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Student Name: Glon Corentin

Student Number: 30044337

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I was given a choice,

but there was no choice

The decision-making of patients with shoulder pain regarding their treatment

List Of Contents

Acknowledgements

I would like to thank Audrey, my dear wife, along with Camille, Clémentine and Suzie, my beloved daughters, for their support and all the time they've let me devote to this work.

During this MSc course, my fellow Sylvain has been a support and a stimulation, I thank him for this.

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Lastly, I would like to express my gratitude to Adrian Walker for his supervision, his availability and his fast answers. His guidance made me reframe and cast a new glance on my findings.

Abstract

Rationale :

Shoulder pain is a common and disabling condition that affects patients in various aspects of their lives. The most frequent diagnosis for shoulder pain is Rotator Cuff Related Shoulder Pain (RCRSP), and its management is challenging. The clinical practice guidelines recommend exercise therapy as the principal approach, yet less recommended management options are frequently employed: surgery rates are actually increasing, even though the results are comparable to exercise therapy.

This inadequate transfer from guidelines to clinical practice is concerning, and this study contributes to the current focus on this issue. The decision-making process for RCRSP management has been insufficiently researched, and the patient's perspective on this process has been insufficiently explored. Moreover, the application or advantages of shared decision-making in this context have not been assessed yet.

Aims :

The objective of this study is to gain a better understanding of the treatment decision-making of French patients with rotator-cuff related shoulder pain (RCRSP). Furthermore, the research seeks to depict the involvement of healthcare providers in this choice.

Methods :

This qualitative study was conducted following a Constructivist Grounded Theory methodology. Theoretical sampling was employed to recruit 9 patients with RCRSP. One-on-one interviews were used to collect the subjective experience of participants. A constant comparative was conducted concurrently with the data collection, to develop a theory explaining the decision-making process.

Results :

Generally, participants were able to express their values and preferences but the general practitioners were responsible for selecting the management option. The participants held biomechanical beliefs that influenced their perceptions of the treatments. They ranked treatments in a hierarchy and viewed surgery as the most effective option. Physiotherapy was appreciated, but some participants expressed doubts about its effectiveness. Exercise therapy was viewed with caution and some participants considered it potentially hazardous.

Although the participants did not choose their treatment, they were responsible for deciding when to try a new option and actively sought this change. Four driver categories were identified to explain this process: the symptoms, the past experiences, the treatment representations and external factors.

Conclusion :

Findings revealed how patients are involved in the choices related to the management of their RCRSP. The behaviours outlined contribute to deviations from the guidelines, and implementing shared decision-making is suggested as a potential solution. Additionally, the developed theory offers guidance to HCPs on the factors they should address with their patients, through effective communication and education.

Keywords :

Rotator cuff related shoulder pain
Treatment decision-making
Shared decision-making
Constructivist grounded theory
Expectations

1- Background

1-1 Epidemiology

Rotator cuff related shoulder pain (RCRSP) is the most common shoulder pain (Luime et al., 2004), but there is no epidemiological data for this condition in France (HAS, 2019). We can however compare it to other countries: a systematic review of prevalence (Lucas et al., 2022) shows that high income nations have higher rates of shoulder pain, with a median of 16.9%. In a cross-sectional study by Parsons et al. (2007), 17% of the population had suffered from shoulder pain over the last 4 weeks, and it is estimated that 1-2% of the population will consult over a year (Tekavec et al., 2012). Age is known to be the biggest risk factor (Leong et al., 2019), and the French population is getting older (Blanpain & Buisson, 2016); this is one of the reasons why Villatte et al. (2020) expect an increase in shoulder surgery in France in the next decades.

In France, 23% of patients undergoing surgery have not received physiotherapy or injection in the previous 12 months (HAS, 2019). This is in contradiction with the guidelines: surgery should only be proposed in case of insufficient results with conservative treatment (Diercks et al., 2014; Rees et al., 2021), and physiotherapy by exercises and education should be the main intervention. The latest French guidelines (HAS, 2023) point out that a treatment involving surgery plus exercise does not appear to have any added value compared with exercise alone for non-traumatic shoulder pain without full-tears (Pieters et al., 2020).

This situation is sufficiently alarming for the health authorities to express concern (HAS, 2019), but it is in line with what is observed in other countries, where surgery rates are too high or do not go down (Jain et al., 2019; Thorpe et al., 2016). Although this research is focused on France, many elements are similar and relevant for other countries.

1-2 Rotator-Cuff related Shoulder Pain

Our understanding of RCRSP has evolved greatly in recent history and this is reflected in the many different names we have used (subacromial impingement, subacromial pain, rotator cuff tendinopathy, non-specific shoulder pain). The umbrella term “RCRSP” was introduced to acknowledge how little is known about the origin of the pain (J. Lewis, 2016). Most other labels point to a tissue or mechanism as the source of pain, which is now considered problematic: these terms promote a pathoanatomical view that make exercise difficult to justify (Boland et al., 2021; White et al., 2020) and pushes toward surgery (Minns Lowe et al., 2018). Such beliefs appear to be prevalent in

people with RCRSP (Boland et al., 2021). We also know that some labels generate fear and anxiety (Cuff & Littlewood, 2018; Stewart & Loftus, 2018; J. R. Zadro et al., 2022), all the more damaging as our understanding of RCRSP is now less pathoanatomical and more psychosocial (Martinez-Calderon, Meeus, et al., 2018; Maxwell et al., 2021). This change in perspective is well illustrated by recent research, showing that psychological distress has a stronger association with pain and function than tear severity (Okafor et al., 2023), or showing that pain self-efficacy has a strong predictive value for the success of shoulder physiotherapy (Chester et al., 2019).

Patients tend to seek a pathoanatomical explanation for their condition (Cridland et al, 2021; Cuff & Littlewood, 2018; Nyman et al, 2012), even though a biomedical diagnosis is not associated with treatment outcomes (Littlewood et al., 2013). The lack of a clear cause is distressing for both patients (Gillespie et al., 2017) and clinicians (Minns Lowe et al., 2018) and could be one of the reasons for the large number of imaging procedures carried out despite the recommendations. Most clinical practice guidelines recommend using ultrasound, MRI and X-rays only when the patient's situation does not improve with conservative treatment or in specific situations which include a history of trauma or sudden weakness (Doiron-Cadrin et al., 2020; Hinsley et al., 2022; Littlewood et al., 2019). These investigations are frequent, costly and can cause harm (Cortes et al., 2019; Lin et al., 2020) by reinforcing the biomedical view of RCRSP. This pathoanatomical vision seems to influence treatment preferences (J. R. Zadro et al., 2022), but it is not clear what discourages the use of physiotherapy. Professionals state that they find it difficult to convince people with RCRSP to use exercise-based treatment (Maxwell, Robinson, et al., 2022; White et al., 2020), but it is not known what are the determinants when patients choose one treatment over another.

1-3 Shared decision-making

SDM has a special value when there is no clearly superior treatment, or when they have different benefits and harms (Hoffmann et al., 2014). It should thus be valuable for RCRSP management, but to the author’s knowledge, its usage has never been studied for this condition.

Although there is no strong consensus on what it should involve (Elwyn et al., 2017), Shared Decision-Making (SDM) is seen as “a hallmark of good clinical practice” (Hoffmann et al., 2014). By considering patients’ values and preferences it contributes to evidence based practice (Djulbegovic & Guyatt, 2017) and can improve care quality. It is therefore promoted by French health authorities (HAS, 2013; *Petit guide de la prise de décision partagée en santé | Sante.fr*, 2023), but SDM implementation actually remains limited (Moumjid et al., 2022).

SDM implementation can be facilitated by decision aids (Stacey et al., 2017), these are generally lacking (Moumjid et al., 2022), especially for musculoskeletal conditions (Tousignant-Laflamme et al., 2017), but there is actually such a document in French for RCRSP (Deville et al., 2020).

1-4 A gap in the literature

This research aims to understand how a patient with RCRSP chooses a treatment. The influence of different healthcare professionals needs to be studied specifically in the French healthcare system. We do not know how patients choose one treatment over another. As Maxwell et al (2021) point out in their systematic review, this decision-making has not been much studied and their search strategy was repeated to include newer publications (Appendix 1). Some authors have considered this question, but focused on frozen shoulder (Jones et al., 2013) or on patients who chose surgery (Minns Lowe et al., 2018; Weekes et al., 2020).

More recently, Maxwell et al. (2022) have contributed to fill this gap in the literature. However, they studied a population that suffered from long-standing RCRSP (more than 1 year in 69% of participants, only 1 participant with pain for less than 3 months). These results may therefore not be transferred to the general population where the natural history appears to be more favourable: Silverstein et al. (2006) reported 88.3% resolving after 1 year. They also conducted their research in Ireland, where the care pathway process differs from that in France, resulting in potential differences: therapists influence patients' understanding of their condition, and guide their decisions (Gillespie et al., 2017; Minns Lowe et al., 2018). In their study using grounded theory, Maxwell et al., (2022) "provide greater conceptual clarity in relation to the factors influencing treatment decision‐making for shoulder pain", but did not generate a theory explaining patients' decisions.

Understanding what influences treatment decisions could help change health behaviours and reduce the gap between guidelines and their application. There is also hope that adherence to evidence-based treatments, such as exercise therapy, could be improved. Adherence to treatment is difficult to achieve and has been described as a major problem by physiotherapists (Hanratty et al., 2016; White et al., 2020). We also know that patient expectations are associated with clinical outcomes (Bialosky et al., 2018; Chester et al., 2018, 2019). The usage of existing French infographics and patient decision aids could be optimised by understanding what guides the choice of treatments.

2- Research Questions

The aim of this study is to comprehend the process of treatment decision-making among French patients with RCRSP.

The secondary objective of this research is to improve our understanding of the influence of the healthcare providers involved in this decision.

3- Methodology And Research Design

Grounded theory is “the most widely used and popular qualitative research method across a wide range of disciplines and subject areas” according to Bryant and Charmaz (2007), and it is increasingly used in physiotherapy (Ali et al., 2019). Grounded theory was a natural methodological choice for this study, as it can make sense of a process (Carter & Little, 2007), and is regarded as one of the most rigorous qualitative methodologies (Ali et al., 2019). Grounded theory is pertinent when little is known, like on this subject, and when complex relationships are being explored (Mellion & Tovin, 2002), like the one between the patient and the healthcare providers.

The constructivist grounded theory (CGT) approach adopted for this project acknowledges the influence of the researcher on the research: knowledge is co-created (Rieger, 2019) and it seems impossible for a physiotherapist to interview patients without accepting that their own profession has an impact on the results. This specific version of grounded theory takes a pragmatist stance rather than the positivist one held in classical grounded theory (Morse, 2021). This calls for a greater reflexivity in the research process. For example, in classical grounded theory, the literature review is delayed to ensure that the theory emerges from the actually collected data (Creswell & Poth, 2018, p. 146; Mellion & Tovin, 2002); The CGT differentiates itself on this point by using the existing literature as a starting point (Charmaz, 2014, p. 30), and it is the reflexivity of the researcher that is the safeguard against preconceived ideas.

In qualitative research, adhering to an 'emergent design' is a widely recommended approach (Creswell & Poth, 2018). This approach entails remaining flexible and adaptable in one's methods, allowing for necessary modifications when emerging data justify it. This adaptability is pronounced in grounded theory, which avoids predetermined theoretical orientations (Mellion & Tovin, 2002). The concurrent process of data collection and analysis empowers researchers to pivot as dictated by the evolving research state, while simultaneously eliciting novel theories and identifying pertinent issues.

3-1 Recruitment

The inclusion and exclusion criteria for this study are similar to previous qualitative studies on RCRSP (Maxwell, McCreesh, et al., 2022; Powell et al., 2023):

Inclusion	Exclusion
Age >=18 years old RCRSP (non specific musculoskeletal shoulder pain, including rotator cuff disease, tendinopathy, tendinosis, subacromial impingement) French speaking Able to express consent	Recent trauma to the shoulder Shoulder pain attributed to cervical spine or visceral origin Shoulder pain attributed to rheumatological diseases Shoulder instability Frozen shoulder

This study used theoretical sampling, which "is the gold standard" in grounded theory (Timonen et al., 2018), where "the analyst simultaneously collects, codes, and analyzes data and decides what subsequent data to collect in order to develop theory as it emerges." (Mellion & Tovin, 2002), however sampling cannot be totally driven by emerging theory, since there is no such theory in the early data collection (Cutcliffe, 2000). There is therefore initial purposeful sampling which is "superseded by theoretical sampling as the data/theory highlight the direction which further sampling needs to follow" (Cutcliffe, 2000). As a starting point, recruitment targeted patients who had undergone different treatments (See participants characteristics in Appendix 2) by sending recruitment packs (See Appendix 3 and 4) to various healthcare providers involved in the management of RCRSP: general practitioners (GP), orthopaedic surgeons specialising in the shoulder, rheumatologists and physiotherapists (PT). Sampling across different treatment choices also brings variation, which is a usual sampling mode that helps reflect differences and various perspectives (Creswell & Poth, 2018; Cutcliffe, 2000).

"Theoretical sampling can be extremely challenging to implement" (Timonen et al., 2018), and the author mostly relied on other people for recruitment. Some healthcare providers, who expressed a special interest in the research, were asked if they could recruit patients with specific characteristics (for example a patient who had a strong disagreement with the GP on the best treatment), to explore "the concepts that are emerging in the data" (Timonen et al., 2018). The author also recruited some participants on Facebook through a support group for RCRSP patients.

According to Bryant and Charmaz (2007), participants should be willing to participate but also be reflective and have the time and ability to share their experience. For these authors, not every volunteer should be included because of these reasons. In this study, recruitment was too difficult to refuse any participant, and every volunteer was accepted. Conversely, it's difficult to know who didn't

want to take part: recruitment was indirect and persons who did not want to participate never contacted the researcher. One physiotherapist decided not to ask a patient to participate because he was worried it could alter their therapeutic alliance.

3-2 Participant information and consent

After receiving the patient information form (Appendix 5 shows the English version of this document) from the referring healthcare practitioner or by the author, patients are able to contact the researcher by email or telephone (or private message for patients recruited on Facebook) if they are willing to join the study. Every participant received this information about the study and had the opportunity to ask questions before giving written consent (Appendix 6 shows the English version). Participants were also explained how the data would be anonymised and stay confidential, which contributes to a trust relationship and helps achieve the study objectives (Orb et al., 2001).

