐	☐
Medication	☐	☐	☐	☐	☐
Hydration	☐	☐	☐	☐	☐
Alcohol Intake	☐	☐	☐	☐	☐
Caffeine Intake	☐	☐	☐	☐	☐
Screen Time	☐	☐	☐	☐	☐
Exercise Intensity/Calorie burned	☐	☐	☐	☐	☐
Exercise Duration	☐	☐	☐	☐	☐
Walking/Running Distance	☐	☐	☐	☐	☐
Sleep Quality	☐	☐	☐	☐	☐
Sleep Duration	☐	☐	☐	☐	☐

22. Does your self-management routine involve the use of any data types from above? If YES, please specify below.

23. Is there any data from your self-management routine that is missing from the list?

24. What is your overall opinion on the uMotif petal scale?

More info

25. When would you be most likely to review the uMotif data yourself? Please choose all that apply.

- [ ] Periodically as part of my self-management routine
- [ ] Before I go to a doctor's appointment
- [ ] When there are changes in my treatment, e.g., new prescription
- [ ] After attending a rehabilitation course
- [ ] When there is something out of ordinary with my symptoms
- [ ] After I have sustained an injury
- [ ] When I feel confident about my ability to self-manage AS
- [ ] When I feel negative about my ability to self-manage AS
- [ ] When I don't feel motivated to exercise
- [ ] When I feel my condition is improving
- [ ] When I feel my condition is degrading
- [ ] When my condition has remained stable for a period of time
- [ ] Whenever it springs to mind, but it's not something I would schedule
- [ ] I want the application to tell me when it's time to review my data

25.a. If there are other causes for reviewing your own data, please specify below.

26. To what extent would you like to be able to explore and analyze your own uMotif data? Please choose the most appropriate answer.

- ○ Not at all. I'd leave it for my clinician to review the data and tell me what they find
- ○ I'd like to see a summary of my data, but only for the important aspects
- ○ Show me a summary but allow me to explore the details at my own will
- ○ I'd like to review and analyse the data by myself
- ○ I'm not sure
- ○ Other

26.a. If you selected Other, please specify:

27. What value have you gained from using the uMotif application with regard to understanding and management of your AS?

28. Overall, has the uMotif application met your expectations? If not, what do you think could be done to improve it?

Section 4: Sharing Data with Clinicians

This section is about sharing and using your uMotif data with your AS healthcare professionals.

Your self-tracking data is not only useful for improving your own understanding of the disease but also that of others. Clinicians may use it to provide better treatment and help you make sense of the data so that you take full advantage of the technology.

29. How comfortable do you feel about sharing the following types of data from uMotif with your health professionals? Please rate from 1 (Not al all comfortable) to 5 (Completely comfortable).

Please don't select more than 1 answer(s) per row.

	1	2	3	4	5
Daily symptoms (e.g., pain, fatigue)	☐	☐	☐	☐	☐
Medication and AS-related exercise (i.e., stretches)	☐	☐	☐	☐	☐
Lifestyle (e.g., sleep, hydration, exercise)	☐	☐	☐	☐	☐
Mental status (e.g., mood, confidence)	☐	☐	☐	☐	☐
Any note/diary entries you've made	☐	☐	☐	☐	☐

29.a. If you indicated that you would be unwilling to share any of the above data, please explain why.

30. How do you expect you uMotif data to be used by health professionals? What do you expect them to look for in your data?

31. How important do you think it will be for your health professionals to review and analyze the uMotif data that you have collected? Please rate from 1 (Not at all important) to 5 (Extremely important).

Please don't select more than 1 answer(s) per row.

	1	2	3	4	5	
Not at all important	☐	☐	☐	☐	☐	Extremely important

32. How useful do you think your uMotif data will be for decisions that health professionals make about **your** treatment? Please rate from 1 (Not at all useful) to 5 (Extremely useful).

Please don't select more than 1 answer(s) per row.

	1	2	3	4	5	
Not at all useful	☐	☐	☐	☐	☐	Extremely useful

33. How important do you think it will be for you to have discussions about your uMotif data during **your clinical appointments**? Please rate from 1 (Not at all important) to 5 (Extremely important).

Please don't select more than 1 answer(s) per row.

	1	2	3	4	5	
Not at all important	☐	☐	☐	☐	☐	Extremely important

34. How useful do you think it will be for you and your clinicians to discuss the following about your self-tracking data? Please rate from 1 (Not at all useful) to 5 (Extremely useful).

Please don't select more than 1 answer(s) per row.

	1	2	3	4	5
Long-term changes (e.g., trend, progression)	☐	☐	☐	☐	☐
Short-term changes (e.g., spikes)	☐	☐	☐	☐	☐
Recurring patterns (e.g. weekly, seasonal)	☐	☐	☐	☐	☐
Data outliers (e.g., extremes)	☐	☐	☐	☐	☐
Correlations (e.g., flares and exercise)	☐	☐	☐	☐	☐
Changes in correlations	☐	☐	☐	☐	☐
Achievement of targets/expectations	☐	☐	☐	☐	☐
Comparisons with other patients	☐	☐	☐	☐	☐
Gaps in data where tracking did not take place	☐	☐	☐	☐	☐

34.a. Is there other data insight that you may wish to discuss?

35. Has using uMotif highlighted any questions, topics or issues that you would like to discuss with your doctor? Please list them below.

36. How useful do you think **your** uMotif data will be for decisions that health professionals make about the way they treat **other patients**? Please rate from 1 (Not at all useful) to 5 (Extremely useful).

Please don't select more than 1 answer(s) per row.

	1	2	3	4	5	
Not at all useful	☐	☐	☐	☐	☐	Extremely useful

37. Do you have any concerns about your uMotif data being used by your consultant, or discussed during your clinical appointments?

Additional Comment

38. Please share any additional comments or suggestions you have about Project Nightingale, the uMotif app or self-tracking for AS.

Conclusion

This is the end of the questionnaire.

Thanks for participating.

Figure C-1: Patient event flyer

Appendix D

Study 4 - CoUs-axSpA

D.1 CoUs-axSpA - Email Communications

D.1.1 Patient Invitation Email

Dear Patient,

Thank you for taking part in Project Nightingale and for supporting our research.

I am writing to invite you to take part in a study (CoUs-axSpA) where you will be able to review and discuss your self-tracking data your consultant rheumatologist during the next telephone check-up appointment. This refers to the data that you have collected through the uMotif app. Doing so will help us improve the use of self-tracking technology in the future.

Why am I invited? - You are invited to take part because you are a registered patient at RNHRD and a Biobank participant. In addition, you have also used the uMotif app consistently within the last months.

How will the study be conducted? - This study will be conduct remotely and will take about three hours to complete.

Do I have to take part? - Your participation is entirely optional. Your treatment will not be affected in any way should you refuse to participate. However, we would encourage you to take the opportunity to review this data with your consultant.

You do not have to do anything if you do not wish to participate. However, if you are interested or would like to know more, please reply to this email and a researcher will

be in touch shortly. An Information Sheet containing more details about the study is attached to this email. We urge you to careful read through it before you decide to take part.

We hope to hear from your soon.

** This project is sponsored by the Royal United Hospitals (RUH) Bath NHS Foundation and is part of a PhD research program. The chief investigator is Dr Raj Sengupta, Consultant Rheumatologist at RNHRD. It has been reviewed by the NHS Research Ethics Committee [reference: 20/SC/0140] and the Research Ethics Approval Committee for Health (University of Bath) [reference: EP 19/20 045]. IRAS project ID: 271239.*

Best
Will

William Hue (Msc)
Principal Investigator, Doctoral Candidate
Department of Computer Science
University of Bath

[Attachment: Patient Information Sheet]

D.1.2 Patient Invitation Follow-Up Email

Dear Patient,

Thank you for your interest in the CoUs-axSpA study. Before you decide to take part, please make sure you have read and understood all information in the Participant Information Sheet which was attached to the last email. If you have any remaining questions, please do not hesitate to ask the research team by replying to this email.

If you do not have questions and would like to proceed with your participation, please click the link below and complete an online consent form (when asked of your Participant ID, please enter XX):
`https://bathreg.onlinesurveys.ac.uk/cous-axspa-patient-consent-form`

* Please download the completed consent form for your record when prompted. You

may also ask the research team to send you a digital copy of this at a later time.

We'll be in touch with you with your data and instructions once we have received your consent form. Please reply to this email if you have encountered any difficulties.

Best
Will

William Hue (Msc)
Principal Investigator, Doctoral Candidate
Department of Computer Science
University of Bath

D.1.3 Patient Pre-Study Briefing Email

Dear Patient,

Thank you for completing the consent form and welcome to the CoUs-axSpA study.

Please find your recent Project Nightingale data attached to the email. This datasheet contains your uMotif data from up to 12 months prior to start of the project (24/02/2021). We have made your datasheet available in **excel**, **.pdf** and **.png** format. You may choose to use any format you like as the information they contain is identical. We recommend that you use a laptop or desktop computer with a decent screen size.

When you're ready to review the data, please click the link below (when asked of your Participant ID, please enter **XX**): `https://bathreg.onlinesurveys.ac.uk/cous-axspa-patient-data-preview-questionnaire`

Please read the instructions before you start reviewing the data. You will be asked to complete a questionnaire after you have reviewed the data. This activity will not be timed.

** Please download the completed questionnaire for your record when prompted. You may also ask the research team to send you a digital copy of this at a later time.* ***We recommend that you keep a copy of this and have it ready to use for the appointment.***

Once you have reviewed your data and have completed the questionnaire, the outpatient team will get in touch with you to confirm the time and date of your appointment.

Best
Will

William Hue (Msc)
Principal Investigator, Doctoral Candidate
Department of Computer Science
University of Bath

[Attachment: Patient's Project Nightingale Datasheets]

D.1.4 Patient Post-Study Follow-Up Email

Dear Patient,

Thank you for taking part in the CoUs-axSpA study and for attending your check-up appointment.

We hope the conversation you had with your clinician about your self-tracking data was helpful. We would like to invite you to complete a post-study questionnaire.

Please click the link below to complete the questionnaire (when asked of your Participant ID, please enter **XX**): `https://bathreg.onlinesurveys.ac.uk/cous-axspa-post-study-questionnaire`

** Please download the completed questionnaire for your record when prompted. You may also ask the research team to send you a digital copy of this at a later time.*

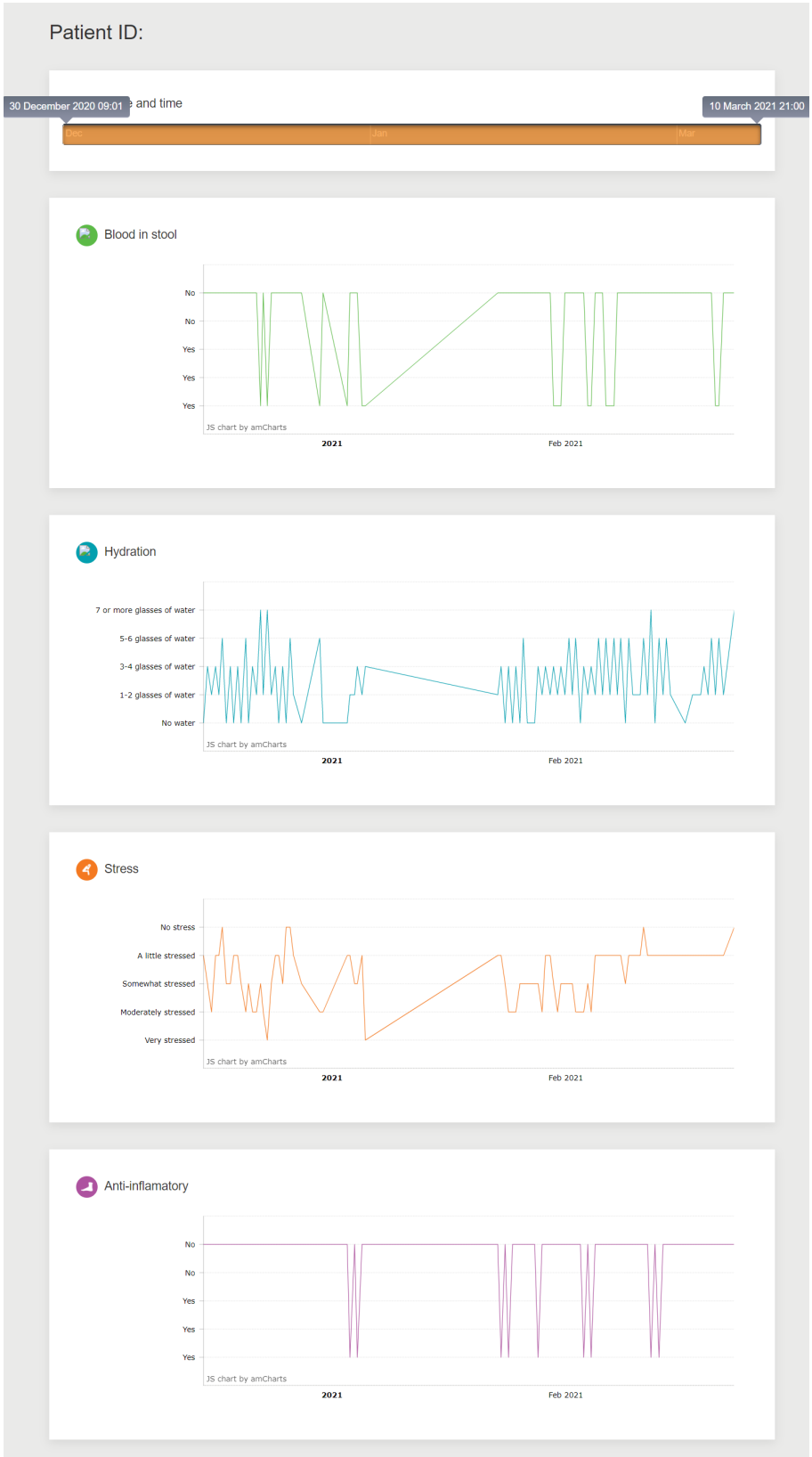
We would like to thank you for your participation in the study and for supporting research. If you have any further questions, please feel free to contact us through email.

Best
Will

William Hue (Msc)
Principal Investigator, Doctoral Candidate

Department of Computer Science
University of Bath

D.2 CoUs-axSpA - Project Nightingale Datasheets (Mock Data Set)


Patient ID:
30 December 2020 09:01
and time
10 March 2021 21:00
Dec
Jan
Mar
Blood in stool
No
No
Yes
Yes
Yes
JS chart by amCharts
2021
Feb 2021
Hydration
7 or more glasses of water
5-6 glasses of water
3-4 glasses of water
1-2 glasses of water
No water
JS chart by amCharts
2021
Feb 2021
Stress
No stress
A little stressed
Somewhat stressed
Moderately stressed
Very stressed
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2021
Feb 2021
Anti-inflamatory
No
No
Yes
Yes
Yes
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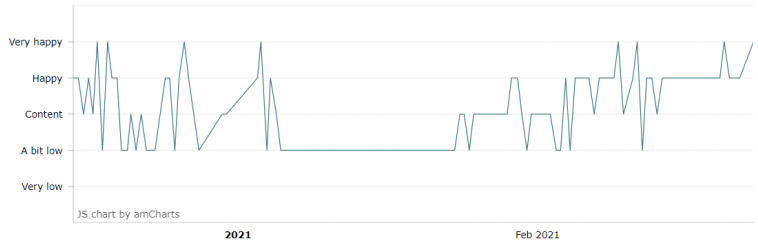
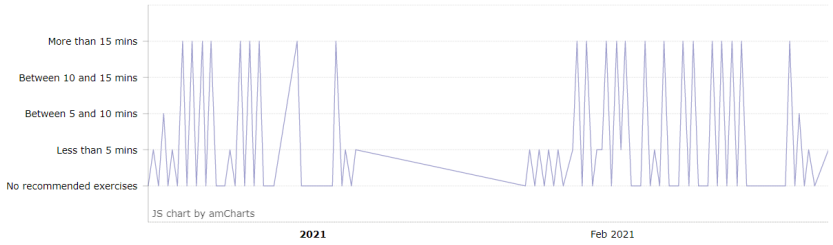
2021
Feb 2021

Mood

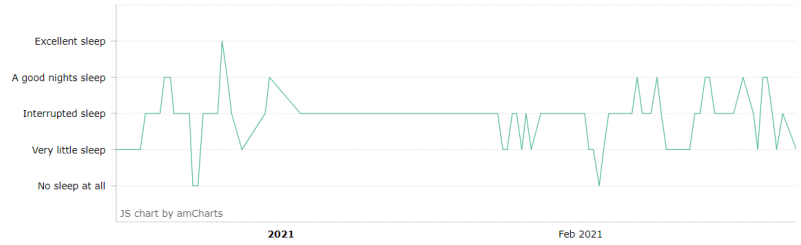


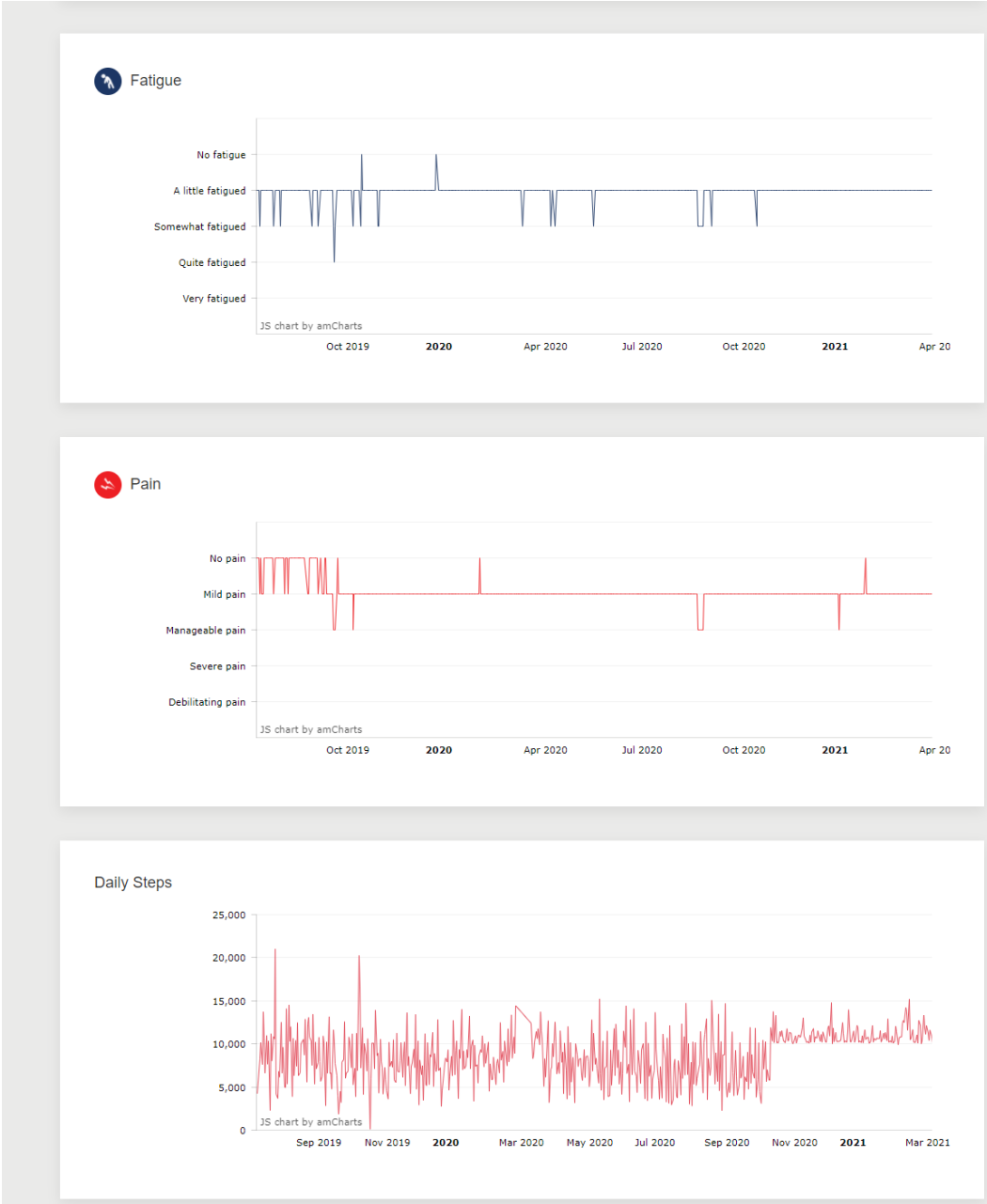
Recommended Exercise



Flare Status

Sleep Quality





D.3 CoUs-axSpA - Research Protocol

Supporting Collaborative Use of Patient Self-Tracking Data in the Context of Axial Spondyloarthritis (axSpA) Clinics

Short Title: CoUs-axSpA

Research Protocol (v3.0)

20th February 2021

IRAS Project ID: 271239

Funder: This project is part of a PhD Studentship and is funded by the University of Bath

Sponsor: Royal United Hospitals Bath NHS Foundation Trust, Combe Park, Bath, BA1 3NG UK
Tel: [redacted]

Start Date: 24/02/2020 End Date: 24/08/2021

This protocol describes the CoUs-axSpA study and explains information regarding procedures and participant recruitment. It will adhere to the principles set out by the Declaration of Helsinki. Activities will be conducted in compliance with this protocol, the GDPR and any other regulatory requirements.

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor.

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

On behalf of the Study Sponsor:

Dr Kelly Spencer

Research Manager Operations

Royal United Hospitals, Bath

Signature: ..... Date: ...../03/2020

Chief Investigator:

Dr Raj Sengupta (RS)

Consultant Rheumatologist and lead for Ankylosing Spondylitis

Royal National Hospital for Rheumatic Diseases (RNHRD) at the Royal United Hospitals, Bath

Signature: [redacted] Date: 04/03/2020

Principal Investigator:

Weihua Zhang (WZ)

PhD Candidate

Department of Computer Science, University of Bath

Signature [redacted] Date: 04/03/2020

Co-Investigator:

Rosie Barnett (RB)

Research Assistant

Departmen[redacted]d Hospitals, Bath

Signature: ..... Date: ..04../..03../..2020..

Co-Investi

Dr Simon Jones (SJ)

Senior Lecturer

Department of Computer Science, University of Bath

Signatur[redacted]..... Date: ..04../..03../..2020..

KEY STUDY CONTACTS

On behalf of the Study Sponsor:

Dr Kelly Spencer

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Combe Park, Bath BA1 3NG

Telephone: [redacted]

Email:[redacted]

Chief Investigator:

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Email: [redacted]

LIST OF CONTENTS

STUDY SUMMARY

'Self-tracking' is the practice of systematically recording data about one's health conditions or activities. In the context of Axial Spondyloarthritis (axSpA), this involves the collection of data such as symptoms, medication and physical activities. Currently, Royal National Hospital for Rheumatic Diseases (RNHRD)'s Project Nightingale uses a health-monitoring smartphone application (uMotif) and wearable devices to enable axSpA patients to engage in self-tracking. Though the project has generated a substantial amount of data, the use of this data in the clinical setting remains unexplored.

Our project will use qualitative research methods such as observations, questionnaires and interviews to investigate how axSpA patients and their clinicians use and discuss self-tracking data in a realistic setting, e.g., prior to, during, or following a clinical appointment. Participants of Bath Biobank (13/SW/0096) and Project Nightingale will be eligible to take part, provided that they have generated at least 30 entries of self-tracking data using the uMotif application within any 3-month window in the 12 months that leads to the project's start date. The study will take place at RNHRD and online over the course of 6 months. Research activities will be carried out on the day of patient's scheduled telephone check-up and online through email and questionnaires. The total time commitment required of each patient participant will not exceed 4 hours.

This study will allow us to explore potential challenges and opportunities that are associated with the clinical uses of self-tracking data regarding activities such as agenda setting, sensemaking, target setting and action planning. The findings of the study will inform the design of information technology that facilitates patient-clinician collaboration around self-tracking data. This study is conducted by researchers from the Department of Computer Science at the University of Bath and RNHRD.

KEYWORDS	Axial Spondyloarthritis; axSpA; CoUs axSpA; Bath Biobank; Project Nightingale; Self-Tracking; Personal Informatics; Patient-Generated Data; Patient Self-Reporting; uMotif; Patient-Clinician Collaboration; Human-Computer Interaction

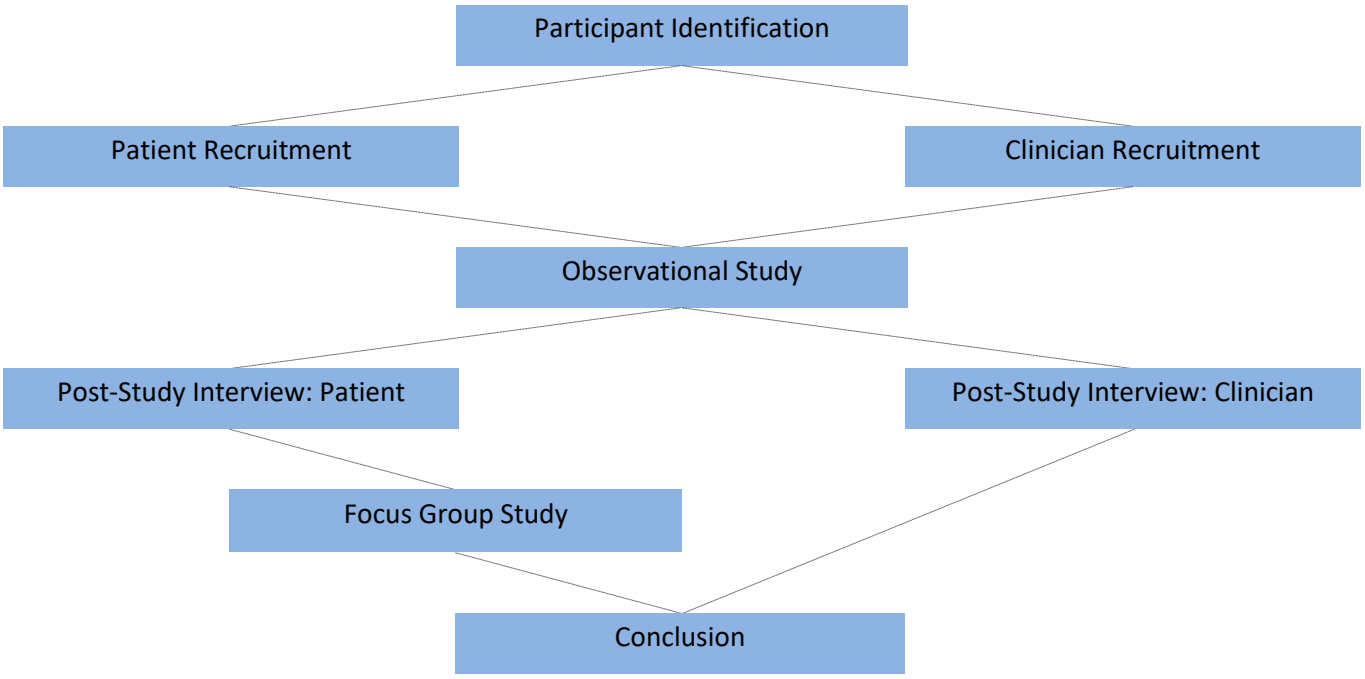
ROLES & RESPONSIBILITIES OF STUDY STEERING GROUPS AND INDIVIDUALS

The research committee consists of experienced individuals including a consultant rheumatologist from RNHRD (RS) and academic researchers from the University of Bath (WZ, RB, SJ). The Chief Investigator (RS) is responsible for the conduct of the whole research project. He will be supervising the research team and be readily available to communicate with the Research Ethics Committee (REC) and other review bodies during the application process and where necessary during the conduct of the research. The Principal Investigator (WZ) will be responsible for the conduct of the research at the research site (RUH) and researcher's institution (i.e., University of Bath). Co-Investigator RB will assist with the conduct of the research on-site. Co-Investigator SJ will help carry out data analysis following data collection.

PROTOCOL CONTRIBUTORS

The study protocol was developed by a team of experienced individuals including academic researchers from the University of Bath and a consultant rheumatologist from RNHRD (RUH). Dr Kelly Spencer (R&D manager) and Janine McCaulder-Ojeda (R&D office) at RUH have given practical advice on preparation of submission to HRA. This study will also be reviewed by the University of Bath's Search Research Ethics Approval Committee for Health (REACH) upon receiving HRA and NHS REC approval. All members of the research team who will be handing patient data have completed the required training. The design of the study has been informed by previous publications of the Principal Investigator (WZ) as well as a recent Patient and Public Involvement (PPI) event related to Project Nightingale.

STUDY FLOW CHART



SCHEDULE OF PROCEDURES

Events & Procedures	2021						
	Feb	Mar	Apr	May	Jun	Jul	Aug
Participant Identification	x	x					
Participant Recruitment		x	x	x			
Observational Study			x	x	x		
Clinician Interviews			x		x		
Data Analysis				x	x	x	
Publication & Dissemination					x	x	x

CoUs-axSpA

STUDY PROTOCOL

This protocol describes the study "Supporting Collaborative Use of Patient Self-Tracking Data in the Context of Axial Spondyloarthritis (axSpA) Clinics: A Qualitative Exploration" or CoUs-axSpA for short. This protocol outlines the study's background, objectives, design, recruitment as well data collection, analysis and dissemination. The protocol also describes how the CoUs-axSpA research committee will ensure ethical and regulatory compliance. All investigators must follow the protocol strictly throughout the study to ensure their conducts are in line with NHS policies. Accidental protocol deviations can happen at any time. They must be adequately documented on the relevant forms and reported to the Chief Investigator and Sponsor immediately. Deviations from the protocol which are found to frequently recur are not acceptable, will require immediate action and could potentially be classified as a serious breach.

1 BACKGROUND & RATIONALE

This study aims to explore the uses of patient self-tracking data in the setting of Axial Spondyloarthritis (axSpA) clinics. The project is associated with the Royal National Hospital for Rheumatic Diseases (RNHRD)'s Bath Biobank (13/SW/0096) and Project Nightingale which uses a health-monitoring smartphone application (uMotif) and wearable devices (e.g., FitBit, Garmin) to enable axSpA patients to engage in self-tracking. Self-tracking refers to the practice of systematically recording data about one's health conditions or activities. In the context of axSpA, this involves the collection of disease-related data such as symptoms, medication and physical activities. Over the past few years, self-tracking among patients with chronic conditions has become more and more pervasive and prolific thanks to the fast-growing market of consumer self-tracking technology. The increasing attention from health researchers, providers and policymakers has made self-tracking an emerging domain in healthcare research.

Recent research highlighted the potential value of self-tracking and patient self-tracking data in the management and treatment of chronic conditions, e.g., Parkinson's disease (Mentis et al., 2017), irritable bowel syndrome (Chung et al., 2016), chronic fatigue syndrome (Davies et al., 2019), Migraine (Schroeder, 2018). Compared to traditional ways of collecting patient-reported outcomes (such as paper questionnaire issued during annual check-ups), self-tracking mobile applications allow for real-time reporting of health data, thereby providing a more accurate representation of the disease experience by removing recall bias (Hue et al., 2019). Meanwhile, sensor-rich devices and smartphones (e.g., Fitbit, iPhone) have enabled patients to engage in the automatic tracking of their physical activities (e.g., steps, sleep, heart rate), generating information which could potentially supplement existing clinical data.