3-3 Right to withdraw

The participant's right to withdraw is set out in writing on both the patient information document and the consent form. It was reiterated verbally at the start and end of each interview.

3-4 Confidentiality and anonymity

In order to maintain patients anonymity, each participant was given an identification number that protects their true identity. These pseudonyms are used consistently throughout this thesis to refer to each interviewee. In addition, all audio recordings, transcripts, forms and related data were securely stored on password-protected and encrypted devices (see Appendix 12). Access to these materials was restricted to the author and will be deleted by the researcher five years after publication to allow for secondary analysis if needed (Creswell & Poth, 2018). The researcher took steps to ensure that no direct or indirect reference could be made to participants in a way that might reveal their identity and all identifying details were carefully omitted from the transcription. When specific details or contextual information were necessary for a full understanding of the research findings, this information was generalised and disguised to prevent identification.

3-5 Ethical considerations

The generation of new knowledge cannot be achieved at the expense of the safety, confidentiality, well-being, and autonomy of the participants. The declaration of Helsinki (World Medical Association, 2013) underscores the imperative of upholding ethical standards in research involving human participants. Recognising and considering one’s own background and biases are key

to reflexivity, Charmaz (2014) explains how it contributes to both research ethics and quality. The author describes practical techniques that promote reflexivity, such as memos and field notes, or asking if you can ask a question during the interviews ("May I ask you if..."), these procedures were applied during the research as well as possible.

Sheffield-Hallam University ethics form UREC-2 was completed and approved (Appendix 7), and additional ethical clearance was obtained from a french ethical board (GNEDS, See Appendix 8). To comply with French regulations, declarations were made to CNIL (Appendix 9) and on DataHub (Appendix 10).

3-6 Mitigating risks

Patients with RCRSP report not being confident in their own bodies (Littlewood et al., 2013; Page et al., 2019), some feel isolated and sad (Maxwell et al., 2021). Minns Lowe et al. (2014) even report suicidal thoughts in some patients. The emotional safety of the participants was thus a particular focus during the interviews. The interviewer was careful not to pass judgement on the treatments received by the patients.

Some specific questions were also omitted to avoid potential distress (Råheim et al., 2016) when the researcher felt it was an overly sensitive subject. The interviewer avoided topics that might lead patients to question the validity of their treatments. However, these topics were explored if patients had already expressed that a treatment was not appropriate and could not help them.

The project safety plan can be found in Appendix 11.

3-7 Data collection

Data were collected in semi-structured 1:1 interviews, between 1st August and 17th October 2023. This is the most common data collection method in grounded theory (Foley et al., 2021; Foley & Timonen, 2015). Participants were able to choose either telephone or online meetings, which were then recorded in audio-only or audio/video formats as they wished. Data Management Plan is presented in Appendix 12.

Prior to commencing recording, the author introduced himself, mentioning he was a self-employed physiotherapist and MSc student. He stated the research objectives as well as how the data would be stored and utilised. The interviewee was subsequently asked if they had any questions before reiterating their consent. The participants were reminded of their right to withdraw from the

study at any given point and the interviewer ensured his contact details were available for participants to access if they wished to exercise this right.

After recording had started, some participant's characteristics were collected (Appendix 13 shows an English translation) before proceeding with the interview.

In constructivist grounded theory, the use of an interview guide is recommended even to experienced researchers (Charmaz, 2014, p. 62). The interviews were however flexible enough to allow the exploration of relevant topics as they arose, to enable rich data collection. The initial interview guide also evolved during the research: as the theory emerged, new themes had to be explored and were added (see Appendix 14), as expected in grounded theory (Foley et al., 2021).

3-8 Data analysis

Verbatim transcription was conducted in three stages. The first stage involved using WhisperX (Bain et al., 2023), a free, open-source, and offline program. Although it is one of the best transcription programs currently available, a second stage of manual corrections was necessary. A final round of corrections was carried out, along with data anonymisation.

Data collection and its concomitant analysis are characteristic of grounded theory. The process involved the steps described by Charmaz (2014), and are presented in Appendix 15. The initial coding was done in the form of comments in Libreoffice to facilitate unconstrained open coding. Focus coding refined those into broader categories (See Appendix 16), and this was performed using the offline and open-source software Taguette (Rampin & Rampin, 2021). Throughout analysis, reflective memos were written in a separate file, facilitating constant comparison.

Theoretical saturation (Aldiabat & Le Navenec, 2018) was reached after 9 interviews: no new themes or patterns emerged from the data anymore. The theory that was developed is presented in the next chapter, and tries to explain the patient decision-making process and the contribution of HCPs to that choice.

All the interviews, coding and analysis were conducted in French to preserve the authenticity of the data and improve research trustworthiness (Yunus et al., 2022). The author translated the theory into English for this dissertation, along with the participants' quotes that are presented below.

4- Findings

The theory generated from this study is presented here and illustrated with the situation of Patient 1, with all the figures relating to her.

4-1 The general theory :

Participants perceived the treatment options as a "therapeutic gradient" (patient 7), or as in a stepped-care model, with increasingly powerful options. The different treatments are not seen as alternatives that could be better suited to specific individual situations, but as a next step to try if the results of the previous one are not satisfying. Patients may go through different steps as their symptoms persist. The number and the order of those steps varies from patient to patient, but the first step is always "wait and see" and surgery is considered as the highest step, or the most effective treatment, but also a last resort.

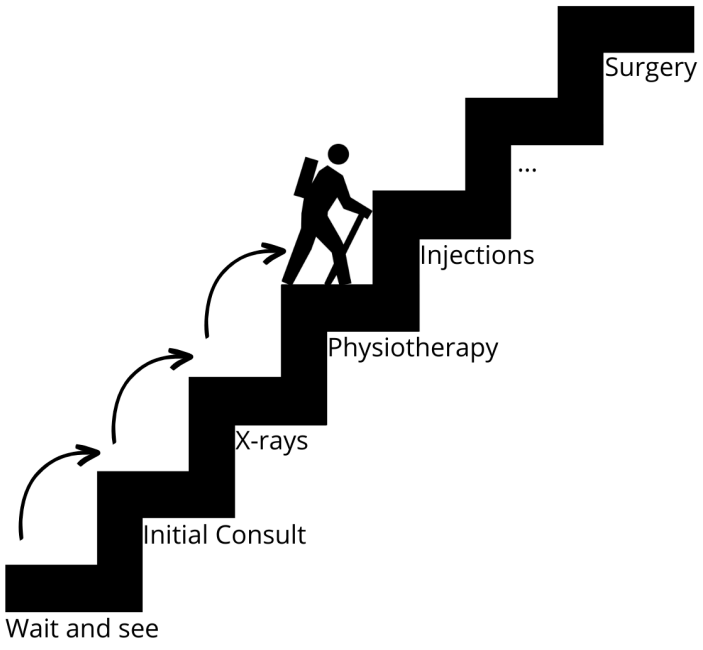


Figure 1: Patient 1 first consulted her GP after a few months of shoulder Pain. She was sent for x-rays and was prescribed physiotherapy. She knows that injections are the next step if the results are not satisfactory.

The participants did not describe themselves as actors in the choice of their treatment, or only at specific moments. These choices were largely made by the general practitioner (GP), who has a central role, and acts as a gatekeeper. This role was obvious when patients changed doctors: changes in treatment were then possible, “We moved house and changed doctors. And that doctor admitted that she wasn't necessarily in a position to help me, so she referred me to a surgeon, which no other doctor

had done before" (Patient 3). Most participants said that even though they were not presented with the different management options, they had been able to express their concerns, doubts and expectations. This probably influenced the healthcare practitioners in their choices of a treatment.

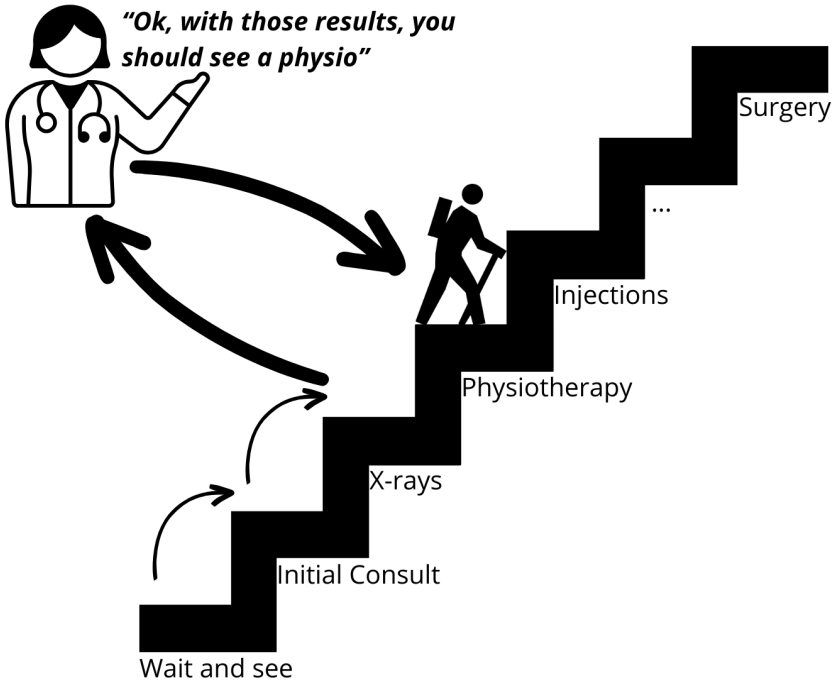


Figure 2: After X-rays, Patient 1 went back to the GP who decided to prescribe physiotherapy.

Even though patients don't actively choose the next treatment, they are responsible for the decision to go to the next step. For example, after a few sessions, Patient 2 decided to stop physiotherapy and go back to her doctor for another solution. Briefly put, the patient evaluates the step they are on and the GP is responsible for choosing the next one.

Instead of a sole moment of decision-making involving both the patient and their practitioner, as described in SDM, the participants portrayed a decision that was made by the practitioner and continuously questioned. This questioning can make the patient stay on the same step, or decide to go back to the GP, expecting to climb to the next step. For example, Patient 2 went to her physiotherapist to get shoulder exercises, even though she thought it was dangerous. However she says "I didn't do them any more, I stopped very quickly".

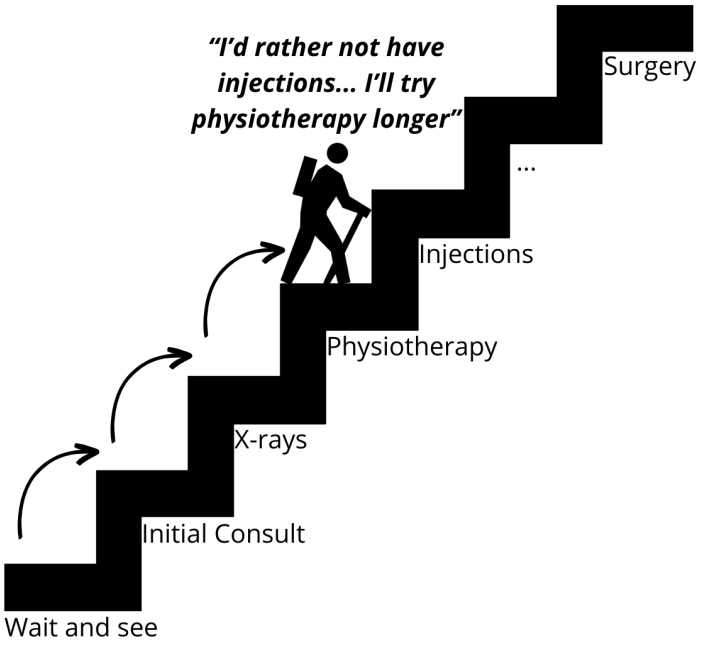
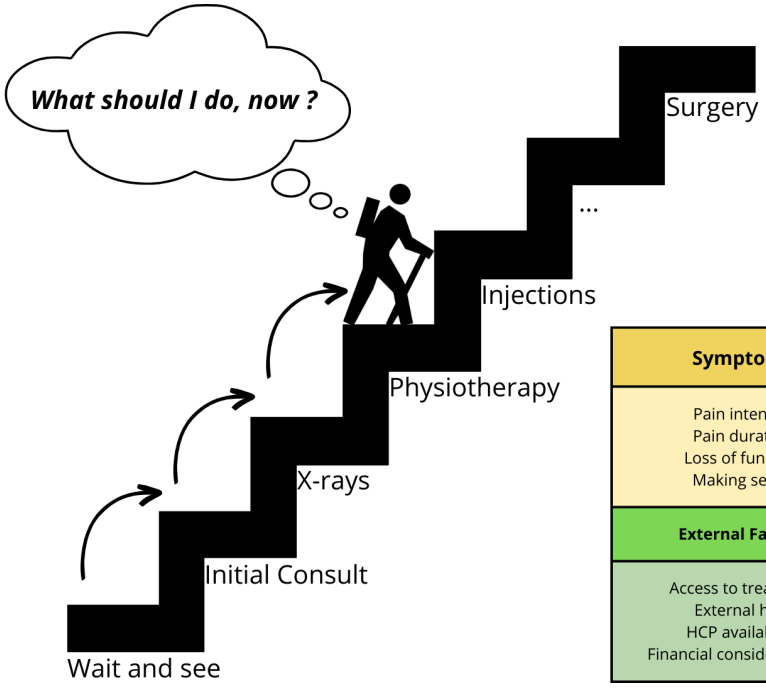


Figure 3: Patient 1's state has improved but is still not perfect. As an injection is not what she wants, she decides to continue with physiotherapy.

4-2 Evaluating the situation

The choice of a treatment is a complex process, and hard to isolate from the care pathway as a whole. The developed theory also explains the need to consult a doctor, or wanting imaging. The author has therefore changed his initial perspective on his research: treatment is not the only element to be considered; the various consultations and the use of imaging are steps in the patient journey and are included in this study.

When the patient evaluates his situation, four categories of factors play a part: the symptoms, the previous experiences, external factors and the treatment representations. They weigh on the desire to find a new solution, or to continue in the same way. Some common factors apply to all treatment options and will be discussed first. Specific factors for each step of the care pathway will be further developed in a later section (4-2-5 Specific Factors).