While many studies have been conducted to understand the value of patient self-tracking data from a cohort perspective, few have investigated the uses of said data by interested/relevant individuals in the clinical setting (Hue, 2019). It has been demonstrated in rheumatoid arthritis (RA) research that by integrating patient self-tracking data into clinical conversations, patients and clinicians could benefit from gaining a 'bigger picture' of the disease experience. Meanwhile, having conversations about self-

tracking which focus on patients' disease experience allowed for a more patient-centred care approach, with patients feeling more engaged with clinical evidence-gathering and decision-making.

Even so, the use of self-tracking data in the context of axSpA remains largely unexplored. Furthermore, past research involving patients' and clinicians' uses of self-tracking data often fail to recognise or incorporate situational barriers (e.g., time constraints, existing clinical procedure) in the study designs. This research project aims to provide a realistic representation of what a scheduled axSpA clinical appointment would look like with conversations about self-tracking data integrated into the existing clinical activities. This will help us find the best way of naturally incorporating self-tracking data into the existing clinical procedure. This will also allow us to identify collaboration challenges which would be otherwise ignored in a study that is removed from the clinical environment and generate design implications for potential technological solutions.

Past research suggested that patients and healthcare providers often differ in motivation when it comes to the use of self-tracking data. Our goal is to understand axSpA patients' and clinician's data-using goals and priorities and therefore help establish common ground during clinical consultations. One of the potential challenges is the conflicting agendas between axSpA patients and their clinicians regarding the use of their allocated consultation time. axSpA clinicians usually need to complete a set of predefined tasks during check-ups. This puts on clinicians the pressure to finish on time to avoid delays because they often need to see multiple patients back-to-back on the day of check-ups. This will also likely shape clinician's data-using goals and priorities. On the other hand, expert patients and patients who are self-tracking enthusiasts may have clear visions of the topics they'd like to discuss in regard to the use of their data during check-ups, e.g., self-management theories, perceived patterns.

We seek to understand how the disparity in patients' and clinicians' motivations and agendas can influence collaborative behaviours while exploring options that may help establish consensus around data-use and shared priorities. We propose that data-driven preparation/preview before consultation could be useful in addressing problems such as unfamiliarity with data and help patients formulate and prioritise topics they may wish to discuss during face-to-face conversations with their clinicians and vice versa. Earlier research suggested that the ability to create "markups" and annotations on datasheets (consisting of spreadsheets and visualisations) could benefit conversations around self-tracking data. We experiment with this idea with a pre-study online questionnaire which will be completed by patients prior to the study. The researcher will provide patients with datasheets consisting of visualisations of patients' own self-tracking data (from Project Nightingale) via email to allow patients time to familiarise themselves with the data. The researchers will investigate how patients' data preview behaviours potentially influenced clinical conversations about self-tracking data in a post-study interview.

This study will also allow us to investigate potential sensemaking barriers to the acquisition of data insights that are based on patient self-tracking data, e.g., unfamiliarity with the data, lack of disease-related expertise, lack of contextual information, suboptimal data representation. Since erroneous interpretation of clinical data could potentially misguide decision around treatment and self-

management, it is paramount that we identify and address these challenges when integrating self-tracking into axSpA clinics.

The study will yield design implications for technology that supports the collaborative uses of patient self-tracking data in the clinical setting. Researchers may come up with prototype software interface designs to help address these issues as the result of the study. We will take a user-centred approach to help us understand and evaluate the requirements and expectations of the end users of the interface, i.e., axSpA patients and clinicians. Our aim is to co-develop (with axSpA patients and clinicians) a set of design guidelines for future collaborative work around patient self-tracking data.

The clinical integration of self-tracking data could lead to a more personalised and patient-centred approach to the treatment and management of axSpA. This could influence the way patients view and use self-tracking data following a clinical appointment. We will investigate this through a post-study online questionnaire (see section 3 STUDY DESIGN & METHODOLOGY).

2 RESEARCH AIMS & OBJECTIVES

This study aims to explore the uses of patient self-tracking data in the setting of Axial Spondyloarthritis (axSpA) clinics. More specifically, this study will investigate how axSpA patients and their clinicians use and discuss self-tracking data from Project Nightingale prior to or during a scheduled clinical appointment. We aim to explore axSpA patients' and clinicians' opinions on collaborations around self-tracking data and identify potential challenges and opportunities that are associated with the clinical uses of said data.

2.1 Research Questions

The study is designed to address the following low-level research questions:

i. How will conversations about patient self-tracking data be integrated with existing clinical activities during check-ups?

The observational study (where the researcher will sit in and observe a clinical check-up between a patient participant and clinician participant) will allow researchers to investigate how conversations about patient self-tracking data can be naturally integrated into clinical check-up sessions. This will help us understand whether having conversations about self-tracking data could potentially benefit existing clinical activities or is best served as a stand-alone activity.

ii. Are there differences in motivation between axSpA patients and clinicians regarding the uses of patient self-tracking data?

One of the potential challenges regarding the clinical uses of patient self-tracking data is the conflicting agendas between patients and their clinicians. This is often exacerbated by limited consultation time

and the disparity in disease-related knowledge as well as motivation between axSpA patients and clinicians. This study will explore opportunities for developing technology-based solutions that can help identify axSpA patients' and clinicians' data-usage goals and establish shared priorities.

iii. What potential role could data preview play in patient-clinician collaboration around the clinical use of self-tracking data?

Not all patients review their self-tracking data before attending clinical check-up appointments. Unfamiliarity with self-tracking data could lead to inefficient use of consultation time and imbalanced communication dynamics. We want to give patients the opportunity to freely explore and curate their data prior to speaking to their clinicians. We do this by allowing patients time to familiarise themselves with the data and make comments which will be utilised during the scheduled clinical appointment.

iv. What are the potential sensemaking challenges regarding the use of patient self-tracking data?

A well-known issue within self-tracking research is that users often encounter sensemaking barriers when trying to obtain data-driven insights (e.g., seasonal changes, correlations, disease progression). These barriers include unfamiliarity with data, lack of technical or disease-related expertise, lack of information to help contextualise self-tracking data, inappropriate data representation etc. Meanwhile, erroneous interpretations of data could lead to ineffective decisions regarding the treatment of the disease. It is paramount that we identify these challenges when integrating self-tracking into axSpA clinics.

v. How can we design technology to support the use of patient self-tracking data and help solve emerging issues related to the integration of said data in the clinical setting?

The study will generate design implications that are related to the clinical uses of patient self-tracking data (e.g., agenda setting, sensemaking, target setting and action planning). Researchers may use these design implications to come up with prototype software interfaces to help address these issues.

vi. How might clinical integration of self-tracking data influence patient's perspectives on self-management following the appointment?

The integration of self-tracking data may lead to a more personalised and patient-centred approach to the treatment and management of axSpA. This could potentially shape the ways that patients view and use self-tracking data following a clinical check-up appointment. We will investigate this topic through a post-study questionnaire consisting of open-ended questions.

The above research questions may be updated as more information is obtained over the course of the research.

2.2 Outcome

This project is a qualitative study and therefore does not involve a typical outcome measure as those often used in quantitative studies. Researchers will observe participants' uses of self-tracking data and participants will answer semi-structured interview questions in which thematic analysis (Braun & Clarke, 2006) will be applied (qualitative analysis). The primary outcome is gaining an in-depth understanding of the challenges and opportunities associated with the clinical uses of (axSpA) patient self-tracking data. Content analysis (Downe-Wamboldt, 1992) which is generally considered a qualitative analytic approach may also be applied to the transcripts of the study. This approach allows researchers to generate codes and count their frequency of appearance in the transcript of interviews and conversations about self-tracking data. This approach is widely used in communication research and may help researchers explore relationships of words to see associations of ideas. The researcher WZ and his supervisor SJ both have relevant experience of these methods of analysis. Statistical analysis is not needed for this study.

3 STUDY DESIGN & METHODOLOGY

This is a qualitative, exploratory study co-designed by experienced researchers from the University of Bath and the Royal National Hospital for Rheumatic Diseases (RNHRD). This research is of inductive nature and hence will not involve the formulation and testing of hypotheses (see section 3.3 Justification for the Methodology). This project is expected to start in February 2021 and end in August 2021. Patient participation will take place over the course of up to 2 months (from recruitment to the end of data collection). The total commitment required will not exceed 4 hours per patient and 15 check-ups per clinician. Participants will be able to withdraw from the study at any time. All research activities involving participants will be audio-recorded with consent, transcribed verbatim and anonymised. The researchers will also take field notes during observations and interviews. The researchers will collect and retain used datasheets with consent.

3.1 Participant Recruitment

Potential patient participants will be contacted via their chosen method of communication (per Biobank ethics 13/SW/0096) about the project by authorised hospital staff at least 30 days prior to their scheduled telephone check-up appointment. We expect to recruit 15-24 patient participants in total (see section 3.3 Justification for the Methodology). We determined this sample size having considered the number of eligible patients who will be available for the data collection period as well as the response rate of similar projects. This sample size is comparable to past studies in related fields, i.e.,

Human-Computer Interaction (HCI) and health-related self-tracking. It will allow us to generate a sufficient amount of data for the intended qualitative analyses.

The patient contact email will include the following information: project summary, Patient Information Sheet (PIS) and contact details of the research team (see APPENDICES). Participants will be able to register their interest by replying to the contact email or via telephone. Patients will be given enough time to consider the information. Interested patients will be contacted by the research team via telephone a few days later to discuss the study and finalise their participation in the study (same day as patients' scheduled telephone check-up appointments). Informed consent will be taken in online prior to the study. The online consent form will be hosted via onlinesurveys.ac.uk, a secure, GDPR approved survey website endorsed by the University of Bath.

Interested clinicians will be identified via (work) telephone calls, emails or face-to-face conversations prior to the study. We will recruit 1-4 clinician participants for this study in total (see section 3.3 Justification for the Methodology and 4.3.1 Sample Size Justification). Clinician participants will not be responsible for conducting research activities (i.e., no unsupervised research activities will be carried out). Recruitment of clinician participants will begin immediately after the project is approved. The appropriate Clinician Information Sheet (CIS) will be sent out via email. Clinicians will be given enough time to consider the information. The researcher (WZ) will have a conference call with interested clinicians to discuss the study and address any concerns before their participation is finalised and consent given. Consent forms will be completed online and to be hosted through onlinesurveys.ac.uk, a secure, GDPR approved survey website endorsed by the University of Bath. All participants will be sent a newsletter summarising the results when the study has been completed if they wish.

3.2 Study Procedure

This study will help us understand how conversations around patient self-tracking data take place in a realistic clinical setting. axSpA patients who have signed up to Bath SpA Biobank project (13/SW/0096) and have generated at least 30 entries of uMotif data within any 3-month period in the 12 months leading up to the project start date (expected 24/02/2021) will be eligible to participate. We estimate that around 25-30 patients will be eligible to participate by project start date based on existing records (see section 4.3.1 Sample Size Justification). axSpA clinicians whose routine job responsibility includes consultation with axSpA patients during check-ups would be eligible to participate. See also section 4.2.1 Inclusion Criteria and 4.2.2 Exclusion Criteria.

The following research activities (Part 1, 2 and 3) will take place on the day of participating patient's scheduled telephone check-up appointment. Part 1, 2 and 3 will take place only once for each patient participant, while clinician participants are expected to engage in Part 2 for up to 15 times over the course of 6 months.

Part 1: Observational Study (2 hours 10 minutes)

1. Patient Data Preview

The participating patient will receive an email containing their recent self-tracking data (up to 12 months) alongside instructions on what to do with it. Participating patient will be encouraged to spend at least 5 minutes reviewing and exploring the data and be informed that they will be given the opportunity to discuss the data with their clinician. Patients will also be asked to pay attention to anything they may wish to discuss with the clinician during the upcoming telephone check-up.

Participants will be asked to complete an online questionnaire focusing on their experience with reviewing the data. The questionnaire will be hosted via onlinesurveys.ac.uk, a secure, GDPR approved survey website endorsed by the University of Bath. The questionnaire consists of questions such as “How long did you spend familiarising yourself with the data?”, “Did you encounter any difficulties reviewing or understanding your data?”, “Did reviewing the data reveal anything interesting or useful”, “How do you feel about having a conversation about your data with the clinician?” etc. (see APPENDICES). Participants will also be asked of any questions, topics or issues they may wish to discuss with the clinician during the upcoming check-up. They will be able to provide additional details about these topics or issues using specific data points and assign priorities to them. Participant will be able to skip any questions if they wish to do so and their response to the questionnaire will be made available for download.

2. Joint Review of Patient Data (approx. 60 minutes)

The researcher (WZ) will arrive in the clinician’s office 15 minutes before the scheduled telephone check-up to allow for preparation. Participating clinician will be given a copy of the participating patient’s self-tracking data (i.e., datasheets). After the clinician has had time to review the data, Participants will attend their telephone check-up appointment as normal. Participants will be reminded that their conversations will be audio-recorded, and that the researcher will be taking notes throughout the session. The researcher will answer any questions the participants may have and confirm their willingness to take part before the check-up begins. The researcher will sit in to observe and record the telephone consultation without interrupting either participant. There is no constraint on the time that can be spent on the discussion of patient self-tracking data. However, the entire check-up session will not exceed 45 minutes. Once the telephone check-up is concluded and patient has exited the session as per usual (by hanging up), the researcher will ask participating clinician to reflect on the consultation experience and record their thoughts (with consent) with a Dictaphone provided by the researcher. The researcher (WZ) will stop the recording and collect the Dictaphone at the end. All recordings will be transcribed verbatim and anonymised. See also section 6 DATA & CONFIDENTIALITY.

3. Post-Study Questionnaire

Following the telephone check-up appointment, participating patients will be contacted by the research through email. Participants will be asked to reflect on their experience in using and discussing self-tracking data with the clinician during the check-up session. Participants will be asked to complete an online questionnaire which will be hosted via onlinesurveys.ac.uk, a secure, GDPR approved survey website endorsed by the University of Bath. Patient will be encouraged to review the answers they provided in the pre-study questionnaire prior to their conversation with the clinician. The questionnaire consists of questions such as “Was discussing your data with the clinician useful?”, “Do you think that reviewing your data prior to the conversation was helpful?”, “Did you encounter any difficulties or issues discussing your data with your clinician?”, “Did discussing the data with your clinician reveal anything interesting or useful?”, “Has the discussion about data changed your thoughts or opinions about the value of collecting self-tracking data?” etc.

Part 2: Post-Study Qualitative Interview – Clinicians (2 x 30 minutes)

Two 30-minute qualitative interviews will be scheduled with each clinician participant near the end of April and June 2021. These interviews will focus on the clinician’s experiences with self-tracking conversations at the interim and final stages of the study. The interviews will be conducted in a semi-structured manner and consist mainly of open-ended questions, such as “Have the conversations about self-tracking data influenced your decision-making process?”, “Did you learn anything new from the patient’s self-tracking data as the result of the conversation?”. The researcher may ask participating clinician to elaborate and expand on their answers. The researcher will follow a schedule of topics to ensure consistency. These interviews will be audio-recorded and with consent, transcribed verbatim and anonymised.

3.4 Justification for the Methodology

The qualitative research methodology has been chosen to allow us to understand patients’ and clinicians’ perspectives on the clinical uses of patient self-tracking data. The combination of notes and audio-recording transcripts will provide rich information which allows in-depth and comprehensive analysis of the human behaviours demonstrated by axSpA patients and their clinicians during the study. Pre- and post-study questionnaires are used to allow participants to elaborate on what they meant and enable us to understand the “how” and “why” of the behaviours and help researchers generate design implications. The sample size is sufficient for qualitative research in human-computer interaction.

3.5 Interim Data Analysis

Interim analysis will be carried out in May. Researchers will conduct qualitative data analysis, e.g., thematic analysis, content analysis to generate summary of findings and design implications.

3.6 Broad Timetable

Participant identification	February 2021
Recruitment	March 2021 – May 2021
Observational study	April 2021 – June 2021
Data analysis	May 2021 – July 2021
Dissemination and publication	June 2021 – August 2021

3.7 List of Non-Clinical Interventions or Procedures

Intervention or procedure	If this intervention will be repeated (and how many times)	Average time taken	Who will be involved?	Location
Patient consent	No	10 minutes	Researcher (WZ), patient participant	RNHRD
Observational study	Yes – up to 15 check-ups per clinician; patients will not repeat this procedure.	2 hours	Researcher (WZ), patient participant and clinician participant	RNHRD
Clinician consent	No	10 minutes	Researcher (WZ), clinician participant	RNHRD
Clinician post-study interview	Yes – repeated once	30 minutes	Researcher (WZ), clinician participant	RNHRD

3.7 Participant Time Commitment

All study procedures will occur only once for each patient participant. For clinician participants, Joint Data Review (see section 3.1 Participant Recruitment) is expected to occur as many times as the total number of participants that they would see over the course of the study (unless drop-out happens). No participant will be asked to remain in the study more than 2 hours at a time. This study will be spread out over a period of 6 months depending on participating individual's schedule. The total time commitment will be up to 4 hours for patient participants and up to 1 hour per check-up for clinician participants plus up two 30-minute qualitative interviews. All participants will understand that they can remove their data or participation from the study at any time without giving a reason up until the start of data set analysis.

3.8 Dealing with Researcher Effects and Researcher Bias

All of the researchers of this collaborative research team (RNHRD and University of Bath) have equipoise regarding the study as well as experience of recruiting rheumatology participants for research. All study activities involving patients, such as interviews and focus groups will be recorded. Any researchers found not to possess equipoise will elicit retraining.

3.9 Involvement of Prisoners

This study does not involve prisoners.

4 PARTICIPANT RECRUITMENT

4.1 Involvement of Patients and Clinicians

Patients and clinicians will be involved in the undertaking of the research only in the capacity specified in 3. STUDY DESIGN & METHODOLOGY. The researcher (WZ) has sufficient understanding of the needs and expectations of axSpA patients and clinicians as he has conducted previous studies that address these topics. He is experienced in engaging in self-tracking and health-related conversations with axSpA patients and clinicians. He is also familiar with the axSpA healthcare pathway and clinical procedure. He will ensure that the study will be understood and of interest to axSpA patients and individuals.

Patient(s) may be involved in creating a newsletter summarising the findings of the study which will be sent out to all participants. Patient involvement in the newsletter will help clarify how the results are presented and make sure they are easily understood. The patient(s) will receive a draft of the newsletter and they will be invited to comment.

4.2 Eligibility Criteria

Sample group or cohort to be studied in this research:

Inflammatory and musculoskeletal patients and clinicians

Gender: Male and female (and others)

Lower age limit: 18 years

Upper age limit: No upper age limit

4.2.1 Inclusion Criteria

Patient Participants:

- Adults aged 18 years and older
- Diagnosed of axSpA (ankylosing spondylitis or non-radiographic Axial Spondyloarthritis)
- Have consented to the Bath SpA Biobank study (13/SW/0096)

- Have signed up to Project Nightingale under Biobank (13/SW/0096)
- Have generated 30 entries of uMotif data within any 3-month window over the last 12 months
- Have the ability to give consent for participation
- Sufficient communicative ability allowing individuals to participate in the research study
- Have scheduled telephone check-up appointment between April 2021 and June 2021

Clinician Participants:

- A healthcare professional at RNHRD who regularly does axSpA clinical check-ups
- Be available to attend scheduled telephone check-ups between April 2021 and June 2021
- Ability to give written consent for participation
- Sufficient communicative ability allowing individuals to participate in the research study

4.2.2 Exclusion Criteria

Patient Participants:

- Individuals under the age of 18 years
- Have severe physical difficulty attending the focus group
- Unable to consent for themselves

Clinician Participants:

- Individuals under the age of 18 years
- RNHRD staff involved with reviewing the data and contributing to the analysis (none expected)

4.2.3 Communication Needs

Inclusion/exclusion criteria for the study indicates that participants must adequately understand English in order to understand the reason why the project is being carried out to make an informed decision to participate and have their data processed and securely store by the research team. This is primarily based upon the fact that the vast majority of participants of Biobank and Project Nightingale are English-speaking therefore do not require interpreters. If there were to be an occasion where an interpreter is needed, the research team will review it on a case by case basis. However, this is unlikely due to the qualitative nature of the research and the resources that are required. If this need is identified for multiple participants, then this could be considered for future studies.

4.3 Sample Size and Sampling Technique

We use a purposive sampling approach to recruit participants for the study. See below for estimated sample size (which is subject to change due to the ongoing impact of the COVID-19 pandemic):

Total UK sample size: 17-28 (15-24 patients, 1-4 clinicians)

Total international sample size (not including UK): 0

Total in EEA (not including UK): 0

4.3.1 Sample Size Justification

The research team estimates that by the time the project is expected to start, there will be approximately 50-60 potential participants who will be eligible to participate in the study in which 25-30 potential participants will have scheduled clinical appointment between April and June. This study is designed on an inclusive basis as we wish to capture a wide range of patient perspectives through the recruitment of a cohort that is diverse and representative of the condition. However, not all patients who are eligible will wish to participate in the study due to a variety of reasons. The research team will respect participants' choices while doing their best to address participants' concerns with regard to participation. Thus, we estimate the final number of patient participants to fall around 15-24. This number is sufficient for qualitative studies of similar nature.

It is common practice in the context of axSpA clinics for patients to see different clinicians when they attend their clinical check-ups. This provides a fair amount of flexibility when it comes to recruiting clinician participants. We wish to capture multiple clinician perspectives while minimising the workload of each clinician participant. We estimate that 1-4 clinician participants would be sufficient for this study. Since patients' check-up visits will be spread out over the course of 3 months, we conclude that the study will not cause major disruption to the clinical procedure at this scale. We predict the combination of an observation, questionnaires and interviews will yield the appropriate amount of data for the proposed qualitative analyses.

The above sample size is subject to change due to the ongoing impact of the COVID-19 pandemic.

4.4 Identifying Potential Participants

Patient Participants:
Participants will be identified by the Principal Investigator (WZ) based on the inclusion and exclusion criteria at the beginning of the research project. The main criteria are that patients must have signed up to RUH/RNHRD's Biobank and Project Nightingale and must have generated at least 6 months of self-tracking data using the uMotif application, while having a scheduled clinical check-up appointment between April 2021 and June 2021. At least three members of the research team (RS, WZ, RB) have direct access to the patients' Project Nightingale data. Patient appointment information along with required demographic information from RUH/RNHRD's electronic patient record system, Millennium will be provided through RNHRD's data controller and relayed to researchers. The researchers will compare the records and identify potential eligible participants based on the Inclusion/exclusion criteria. Once identified, potential participants will be contacted about the study via email (per Biobank ethics).

Clinician Participants:
Clinician participants will be identified through hospital admin and contacted via work telephone, email or face-to-face by the researcher (WZ).

4.5 Initial Contact

The potential patient participants of the study as identified by the researchers will first be approached by authorised staff member via patients' chosen method per Biobank ethics (13/SW/0096). Interested participants will then be approached by the researcher (WZ) regarding further information via their chosen method. Clinician participants will be first approached via email or telephone call by the researcher (WZ).

Patient will only be approached for this study if they have previously signed up to the Bath SpA Biobank as described above. Participants of the Biobank have signed: "I agree that my medical records may be

looked at by authorised research team members to find further relevant data if required for specific studies and that my information will be kept confidential AND I agree for the members of the research team to contact me about appropriate projects, using my preferred method of contact. I understand there is no obligation to take part and I will only be given information about the projects." Additional consent for this will also be taken via the study consent forms.

4.6 Obtaining Informed Consent

After potential patient participants have been identified, authorised staff member will contact said patients via their chosen method of communication (per Biobank ethics). Potential patient participants will have already consented to be approached for research projects. Potential patient participants will receive project summary, Patient Information Sheet (PIS) and contact details of the research team. Participants will register their interest by replying to the email or telephone the research team. They will be encouraged to spend time reading the PIS and discuss participation with close others. The researcher (WZ) will contact interested patients within a few days of receiving the email reply or telephone call (or as long as they need) to discuss participation and have any questions answered. Patients will attend their scheduled telephone check-up like usual and participation/consent will be finalised online prior to the study. Authorised hospital staff and research team members may get in touch to discuss options to reschedule the appointment to an earlier/later time of the same day.

Researchers will receive consent for study participation including consent for audio recording and for retaining of any drawings the participants made during the study. Patient participants will be made aware of the making of any audio-recordings and consent will be checked for the use of anonymised quotations in the reports and publications of the research findings. The researcher will go through the consent form with participants and answer any questions during the consenting process. The researcher (WZ) has received trainings on Good Clinical Practice including validated informed consent training and is experienced in obtaining consent from patient participants in previous scientific studies. Participants will receive a digital copy of their consent form.

Clinician participants will be contacted via telephone or email. They will receive the appropriate clinician information sheet (CIS) via their preferred method of communication. Contacted clinicians will be given a suitable amount of time to consider the information and discuss their participation with close others. The researcher will contact the interested clinicians a few days after receiving the CIS (or as long as they need) to discuss their participation. The researcher (WZ) will schedule a meeting with interested clinicians and answer any questions they may have regarding participation. The researcher will go through the appropriate consent form and remind clinician participants that the consent involves the use of and audio-recorder and that anonymised quotations and drawings during the study may be used in publications and reports. Clinician participants will receive a copy of their digital consent form. All information sheets and consent forms are designed to be in line with the HRA, RUH and University of Bath guidelines.

4.7 Participant Sign-Up Window

Potential participants (patient and clinician) will have as long as they need to decide to take part, within the time constraints of the study. Potential participants will be encouraged to make a decision up to 7 days before the scheduled clinical check-up appointment, so that the researcher team will have enough time to retrieve their up-to-date Project Nightingale data. If potential participants decide they need more time to think about the study, the research team will get in touch to discuss potential

options for rescheduling the study. Interested participants will be able to telephone the research team to discuss participation. Valid informed consent will be acquired online prior to the study.

Potential participants will be encouraged careful go through the PISes and discuss their participation with close others. Sufficient opportunities have been put in place for potential participants to discuss details about the study and have their questions answered. A minimum of 48 hours after receiving the PIS will be given to participants before contact by the researcher regarding participation.

5 RISKS & BENEFITS

This chapter describes the potential for risks and benefits to participants and researchers from conducting the research as well as how the research team plan to address them.

5.1 Potential Risks for Participants

There are no anticipated risks associated with the participation of the study. There is however a small burden in that it will take a few hours of patient's and clinician's time (see section 3.6 List of Non-Clinical Interventions or Procedures). The durations of all research activities as specified in 3. STUDY DESIGN & METHODOLOGY were chosen with the aim of gaining sufficient information for data analysis whilst not taking an excessive amount of time. All Phase One research activities will be carried out around regular clinical check-ups which minimises travel and time required for both patient and clinician participants. We only require participating patients to make a one-time trip to the hospital for the focus group study in Phase Two.

Both patient and clinician participants will be familiar with the clinical consultation process during check-ups. The likelihood of the addition of self-tracking data causing excessive work and cognitive burden for either group of participants is extremely low. In addition, we have spoken to a number of potential patient and clinician participants in previous studies and Patient and Public Involvement (PPI) sessions about whether research that involves interviews and additional activities during check-ups would be a burden and we are confident that the vast majority of patients and clinicians would have no issue with the time requirement. We will make every effort to ensure that participants are informed and have their voice heard throughout every stage of the research.

Furthermore, participants will understand that participation in the study is completely voluntary and they can withdraw it at any given time without a reason. Data can be withdrawn before analysis happens when all recordings and transcripts are anonymised, making it impossible to identify individual's data. Access to patient identifiable information will only be given to authorised research team members. Anonymised data will be backed up and stored on the secure servers at the University of Bath. Anonymised study documents will be secured in locked cabinets, in access-restricted rooms at the University of Bath. Data will be anonymised using generated unique identification numbers.

In the highly unlikely scenario where participants become slightly distressed over the use of self-tracking data for any other reasons at any point during the study, they will be given the option to withdraw from the study without any negative repercussions and without giving a reason. The participant will be offered the opportunity to speak to the Chief Investigator or (with the patient's consent), the researcher will make the Chief Investigator aware. If the matter is considered a safeguarding issue, RUH/RNHRD procedure will be followed. In the highly unlikely scenario where a participant, who has given informed consent, loses capacity to consent during the study, the research

team would withdraw all identifiable data collected from the study. Data which is not identifiable to the research team may be retained. No human tissues will be collected in this study.

5.2 Potential Risks for Researchers

There are no potential risks associated with the research project for the researchers. Researcher will be based in RNHRD when conducting research activities and no lone working will be required.

5.3 Sensitive Topics and Disclosure

Although no research activities (see section 3.6 List of Non-Clinical Interventions or Procedures) will include topics that are of sensitive, embarrassing or upsetting nature, possible disclosure of information is present in all research projects. The researcher will discuss the issues of disclosure before all participant activities as part of discussions regarding confidentiality. If disclosure occurs, the researcher will contact the Chief Investigator and the appropriate action will be taken using clinical protocols at the RUH and RNHRD. No criminal or other disclosure requiring action could occur during the study.

5.4 Screening of Identifiable Personal Information

Patient identifiable information will only be accessed to contact individuals who have previously signed up to the Bath Biobank (13/SW/0096), and therefore giving explicit consent to be contacted for research. Patient information (such as name, telephone number, address etc.) of those who have signed up to Biobank will be accessed by researchers at the R&D office (RUH, Bath) and RNHRD. Patients who have not signed up to the Biobank will not be approached and information will not the screened or viewed. See also section 6 DATA & CONFIDENTIALITY.

5.5 Potential Benefits for Participants

Participating patients will benefit from taking part in the research project, in which their perspectives and experiences are sought on the uses of their own self-tracking data (either by themselves and with their clinician). Participating patients will receive expert opinion from clinicians regarding their self-tracking (i.e., Project Nightingale) data and will be able to keep the data if they wish to (as permitted by the Biobank ethics (13/SW/0096)). Patients will also be able to share with researchers their thoughts on the design and use of technology in context of axSpA clinics and self-tracking. Participating clinicians will also benefit from taking part in the research project, in which their perspectives and experiences are sought out on the uses of their patients' self-tracking data. Participating clinicians will be able to share with researchers their thoughts on the use of patient self-tracking data in a clinical setting.

6 DATA & CONFIDENTIALITY

The Bath Biobank stipulates: "All participant data will be held in the strictest confidence. Only the Investigator and research staff will have access to participant data." The research committee will ensure there is no breach of any duty of confidentiality owed to study participants.

Each participant will be assigned a unique study identification (ID) number. This study ID will be used as identifying information on the questionnaires and assessment forms, and on the blood/DNA/RNA samples. Only the Principal Investigator and research staff will have access to the complete list of participants (name, address, date of birth, hospital identification number) enrolled and their study ID number. A participant log will be maintained separately from the database and will be password protected. The patients will be identified using a study ID only. Patient's address, telephone number will not become part of the Biobank data. The clinical data stored in the database will be identified using ID and date of birth only.