Symptoms	Previous experiences
Pain intensity Pain duration Loss of function Making sense	Relationship with HCP positive or negative experiences
External Factors	**Treatment representations**
Access to treatment External help HCP availability Financial considerations...	Beliefs on condition Beliefs on Treatment Personal values

Figure 4: Patient 1 is having physiotherapy sessions, and evaluating her situation

4-2-1 The symptoms

Unsurprisingly, pain intensity and duration are important factors and often made the participants look for a new management option: “So when you've had one, two or three painful episodes, it's true that there comes a time when you say "stop". You tell yourself that there's no other solution anyway” (Patient 4).

Loss of function is another key factor, both in professional movements and in everyday or leisure activities. “You see, just lifting a weight was triggering very sharp pains in my weights. That's why I sought help. More than... Otherwise I wouldn't have gone to the doctor, I'm not basically a softy.” (Patient 3). “It was flamenco that really made me realise that I had a problem with my arm and that I needed to see a doctor…” (Patient 1).

Some participants reported that not understanding their symptoms was distressing, and encounters with HCPs were seen as opportunities to better understand and make sense of their symptoms. “I suspected that it wasn't necessarily broken. Because when it's broken, when there's something broken, it's different. But I still wanted his opinion. So it was a doctor.” (Patient 8). “I said to myself, maybe there's something else I feel. So I was a bit worried and then, when the radiologist explained what was going on, it's true that he reassured me.” (Patient 1).

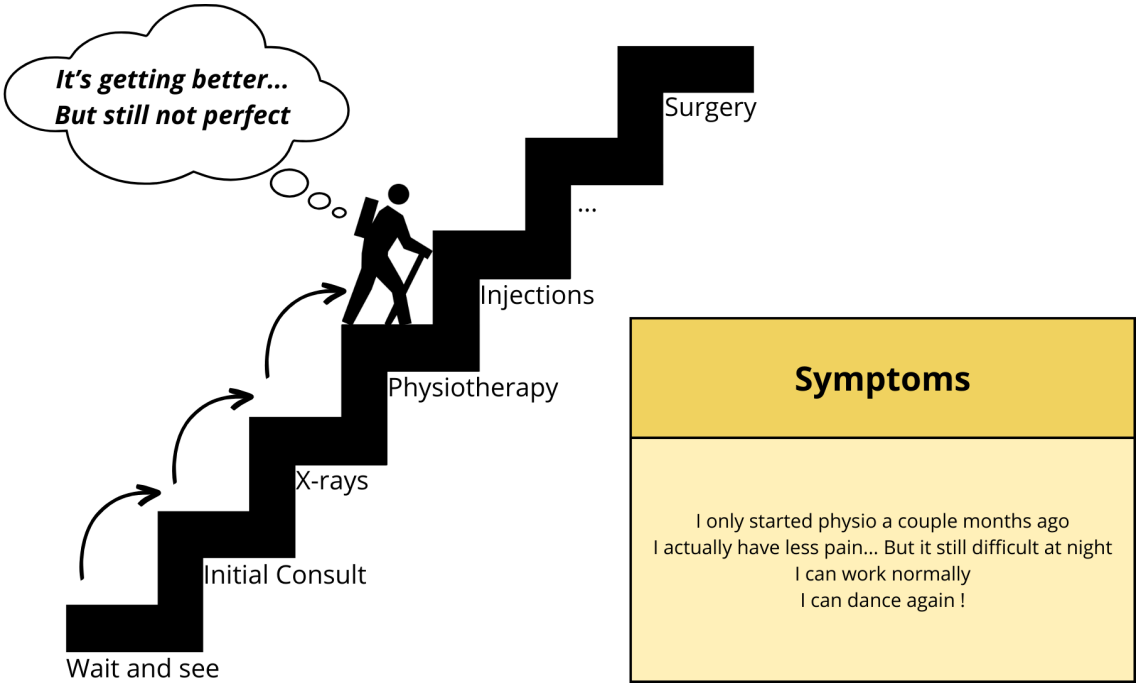


Figure 5: Patient 1 considering her symptoms

4-2-2 Past experiences

Prior experiences are important contributors to the behaviour of patients, medical history therefore plays an important role. Having already undergone certain shoulder treatments had an obvious impact on the participants' behaviour, making them seek or avoid specific ones: "If the pain was the same, yeah, I'd feel like I'd have to do the same thing again, it would be complicated to do anything else" (Patient 7), or "I didn't want to repeat the shoulder operation because it had been complicated the first time." (Patient 4). Experiences related by family and friends also had an impact on some participants' behaviours, for example Patient 4 delayed surgery because of her brother's experience with it.

The same treatment, or a similar one on a different body region can also change the patient's behaviour. For example, having had tendonitis before, Patient 6 thought: "Well, I'll wait, it'll pass". Patient 2 believed that an injection could be a solution because it had resolved her De Quervain's tenosynovitis several years prior. Patient 5's confidence in physiotherapy was reinforced by the good results obtained on the other shoulder, even though imaging showed a very different situation.

More broadly, previous experiences with specific healthcare professionals or with a whole profession can play a role. Patient 1 describes how her relationship with her GP is a facilitator: "I'm lucky to have found someone who's good, someone I trust, so it's easy to go and see her because she's

approachable". On the contrary, Patient 9 always had "a complicated relationship with the medical professions", and will only consult as a "last resort".

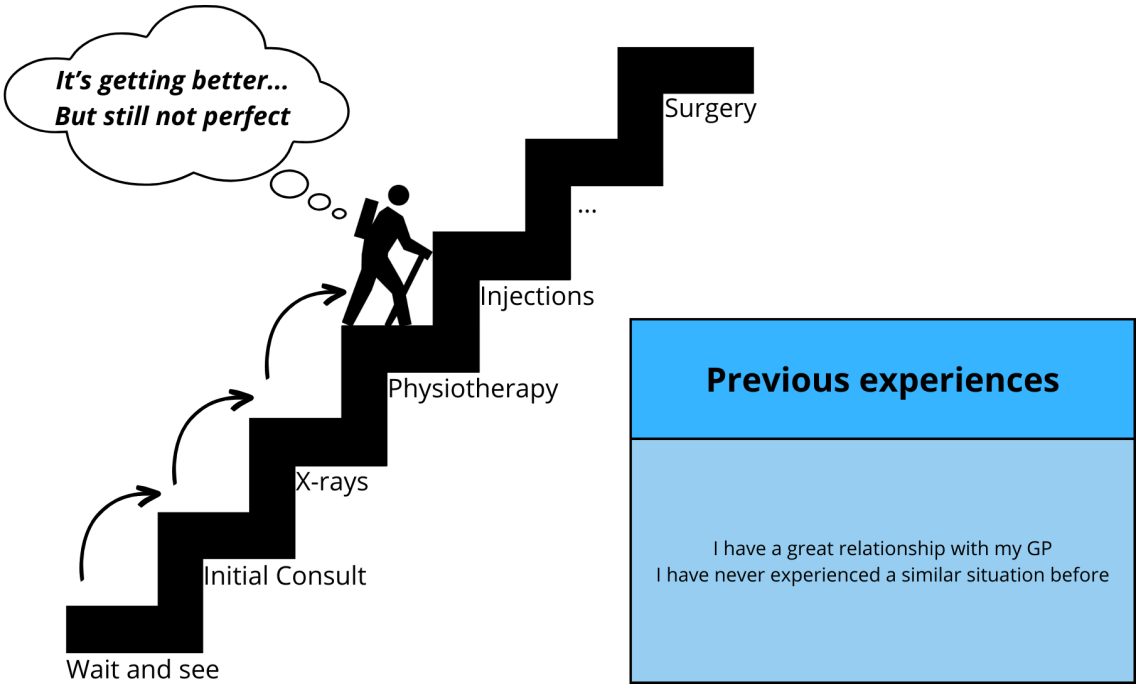


Figure 6: Patient 1 considering her situation in the light of previous experiences

4-2-3 External factors

It was often reported by participants that factors independent of them or the HCPs played a role too. Patients stated that delays in obtaining an appointment could be discouraging, or that the travel times to consult a physiotherapist were a barrier (Patient 3).

The patient's specific healthcare system and financial considerations also fall in that category: "They're going to have me undergo a whole range of tests that are going to cost me an arm and a leg, so to speak. So, no, I don't want to... my finances are a bit tight and I don't want my money to go down that drain." (Patient 9).

The external factors that can act as obstacles or facilitators are varied and numerous, but it seems interesting to note that some service policies or guidelines were seen as such a barrier by a participant of this study: Before surgery could be considered, Patient 4 should have had injections. It was her diabetes that made her avoid this unwanted treatment.

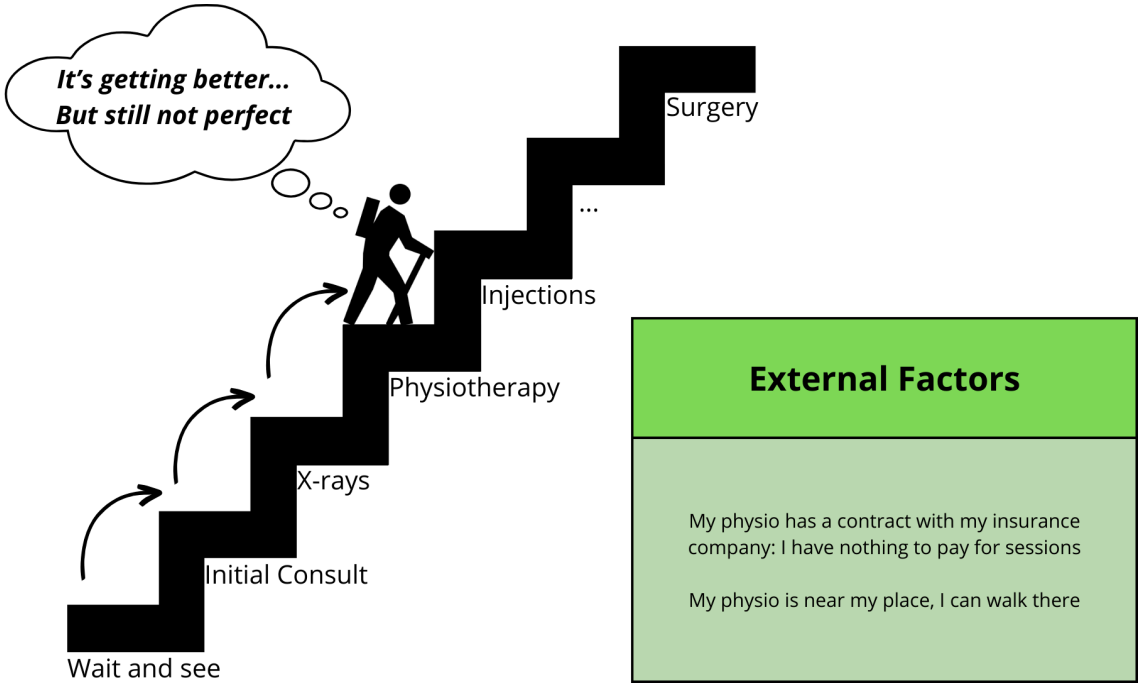


Figure 7: External factors contributing to Patient 1's evaluation of her situation

4-2-4 Treatment representations

When presented with a treatment, patients appraise how helpful it can be: they mostly consider whether it will get to the root of the problem or whether it will just be a form of pain management. Whether evidence-based or not, the representations about the treatment and the condition are important determinants of patient behaviour. For example, Patient 6 explains that "working muscles on the side" can "make this calcification disappear" which she believes is necessary to resolve her symptoms; this belief strongly increases her adherence to exercise therapy. Since patients expect a treatment to specifically target the origin of the problem, identifying it is seen as a prerequisite: "If I knew [the source of pain], I think I'd have found the solution to stop having it" (Patient 4).

Before considering the representations of each treatment option, it is essential to acknowledge the prevailing consensus among participants that pain and function are correlated with anatomical damage. In this widely shared pathoanatomical perspective, surgery stands out as the ultimate treatment, as it is perceived as directly targeting the anatomical source of symptoms. When an improvement was felt with conservative treatment, it was attributed to an hypothetical improvement in the tissues. HCPs seem to share those beliefs: Patient 5 remembers his physio told him, "There are fibres that have had to recover or I don't know what, I don't know how you do it".

However, two participants don't hold strong pathoanatomical beliefs, and don't really consider what is happening inside their shoulder when they experience pain. They were perplexed when asked what was the cause of their pain and they both expressed that they don't know anatomy ("I have no knowledge of anatomy" Patient 7), and are not really interested in knowing how their shoulders work ("I don't really know what's going on. I just know that I have this pain that prevents me from moving" Patient 9).

These two participants were the ones with the least contacts with HCPs for their shoulder pain. They both feel that their imaging was not carried out to get a diagnosis but to rule out serious pathologies. They received little explanations on the source of symptoms or on the way resistance training could help. It seems plausible that HCPs encounters tend to reinforce pathoanatomical views. Numerous participants reported HCPs' speeches that blamed an anatomical structure or a biomechanical process; these are presented in Appendix 17. This could also be reinforced by examinations when they are not done to exclude some conditions, but "just to see" (Patient 8).