Data will be stored at the RUH Bath NHS Foundation Trust Rheumatology service based at the Royal National Hospital for Rheumatic Diseases, or the University of Bath, which has a clear research mandate that provides a strong commitment to respect a participant's privacy and safeguard the confidentiality of data collected.

This study will adhere to these guidelines. Any data kept at the University of Bath will be anonymised, and study participants only referred to by study ID. Servers at the University of Bath are backed up daily allowing for reliable data protection to avoid the loss of data and require specific University identification to log on to access the secure files where data may be kept. The GDPR and all applicable regulations will be adhered to strictly.

6.1 Storage and Use of Personal Data During the Study

The study will involve the undertaking of the following activities:

- Use of personal information (e.g., email, telephone number, name, gender, address)
- Publication of direct quotations from respondents
- Use of audio/visual recording devices
- Storage of personal data on the following: manual files (including paper or film), NHS computers, university computers

The following steps will be taken to prevent potential data breach:

Participants' personal contact details will only be used on consent forms and to allow the research team to contact the participants. Digital consent forms will be kept in an on-site datastore designated by Royal United Hospitals (RUH).

Participants will be allocated a unique identification number. This number will be used in all research activities prior to the transfer of data so that data is anonymised at source. A list of the names and corresponding identification numbers will be kept separately and secure on an encrypted password protected server at RUH. No personal identifiable information will be stored on University of Bath computers.

Audio recordings will be encrypted, password protected and stored on a secure University of Bath server. This will enable researchers to check recordings if necessary while reports are being written. Transcripts will be anonymised and stored on a secure, password protected University of Bath server. Original copies of the datasheets and work produced by participants via pen and paper, such as doodles and drawings will be scanned and anonymised at source using unique study IDs. Original datasheets (anonymised at source) will be kept in a locked filing cabinet in a locked office within the RUH.

Scanned datasheets will be dated and named appropriately based on the research activity during which the work was produced and participant(s)' unique identification number(s), e.g., ScannedDatasheets_Ph1_Pt2_P12_C01_01-04-2021.pdf. Scanned datasheets will be anonymised at source and stored on a secure, password protected University of Bath server.

6.2 Physical Security Arrangements for Storing of Personal Data

Participants will be allocated a unique identification number (study ID), e.g., P01, C01. This number is used on datasheets and field notes prior to the transfer of data, thus anonymised at source. A list of the names and corresponding identification numbers will be kept separately and secured on an encrypted password-protected server at RUH. Audio recordings will be encrypted, password protected and stored on a secure University of Bath server. This will enable us to check recordings if necessary while reports are being written. Transcripts and scanned copies of used datasheets will be anonymised and stored on a secure, password-protected University of Bath server. Original copies of the patient self-tracking datasheets will (anonymised at source) will be kept in a locked filing cabinet in a locked office within the Royal National Hospital for Rheumatic Diseases (RNHRD).

The researchers will only have access to personal data that is necessary to screen participants based on inclusion/exclusion criteria and to contact participants. The folders containing the data will be restricted to only those researchers with permission to view them. Servers at the University of Bath are backed up daily allowing for reliable data protection to avoid the loss of data and require specific University identification to log on to access the secure files where data may be kept. Any data kept on the University of Bath servers will be fully anonymised and participants only referred to by their study ID.

6.3 Ensuring the Confidentiality of Personal Data

Personal data is kept securely as described above. Any data or inventories are anonymised at source and exchanged for a unique study ID for each participant. This will ensure confidentiality and that no personal details or identifiable information is on any document other than the consent form and list of participants. Thus, all personal data is anonymised.

All audio recordings will be encrypted, password protected and stored on a secure University of Bath server.

Transcripts will have all personal details and identifiable information removed and stored on an encrypted password-protected University of Bath server.

Original datasheets (anonymised at source) will be kept in a locked filing cabinet in a locked office within the Royal United Hospitals (RUH).

Scanned datasheets will not have personally identifiable information on them. Instead, participant's unique study ID will be used. Scanned datasheets will be stored on an encrypted password-protected University of Bath server.

Names or identifiable information will not be published. Identifiable information or identifiable characteristics will be anonymised on transcripts and quotations. Quotations will be used in relation to specific themes derived from the analysis.

Data will be collected and maintained in accordance with GDPR.

6.4 Access to Participants' Personal Data

The researchers will only have access to personal data that is necessary to screen participants based on inclusion/exclusion criteria and to contact participants. Clinical outcome measures such as Bath Ankylosing Metrology Index (BASMI) score will be used by participating clinicians and patients as part of their routine clinical consultation. Data from the Bath SpA Biobank, namely Project Nightingale data will be accessed by authorised research team member. This does NOT contain personally identifiable information and uses unique study ID for each participant. Researcher WZ, who is a PhD student and HCI researcher at the University of Bath will be interacting with the personal data described above.

6.5 Where Will Data Generated Be Analysed and by Whom?

The data will be analysed on a secure University of Bath server. Unique study IDs will be used and therefore no personal identifiable information will be stored on the server. Thus, all data is anonymised at source. The data will be analysed by the study researchers mentioned in this application and the research protocol.

All recordings, transcripts and scanned datasheets required for data analysis will either be transferred from the RUH/RNHRD to the University of Bath via encrypted NHS email (to NHS email) or via hardware-encrypted pen drive. All anonymised research data will be stored on a secure, password-protected University of Bath server. Digital consent forms will be kept in a secure datastore designated by Royal United Hospitals (RUH).

The Chief Investigator (RS) will act as the custodian for the data generated by the study.

6.6 Long Term Arrangements for Storage of Research Data

All personal identifiable information will be removed within three months of the projected finish date. Anonymised research data such as transcripts and researcher's field notes will be stored securely at the University of Bath for 10 years according to the university guidelines (https://www.bath.ac.uk/guides/research-data-policy-guidance/). Data will be destroyed after this time. Only authorised members of the research team will have access to this server.

All un-anonymised information as well as physical research data will be stored securely within the research department (requiring access keys) at RUH for 7 years after the conclusion of the study according to RUH guidelines. After this period retention will be reviewed and data would be destroyed if no longer needed, and hard copies disposed of via confidential waste.

7 DATA ANALYSIS

Transcripts of the observational and focus group study are qualitative data and will be analysed using thematic analysis. This method allows a flexible and rigorous approach to identifying, analysing and presenting themes associated with a research question (Braun & Clarke, 2006). This qualitative analysis will allow us to capture meaning interactions between axSpA patients and their clinicians surrounding the use of patient self-tracking data. Verbatim transcripts will be created from audio recordings. The first researcher/coder will read the transcripts several times for familiarisation and highlight codes arising from the data. A second researcher/coder will then independently review these codes for rigor and consistency. Any disagreements or suggestions over the codes will be discussed and clarified between

the researchers. Reoccurring codes will be grouped into themes and corresponding sub-themes and a recursive process will occur, with a third researcher independently reviewing the data. Quotations will be highlighted to document the highlighted themes.

Throughout analysis the perspectives of the participants will be important, with careful consideration taken of the context within which the discussions derived. Descriptive accounts will be formed and theoretical explanation for behaviour, opinions and decisions developed. A further content analysis will be applied to the data, to determine how often things were said, by whom and if there are any patterns to the structure of consultation, interviews or focus groups. This will help identifying the difference in motivation and clinical agenda between axSpA patients and clinicians with regards to the uses of self-tracking data.

8 PUBLICATION & DISSEMINATION POLICY

All reports and presentations will be written by members of the researcher team via joint authorship and significant others (e.g., those who have helped in the identification of participants) will be acknowledged within the paper. The findings of this project will be conveyed in academic conferences and reported in established scientific journal(s). All members of the research team will have the opportunity to read, comment and adjust the drafts of the paper for publication. All authors will have:

- Made a considerable contribution to the origin and design of the project and/or analysis/interpretation of the data
- Had a critical involvement in drafting or revising study documents/write up for intellectual content
- The opportunity to approve the final draft for submission to publication
- Agreed their accountability to ensure the work meets standards of accuracy and integrity for the research area investigated

9 ETHICAL CONSIDERATIONS

This study does not raise any significant issues. It is a qualitative, non-CTIMPs study where researchers will have no physical interactions with the patients. All research activities will be clearly documented, and no unspecified research activity will be carried out at any point during the study. No research activities will be conducted prior to receiving approval from all relevant research ethics committees, i.e., REC (NHS), HRA, REACH (UoB). Researchers will strictly follow the study protocol throughout the project and only interact with patients during pre-determined research activities as specified in the Research Protocol, except when addressing queries related to the study through researchers' NHS email. Researchers will never contact the patients using private email addresses. All researchers who will be interacting with patients or handling patient data will have received the appropriate training (Good Clinical Practice training, Information Governance training) to ensure that their conduct is compliant with NIHR and HRA's guidelines and all relevant legislations (GDPR, DPA). Researchers will never attempt to treat the patients in any way or provide advice/instructions on medication, self-management or other aspects of the condition that may influence patient's health. There are no known risks or adverse reactions (AR) associated with the study. Patients will have the opportunity to view their self-tracking data (i.e., recorded via the uMotif app as part of Project Nightingale) and discuss this data with their axSpA clinicians.

Researchers will not offer any data insights that will influence treatment or patients' self-management decisions.

All research activities involved in the project will be clearly communicated to potential participants during recruitment (prior to the obtaining of informed consent). Participants have the right to withdraw from the study at any time and the right to withdraw their data, providing it has not yet been anonymised. Participants also have the right to keep their Project Nightingale data if they wish to. We do not believe there are any risks from participation in this study. There will not be activities that expose participants to physical or mental discomfort during the study. The questions which will be asked during the interviews and the focus groups are not of a sensitive nature. The project will be covered by the NHS indemnity schemes.

The study will only require minimal administrative work (which involves hospital staff) such as sending recruitment emails, appointment scheduling and room booking. It will cause little to no disruption to the regular axSpA clinical procedure. Data-sharing between authorised hospital staff, Project Nightingale's data controller (uMotif) and the research team will be carried out periodically (to minimise risk and administrative work). The study design aims to give a realistic representation of the axSpA clinics while allowing researchers enough flexibility to conduct research activities in a time-efficient manner.

The following ethical, legal and managerial concerns have been raised and addressed by the research team during study design:

9.1 Data-Handling

The researchers will make use of secondary data from previous research, namely RUH/RNHRD's Biobank (13/SW/0096), i.e., Project Nightingale, alongside basic patient demographic information (e.g., gender, age, clinical outcome measures) from the electronic health record system which is necessary for contacting and screening potential participants as well as conducting data analysis. These data will only be shared with members of the research team who have completed the necessary training regarding the handling of patient data. The information required by the research team will be provided by authorised staff member and Project Nightingale's data controller, uMotif.

Primary data generated from the study as well as digital consent forms will be stored safely in the sponsor (RUH/RNHRD)'s designated data store. Any data generated will be anonymised at source and exchanged for a unique study ID for each participant. Electronic source data will be stored on a secure and password protected RUH server. The folders containing the data will be restricted to researchers with permission to view them only. Researchers will make sure that all data is erased form Dictaphones used after each audio-recording session following the backup of source data. All transport of anonymised data will be carried out via researchers' own NHS email (to NHS email) or with a hardware-encrypted flash drive to prevent data breach. Anonymised transcripts of interviews will be stored on a secure University of Bath research data server during data analysis. Data access will be strictly limited to the Chief Investigator, Principal Investigator and qualified members of the research team. The research team will make sure that all data-handling activities are carried out in accordance to relevant legislations such as DPA, GDPR and guidelines set out by the NHS REC, HRA, NIHR and the University of Bath. See section 6 DATA & CONFIDENTIALITY.

9.2 Qualification of the Research Team

The study protocol was developed by a team of experienced individuals including academic researchers from the University of Bath and a consultant rheumatologist from RNHRD and has been reviewed by the

R&D department at RUH. The project will also be reviewed by the University of Bath's Research Ethics Approval Committee for Health (REACH). All members of the research team who will be handing patient data have completed the required training. The design of the study has been informed by previous publications of the Principal Investigator (WZ) as well as a recent Patient and Public Involvement (PPI) event related to Project Nightingale.

9.3 Consent for Contact

Potential patient participants of the study will be identified through Project Nightingale data (which will be provided by the data controller, uMotif) and matching patient demographic information provided by authorised staff member. Participants of RUH/RNHRD's Biobank study (13/SW/0096) and Project Nightingale will be eligible to take part given that they have generated at least 6 months' worth of data. The Biobank's ethics will allow potential participants to be contacted by email regarding future tie-in studies.

9.4 Conflict of Interest

We do not consider there to be any conflicts of interest in the study.

9.5 Auditing of Research Conduct

The Royal United Hospitals Bath NHS Foundation Trust Research & Development Office audit/monitor a percentage of research studies sponsored by the Royal United Hospitals Bath NHS Foundation Trust as part of their research governance responsibilities

10 ETHICAL AND REGULATORY COMPLIANCE

10.1 Ethical Approval

To acquire ethical approval this project will be submitted to the NHS Research Ethics Committee (REC) and HRA via the Integrated Research Application System (IRAS). This study will recruit SpA patients who have signed up to the Bath Spondyloarthritis Biobank; REC (South West Central Bristol REC, reference: 13/SW/0096). This project will also be reviewed by the University of Bath Research Ethics Approval Committee for Health (REACH) to additionally assess ethical suitability in addition to the NHS REC.

10.2 Regulatory Review & Compliance

Before any site can enrol patients into the study, the Chief Investigator/Principal Investigator or designee will ensure that appropriate approvals from participating organisations are in place. Specific arrangements on how to gain approval from participating organisations are in place and comply with the relevant guidance. Different arrangements for NHS and non NHS sites are described as relevant.

For any amendment to the study, the Chief Investigator or designee, in agreement with the sponsor will submit information to the appropriate body in order for them to issue approval for the amendment. The Chief Investigator or designee will work with sites (R&D departments at NHS sites as well as the study delivery team) so they can put the necessary arrangements in place to implement the amendment to confirm their support for the study as amended.

10.3 Amendments

Protocol amendments will be submitted and coordinated by the Principal Investigator (WZ) and reviewed and discussed with member of the research team, documented with updated version numbers and will be signed off by the Chief Investigator (RS).

If the sponsor wishes to make a substantial amendment to the REC application or the supporting documents, the sponsor must submit a valid notice of amendment to the REC for consideration. The REC will provide a response regarding the amendment within 35 days of receipt of the notice. It is the sponsor's responsibility to decide whether an amendment is substantial or non-substantial for the purposes of submission to the REC.

Amendments also need to be notified to the national coordinating function of the UK country where the lead NHS R&D office is based and communicated to the participating organisations (R&D office and local research team) departments of participating sites to assess whether the amendment affects the NHS permission for that site. Note that some amendments that may be considered to be non-substantial for the purposes of REC still need to be notified to NHS R&D (e.g., a change to the funding arrangements).

11 SPONSORSHIP & FUNDING

This project is sponsored by the Royal United Hospitals Bath NHS Foundation Trust who will provide insurance and sponsorship for public liability and professional negligence as well as indemnity (through NHS Indemnity Scheme). This project is part of a PhD studentship funded by the University of Bath.

The Royal United Hospitals Bath NHS Foundation Trust takes ownership of the full study data set. Anonymised study data may be shared with researchers at University of Bath. Only the research steering group will have access to the full study dataset in order to ensure that the overall results are not disclosed by an individual study site prior to the main publication. If it is envisaged that dataset will be used for secondary analysis this can only be undertaken with the consent of the participants. All patient documentation should reflect the future use of these data in research. On completion of the study, the data will be analysed and tabulated, and a Final Study Report will be prepared by the steering group.

12 REFERENCES

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. Qualitative Research in Psychology, 3 (2), pp. 77-101.