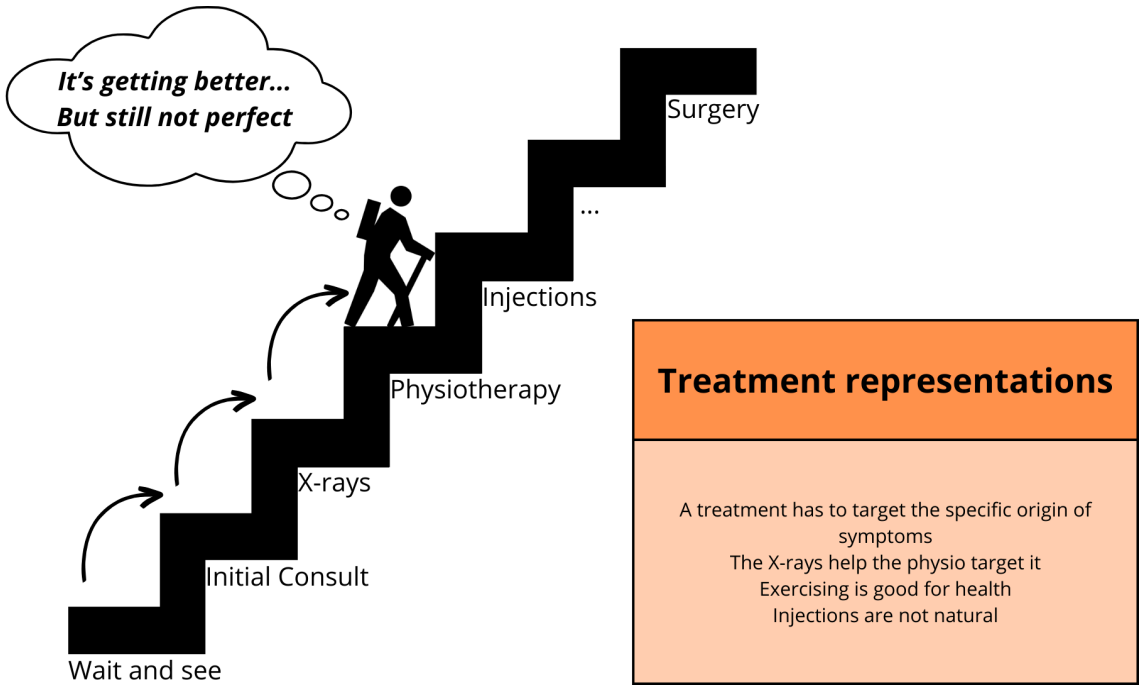


Figure 8: Treatment representations for Patient 1

4-2-5 Specific Factors

In addition to the common factors described above (the symptoms, previous experiences, external factors, and treatment representations), specific factors can play a part in the patient's behaviour at each step of his care pathway.

A- The initial consultation

The initial consultation was frequently delayed until pain or disability was important or unbearable. The behaviour of some participants was significantly influenced by the necessity or desire to go on living, and particularly working, without consulting (and risking sick leave). See Appendix 18 for relevant quotes.

For some patients, this seems to be explained by a certain trust in natural evolution ("And I said to myself, well, I'll wait, it'll pass. And then, well... then I thought, no, I have to go to the doctor now, enough is enough" Patient 6). This faith in natural evolution is not preserved in more complicated cases: for Patient 2, if she had postponed the surgery "the repair might have been more complicated, more complex".

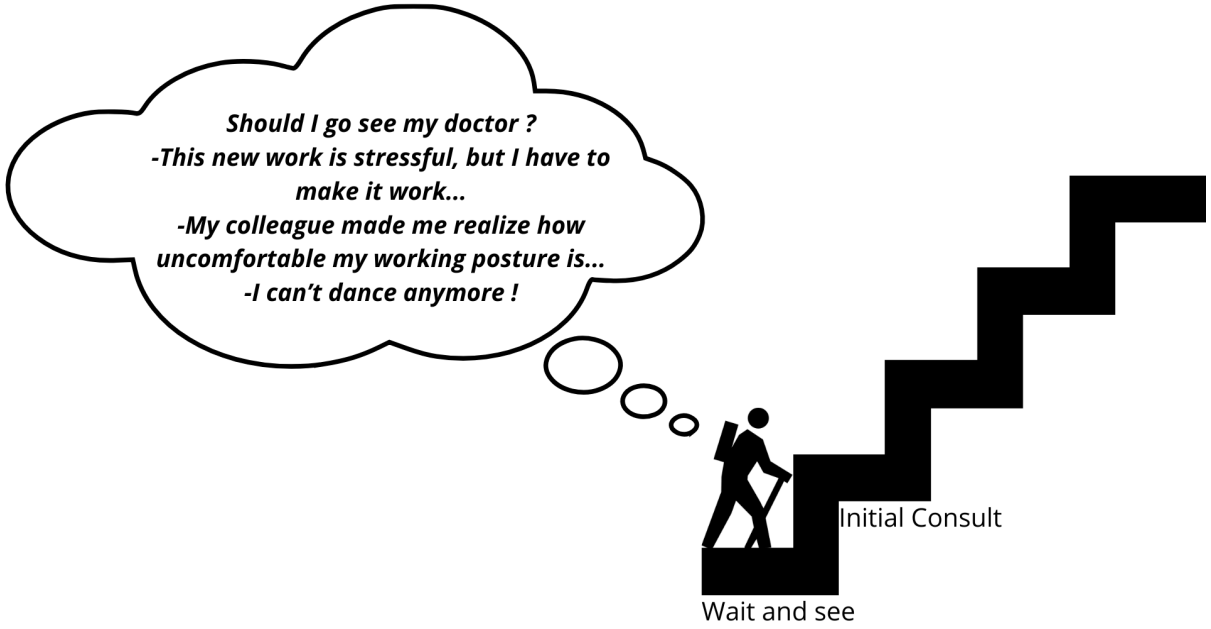


Figure 9: Specific factors for patient 1 when considering initial consultation

B- Imaging

Imaging plays a special role in the patients' care pathway and no reluctance to use it was ever reported. On the contrary, Patient 3 would like a new MRI "to at least check that the bursitis and tendonitis have gone" and Patient 5, a retired physician, called former colleagues to get two MRIs and two ultrasounds examinations. The imaging results are considered indisputable and capable of finding the origin of the complaint, they are therefore considered as important for diagnosis ("To at least get a diagnosis. Exactly." Patient 2), and to guide the treatment ("It's important for [the physiotherapist] to see what's going on so that he can work on the problem." Patient 1).

This importance is obvious from the emotional impact imaging has: the patient's subjective symptoms are suddenly perceived as objective and real (“For me, it was reassuring because I'd said to myself "No, it's not in your head. In fact, you've really got something."” Patient 2). The prospect of further tests can be a source of concern (“I was a little worried because, as the GP also wanted to make sure there was no illness… When I hear the word illness, that's when you think of everything.” Patient 1), and the results can be either reassuring (“It's a relief for me, because when the doctor did the ultrasound, he told me there was nothing wrong with the cuff.” Patient 6) or worrying (“I was sulking, you know. I was a bit worried.” Patient 5).

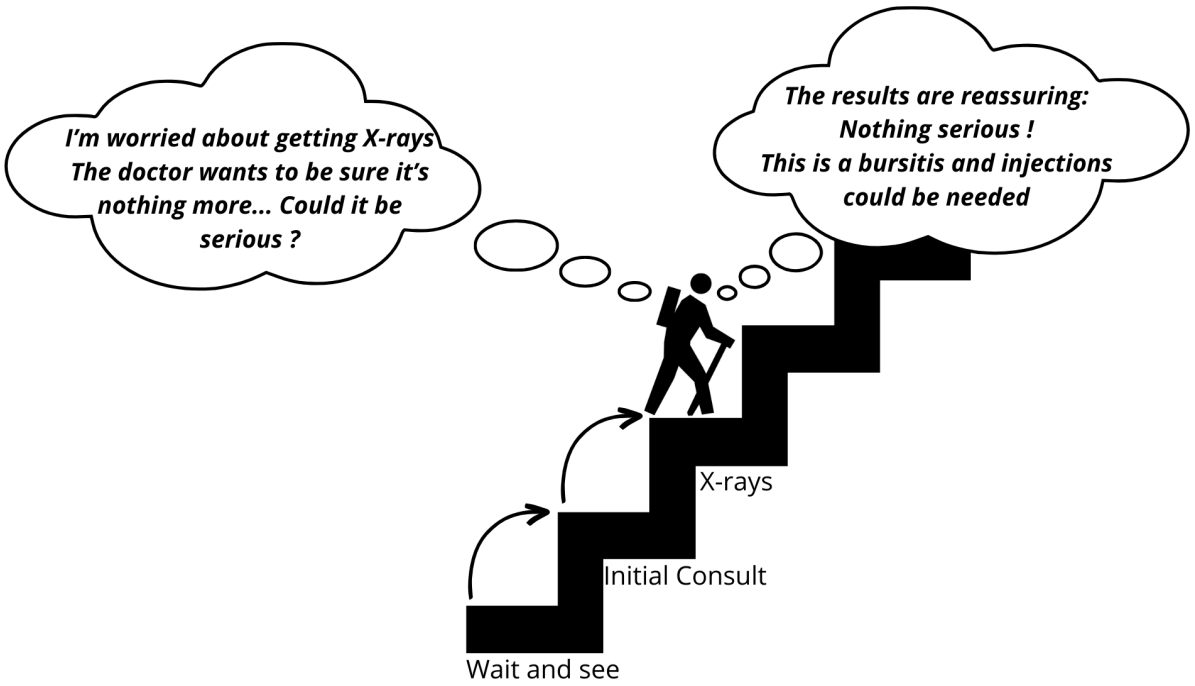


Figure 10: Patient 1’s considerations before and after getting X-rays

C- Physiotherapy

As the interviewer identified himself as a physiotherapist, it is possible that patients with the most negative views of this therapy did not express them as strongly or did not take part in the study. However, some patients voiced doubts regarding physiotherapy’s potential to cure them: “Healing ? I don't think so. Relaxing ? Yes. Promote care and healing ? Yes. Heal completely ? No, I don't think so. I don't believe in miracles, I'm sorry” (Patient 4).

Some participants voiced concerns about the safety of exercise treatment: “I think this is something that needs to be done tactfully and carefully” (Patient 8), “He made me lift weights of 3 kilograms, 3.5 kilograms. And in fact, I couldn't do it. And I think that aggravated it” (Patient 2), “if the movement isn't good, there's no point in doing it [...] it can even be dangerous” (Patient 7).

The failure of the GP to present treatment options is reflected in physiotherapy: participants did not report any explanation or comparison of rehabilitation techniques. It appears that physiotherapists used the treatments they deemed most suitable without consulting the patient.

This can be linked to the insufficient amount of individual time that certain patients have mentioned experiencing: “Without explaining. Then he'd put me in the room. He'd show you the exercise and then you'd do it on your own. After that, you did it on your own, and then it was goodbye” (Patient 2), “I stopped having physio sessions because... frankly... I had a physio, I was alone in the room, I was doing exercises and I could see him, what? Three minutes to set up” (Patient 4).

By contrast, a good relationship and the amount of time spent with the physiotherapist had a positive effect on patient satisfaction and adherence: “I trusted him because he listened very carefully to what I was feeling too” (Patient 1), “He explains things very well and is very composed” (Patient 6).

Two participants have expressed their appreciation for the natural character of physiotherapy: “I find it more natural” (Patient 6).

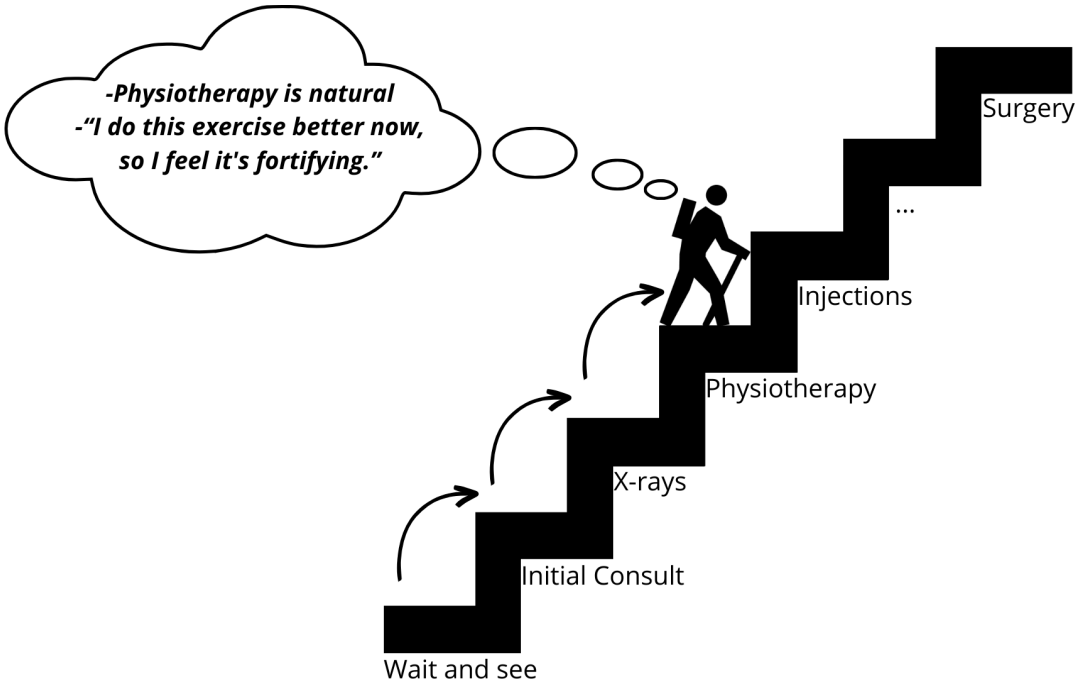


Figure 11: Patient 1’s considerations on physiotherapy

D- Injections

Injections are considered to be a highly accurate treatment option and therefore fit well within a pathoanatomical view of symptoms: “Logically, it's the anti-inflammatory which is injected, which

is put directly into the painful area, so it should act directly in that area" (Patient 3). However, some patients perceived its unnaturalness as off-putting: "I'm more in favour of gentle, natural medicine." (Patient 1).

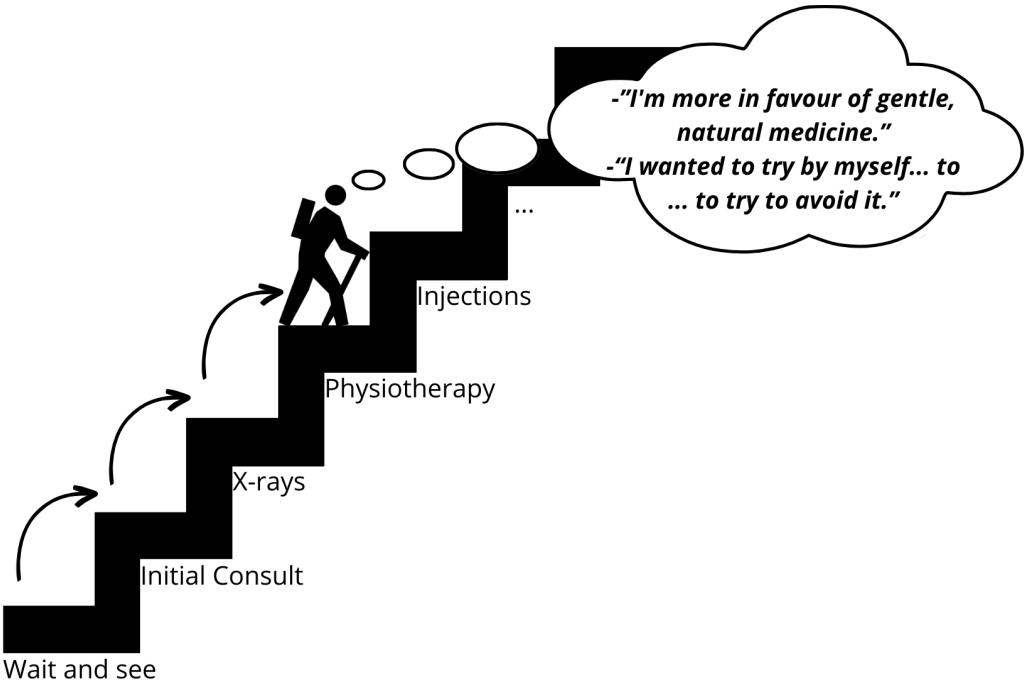


Figure 12: Patient 1 considering injections

E- Surgery

Surgery is the treatment that participants in this study refused the most. Unlike other HCPs, the surgeons explained the treatment they suggested, the prognosis and actively sought consent. Patient 3 recalls: "[the surgeon surgeon] left the choice up to me. He suggested I consult another doctor".

Only one participant had doubts regarding the effectiveness of surgery ("We're not going to rush and butcher things, when there's a favourable development" Patient 5), while the other refusals were due to the perceived post-operative challenges. In a vision where the symptoms stem from damaged tissue, surgery is viewed as the treatment that "repairs, like when you break a car" (Patient 2).

Patients went to surgery as a last resort, after trying other treatments. There was some reluctance, but Patient 3 "was relieved that [the surgeon] suggested the procedure, which is what I wanted anyway", she remembers: "I'd been thinking for 3-4 years that it would probably be the only thing that could relieve my shoulder". Retrospectively, every patient thinks it was the only solution anyway "I don't know what we could have done, given that the tendon [...] was going in all

directions... The acromion, I don't know what we could have done, if we hadn't gone there mechanically." (Patient 2). See Appendix 19 for other quotes.

5- Discussion

The objectives of this research were to gain knowledge about patients' treatment decision-making and the impact of healthcare practitioners on this process. Nine participants were interviewed and a theory was generated to explain the process. The factors influencing this decision can be grouped into four categories: the symptoms, the previous experiences, the representations (Boyer, 2021), and external factors. The central role of the GP is obvious: as a gatekeeper, he chooses the next step in the care-pathway.

The participants describe a management that is inconsistent with the guidelines and the results could help to bridge the gap between recommendations and practice. This is the first topic of this chapter. This research has clinical implications, mostly related to communication, which will constitute the second topic. Since exercise therapy is the most recommended treatment, there is a focus on the clinical implications for a physiotherapist.

Throughout this chapter, the results will be compared with existing literature, and new perspectives for research will be suggested. The strengths and limitations of this work are also discussed at the end of the chapter.

5-1 Comparison to guidelines

The care reported by the participants in this study is rarely in line with current evidence, and this initial observation is important, because the main interest of this research could be to help in implementing guidelines to provide clinical benefit. Patients' attitudes toward a concept of stepped-care management have already been considered (Cuff & Littlewood, 2018), but this was based on the invasiveness of the treatments, rather than on perceived efficiency. This hierarchy among treatments, which forms the backbone of the developed theory, is at odds with the current evidence.

The latest French guidelines (HAS, 2023) are generally opposed to subacromial decompression surgery, which isn't more effective than diagnostic or placebo arthroscopy (Beard et al., 2018; Paavola et al., 2021) and not superior to physiotherapy (Ketola et al., 2017). For rotator cuff repair of atraumatic tears, the debate remains open, and the french authorities postponed their opinion (HAS, 2023): surgery doesn't seem to be superior to physiotherapy at one year (Kukkonen et al., 2014), two years (Kukkonen et al., 2015), and five years (Moosmayer et al., 2014), but seems to gives better outcomes at 10 years (Moosmayer et al., 2019). Overall, the idea that surgery is the most efficient treatment for shoulder pain is debatable, especially if there is no tendon tear.

The position of physiotherapy in this perceived hierarchy is just as undeserved: some participants think that it can only bring pain modulation, and some think exercise therapy can be dangerous. This difficulty has already been reported by therapists (Bernhardsson et al., 2017; White et al., 2020), and it is an obstacle to the implementation of recommendations: physiotherapy with active rehabilitation is the most advocated treatment in guidelines, both in France (HAS, 2023) and abroad (Lafrance et al., 2022; Littlewood et al., 2019; Rees et al., 2021). Passive physiotherapeutic treatments such as manual therapy could also have a role (Pieters et al., 2020), and are included in the French recommendations as an additional treatment, even though recent evidence casts doubt on their value (Paraskevopoulos et al., 2023). In any case, they should not be given the importance that participants attach to them. This appeal for massage, ultrasounds or even invasive treatments like dry-needling or injections is well described (Bernhardsson et al., 2017; White et al., 2020). Interestingly, pain during exercise was not described as a barrier by participants in this study, whose concern was on the potential tissular damage.

5-2 The pathoanatomist conception

The participants' doubts on physiotherapy's efficacy are related to the idea that anatomical structures have to be fixed or repaired. RCRSP was described by participants in terms very similar to those noted by Cuff and Littlewood (2018) "where tissues in the shoulder were seen to be compressed, abrased or inflamed while the shoulder was moved". This pathoanatomist conception is widely described in the literature (Cridland et al., 2021; Cuff & Littlewood, 2018; Gillespie et al., 2017; Meehan et al., 2020; White et al., 2020) and presents a significant obstacle to the application of guidelines. This understanding is reflected by the favourite internet sources of patients: websites associated with technical details of surgery are the most commonly searched for (Khalil et al., 2023). However, tissular damage does not explain well patients' pain and function, for example more 70% of elite rock climbers have MRI signs of rotator cuff tendinosis, subacromial bursa and biceps tendinosis (Cooper et al., 2022), and the results of rotator cuff tear repair are quite similar whether or not the suture was a success (Carr et al., 2017). During the interviews, the author decided not to confront patients with this evidence, as it could have interfered in current treatments, but it would be interesting to investigate how those beliefs could be modified.

This research didn't try to identify the origins of this biomedical conception, but HCPs influence was obvious, as described in other studies (Gillespie et al., 2017; Littlewood et al., 2013; Stewart & Loftus, 2018; J. R. Zadro et al., 2022). The French guidelines were updated during this research, and partly incorporated these authors' conclusions by using a new label: "subacromial pain syndrome", rather than "subacromial impingement". More generally, HCPs should be careful about the terminology they use (Cuff & Littlewood, 2018), as it can influence management (Moffatt et al.,

2024). Patient 9 reported that she didn't get any explanations on her "tendonitis" diagnosis: her understanding of her condition is only based on this single word, which she therefore defines as inflammation in the tendon.

Identifying other contributors to this conception could also be beneficial, as "biomedically framed beliefs [...] create barriers to rehabilitation" (Boland et al., 2021) and negatively impacts patients' behaviours. Human health behaviours are complex, not entirely conscious, and are "located in complex social environments and cultures" (Kelly & Barker, 2016). These social and cultural factors and the detrimental biomedical context in which patients live is evident from reading some of the articles published in the mainstream press in November 2023 (Bouvet, 2023; Duran, 2023): these articles suggest that physiotherapy can be harmful, they promote Neer's conception of subacromial impingement (Neer, 1972) despite evidence that this concept should be abandoned (J. Lewis, 2018), they also fail to mention the importance of lifestyle factors (Littlewood et al., 2023) such as smoking (Challoumas et al., 2020; Millar et al., 2021), metabolic disorders (Rechardt et al., 2010; Viikari-Juntura et al., 2008) or sleep (Nijs & Reis, 2022). By focusing on non-modifiable factors such as anatomy, these two articles put the patient in a passive situation, where the solution can only come from an external source, which is negative for the management (J. Lewis et al., 2021; J. Lewis & O'Sullivan, 2018).

5-3 Healthcare practitioners responsibility

5-3-1 Knowledge

The two general press articles mentioned in the previous paragraph (Bouvet, 2023; Duran, 2023) quote surgeons and rheumatologists, with views that conflict with guidelines. This raises the question of HCPs knowledge of recent evidence on RCRSP. The management described by the participants in this study is far from recommendations, but very similar to what is reported in other countries (Smythe et al., 2021), so this question isn't specific to France. According to Riera et al., (2021), French physiotherapists offer care that is fairly consistent with current evidence, and comparable with other countries (Bury & Littlewood, 2018; Pieters et al., 2019; Smythe et al., 2020; J. Zadro et al., 2019). The GPs' knowledge is crucial since they have a special role in the pathway of RCRSP patients. To the author's knowledge, this hasn't been studied in France, but we have valuable studies from the UK (Artus et al., 2017) and Canada (Lowry, Lavigne, et al., 2023), where GPs prescribed more tests, imaging and injections than recommended. These two surveys show an overall appropriate knowledge, but confirm the notion that physicians are not very confident in their diagnosis and treatment choice (Maxwell, Robinson, et al., 2022; Saunders et al., 2023). The overuse of imaging was not correlated to this lack of confidence (Artus et al., 2017). All of this data originates

from surveys or self-reports, which could lead to biassed results as participants may have a special interest in the topic. It is challenging to determine the extent of HCPs' knowledge, but there is no evidence indicating that it is insufficient.

5-3-2 Behavioural response

The evidence-application gap cannot be reduced to a lack of knowledge, the behaviour of HCPs when they face the patients and their complaints has to be considered too. For Hoffmann et al. (2020), clinicians learn the evidence, but are not trained enough in ‘applying the evidence’.

The patient’s desire to understand the source of the symptoms, and the associated longing for imaging was obvious in this research, and expressed in other studies (Cridland et al., 2021; Saunders et al., 2023). For Lowry, Desmeules, et al. (2023), it is actually what motivated most shoulder pain consultations. This desire to obtain a diagnosis rather than treatment could be an important notion: HCPs hold the belief that ‘doing something’ is better than ‘waiting and watching’ (J. S. Lewis et al., 2020) and in the study by Saunders et al. (2023), they failed to identify patients’ worries about a serious underlying condition. Physicians could therefore feel pressured to suggest a treatment when the patient was actually looking for explanations and reassurance.

HCPs involved in RCRSP management also describe that changing their practice is hard and they sometimes rely on their usual approach even when it conflicts with guidelines (Maxwell, Robinson, et al., 2022). Some GPs also question the usefulness of guidelines, with regular updates to recommendations strengthening the impression that they were ill-suited from the start (Ottenheijm et al., 2014).

Patients often present in primary care expecting a referral to a specialist or imaging (Wilson et al., 2001). As this is at odds with recommendations, it is a potential disagreement between patient and HCP that can feel threatening to the interlocutors (Itzchakov et al., 2023). When such situations arise, HCPs sometimes choose to accept to refer (Maxwell, McCreesh, et al., 2022; Panchal & Hendrick, 2023). These deviations from the recommendations are portrayed as a strategy to provide reassurance or improve therapeutic alliance. This kind of compromise can also take the form of a GP offering an injection for pain relief, or a physiotherapist using “hands-on” treatment. Imaging overuse in low-back pain has been more studied and is also linked to clinicians’ discomfort with uncertainty, fear of missed pathology and litigation (Blokzijl et al., 2021; Espeland & Baerheim, 2003; Lam et al., 2020; Sears et al., 2016; Slade et al., 2016). The lack of time to explain why imaging is unnecessary is also mentioned in some studies (Hall et al., 2019; Lam et al., 2020; Slade et al., 2016). Imaging can be detrimental (Brownlee et al., 2017; Panchal & Hendrick, 2023; Rajasekaran et al., 2021; Sajid et al.,

2021) and reinforces pathoanatomical beliefs (Dunn et al., 2016; Sajid et al., 2021), but unmet needs and dissatisfaction with care can contribute to poor outcomes too (Panchal & Hendrick, 2023; Sharma et al., 2021). Clinicians therefore face a difficult choice and SDM could offer a potential solution.

5-4 Shared decision-making

As developed in the results section, this study found little evidence of SDM in the participants' care pathways, which is consistent with the findings of Maxwell et al. (2022). This doesn't seem surprising since shared-decision making has a slow adoption rate (Joseph-Williams et al., 2017). In this research, all exceptions to clinician-led decisions were related to surgical procedures: multiple participants were given the choice and refused surgery, however, all but one underwent the procedure in the end. In France, surgeons and general practitioners are subject to the same deontological obligations (*Article 35 - Information du patient*, 2019). The duties to provide information and obtain consent apply in the same way, however, additional obligations exist for surgical procedures, this could contribute to greater patient involvement in the decision to proceed with surgery.

It is worth noting that a single participant in this study had an important role in the choice of his management: Patient 5 recalls "I had a nice chat with [the sports doctor], I argued my case" and he acknowledges that being a retired physician made this interaction possible, as if being on equal footing with the clinician was the only means of avoiding a top-down decision.. This shift in the power between HCPs and patients is a prerequisite to SDM (Elwyn et al., 2017), and it is actually one of the obstacles to its implementation (Joseph-Williams et al., 2017). This power relationship could also explain why some participants engaged in a treatment even if they didn't believe in it, or even if they thought it might be dangerous.

Most patients with musculo-skeletal pain want to be involved in decision-making (Lin et al., 2020), but we have to acknowledge some patients with RCRSP have a preference for the decisions to be led by the GPs (Saunders et al., 2023). This was not expressed in this study, but it should of course be respected. However, it does not mean that shared decision making shouldn't be used with them. Even though the aim of SDM is to make a choice (Hoffmann et al., 2014), it should not be reduced to that: sharing information and improving communication opens up other possibilities such as adjusting expectations about a specific treatment, changing a pathoanatomist's view of the condition, or showing that there is no point in carrying out an additional examination (Hoffmann et al., 2020). Patients make different choices when they are aware of the benefits and harms they can expect from a treatment (Stacey et al., 2017). All these points make SDM relevant in the management of RCRSP.