Chung, C.F., Dew, K., Cole, A., Zia, J., Fogarty, J., Kientz, J.A. and Munson, S.A. (2016). Boundary negotiating artifacts in personal informatics: Patient-provider collaboration with patient-generated data. In Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing, pp. 770-786

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Mentis, H.M., Komlodi, A., Schrader, K., Phipps, M., Gruber-Baldini, A., Yarbrough, K. and Shulman, L. (2017). Crafting a view of self-tracking data in the clinical visit. In Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems, pp. 5800-5812.

Schroeder, J., Chung, C.F., Epstein, D.A., Karkar, R., Parsons, A., Murinova, N., Fogarty, J. and Munson, S.A. (2018). Examining self-tracking by people with migraine: goals, needs, and opportunities in a chronic health condition. In Proceedings of the 2018 Designing Interactive Systems Conference, pp. 135-148

APPENDICES

1 CV of Chief Investigator

CURRICULUM VITAE

Name: Dr Raj Sengupta
Present appointment: *(Job title, department, and organisation.)*
Consultant Rheumatologist and Visiting Senior Lecturer, University of Bath, UK
Research experience:
I have published 34 original publications with 405 citations and an h-index14. I have been a Lead Applicant on grants totalling approx. £600,000 and a co-applicant on grants totalling £1.2 million. I have been a PI on 18 commercial clinical trials.
Research training: GCP 2018.
Publications 2019: Mohammad H Derakhshan, Nicola J Goodson, Jonathan C Packham, **Raj Sengupta**, Anna Molto, Helena Marzo-Ortega, Stefan Siebert, BRITSpA and COMOSPA Investigators. Increased Risk of Hypertension Associated with Spondyloarthritis Disease Duration: Results from the ASAS-COMOSPA Study. The Journal of Rheumatology January 2019, jrheum.180538; DOI: https://doi.org/10.3899/jrheum.180538 Hue W, Jones S, **Sengupta R**. Exploring the Future Role of Self-Tracking Data in the Rheumatology Clinic. Stud Health Technol Inform. 2019;259:33-38. MacFarlane GJ, Pathan E, Siebert S, Packham J, Gaffney K, Choy EH, **Sengupta R** , Atzeni F, Martin KR, Jones GT & Dean L. ' AxSpA patients who also meet criteria for fibromyalgia : identifying distinct patient clusters using data from a UK national register (BSRBR-AS) ' BMC Rheumatology 2019, vol. 3 , 19 , pp. 19 . https://doi.org/10.1186/s41927-019-0066-7 Alice Heaney, Stephen P McKenna, Peter Hagell and **Raj Sengupta**. Improving scoring precision and internal construct validity of the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) using Rasch Measurement Theory. The Journal of Rheumatology Vol. 46, Issue 6 1 Jun 2019 Fariz Yahya, Karl Gaffney, **Raj Sengupta**. Exploring sub-optimal response to tumour necrosis factor inhibitors in axial spondyloarthritis. Rheumatology Advances in Practice, Volume 3, Issue 1, 2019, rkz012. Timothy J P Bray, Alexis Jones, Alexander N Bennett, Philip G Conaghan, Andrew Grainger, Richard Hodgson, Charles Hutchinson, Maria Leandro, Peter Mandl, Denis McGonagle, Phill O'Connor, **Raj Sengupta**, Marianna Thomas, Andoni Toms, Naomi Winn, Margaret A Hall-Craggs, Helena Marzo-Ortega, Pedro M Machado, British Society of Spondyloarthritis (BRITSpA), Recommendations for acquisition and interpretation of MRI of the spine and sacroiliac joints in the diagnosis of axial spondyloarthritis in the UK, Rheumatology, , kez173, https://doi.org/10.1093/rheumatology/kez173 Abbie Jordan, Hannah Family, Kelly Blaxall, Fiona M. Begen and **Raj Sengupta**. Use of Complementary and Alternative Medicine in Axial Spondyloarthritis: A Qualitative Exploration of Self-Management. *J. Clin. Med.* **2019**, *8*(5), 699; https://doi.org/10.3390/jcm8050699 Peter C Rouse, Martyn Standage, **Raj Sengupta**. Living with Ankylosing Spondylitis: An open response survey exploring physical activity experiences. Rheumatology Advances in Practice, Volume 3, Issue 2, 2019, rkz016, https://doi.org/10.1093/rap/rkz016 Raybone K, Family H, **Raj Sengupta**, et al (Un)Spoken realities of living with axial spondyloarthritis: a qualitative study focused on couple experiences BMJ Open 2019;9:e025261. doi: 10.1136/bmjopen-2018-025261

Signature:	**Date:**
[redacted]	4th October 2019

2 CV of Principal Investigator

Name:	
Weihua Zhang	
Present appointment: *(Job title, department, and organisation.)*	
PhD Candidate Department of Computer Science University of Bath	
Address: *(Full work address.)*	
1W 4.51, University of Bath, Bath BA2 7AY	
Telephone number:	**Email address:**
[redacted]	[redacted]
Qualifications:	
MSc Management and Information Technology BSc (Hons) Computer Information Systems	
Professional registration: *(Name of body, registration number and date of registration.)*	
N/A	
Previous and other appointments: *(Include previous appointments in the last 5 years and other current appointments.)*	
N/A	
Research experience: *(Summary of research experience, including the extent of your involvement. Refer to any specific clinical or research experience relevant to the current application.)*	
29/11/2017 - 04/2018 Clinical Observation / Qualitative Study, Royal National Hospital for Rheumatic Diseases (RNHRD). Chief investigator. Shadowed Ankylosing Spondylitis (AS) clinicians. Sat in and observed 28 scheduled clinical check-ups. Conducted qualitative analysis on anonymised field notes and transcripts. 18/06/2018 Patient & Public Engagement / Information Day, RNHRD. Speaker. Gave talk on research about self-tracking and AS. Answered questions about patient's use of self-tracking technologies. 22/8/2019 Patient & Public Engagement / Information Day, RNHRD. Co-investigator. Gathered feedback on participants' self-tracking experience with Project Nightingale. Generated design implications for future research. 03/10/2019 Research Project "Understanding How People Living with Axial Spondyloarthritis Use and Engage with Self-Tracking Technology and Patient-Generated Data". Research Ethics Approval Committee for Health (REACH) reference: EP 18/19 078. Chief investigator. Demonstrated rigorous considerations for research ethics, patient welfare, data analysis and post-study data management. Used appropriate method for collecting participant consent. Gained experience with the participant informed consent process.	
Research training: *(Details of any relevant training in the design or conduct of research, for example in the Clinical Trials Regulations, Good Clinical Practice, consent or other training appropriate to non-clinical research. Give the date of the training.)*	
10/2017 Academic integrity training & test. The researcher is well-equipped for conducting rigorous and original academic work.	

10/2017 Introduction to research data management. Received training on good practice in data protection and privacy. The researcher will make sure all data-handling is compliant with GDPR and Data Protection Act.

11/2017 Questionnaire design, development and validity of a new measure. Received training on how to design quality survey for scientific research.

15/05/2018 Bath Spondyloarthritis Research Consortium (Bath SPARC) meeting, University of Bath. The researcher and his projects are supported by Bath SPARC whose members include academics, health researchers and professionals. The consortium's ongoing support helped equip the researcher with adequate understanding of AS, its healthcare pathway and clinical practice.

26/02/2019 The RUH and the University of Bath Research Showcasing Event, Postgraduate Medical Centre, Royal United Hospital. Presented poster and demonstrated prototype software. Networked with healthcare researchers and practitioners.

14/11/2019 Good Clinical Practice (GCP) e-learning course

11/2019 Valid Informed Consent (VIC) training (ongoing)

11/2019 Information governance training

Relevant publications: *(Give references to all publications in the last two years plus other publications relevant to the current application.)*

06/2019	**Designing Interactive Systems (DIS) 2019 - San Diego, United States** *Author, Presenter* Hue, W., 2019. Supporting Collaborative Use of Self-Tracking Data in the Context of Healthcare and Chronic Conditions. *DIS Doctoral Consortium. DIS '19 Companion, June 24-28, 2019, San Diego, CA, USA*. http://dx.doi.org/10.1145/3301019.332487
04/2019	**Healthcare of the Future 2019 - Biel, Switzerland** *Co-author, Presenter, Best Paper Winner* Hue, W., Jones, S. and Sengupta, R., 2019. Exploring the Future Role of Self-Tracking Data in the Rheumatology Clinic. *Studies in health technology and informatics*, 259, pp.33-38.

Signature:	**Date:**
[redacted]	21/10/2019

3 CoUs-axSpA Patient Information Sheet (v3.0)

See in thesis appendices.

4 CoUs-axSpA Clinician Information Sheet (v3.0)

See in thesis appendices.

5 CoUs-axSpA Patient Consent Form (v3.0)

See in thesis appendices.

6 CoUs-axSpA Clinician Consent Form (v3.0)

See in thesis appendices.

7 CoUs-axSpA Clinician Interview Topics

Questions	Rewording	Follow-Up Questions
Would you have spent time reviewing the patient's self-tracking data before an upcoming clinical appointment as part of your check-up routine?	*How would you incorporate patient self-tracking data into your preparation for the upcoming clinical appointment?*	*If so, what why do you think it might useful to review the patient's self-tracking data before the clinical appointment?*
Do you think being able to review your patient's self-tracking data before the check-up influenced the conversation you had with the patient?	*Did it help you identify any topics you wanted to talk to the clinician about?*	*What are these topics? Like setting targets, planning for treatment etc.*
Were you able to effectively bring up the self-tracking topics that you wanted to talk about during conversation?	*- How did these topics come up?* *- Did they naturally emerge?* *- Was it you or the patient who brought them up?*	*If not, what could be the reason(s)?*
How well do you think patient self-tracking data and conversations around it was integrated into the exisiting clinical procedure?	*Did it feel natural to you when the conversation started to shift towards self-tracking?*	*Do you think having conversations like this put pressure on other activities or the consultation time?*
Did you learn anything new from patient self-tracking data as the result of the conversations you had with the patients?	*In what ways do you find your conversations with the patients beneficial?*	*Have the conversations about self-tracking data influenced your decision-making process?*
Overall, what is your data-using goal when it comes to the use of patient self-tracking?	*Do you have a vision for the future use of patient self-tracking data by axSpA professionals in the clinical setting?*	*Do you feel that your patients share these goals with?*

Overall, did you have a positive experience with the conversation you had with the patients about self-tracking?	*Was there any difficulty regarding having conversations about self-tracking with your patients?*	*What would have made the consultation experience better in your opinion?*
Do you feel that review of self-tracking data with patients is necessary for you and the patients to effectively understand and use self-tracking data?	*Did you experience any difficulties when trying to understand patient data?*	
What role do you think technology has to play in the clinical and collaborative use of self-tracking data?	*What's your attitude towards information technology in the axSpA check-ups?*	
Do you feel like you're more or less likely to engage in conversations with patients with regard to their self-tracking data in the future?	*Has your view on patient self-tracking and self-tracking data changed since you took part in the project?*	

8 CoUs-axSpA Pre-Study and Post-Study Questionnaire

See in thesis appendices.

D.4 CoUs-axSpA - Patient Information Sheet

PATIENT INFORMATION SHEET (PIS) – v3.0 20/01/2021

Supporting Collaborative Use of Patient Self-Tracking Data in the Context of Axial Spondyloarthritis (axSpA) Clinics

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please read the following information and discuss with others if you wish. Please ask us if anything is not clear.

Why are we doing this study?

We would like to understand what patients with Axial Spondylarthritis (axSpA) and their clinicians think about "self-tracking" - the practice of recording health and activity data through smart phone apps and/or wearable devices (e.g., Fitbit). Currently, the Royal National Hospital for Rheumatic Diseases (RNHRD)'s Project Nightingale uses a health-monitoring smart phone app (uMotif) and wearable devices to enable axSpA patients to self-track. Data collected includes symptoms, medication and levels of physical activity. We would like to explore how or if self-tracking is approached in clinic, and whether there are any difficulties or opportunities with the use of self-tracking data. This will help us to improve self-tracking information technology in the future.

Who is sponsoring this study?

This project is sponsored by the Royal United Hospitals (RUH) Bath NHS Foundation and is part of a PhD research program. It has been reviewed by the NHS Research Ethics Committee [reference: 20/SC/0140] and the Research Ethics Approval Committee for Health (University of Bath) [reference: EP 19/20 045]. IRAS project ID: 271239.

Why have I been invited to take part?

You are being invited to take part because you are an axSpA patient at the RNHRD and registered with the Bath Biobank. You have also used the uMotif app consistently within past 12 months. We would like to give you the opportunity to review this data with your consultant.

What will happen if I take part?

This study will take place around your next check-up appointment. You have the option to undertake it remotely if you wish to. The study will take no more than 6 hours to complete. 15-24 participants in total are expected to take part in the study.

If you do decide to take part, all the research activities will be audio-recorded with your permission and the researcher will make notes during these activities. All your conversations and data will be kept confidential. This is a qualitative study which consists of three parts:

Pre-Study Questionnaire

If you are interested in taking part, you will be contacted by a researcher who will talk you through the study and answer any questions you may have. You will be asked to sign an online consent form to say you are happy to take part. You will have everything you need, including your self-tracking data sent to you via email. This is then followed by an online questionnaire and we may ask you questions such as "Please describe how you have made use of the data that was sent to you" and "What topics would you like to discuss with your clinician during the upcoming check-up?". We will ask you to write down any thoughts you have on your self-tracking data or you may want to draw or highlight anything you think is important. You may skip any questions if you wish to do so.

Joint Review of Patient Data

You will need to attend your routine check-up appointment as normal, in-person or remotely based on your choice. However, we may need to change your check-up session to a different time of the day to accommodate the research appointment and we will contact you if we need to do this. The check-up session will last about 45 minutes. You may like to discuss any observations that you have made about your self-tracking data with your clinician. This session will be audio-recorded and then transcribed by a researcher.

Post-Study Questionnaire

You will be asked to complete a second online questionnaire following the telephone check-up. The researcher will invite you to share your experience with the use of self-tracking data during the check-up session. You may skip any questions if you wish to do so.

Do I have to take part?

No, taking part is voluntary. If you take part, we will ask you to sign a digital consent form and give you a copy to keep. You will be free to withdraw at any time. If you withdraw from the study, we will keep the information about you that we have already obtained unless you contact the researcher within 14 days of data collection.

You do not have to give a reason if you decide not to take part, nobody will be upset and the care you receive will not be affected.

What are the possible benefits and risks of taking part?

Your participation is voluntary. There is unlikely to be any personal benefit to taking part in the study. However, taking part may help us improve self-tracking technology in the future.

We do not anticipate any risk or discomfort in talking about your experiences. However, if it makes you feel worried about your condition, you will be able to talk with the researcher afterwards, who can arrange for you to see your clinical nurse specialist or rheumatologist.

Will my taking part in this study be kept confidential?

Yes. Any data that we collect as part our research will be kept safe and confidential and will be anonymised with a code number so you cannot be identified.

How will we use information about you?

We will need to use information from you, your medical records and your healthcare professionals for this research project.

This information will include your name, NHS number, contact details and Project Nightingale data. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

What will happen to my data after the study?

Your name or other identifying information will not be disclosed in any presentation or publication of the research. Audio recordings will be destroyed after transcription and will not be kept after the study. Transcriptions will be anonymised at source. Your data will be stored securely at RUH for a period of 7 years, and on secure research data servers at the University of Bath for a period of 10 years.

Anonymised data may be shared with researchers in the future to carry out other research into axSpA. This means that you would not be able to be identified from this data.

We will give you the option to receive a summary of the results at the end of the study. Any end-of-study reports/summaries etc. will not include any identifiable information about you and will only show the overall findings of the project.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by contacting the Data Protection Officers at RUH <ruh-tr.IGQueries@nhs.net>
- by asking one of the research team or by ringing us on +44 7414925601

What to do now?