During SDM, discussing natural history is customary (Hoffmann et al., 2020), and Lewis (2022) recommends presenting a ‘wait and see’ approach to patients with RCRSP. Participants reported putting off their first medical consultation for a long time, which confirms a recent discovery by Lowry, Desmeules, et al. (2023). In this situation, it can be harder to explain that natural evolution is supposed to be positive, and Patient 9 expressed her irritation at the subject: “I can do it myself, wait it out. I don't need a doctor for that”.

Time constraints are a known barrier to SDM (Joseph-Williams et al., 2017). However, patients have a strong demand for information and for HCPs to take sufficient time to provide these explanations (Lowry, Desmeules, et al., 2023). Even though patient-centred care is more time-consuming, it is more cost effective in the long term (van Leersum et al., 2019). A better knowledge of how SDM could benefit their patients (Joseph-Williams et al., 2017) could help HCPs see the time spent on SDM as an opportunity to raise expectations and reduce concerns (Oh et al., 2012). However, we have to be cautious regarding SDM benefits in musculoskeletal care as we lack high quality evidence on the subject (Tousignant-Laflamme et al., 2017).

Nethertheless, Shared-decision making value shouldn’t be reduced to its clinical benefits, and Elwyn et al. (2013) warn against this distortion. It has an ethical value, related to the principle of autonomy, which has two conditions: liberty and agency (Beauchamp & Childress, 2019). This means that HCPs must refrain from trying to control, and allow the patients to act by themselves, even if they don’t understand the choices they are making. This is important because RCRSP, and chronic pain in general, can affect an individual on many levels (Feltri et al., 2023; Maestroni et al., 2020), and actually change how they make choices (Apkarian et al., 2004; Białaszek et al., 2023; Bilika et al., 2022).

5-5 The roles of communication and relationship

SDM and communication are closely linked, and both are essential to person-centred care (Lin et al., 2020). Maxwell et al., (2022) presented HCP-patient relationship as a “strong influence on treatment decision-making”. Therapeutic alliance also has an impact on outcomes in physiotherapy (Kinney et al., 2020). It has been identified as a key factor for education and adherence to treatment (Barrett et al., 2018; White et al., 2020), which was confirmed by some participants of the present study (“He knows me well enough to have a good chat and he also explains a fair bit” Patient 3). Although communication and HCP-patient relationship were frequently mentioned and recognised as “very important” (Patient 1), this study did not elucidate their role in the decision-making, and they should be explored in future research.

Exploring patients' perspectives can be hard (Murtagh, 2023), the theory developed in this research highlights what should be considered by HCPs. This study confirmed that symptoms are a strong driver (Weekes et al., 2020), and effective communication can help to modify them: by increasing self-efficacy, a positive communication can decrease pain intensity and pain interference (Ruben et al., 2018). Giving a different understanding of the symptoms can make them less threatening (Martinez-Calderon, Struyf, et al., 2018). This can be compared to the "making sense of pain" component of cognitive functional therapy (O'Sullivan et al., 2018), which is helpful for fear-avoidance behaviours (Bunzli et al., 2017). Similarly, changing catastrophizing levels can modify pain intensity and disability (Martinez-Calderon, Meeus, et al., 2018; Martinez-Calderon, Struyf, et al., 2018).

Past experiences are the second identified driver. Effective communication can help HCP explore these, understand what made them positive or negative, and adapt the management accordingly.

Similarly, good communication can help explore patients' representations of the disease and therapeutic options; education and management can then be tailored accordingly. Patients' decision-making is often based on unrealistic expectations of the treatments (Hoffmann & Del Mar, 2015). Communication can also prevent iatrogenic consequences of imaging by reframing them in non-threatening language (Rajasekaran et al., 2021). Patient 2's physiotherapist advised against consulting a surgeon, told her it would be pointless and that she shouldn't be operated on, and gave her an exercise programme. With expeditious consultations and no further explanation, this message was inaudible and could be counter-productive with a reactant patient (Beutler et al., 2018). Two participants described the origin of RCRSP as an imbalance between load and capacity, but none described exercise as a way to increase capacity or tolerance (Millar et al., 2021). These patients would probably be receptive to a new vision of exercise as a way to progressively put load on the shoulder, to make it stronger and resilient. This understanding could improve adherence to exercise treatment but relies on a strong therapeutic relationship (Powell et al., 2023).

External factors, the fourth driver, are less accessible to communication. However, their identification can be facilitated by a good therapeutic relationship and open discussion. For example, certain participants described distance to the physiotherapy clinic as a barrier, identifying this could make the physiotherapist suggest remote consultations, that have recently been authorised in France. Adherence to home exercise programs could also be improved by using apps with remote support (Lambert et al., 2017).

5-6 Dissemination

Several participants will receive a summary of the research findings after the viva, as they requested. HCPs who expressed their interest for this research will also receive a report, regardless of their participation in recruitment. Other dissemination options will only be considered in consultation with the dissertation supervisor at the end of the course.

5-7 Strengths and Limitations

This is one of the few studies to consider patients' decision-making regarding the treatment of RCRSP, which had not yet been investigated in France. Despite a harder than expected recruitment, theoretical saturation has been reached and patients with different management options were included. They expressed contrasted opinions on the different treatment options and a theory was generated.

Data collection and analysis were completed by a single individual, who is an inexperienced researcher and a physiotherapist. This could have influenced the recruitment, the interviews and the analysis. For Newton et al. (2012) a qualitative research conducted with sensitivity, appropriate reflexivity and within a constructivist framework can be considered acceptable, even if it relies on the interpretation of a single researcher. The author's reflexivity was improved by the use of memos (Charmaz, 2014), but it was the only measure to prevent this potential impact: getting participants' feedbacks on the transcriptions and preliminary results would have increased credibility but was not possible within the timeframe. The author also tried to implement guidelines designed to improve the quality of grounded theory studies (Charmaz & Thornberg, 2021).

This dissertation adopts the COnsolidated criteria for REporting Qualitative research (COREQ, Appendix 20) (Tong et al., 2007).

6- Conclusion

The management of RCRSP poses a challenge, and surgery rates are increasing despite higher costs and similar outcomes to conservative care (Myers et al., 2021). Constructivist grounded theory was used to understand how patients reach a decision regarding their treatment course, and how HCPs influence this choice.

Participants perceived a hierarchy in the management options, with surgery at the top, viewed as the most effective one. This is related to the belief that an anatomical structure has to be identified and fixed, if symptoms are to be eradicated. All participants were receptive to a stepped-care model beginning with conservative treatment, but some patients felt like surgery was the only option that could help them.

The 'wait and see' management option wasn't well perceived among participants, especially when they had delayed their initial consultation with the GP until they had reached high levels of pain or disability. In any case, the role of the GP was thereafter central in the management: although the patients mostly felt that they could express their views, the GP chose the treatment option by themselves, and didn’t present alternatives to the patient.

Overall, the participants had high levels of trust in HCPs, and some followed the GP's decision even when it went against their beliefs. However, patients constantly reassessed the situation and could decide at any time that the results were not good enough and eventually reconsult their GP. Subsequently, patients were frequently referred to specialists, underwent imaging or received a new treatment.

This appraisal is driven by four categories: the symptoms play an important role, but participants also expressed how important understanding them was. Past treatment experiences, whether recounted by family members or experienced personally, influence expectations and weigh heavily on decision-making. External factors, such as the availability of HCPs, also exert an influence. Finally, based on their representations, patients evaluate for themselves the benefits of the treatment for their condition.

How patients perceive RCRSP is therefore important, and a biomedical understanding was obvious in most cases. Pain was commonly attributed to inflammation or tissue damage; in this case, surgery looks like the most pertinent option. In our society, these pathoanatomical beliefs seem to be ingrained and perpetuated. HCPs have a responsibility, but more research is needed to understand where they come from and how they can be altered.

The care pathways described by participants do not conform to the recommendations, yet HCPs' knowledge does not appear to be the root cause of these deviations from the guidelines. Instead, they could be a behavioural response to patients' requests. SDM could facilitate change in this regard, while providing additional ethical benefits.

This research has other clinical implications: by informing the HCPs on the determinants they should address during patient education and in their communication, this theory enlightens them in their management of shoulder pain.

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Appendices

Appendix 1: Literature Review

Maxwell et al. (2021) conducted a comprehensive literature review in 2020 and highlighted a lack of studies on the treatment decision-making. Their search strategy has been repeated for this dissertation, with a limitation on publication dates from 2020 onwards:

Search #1	shoulder OR arm OR glenohumeral joint OR “upper limb” OR upper-limb OR subacromial OR sub-acromial OR “rotator cuff” OR rotator-cuff
Search #2	Pain OR tear OR surgery OR injury OR impingement OR bursitis OR tend*
Search #3	#1 AND #2
Search #4	"painful arc syndrome” OR "frozen shoulder" OR "adhesive capsulitis" OR adhesive-capsulitis OR “subacromial impingement syndrome” OR “shoulder impingement syndrome”
Search #5	#3 OR #4
Search #6	experience* OR perspective* OR perception* OR attitude* OR expectation* OR perceive* OR “decision making” OR understanding
Search #7	qualitative* OR “qualitative research” OR “Qualitative stud*” OR interview* OR survey* OR "focus group*" OR questionnaire OR videorecording OR audiorecording OR ethnomethodolog* OR ethnological OR ethnograph* OR phenomenol* OR "grounded theor*" OR grounded-theor* OR “thematic analysis” OR “Content analysis” OR narrative* OR transcript* OR transcrib* OR “framework method” OR “framework analysis” OR “field notes” OR field-notes OR “field stud*” OR “purposive sampling” OR “theoretical sampling” OR “hermeneutic*” OR “constant comparative method”
Search #8	#6 AND #7
Search #9	#5 AND #8

Sixty-two unique results in CINAHL Complete and MEDLINE were identified. Abstracts were then screened to assess relevance to RCRSP treatment decision-making.

Appendix 2: Participants characteristics

Patient		1	2	3	4	5	6	7	8	9
Age		60-69	50-59	40-49	50-59	70-79	60-69	40-49	40-49	50-59
Gender		F	F	F	F	M	F	M	M	F
Employment		Part-Time	Full-time	Job hunting	Unable to work	Retired GP	Retired	Full-time	Full-time	Full-time
Symptoms Duration (median 11 months)		8 months	9 months	13-14 years	13 years	11 months	4-5 months	2 weeks (second episode)	11 years	3 Months (multiple episodes)
Involved HCPs	GP	✔	✔	✔	✔	✔	✔	✔	✔	✔ (only for a previous episode)
	Surgeon		✔	✔	✔					
	Rheumatologist			✔	✔					
	Radiologist	✔	✔	✔	✔	✔	✔	✔ (only for a previous episode)	✔	✔ (only for a previous episode)
	Physio-Therapist	✔	✔	✔	✔	✔	✔	✔ (only for a previous episode)	✔	
	Others		Osteopath Naturopath Etiopath Magnetiser	Osteopath		Sports doctor			Osteopath	
Received Injections			✔	✔	✔		Not for this shoulder			
Surgery			✔	✔	✔					
Interview duration		40 minutes	45 minutes	36 minutes	60 minutes	36 minutes	33 minutes	16 minutes	43 minutes	35 minutes

Appendix 3: Recruitment pack - Email and Poster

An email was sent to HCPs who might be interested in this research and in referring patients to me. All the emails were personalised, so this one is just an outline.

Hello [HCP name]!

[Reminder of the circumstances of our previous exchanges, where I explained my research project]

I'm going to need to interview patients, to talk about how they decided on the treatment they will undergo for their rotator cuff related shoulder pain. And I'd like your assistance in the recruitment process. Here are three documents that may interest you:

-A simple flyer, quick to read and explaining my search for patients to include [see below]

-A more comprehensive document, aimed at professionals [see Appendix 4]

-An information document aimed at patients who might be interested. It's with this last document that recruitment begins, with my contact details included so that they can get in touch with me. [see Appendix 5]

So if you could ever provide this last document to patients suffering from shoulder pain, I'd be very grateful. Don't hesitate to let me know what you think, I'd love to hear from you! I can print and post you copies of this document if you like.

Thank you very much for reading!

Appendix 4: Recruitment pack - HCP Information

Titre de l'étude :	Prise de décision des patients souffrant de douleurs à l'épaule concernant leur traitement
Chercheur principal :	Corentin Glon
Numéro de Téléphone :	(+33) 06 51 50 12 97

Dans le cadre de mon master (MSc Specialist Physiotherapy Practice - Sheffield Hallam University), je mène une étude qualitative sur la façon dont les patients choisissent le traitement qu'ils suivront pour leur épaule douloureuse.

J'ai besoin de votre aide pour recruter des patients et je vous serais très reconnaissant si vous preniez le temps de lire ce document, avant d'en parler à des patients si vous le souhaitez.

1. Objectifs

L'objectif est de comprendre comment une personne souffrant de douleurs liées à la coiffe des rotateurs décide du traitement qui lui convient le mieux : chirurgie, infiltrations, kinésithérapie, repos, attendre que ça passe… La prise de décision entre les nombreuses options a peu été étudiée, et on ne sait pas comment les professionnels de santé guident leurs patients dans cette décision.

2. Critères de recrutement

Je souhaite interviewer des adultes ayant mal à l'épaule et parlant français. Le diagnostic peut être une tendinopathie(s), tendinite(s), bursite(s), une rupture partielle de la coiffe, ou encore un conflit sous-acromial, une douleur liée à la coiffe des rotateurs ou une douleur non spécifique de l'épaule.

Les critères d'exclusion sont la rupture complète de la coiffe des rotateurs, un traumatisme récent de l'épaule ou si la douleur peut être attribuée à une autre région (douleur cervicale ou viscérale par exemple).

Si un patient remplit ces critères je serai ravi que vous lui donniez mes coordonnées (page suivante).

3. Qu’est-ce que ça implique pour mes patients ?

Un patient qui décide de participer se voit proposer un horaire pour un entretien téléphonique ou en visioconférence, selon sa préférence. Ces entretiens devraient durer entre 30 minutes et 1 heure maximum. Il ne sera pas rémunéré pour ce temps.

A tout moment le patient peut décider de se retirer de l’étude (avant, pendant ou après l’entretien, jusqu’à la publication).