You can register your interest by emailing us at [redacted] within 14 days of receiving the information sheet. We will be in touch with you shortly after to discuss your participation and answer any questions you may have. Please contact us if you would like more time to consider.

Contact Information

Chief Investigator: Dr Raj Sengupta
Email: [redacted]
Tel: [redacted]

Principal Investigator: Weihua Zhang
Email: [redacted]
Tel: [redacted]

This page explains how health researchers use information from patients.
If you are asked to take part in research, you can ask what will happen in the study.

What is patient data?

When you go to your GP or hospital, the doctors and others looking after you will record information about your health. This will include your health problems, and the tests and treatment you have had. They might want to know about family history, if you smoke or what work you do. All this information that is recorded about you is called patient data or patient information.

When information about your health care joins together with information that can show who you are (like your name or NHS number) it is called identifiable patient information. It's important to all of us that this identifiable patient information is kept confidential to the patient and the people who need to know relevant bits of that information to look after the patient. There are special rules to keep confidential patient information safe and secure.

What sort of patient data does health and care research use?

There are lots of different types of health and care research.

If you take part in a clinical trial, researchers will be testing a medicine or other treatment. Or you may take part in a research study where you have some health tests or answer some questions. When you have agreed to take part in the study, the research team may look at your medical history and ask you questions to see if you are suitable for the study. During the study you may have blood tests or other health checks, and you may complete questionnaires. The research team will record this data in special forms and combine it with the information from everyone else in the study. This recorded information is research data.

In other types of research, you won't need to do anything different, but the research team will be looking at some of your health records. This sort of research may use some data from your GP, hospital or central NHS records. Some research will combine these records with information from other places, like schools or social care. The information that the researcher collects from the health records is research data.

Why does health and care research use information from patients?

In clinical trials, the researchers are collecting data that will tell them whether one treatment is better or worse than other. The information they collect will show how safe a treatment is, or whether it is making a difference to your health. Different people can respond differently to a treatment. By collecting information from lots of people, researchers can use statistics to work out what effect a treatment is having.

Other types of research will collect data from lots of health records to look for patterns. It might be looking to see if any problems happen more in patients taking a medicine. Or to see if people who have screening tests are more likely to stay healthier.

Some research will use blood tests or samples along with information about the patient's health. Researchers may be looking at changes in cells or chemicals due to a disease.

All research should only use the patient data that it really needs to do the research. You can ask what parts of your health records will be looked at.

How does research use patient data?

If you take part in some types of research, like clinical trials, some of the research team will need to know your name and contact details so they can contact you about your research appointments, or to send you questionnaires. Researchers must always make sure that as few people as possible can see this sort of information that can show who you are.

In lots of research, most of the research team will not need to know your name. In these cases, someone will remove your name from the research data and replace it with a code number. This is called coded data, or the technical term is pseudonymised data. For example, your blood test might be labelled with your code number instead of your name. It can be matched up with the rest of the data relating to you by the code number.

In other research, only the doctor copying the data from your health records will know your name. They will replace your name with a code number. They will also make sure that any other information that could show who you are is removed. For example, instead of using your date of birth they will give the research team your age. When there is no information that could show who you are, this is called anonymous data.

Where will my data go?

Sometimes your own doctor or care team will be involved in doing a research study. Often, they will be part of a bigger research team. This may involve other hospitals, or universities or companies developing new treatments. Sometimes parts of the research team will be in other countries. You can ask about where your data will go. You can also check whether the data they get will include information that could show who you are. Research teams in other countries must stick to the rules that the UK uses.

All the computers storing patient data must meet special security arrangements.

If you want to find out more about how companies develop and sell new medicines, the Association of the British Pharmaceutical Industry has information on its website.

What are my choices about my patient data?

- You can stop being part of a research study at any time, without giving a reason, but the research team will keep the research data about you that they already have. You can find out what would happen with your data before you agree to take part in a study.
- In some studies, once you have finished treatment the research team will continue to collect some information from your doctor or from central NHS records over a few months or years so the research team can track your health. If you do not want this to happen, you can say you want to stop any more information being collected.
- Researchers need to manage your records in specific ways for the research to be reliable. This means that they won't be able to let you see or change the data they hold about you. Research could go wrong if data is removed or changed.

What happens to my research data after the study?

Researchers must make sure they write the reports about the study in a way that no-one can work out that you took part in the study.

Once they have finished the study, the research team will keep the research data for several years, in case they need to check it. You can ask about who will keep it, whether it includes your name, and how long they will keep it.

Usually your hospital or GP where you are taking part in the study will keep a copy of the research data along with your name. The organisation running the research will usually only keep a coded copy of your research data, without your name included. This is kept so the results can be checked.

If you agree to take part in a research study, you may get the choice to give your research data from this study for future research. Sometimes this future research may use research data that has had your name and NHS number removed. Or it may use research data that could show who you are. You will be told what options there are. You will get details if your research data will be joined up with other information about you or your health, such as from your GP or social services.

Once your details like your name or NHS number have been removed, other researchers won't be able to contact you to ask you about future research.

Any information that could show who you are will be held safely with strict limits on who can access it.

You may also have the choice for the hospital or researchers to keep your contact details and some of your health information, so they can invite you to take part in future clinical trials or other studies. Your data will not be used to sell you anything. It will not be given to other organisations or companies except for research.

Will the use of my data meet GDPR rules?

GDPR stands for the General Data Protection Regulation. In the UK we follow the GDPR rules and have a law called the Data Protection Act. All research using patient data must follow UK laws and rules.

Universities, NHS organisations and companies may use patient data to do research to make health and care better.

When companies do research to develop new treatments, they need to be able to prove that they need to use patient data for the research, and that they need to do the research to develop new treatments. In legal terms this means that they have a 'legitimate interest' in using patient data.

Universities and the NHS are funded from taxes and they are expected to do research as part of their job. They still need to be able to prove that they need to use patient data for the research. In legal terms this means that they use patient data as part of 'a task in the public interest'.

If they could do the research without using patient data they would not be allowed to get your data.

Researchers must show that their research takes account of the views of patients and ordinary members of the public. They must also show how they protect the privacy of the people who take part. An NHS research ethics committee checks this before the research starts.

What if I don't want my patient data used for research?

You will have a choice about taking part in a clinical trial testing a treatment. If you choose not to take part, that is fine.

In most cases you will also have a choice about your patient data being used for other types of research. There are two cases where this might not happen:

1. When the research is using anonymous information. Because it's anonymous, the research team don't know whose data it is and can't ask you.
2. When it would not be possible for the research team to ask everyone. This would usually be because of the number of people who would have to be contacted. Sometimes it will be because the research could be biased if some people chose not to agree. In this case a special NHS group will check that the reasons are valid. You can opt-out of your data being used for this sort of research. You can ask your GP about opting-out, or you can find out more.

Who can I contact if I have a complaint?

If you want to complain about how researchers have handled your information, you should contact the research team. If you are not happy after that, you can contact the Data Protection Officer. The research team can give you details of the right Data Protection Officer.

If you are not happy with their response or believe they are processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

D.5 CoUs-axSpA - Clinician Information Sheet

CLINICIAN INFORMATION SHEET (CIS) – v3.0 20/01/2021

Supporting Collaborative Use of Patient Self-Tracking Data in the Context of Axial Spondyloarthritis (axSpA) Clinics

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please read the following information and discuss with others if you wish. Please ask us if anything is not clear.

Why are we doing this study?

We would like to understand what patients with Axial Spondylarthritis (axSpA) and their clinicians think about "self-tracking" - the practice of recording health and activity data through smart phone apps and/or wearable devices (e.g., Fitbit). Currently, the Royal National Hospital for Rheumatic Diseases (RNHRD)'s Project Nightingale uses a health-monitoring smart phone app (uMotif) and wearable devices to enable axSpA patients to self-track. Data collected includes symptoms, medication and levels of physical activity. We would like to explore how or if self-tracking is approached in clinic, and whether there are any difficulties or opportunities with the use of self-tracking data. This will help us to improve self-tracking information technology in the future.

Who is sponsoring this study?

This project is sponsored by the Royal United Hospitals (RUH) Bath NHS Foundation and is part of a PhD research program. It has been reviewed by the NHS Research Ethics Committee [reference: 20/SC/0140] and the Research Ethics Approval Committee for Health (University of Bath) [reference: EP 19/20 045]. IRAS project ID: 271239.

Why have I been invited to take part?

You are invited to take part because you are a health professional at the RNHRD whose routine responsibilities include axSpA check-ups. You must be available to attend scheduled clinical check-ups during 01/02/2021-31/07/2021 if you wish to participate.

What will I be asked to do?

You will be carrying out routine check-ups with axSpA patients who practice self-tracking. The researcher will sit in and observe how you use and discuss self-tracking data with patients, either in person or through telephone depending on the patient's choice. To reduce risks related to COVID-19, PPE will be worn by the researcher and participating clinician throughout the study while social distancing measure is strictly observed. This study will take place over the course of 6 months. You may attend up to 15 check-ups and it is entirely up to you on how many check-ups you would like to do. If you do decide to take part, all the research activities will be audio-recorded with your permission and the researcher will make notes during these activities.

Part 1: Joint Review of Patient Data *(1 hour 10 minutes)*

The researcher will arrive in your office 10 minutes before the check-up and you will be given a printout of the patient's self-tracking data (to be used as part of your check-up preparation in any way you wish). The researcher will audio-record the entire check-up appointment (including preparation and wrap-up) using a Dictaphone. The check-up session may last up to 45 minutes and you will not be interrupted by the researcher throughout the process. Once the check-up is concluded, the researcher will ask you to reflect on the consultation experience and share your thoughts.

Part 2: Post-Study Interview *(2 x 30 minutes)*

Two 30-minute telephone interviews will be scheduled with you. These interviews will focus on your experiences with self-tracking conversations during the study. The researcher will ask you questions like: "Have the conversations about self-tracking data influenced your decision-making process?", "Did you learn

anything new from the patient's self-tracking data as the result of the conversation?". The researcher may ask you to elaborate and expand on their answers.

Do I have to take part?

No, taking part is voluntary. If you take part, we will ask you to sign a consent form and give you a copy to keep. You will be able to withdraw your consent to participate at any time without a reason. If you withdraw from the study, we will keep the information about you that we have already obtained unless you contact the researcher within 14 days of data collection.

What are the possible benefits and risks of taking part?

This is an unpaid study and your participation will be voluntary. There is unlikely to be any personal benefit to taking part in the study. However, you will be able to share with the researchers your thoughts on the use of patient self-tracking data in a clinical setting. Data gathered from this study will be used to inform designs of technologies that support the collaborative uses of patient self-tracking data.

There are no anticipated risks associated with this study. We do not expect you to feel any discomfort or embarrassment if you take part in the project. If, however you do feel uncomfortable or appear upset at any time, the researcher will stop the interview right away and may direct you to approach an appropriate support service. PPE and social distancing measures will be used to minimise risks associated with COVID-19.

How will health researchers use information from me and my patients?

We may use your hospital records to get in touch with you (such as name, position and NHS email address). The research team will use this information to make sure that the research is being done properly. Only the research team will have access to information that you provide. Your data will have a code number where appropriate, such as anonymised quotes for scientific publications.

Page 3 to 6 explains how health researchers use information from your patients for the undertaking of the study. Please read it carefully before deciding to whether or not to take part in the study.

You may also visit www.hra.nhs.uk/information-about-patients/ or contact the Data Protection Officers at RUH <ruh-tr.IGQueries@nhs.net> or the University of Bath <dataprotection-queries@lists.bath.ac.uk> for more information.

What will happen to my data after the study?

Your name or other identifying information will not be disclosed in any presentation or publication of the research. Some data may be shared with researchers in the future to carry out other research into axSpA. Your data will be stored securely at RUH for a period of 7 years, and on secure research data servers at the University of Bath for a period of 10 years.

We will give you the option to receive a summary of the results at the end of the study. Any end-of-study reports/summaries etc. will not include any identifiable information about you and will only show the overall findings of the project.

What to do now?

You can register your interest by emailing the Principal Investigator named below within 14 days of receiving the information sheet. We will be in touch with you shortly after to discuss your participation and answer any questions you may have. Please contact us if you would like more time to decide whether or not to take part.

Contact Information

Chief Investigator: Dr Raj Sengupta
[redacted]

Principal Investigator: Weihua Zhang
[redacted]

This document explains how health researchers use information from patients. If you are asked to take part in research, you can ask what will happen in the study.

What is patient data?

When you go to your GP or hospital, the doctors and others looking after you will record information about your health. This will include your health problems, and the tests and treatment you have had. They might want to know about family history, if you smoke or what work you do. All this information that is recorded about you is called patient data or patient information.

When information about your health care joins together with information that can show who you are (like your name or NHS number) it is called identifiable patient information. It's important to all of us that this identifiable patient information is kept confidential to the patient and the people who need to know relevant bits of that information to look after the patient. There are special rules to keep confidential patient information safe and secure.

What sort of patient data does health and care research use?

There are lots of different types of health and care research.

If you take part in a clinical trial, researchers will be testing a medicine or other treatment. Or you may take part in a research study where you have some health tests or answer some questions. When you have agreed to take part in the study, the research team may look at your medical history and ask you questions to see if you are suitable for the study. During the study you may have blood tests or other health checks, and you may complete questionnaires. The research team will record this data in special forms and combine it with the information from everyone else in the study. This recorded information is research data.

In other types of research, you won't need to do anything different, but the research team will be looking at some of your health records. This sort of research may use some data from your GP, hospital or central NHS records. Some research will combine these records with information from other places, like schools or social care. The information that the researcher collects from the health records is research data.

Why does health and care research use information from patients?

In clinical trials, the researchers are collecting data that will tell them whether one treatment is better or worse than other. The information they collect will show how safe a treatment is, or whether it is making a difference to your health. Different people can respond differently to a treatment. By collecting information from lots of people, researchers can use statistics to work out what effect a treatment is having.

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Some research will use blood tests or samples along with information about the patient's health. Researchers may be looking at changes in cells or chemicals due to a disease.

All research should only use the patient data that it really needs to do the research. You can ask what parts of your health records will be looked at.

How does research use patient data?

If you take part in some types of research, like clinical trials, some of the research team will need to know your name and contact details so they can contact you about your research appointments, or to send you questionnaires. Researchers must always make sure that as few people as possible can see this sort of information that can show who you are.

In lots of research, most of the research team will not need to know your name. In these cases, someone will remove your name from the research data and replace it with a code number. This is called coded data, or the technical term is pseudonymised data. For example, your blood test might be labelled with your code number instead of your name. It can be matched up with the rest of the data relating to you by the code number.

In other research, only the doctor copying the data from your health records will know your name. They will replace your name with a code number. They will also make sure that any other information that could show who you are is removed. For example, instead of using your date of birth they will give the research team your age. When there is no information that could show who you are, this is called anonymous data.

Where will my data go?

Sometimes your own doctor or care team will be involved in doing a research study. Often, they will be part of a bigger research team. This may involve other hospitals, or universities or companies developing new treatments. Sometimes parts of the research team will be in other countries. You can ask about where your data will go. You can also check whether the data they get will include information that could show who you are. Research teams in other countries must stick to the rules that the UK uses.

All the computers storing patient data must meet special security arrangements.

If you want to find out more about how companies develop and sell new medicines, the Association of the British Pharmaceutical Industry has information on its website.

What are my choices about my patient data?