4. Y a-t-il des avantages/risques à participer ?

Il n'y a pas d'inconvénients ou de risques à participer à cette étude, mais il n'y a pas non plus de bénéfices attendus pour le patient ou pour vous.

Cependant, vous contribuerez à la recherche et à l'éducation. Les résultats de cette étude pourraient nous aider à proposer à nos patients le traitement le mieux adapté.

5. Qu'adviendra-t-il des résultats de l'étude ?

Cette recherche est la base de mon mémoire de master, les résultats seront donc présentés à mon université. Il est possible que les résultats de l'étude soient soumis pour publication à une revue à comité de lecture et qu'ils soient présentés lors de conférences professionnelles. Dites-moi si vous souhaitez être informés des résultats !

6. Qui supervise, vérifie et assure cette recherche ?

Le commanditaire de l'étude a le devoir de s'assurer qu'elle se déroule correctement et qu'elle est assurée. Dans cette étude, le commanditaire est l'université de Sheffield Hallam.

Cette étude a été approuvée par le comité d'éthique de la recherche de l'université de Sheffield Hallam, ainsi que par le Groupe Nantais d'Éthique dans le Domaine de la Santé.

Si vous avez des questions, des remarques ou qu’un de vos patient est intéressé pour participer, voici mes coordonnées :

Corentin Glon

06 51 50 12 97

pro.corentin.glon@gmail.com

Appendix 5: Participant Information

Sheffield Hallam University

Participant information sheet

Study title:	Decision-making of patients with shoulder pain regarding their treatment
Chief investigator	Corentin Glon
Telephone number	(+33) 06 51 50 12 97

You are being invited to take part in our research study. Before you decide, it is important to understand what involvement in the project will mean for you and why the study is being done. If you wish, you may discuss the study with others. Ask us if you need more information or if you are not clear about anything and take time to decide whether you want to take part or not.

The aim of this study is to understand what makes one choose one treatment rather than another when suffering from shoulder pain.

1. **What is the purpose of the study?**

   The purpose of the study is to understand how someone who is suffering from rotator-cuff related shoulder pain (that is, most painful shoulder conditions) decides which treatment suits them the best: surgery, infiltrations, physiotherapy, wait and see ? We don't really know the reasons behind this choice, or even if patients think they have a choice. It would also be helpful to know how healthcare providers guide their patients in this decision.

2. **Why have I been invited?**

   We would like to recruit adults who speak French and have a painful shoulder, diagnosed as tendinopathy, tendinosis, bursitis, partial cuff tears, subacromial

impingement, rotator cuff pain, rotator-cuff related shoulder pain or non-specific shoulder pain.

If you have a complete rotator cuff tear, a recent trauma on the shoulder or if the pain can be attributed to other body parts, you won't be asked to participate.

3. What will happen to me if I take part?

Should you decide to contact the researcher, he will try to arrange a convenient time for a 1 to 1 interview with the researcher.

It is expected to last 30 to 60 minutes and it will be recorded. This could be either a phone call or an online meeting depending on your preference. In both cases, the time and place is up to you, but a calm place where you can speak freely is recommended.

There is nothing to prepare for the interview, all you have to do is to make yourself available at the mutually convenient time and be ready to talk about your ideas and thoughts, as guided by the researcher.

4. Do I have to take part?

Your decision to participate in the study is entirely voluntary. A copy of the information provided here is yours to keep, along with the consent form if you do decide to take part. You can refuse to participate or withdraw at any time. For example you can refuse the interview, or stop during the interview, you can choose to refuse to answer some specific questions, or ask that your data is erased even after that interview.

5. **Expenses and payments**

You will not be paid for taking part in this study.

6. Are there any benefits/risks in taking part ?

There are no disadvantages or risks of taking part in this research, but there is no intended benefit to you either.

However, you will be contributing to research and education. The information we get from this study could help healthcare providers when discussing best treatment options.

7. How will you use what is recorded and reported about me?

The University undertakes research as part of its function for the community under its legal status. Data protection allows us to use personal data for research with appropriate safeguards in place under the legal basis of public tasks that are in the public interest. A full statement of your rights can be found at: https://www.shu.ac.uk/about-this-website/privacy-policy/privacy-notices/privacy-notice-forresearch

All information that is collected from you during the interview will first be anonymised: any information that could link to your identity will be edited (for example if you mention the name of your employer or your surgeon). The recording and transcript will be kept strictly confidential but the project supervisor and other responsible people at Sheffield Hallam will be able to see that you have been interviewed and may read the edited transcripts of the interviews as part of any audit process.

Direct quotations from the interview may be used when writing up the research, however, your name or any identity-revealing data will be omitted: readers won't know it comes from you.

8. What will happen to the results of the research study?

This study is the final dissertation project of the researcher's Msc, so the results will be presented to his university.

It is anticipated that the results of the study will be submitted for publication in a peer reviewed journal as well as being presented at relevant professional conferences. You may receive a summary of the results if you wish. Simply let us know that you would like to receive a summary of the results and we shall email you, once the project is complete.

9. What will happen to the information when this study is over?

The information collected during this study will be kept in an encrypted form for 5 years, under the researcher's responsibility. During this time, it could be reused in future research projects. Remember that you can ask for your data to be deleted at any time after the interview.

10. Who is sponsoring the study?

The sponsor of the study has the duty to ensure that it runs properly and that it is insured. In this study, the sponsor is Sheffield Hallam University

11. Who has reviewed this study?

All University research is reviewed to ensure that participants are treated appropriately and their rights respected. This study was approved by the Sheffield Hallam University Research Ethics Committee.

If you have any queries or questions please contact:

Principal investigator: C*orentin Glon*
Email: pro.corentin.glon@gmail.com
Phone: (+33) 06 22 86 21 81

Alternatively, you can contact my supervisor: Adrian Walker
Email: aw0115@exchange.shu.ac.uk

Below are details of who to contact if you have any concerns or if adverse effects occur after the study:

You should contact the Data Protection Officer if:

- you have a query about how your data is used by the University
- you would like to report a data security breach (e.g. if you think your personal data has been lost or disclosed inappropriately)

You should contact the Head of Research Ethics (Mayur Ranchordas) if

- you have concerns with how the research was undertaken or how you were treated

hscmr@exchange.shu.ac.uk

- you would like to complain about how the University has used your personal data

Email for Data Protection Officer:
DPO@shu.ac.uk

Postal address: Sheffield Hallam University, Howard Street, Sheffield S1 1WBT.
Telephone: 0114 225 5555

Appendix 6: Consent form

Sheffield Hallam University

Participant Consent Form

Title of Project: Decision-making of patients with shoulder pain regarding their treatment

Researcher: Corentin Glon

Participant Identification Number for this study:

Please Initial box

1. I confirm that I have read the information sheet dated *28/04/23 (v1.1)* 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 my care or legal rights being affected. ☐
3. I agree that the data collected may be used to support other research in the future. This data will not include my personal details. *(Optional)* ☐
4. I understand that information about me collected during the study may be looked at by responsible individuals from Sheffield Hallam University, from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my personal details. ☐
5. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix 7: UREC Form

Sheffield Hallam University

UREC2 RESEARCH ETHICS PROFORMA FOR STUDENTS UNDERTAKING LOW RISK PROJECTS WITH HUMAN PARTICIPANTS

This form is designed to help students and their supervisors to complete an ethical scrutiny of proposed research. The University Research Ethics Policy should be consulted before completing the form. The initial questions are there to check that completion of the UREC 2 is appropriate for this study. The final responsibility for ensuring that ethical research practices are followed rests with the supervisor for student research.

Note that students and staff are responsible for making suitable arrangements to ensure compliance with the General Data Protection Act (GDPR). This involves informing participants about the legal basis for the research, including a link to the University research data privacy statement and providing details of who to complain to if participants have issues about how their data was handled or how they were treated (full details in module handbooks). In addition the act requires data to be kept securely and the identity of participants to be anonymized. They are also responsible for following SHU guidelines about data encryption and research data management. Information on the Ethics Website

The form also enables the University and College to keep a record confirming that research conducted has been subjected to ethical scrutiny.

The form may be completed by the student and the supervisor and/or module leader (as applicable). In all cases, it should be counter-signed by the supervisor and/or module leader, and kept as a record showing that ethical scrutiny has occurred. Some courses may require additional scrutiny. Students should retain a copy for inclusion in their research projects, and a copy should be uploaded to the relevant module Blackboard site.

Please note that it may be necessary to conduct a health and safety risk assessment for the proposed research. Further information can be obtained from the College Health and Safety Service.

Checklist Questions to ensure that this is the correct form

1. Health Related Research with the NHS or Her Majesty's Prison and Probation Service (HMPPS)or with participants unable to provide informed consent

Question	Yes/No
1. Does the research involve? ● Patients recruited because of their past or present use of the NHS	No
● Relatives/carers of patients recruited because of their past or present use of the NHS	No
● Access to data, organs or other bodily material of past or present NHS patients	No
● Foetal material and IVF involving NHS patients	No
● The recently dead in NHS premises	No
● Prisoners or others within the criminal justice system recruited for health-related research*	No
● Police, court officials, prisoners or others within the criminal justice system*	No
● Participants who are unable to provide informed consent due to their incapacity even if the project is not health related	No
2. Is this a research project as opposed to service evaluation	Yes

or audit? *For NHS definitions of research etc. please see the following website* http://www.hra.nhs.uk/documents/2013/09/defining-research.pdf	

If you have answered **YES** to questions **1 & 2** then you **MUST** seek the appropriate external approvals from the NHS, Her Majesty's Prison and Probation Service (HMPPS) under their independent Research Governance schemes. Further information is provided below.
https://www.myresearchproject.org.uk

NB College Teaching Programme Research Ethics Committees (CTPRECS) provide Independent Scientific Review for NHS or HMPPS research and initial scrutiny for ethics applications as required for university sponsorship of the research. Applicants can use the IRAS proforma and submit this initially to their CTPREC.

1. Checks for Research with Human Participants

Question	**Yes/No**
1. Will any of the participants be vulnerable? *Note: Vulnerable' people include children and young people, people with learning disabilities, people who may be limited by age or sickness, people researched because of a condition they have, etc. See full definition on ethics website*	No
2. Are drugs, placebos or other substances (e.g. food substances, vitamins) to be administered to the study participants or will the study involve invasive, intrusive or potentially harmful procedures of any kind?	No
3. Will tissue samples (including blood) be obtained from participants?	No
4. Is pain or more than mild discomfort likely to result from the study?	No
5. Will the study involve prolonged or repetitive testing?	No
6. Is there any reasonable and foreseeable risk of physical or emotional harm to any of the participants? *Note: Harm may be caused by distressing or intrusive interview questions, uncomfortable procedures involving the participant, invasion of privacy, topics relating to highly personal information, topics relating to illegal activity, or topics that are anxiety provoking, etc.*	No
7. Will anyone be taking part without giving their informed consent?	No
8. Is it covert research? *Note: 'Covert research' refers to research that is conducted without the knowledge of participants.*	No
9. Will the research output allow identification of any individual who has not given their express consent to be identified?	No

If you have answered **YES** to any of these questions you are **REQUIRED** to complete and submit a UREC 3 or UREC4). Your supervisor will advise. If you have answered **NO** to all these questions then proceed with this form (UREC 2).

General Details

Name of student	Glon Corentin
SHU email address	c0044337@exchange.shu.ac.uk
Course or qualification (student)	MSc Specialist Physiotherapy Practice
Name of supervisor	Adrian Walker
email address	aw0115@exchange.shu.ac.uk
Title of proposed research	Decision-making of patients with shoulder pain regarding their treatment
Proposed start date	January 2023
Proposed end date	14th December 2023
Background to the study and scientific rationale for undertaking it.	Rotator cuff related shoulder pain is a common condition, and guidelines for the management exist. However, those guidelines are not well implemented. In France many patients undergo surgery even though they didn't try conservative care. Patients want a pathoanatomical explanation and that this bias leads to more passive treatments, but we don't know how patients choose which treatment option to receive. The only study on decision-making was done on patients suffering for more than one year, which is a long duration for this condition.
Aims & research question(s)	The objective is to understand the treatment decision-making of French patients suffering from rotator-cuff related shoulder pain. The secondary objective is to better understand how different health professions influence the patient's choice.
Methods to be used for: 1.recruitment of participants, 2.data collection, 3. data analysis.	This study will use constructivist grounded theory. 1- Patients will be informed of this study by therapists aware of this research project. Interested patients will be given an information pack and will be able to contact the researcher. Theoretical sampling will be used to drive recruitment as needed for a theory to emerge. 2- After potential questions about the study have been answered and consent has been collected, some demographic questions will be asked. Then, in depth semi-structured interviews will be conducted and transcribed verbatim. Field notes will be added to this data. 3- The constructivist grounded theory analysis process is concomitant with data collection. It involves different steps : initial coding, focused

	coding, memo writing and theoretical modelling.
Outline the nature of the data held, details of anonymisation, storage and disposal procedures as required.	Interviews and their transcriptions are the primary source of data, but there are also field notes taken by the researcher during the interviews. All the collected data will be anonymised by the researcher without the use of external services. The created data (codes, memos and analysis) will be stored with the collected data on two PIN-protected USB drives. One of the two will serve as a backup. After this MSc dissertation has been completed, the two USB drives will be kept for 5 years in two separate and secure locations.