- You can stop being part of a research study at any time, without giving a reason, but the research team will keep the research data about you that they already have. You can find out what would happen with your data before you agree to take part in a study.
- In some studies, once you have finished treatment the research team will continue to collect some information from your doctor or from central NHS records over a few months or years so the research team can track your health. If you do not want this to happen, you can say you want to stop any more information being collected.
- Researchers need to manage your records in specific ways for the research to be reliable. This means that they won't be able to let you see or change the data they hold about you. Research could go wrong if data is removed or changed.

What happens to my research data after the study?

Researchers must make sure they write the reports about the study in a way that no-one can work out that you took part in the study.

Once they have finished the study, the research team will keep the research data for several years, in case they need to check it. You can ask about who will keep it, whether it includes your name, and how long they will keep it.

Usually your hospital or GP where you are taking part in the study will keep a copy of the research data along with your name. The organisation running the research will usually only keep a coded copy of your research data, without your name included. This is kept so the results can be checked.

If you agree to take part in a research study, you may get the choice to give your research data from this study for future research. Sometimes this future research may use research data that has had your name and NHS number removed. Or it may use research data that could show who you are. You will be told what options there are. You will get details if your research data will be joined up with other information about you or your health, such as from your GP or social services.

Once your details like your name or NHS number have been removed, other researchers won't be able to contact you to ask you about future research.

Any information that could show who you are will be held safely with strict limits on who can access it.

You may also have the choice for the hospital or researchers to keep your contact details and some of your health information, so they can invite you to take part in future clinical trials or other studies. Your data will not be used to sell you anything. It will not be given to other organisations or companies except for research.

Will the use of my data meet GDPR rules?

GDPR stands for the General Data Protection Regulation. In the UK we follow the GDPR rules and have a law called the Data Protection Act. All research using patient data must follow UK laws and rules.

Universities, NHS organisations and companies may use patient data to do research to make health and care better.

When companies do research to develop new treatments, they need to be able to prove that they need to use patient data for the research, and that they need to do the research to develop new treatments. In legal terms this means that they have a 'legitimate interest' in using patient data.

Universities and the NHS are funded from taxes and they are expected to do research as part of their job. They still need to be able to prove that they need to use patient data for the research. In legal terms this means that they use patient data as part of 'a task in the public interest'.

If they could do the research without using patient data they would not be allowed to get your data.

Researchers must show that their research takes account of the views of patients and ordinary members of the public. They must also show how they protect the privacy of the people who take part. An NHS research ethics committee checks this before the research starts.

What if I don't want my patient data used for research?

You will have a choice about taking part in a clinical trial testing a treatment. If you choose not to take part, that is fine.

In most cases you will also have a choice about your patient data being used for other types of research. There are two cases where this might not happen:

1. When the research is using anonymous information. Because it's anonymous, the research team don't know whose data it is and can't ask you.
2. When it would not be possible for the research team to ask everyone. This would usually be because of the number of people who would have to be contacted. Sometimes it will be because the research could be biased if some people chose not to agree. In this case a special NHS group will check that the reasons are valid. You can opt-out of your data being used for this sort of research. You can ask your GP about opting-out, or you can find out more.

Who can I contact if I have a complaint?

If you want to complain about how researchers have handled your information, you should contact the research team. If you are not happy after that, you can contact the Data Protection Officer. The research team can give you details of the right Data Protection Officer.

If you are not happy with their response or believe they are processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

D.6 CoUs-axSpA - Patient Consent Form

CoUs-axSpA Patient Consent Form

Page 1: Patient Consent Form - v3.0 20/01/2021

Supporting Collaborative Use of Patient Self-Tracking Data in the Context of Axial Spondyloarthritis (axSpA) Clinics

Project Ref: 271239

1. Participant ID (please find this in the recruitment email):

Please INITIAL the following statements if you agree, e.g. write "JS" for John Smith.

2. 1. I confirm that I have read the information sheet dated 20/01/2021 (version 3.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

3. 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

4. 3. I understand that I am free to withdraw the data that I generate during the study provided it has not yet been anonymised (usually within two weeks of data collection). ✱
Required

☐

5. 4. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from University of Bath, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

☐

6. 5. I understand that the data I provide during the study will be used to support other axSpA research in the future, and that my data may be shared with other researchers after being anonymised.

☐

7. 6. I understand that audio recordings will be made during the study and that all audio recordings will be anonymised and destroyed following transcription. I give permission for the anonymised use of my quotes for scientific publications.

☐

8. 7. I understand that my Project Nightingale data may be shared with authorised NHS staff during the study and that all data printout will be retrieved from staff members at the end of the study.

☐

9. 8. I understand that the research team will use records held by the Royal United Hospitals to contact me and provide information about the study. I give permission to be contacted via newsletters with regard to the research findings.

☐

10. 9. I agree with the above and wish to take part in the study.

☐

11. Date:

☐ 31

(dd/mm/yyyy)

Page 2: Thank You

Thank you. Please download this consent form for your record.

We will be in touch with you shortly.

D.7 CoUs-axSpA - Clinician Consent Form

Project Ref: 271239 | Centre Number: | Name of Investigator:

Session ID: | Participant Study ID: | Newsletter:

CLINICIAN CONSENT FORM – v3.0 20/01/2021

Supporting Collaborative Use of Patient Self-Tracking Data in the Context of Axial Spondyloarthritis (axSpA) Clinics

Please INITIAL box

1. I confirm that I have read the information sheet dated 20/01/2021 (version 3.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any repercussions or my legal rights being affected. ☐
3. I understand that I am free to withdraw the data that I generate during the study provided it has not yet been anonymised (usually within two weeks of data collection). ☐
4. I understand that the data I provide during the study will be used to support other research in the future, and that my data may be shared with other researchers after being anonymised. ☐
5. I understand that audio recordings will be made during the study and that all audio recordings will be anonymised and destroyed following transcription. I give permission for the anonymised use of my quotes for scientific publications. ☐
6. I understand that patients' Project Nightingale data may be shared with me during the study and that I will return the datasheets to the investigator at the end of the study. ☐
7. I understand that the research team will use records held by the Royal United Hospitals to contact me and provide information about the study. I give permission to be contacted via newsletters with regard to the research findings. ☐
8. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

D.8 CoUs-axSpA - Pre-Study Questionnaire

CoUs-axSpA Patient Data Preview Questionnaire

Supporting Collaborative Use of Patient Self-Tracking Data in the Context of Axial Spondyloarthritis (axSpA) Clinics

Project Ref: 271239

Participant ID (please find this in the recruitment email): ✱ *Required*

Thank you for taking part in the study. You should have received your recent uMotif self-tracking data via email. You will have the opportunity to discuss this data with the clinician during the upcoming telephone check-up.

We would like you to spend at least 5 minutes familiarising yourself with the data and exploring whether there is anything you may wish to discuss with your clinician during the check-up session. Please answer the questions below after you have done so.

* The information you provide will NOT be shared with clinicians. You may skip any questions if you wish to do so.

1. How long did you spend familiarising yourself with the data?

2. Did you encounter any difficulties reviewing or understanding your data?
If so, please explain these difficulties in as much detail as possible.

3. Did reviewing the data reveal anything interesting or useful?
If so, please describe what the data revealed.

Please explain why you believe this is interesting or useful in as much detail as possible.

4. How do you feel about having a conversation about your data with your clinician?
For example, do you think it will be useful, challenging, intrusive?
Please explain your answer in as much detail as possible.

Do you have any particular concerns about discussing your data with your clinician?
If so, please explain your concerns in as much detail as possible.

5. Has your data helped you to think of questions, topics, or issues that you wish to discuss with the clinician during the upcoming check-up?
If so, please:
- List these questions, topics or issues, below.
- Please refer to any specific data points that caused you to think about this (e.g. My Pain score from Feb 4th to 6th were 'Severe')
- Please explain why you would like to discuss this with the clinician

- Next to each item that you list, please choose how important it is that you discuss this with your clinician (either High Priority, Medium Priority or Low Priority)

	What is the question, topic or issue?	Specific data point(s)	Why would you like to discuss this with the clinician?	How important is it for you to discuss this?		
				High Priority	Medium Priority	Low Priority
Item #1				○	○	○
Item #2				○	○	○
Item #3				○	○	○
Item #4				○	○	○
Item #5				○	○	○

Do you need more space for this question (Question 5)? ✱ *Required*

- ○ Yes
- ○ No

Additional space for Question 5 - Has your data helped you to think of questions, topics, or issues that you wish to discuss with the clinician during the upcoming check-up?

Please:

- List these questions, topics or issues, below.
- Please refer to any specific data points that caused you to think about this (e.g. My Pain score from Feb 4th to 6th were 'Severe')
- Please explain why you would like to discuss this with the clinician
- Next to each item that you list, please choose how important it is that you discuss this with your clinician (either High Priority, Medium Priority or Low Priority)

	What is the question, topic or issue?	Specific data point(s)	Why would you like to discuss this with the clinician?	How important is it for you to discuss this?		
				High Priority	Medium Priority	Low Priority
Item #6				○	○	○
Item #7				○	○	○
Item #8				○	○	○
Item #9				○	○	○
Item #10				○	○	○

6. Is there anything that the data highlighted that you would not wish to discuss with the clinician?
If so, please specify below (and explain why you would not like to discuss this with the clinician).

7. Additional comments

Thank You

Thank you. Please attend your next check-up appointment as normal.

We'll be in touch shortly after the check-up.

D.9 CoUs-axSpA - Post-Study Questionnaire

CoUs-axSpA Post-Study Questionnaire

Page 1

Supporting Collaborative Use of Patient Self-Tracking Data in the Context of Axial Spondyloarthritis (axSpA) Clinics

Project ref: 271239

1. Participant ID (please find this in the recruitment email): ✱ *Required*

Thank you for taking part in the study. We would like to ask you a few questions about your experience in using and discussing self-tracking data during the last check-up.

Before answering the questions below, please review the answers that you provided in the previous questionnaire prior to your conversation with the clinician. This is included in the email. You may skip any questions if you wish to do so.

2. **1. Was discussing your data with the clinician useful?**
If so, please explain why you think this was useful. If not, please explain why this was not useful.

3. **2. Do you think that reviewing your data prior to the conversation was helpful?**
If so, please explain how this has helped. If not, please explain why this was not helpful.

4. **3. Did you encounter any difficulties or issues discussing your data with your clinician?**
If so, please explain any difficulties in as much detail as possible.

5. **4. Did discussing the data with your clinician reveal anything interesting or useful?**

If so, please describe what the data revealed.

6. **5. Do you have any thoughts or feelings about how the data was discussed?**
For example, were you satisfied or unsatisfied with the conversation (and why?)

7. **6. Were you able to discuss all of the things about the data that you wanted to?**
If not, why was this? Please give us as much detail as possible.

8. **7. Do you have any thoughts about what could have made discussions about your data better?**

If so, please tell us how and give us as much detail as possible.

9. **8. Has the discussion about your data changed your thoughts or opinions about the value of collecting self-tracking data?**
If so, please describe how this has changed your opinions.
If not, please tell us why.

10. **9. Additional comments**

Page 2: Thank You

This is the end of the study. Please contact the researcher if you have any questions. Thank you for supporting research. We wish you the best.

D.10 NHS Research Ethics Committee (REC) Approval Letter

South Central - Berkshire B Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0207 1048310

Please note: This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

02 April 2020

Mr Weihua Zhang
Department of Computer Science
University of Bath
Claverton Down
BA2 7AY

Dear Mr Zhang

Study title:	**Supporting Collaborative Use of Patient Self-Tracking Data in the Context of Axial Spondyloarthritis (axSpA) Clinics: A Qualitative Exploration**
REC reference:	**20/SC/0140**
Protocol number:	**N/A**
IRAS project ID:	**271239**

Thank you for your letter of 26 March 2020. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 20 March 2020

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Cover Letter [response to points raised]		26 March 2020

Participant consent form [patient consent form]	2	20 March 2020
Participant consent form [clinician consent form]	2	20 March 2020
Participant information sheet (PIS) [patient information sheet]	2	20 March 2020
Participant information sheet (PIS) [clinician info sheet]	2	20 March 2020

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Cover Letter [response to points raised]		26 March 2020
Interview schedules or topic guides for participants [Interview Topics]	1	29 February 2020
IRAS Application Form [IRAS_Form_05032020]		05 March 2020
Letters of invitation to participant [invitation email]	1	06 March 2020
Participant consent form [patient consent form]	2	20 March 2020
Participant consent form [clinician consent form]	2	20 March 2020
Participant information sheet (PIS) [patient information sheet]	2	20 March 2020
Participant information sheet (PIS) [clinician info sheet]	2	20 March 2020
Research protocol or project proposal [Protocol]	1	29 February 2020
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	29 February 2020
Summary CV for student [Principal Investigator CV]	1	29 February 2020
Summary CV for supervisor (student research) [Supervisor CV]	1	29 February 2020

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

20/SC/0140 **Please quote this number on all correspondence**

Yours sincerely

[redacted]

Sarah Graves

E-mail: berkshireb.rec@hra.nhs.uk

Copy to: *Mr Weihua Zhang*
Dr Kelly Spencer, Royal United Hospitals Bath

D.11 NHS Health Research Authority (HRA) Approval Letter

Dr Raj Sengupta
Consultant Rheumatologist
Royal United Hospitals Bath NHS Foundation Trust
Royal National Hospital for Rheumatic Diseases
Combe Park
Bath
BA1 3NG

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

01 May 2020

Dear Dr Sengupta

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Supporting Collaborative Use of Patient Self-Tracking Data in the Context of Axial Spondyloarthritis (axSpA) Clinics: A Qualitative Exploration**
IRAS project ID:	**271239**
Protocol number:	**N/A**
REC reference:	**20/SC/0140**
Sponsor	**Royal United Hospitals Bath NHS Foundation Trust**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **271239**. Please quote this on all correspondence.

Yours sincerely,

Maeve Ip Groot Bluemink
Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Dr Kelly Spencer*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Cover Letter [response to points raised]		26 March 2020
Interview schedules or topic guides for participants [Interview Topics]	1	29 February 2020
IRAS Application Form [IRAS_Form_05032020]		05 March 2020
Letters of invitation to participant [invitation email]	1	06 March 2020
Participant consent form [patient consent form]	2	20 March 2020
Participant consent form [clinician consent form]	2	20 March 2020
Participant information sheet (PIS) [clinician info sheet]	2	20 March 2020
Participant information sheet (PIS) [patient information sheet]	2.1	28 April 2020
Research protocol or project proposal [Protocol]	1	29 February 2020
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	29 February 2020
Summary CV for student [Principal Investigator CV]	1	29 February 2020
Summary CV for supervisor (student research) [Supervisor CV]	1	29 February 2020

IRAS project ID	271239

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There is only one participating NHS organisation therefore there is only one site type.	This is a single site study sponsored by the participating NHS organisation. You should work with your sponsor R&D office to make arrangements to set up the study. The sponsor R&D office will confirm to you when the study can start following issue of HRA and HCRW Approval.	This is a single site study sponsored by the participating NHS organisation therefore no agreements are expected.	No external study funding has been sought.	A Principal Investigator should be appointed at study sites	No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on **standard DBS checks and occupational health clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

D.12 Good Clinical Practice Certificate

NIHR | National Institute for Health Research

CERTIFICATE OF ACHIEVEMENT

Weihua Zhang

has completed the course

Introduction to Good Clinical Practice (GCP) eLearning

November 18, 2019

Modules Completed:

Introduction to Research in the NHS and other settings

Good Clinical Practice and Standards in Research

Study Set-up and Responsibilities

Informed Consent

Data Collection and Documentation

Safety Reporting

Summary

This course is worth 4 CPD points.

CPD
The CPD Certification Service

NIHR | National Institute for Health Research

THANK YOU FOR BEING A PART OF RESEARCH

As we all know, it is important to invest in continuing professional development (CPD).

The NIHR provides programmes, resources and communities to support your learning.

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