3. Research in Organisations

Question	**Yes/No**
1. Will the research involve working with/within an organisation (e.g. school, business, charity, museum, government department, international agency, etc.)?	No
2. If you answered YES to question 1, do you have granted access to conduct the research? *If YES, students please show evidence to your supervisor. PI should retain safely.*	
3. If you answered NO to question 2, is it because: A. you have not yet asked B. you have asked and not yet received an answer C. you have asked and been refused access. *Note: You will only be able to start the research when you have been granted access.*	

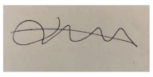
4. Research with Products and Artefacts

Question	**Yes/No**
1. Will the research involve working with copyrighted documents, films, broadcasts, photographs, artworks, designs, products, programmes, databases, networks, processes, existing datasets or secure data?	No

2. If you answered YES to question 1, are the materials you intend to use in the public domain? *Notes: 'In the public domain' does not mean the same thing as 'publicly accessible'.* • *Information which is 'in the public domain' is no longer protected by copyright (i.e. copyright has either expired or been waived) and can be used without permission.* • *Information which is 'publicly accessible' (e.g. TV broadcasts, websites, artworks, newspapers) is available for anyone to consult/view. It is still protected by copyright even if there is no copyright notice. In UK law, copyright protection is automatic and does not require a copyright statement, although it is always good practice to provide one. It is necessary to check the terms and conditions of use to find out exactly how the material may be reused etc.* *If you answered YES to question 1, be aware that you may need to consider other ethics codes. For example, when conducting Internet research, consult the code of the Association of Internet Researchers; for educational research, consult the Code of Ethics of the British Educational Research Association.*	
3. If you answered NO to question 2, do you have explicit permission to use these materials as data? *If YES, please show evidence to your supervisor.*	
4. If you answered NO to question 3, is it because: A. you have not yet asked permission B. you have asked and not yet received and answer C. you have asked and been refused access. *Note You will only be able to start the research when you have been granted permission to use the specified material.*	**A/B/C**

Adherence to SHU policy and procedures

Personal statement	
I can confirm that: ● I have read the Sheffield Hallam University Research Ethics Policy and Procedures ● I agree to abide by its principles.	
Student	
Name: Corentin GLON	Date: 26/04/2023
Signature: 	
Supervisor or other person giving ethical sign-off	

I can confirm that completion of this form has not identified the need for ethical approval by the FREC or an NHS, Social Care or other external REC. The research will not commence until any approvals required under Sections 3 & 4 have been received and any necessary health and safety measures are in place.	
Name: Adrian Walker	Date: 03/07/2023
Signature: A.M.Walker	
Additional Signature if required by course:	
Name: Carol Garcia	Date: 4/7/23
Signature: 	

Please ensure the following are included with this form if applicable, tick box to indicate:

	Yes	No	N/A
Research proposal if prepared previously	☒	☐	☐
Any recruitment materials (e.g. posters, letters, etc.)	☒	☐	☐
Participant information sheet	☒	☐	☐
Participant consent form	☒	☐	☐
Details of measures to be used (e.g. questionnaires, etc.)	☒	☐	☐
Outline interview schedule / focus group schedule	☒	☐	☐
Debriefing materials	☒	☐	☐
Health and Safety Project Safety Plan for Procedures	☒	☐	☐

Appendix 8: French Ethical Board approval

AVIS 23-84-06-294
Groupe Nantais d'Ethique dans le Domaine de la Santé (GNEDS)

Nom du protocole Code et versioning	**DMRCRSP**

Investigateur principal	Mr Corentin Glon, Mr Adrian Walker
Lieu de l'étude	Université de Sheffield-Hallam
Type de l'étude	Qualitative, sur entretiens semi directifs
Type patients/participants	Patients souffrant d'une douleur d'épaule non spécifique
Nombre de patients/participants prévus	20 à 25
Objectif principal	Comprendre le processus de choix d'un traitement plutôt qu'un autre chez les patients français souffrant de douleur d'épaule liée à la coiffe
Objectif secondaire	Comprendre l'influence des différentes professions de santé dans le parcours de soin. Identifier quels professionnels orientent le plus le choix des patients et vers quel traitement. Comprendre comment les professions modèlent les attentes des patients vis-à-vis des traitements

Documents communiqués

Justification de l'étude	OUI
Méthodologie	OUI
Lettre d'information Lettre de consentement	OUI

Remarque générale
Le GNEDS formule d'abord la remarque qu'il n'a pas pour mission de donner un avis sur les aspects scientifiques du protocole, en particulier sur l'adéquation de la méthodologie aux objectifs poursuivis par l'étude. Il ne tient compte des données d'ordre scientifique et méthodologique que dans la mesure où elles ont des implications d'ordre éthique. Dans le cas présent, il se bornera à constater que les objectifs de cette étude et sa méthodologie sont conformes aux principes de l'éthique.

Confidentialité

Confidentialité	OUI
Anonymat	OUI
CNIL	RGPD MR004

Commentaires :

Information et consentement

Consentement :

Recueil nécessaire	OUI
Type consentement préférable	ECRIT
Traçabilité dans le dossier	OUI

Commentaires :

Lettre information précisant :

Titre de l'étude	OUI
But de l'étude	OUI
Déroulement de l'étude	OUI
Prise en charge courante inchangée	OUI
Possibilité de recevoir résultats de l'étude	OUI
Traçabilité dans le dossier	OUI

Commentaires :

Conclusion

Avis favorable	OUI
Révision nécessaire selon commentaires	
Avis défavorable	

GNEDS : Professeur Paul BARRIERE

Nantes le 29 juin 2023

Appendix 9 : CNIL Approval

CNIL.
COMMISSION NATIONALE INFORMATIQUE & LIBERTÉS

Référence CNIL :
2230460 v 0

Déclaration de conformité

au référentiel de méthodologie de référence MR-004

reçue le 27 juin 2023

Monsieur Corentin GLON
MONSIEUR CORENTIN GLON
46 RUE DE LA CONTRIE
44100 NANTES

ORGANISME DÉCLARANT

Nom :	MONSIEUR CORENTIN GLON	**N° SIREN/SIRET :**	491895413 00053
Service :		**Code NAF ou APE :**	8690E
Adresse :	46 RUE DE LA CONTRIE	**Tél. :**	
CP :	44100	**Fax. :**	
Ville :	NANTES		

Par la présente déclaration, le déclarant atteste de la conformité de son/ses traitement(s) de données à caractère personnel au référentiel mentionné ci-dessus.

La CNIL peut à tout moment vérifier, par courrier ou par la voie d'un contrôle sur place ou en ligne, la conformité de ce(s) traitement(s).

Fait à Paris, le 28 juin 2023

RÉPUBLIQUE FRANÇAISE

3 Place de Fontenoy, TSA 80715 – 75334 PARIS CEDEX 07 – 01 53 73 22 22 – www.cnil.fr

Appendix 10 : Health data hub submission

The research project has been submitted to the Health data hub. It can therefore be consulted here :
https://www.health-data-hub.fr/projets/prise-de-decision-des-patients-souffrant-de-douleurs-lepaule-concernant-leur-traitement

Appendix 11: Project safety plan: Risk Assessment Form

Sheffield Hallam University

FACULTY OF HEALTH AND WELLBEING

MA/MBA/MSc Dissertation Proposal

PROJECT SAFETY PLAN: Risk Assessment Form

TITLE:	Decision-making of patients with shoulder pain regarding their treatment	LOCATION:	Nantes, France
PEOPLE AFFECTED:	French adults suffering from rotator cuff related shoulder pain		
ASSESSMENT CARRIED OUT BY:	Corentin Glon		
PROJECT SAFETY OFFICER:	Adrian Walker		
SUPERVISOR:	Adrian Walker		
SIGNATURE OF SUPERVISOR		DATE:	

ACTIVITY	HAZARD ASSOCIATED WITH THE ACTIVITY	HAZARD RATING (High, Medium or Low)	CONTROL MEASURES TO BE TAKEN
Study Inclusion	Not respecting consent	Low	The patients have to reach the researcher by themselves, and they can take their time before signing the consent form.
	Not understanding the study objectives	Low	This is explained in the patient information document, and repeated at the start of the interview. Participants are asked if they have questions
	Not understanding the right to withdraw	Low	This is explained in the patient information document, and repeated at the start of the interview. Patients have the researcher's contact information.
Interview	Technical risks	Low	Interviews will be conducted on participants' own phone or computer

			which ensures they are familiar with it.
	Confidentiality	Low	Interviews will be scheduled and participants will be advised to choose a time and place where they cannot be overheard. Only secure communications means will be used
	Emotional Distress	Low	The researcher should be alert to any signs of distress. Will suggest stopping recording/interviewing if the participant seems too upset to continue.

Please keep this form in your Site File (Section 3 - Ethics) and update as appropriate.

Project Files and Site Files

All studies require a file with the administrative details such as letters and consent forms. If it is a non-NHS project then these are called 'project files', if an NHS project they are called 'site files'. They contain more or less the same things - for details see in the ethics folder on the BlackBoard site.

Appendix 12: Data Management Plan

1- What data will you collect or create?

Interviews will be recorded as audio files for phone calls, and video+audio for online meetings. In both cases, open file formats will be preferred: webM or m4a (mp4).

It is expected that no interview will last more than 1 hour, so 1GB max per video-file can be expected with suitable quality. The other formats sizes are small (around 56MB for a 1 hour audio recording) or negligible (text files).

Those files will then be transcribed verbatim for analysis as text files inside LibreOffice and saved as open document file formats (odt). Identifying data such as names will be removed for anonymity.

Field Notes will be written on paper during interviews and added as comments to the verbatim files. Those notes won't contain personal data, and the original paper will be destroyed after its content has been added to the interview transcript.

2- How will your data be documented and described?

The researcher will take several measures to support the management and analysis of the data.

Transcription: All interview data will be transcribed verbatim, with careful attention to accuracy and completeness. The transcripts will be reviewed for errors and omissions, and corrections will be made as needed.

Field notes: Field notes taken during the interviews will be typed up and added to the data corpus. The notes will be organised by interviewee id number, and will include relevant contextual information, observations, and non-verbal communication.

Data organisation: All data files, including interview transcripts and field notes, will be organised using a consistent naming convention and file structure. This will facilitate efficient retrieval and management of the data throughout the analysis process.

Coding and memoing: The data will be analysed using constructivist grounded theory methods, including iterative coding and theoretical memoing. The coding and memoing process will be done inside LibreOffice, no qualitative software will be used to track the development of codes, themes, or categories throughout the analysis process.

Final report: The final report will include a detailed description of the data collection and analysis methods used in the study, as well as a discussion of the key findings

and their implications. The report will include relevant quotes and examples from the data corpus to support the findings.

Overall, we will take care to ensure that the data collected in this study remains confidential and anonymous, but is still well-documented and described, in order to generate rigorous and credible results.

3- How will you deal with any ethical and copyright issues?

Participants will be provided with an information sheet (Appendix 5) that outlines the purpose of the study, the nature of their participation, and any potential risks or benefits associated with their involvement. They will also be informed of their right to withdraw from the study at any time, without penalty. Informed consent from all participants will be given (Appendix 2) prior to any data collection.

To protect the privacy and confidentiality of participants, pseudonyms will be assigned to participants. Any identifiable information is removed or altered to protect the anonymity of participants.

All data collected in this study will be stored securely using password-protected USB drives. Only the researcher will know this password in order to guarantee the confidentiality of the data.

For the dissertation, the researcher will take care to ensure that any copyrighted materials used in the study, such as published articles or documents, are appropriately cited and used in compliance with fair use guidelines. He will also obtain permission from copyright holders if needed, and will document all permissions obtained in the study records.

4- How will your data be structured, stored, and backed up?

Proper data storage will ensure confidentiality, but also prevent data loss and facilitate analysis. All the qualitative data will use a consistent naming convention and file structure: there will be a folder by participant named by id, and any file related to this participant will be stored there, with the data source and date in the name (eg. “audio-30-04-23.m4a” and “transcript-30-04-23.odt” in the folder “#3”).

Data will be stored on a PIN-protected USB drive, to ensure no unauthorised access could happen. A second PIN-protected USB drive will be used as a backup.

25 interviews would take around 25GB of data at most, but 64GB drives will be preferred.

5- What are your plans for the long-term preservation of data supporting your research?

Data will be stored 5 years after publication. The two USB drives will be stored in different and secure locations.

6- What are your plans for data sharing after submission of your thesis?

The data won't be shared, except for specific relevant quotes that will be presented in the study results to support the analysis.

The study conclusions could be disseminated through conferences and could be published in peer-reviewed journals, but the first objective is the final dissertation of the researcher's MSc.

Appendix 13: Participant's characteristics form

Age							
18-29	30-39	40-49	50-59	60-69	70-79	80-89	90+

Gender			
Female	Male	Not binary	Rather not say

Employment				
Full-Time	Part-Time	Retired	Self-Employed	Unable to work

Duration of shoulder pain	
	Weeks
	Months
	Years

Mean NRS last 15 days (0-10):	

Healthcare providers implied				
GP	Orthopaedic surgeon	Rheumatologist	Physiotherapist	Other

Treatments received
Advice/Education/Pain management
Analgesia/Pain medication
Exercise
Manipulation/Mobilisation
Massage
Injections, specify number: …
Electrotherapy
Surgery
Other, specify: …

Appendix 14: Interview Guide

This is a translation of the interview guide that was used during the interviews. Some questions or themes were not present during the first interviews and were added later. Those are displayed in italic letters.

Introduction

Interviewer presentation
Brief study explanation
Interviewee questions about study
Consent procedure
Reminder of the right to withdraw from the study at any time

Start of recording

Demographic elements collection (Appendix 3)

Interview

This is only a guide and the questions presented here are only examples.

General information	
The person	**The shoulder pain**
Tell me about yourself ! Do you have other health concerns ? Have you seen a physiotherapist before ? How are you dealing with this pain ? Can you tell me more about the impact this shoulder pain had on you ?	When did it start? What caused the pain according to you? Was it the first time you suffered from shoulder pain? How did your pain evolve to date? How do you think this will evolve from now? How would you describe your symptoms? How would you define your shoulder condition, so that I have it in your own words?
Diagnosis	
What made you seek help for your shoulder ? Who did you consult ? Who made the diagnosis ? How did you feel about this diagnosis, at the time ? How was your understanding of your condition at that point ? What information did you receive about your shoulder pain ? Do you think this information explains what you feel in your shoulder ? How confident in this diagnosis have you been ? Did you ever feel like additional examinations were needed ? How did you react to your xrays/US results ? *How would you react if your imaging showed nothing worth noting ? Would it be a source of worries or reassurance ?*	

Treatment and Decision-making
When that diagnosis was made, what was the next step ? What are the possible treatments for your shoulder condition according to you ? Did you feel like you had a choice ? How involved were you in choosing this treatment ? How did you feel about this choice ? What could have made you reach a different decision ? How would you feel if you had nothing to say in this choice ? Or if you were the only one making this choice ? *In the same situation, with the same pain and the same imaging, do you think everyone should get the same treatment ?* *According to you What is the most effective treatment for shoulder pain ? Should everyone get it ?* *Do you think this treatment (each option) could be useful ? How would it work ?* Do you find that the mode of action of this treatment is consistent with the explanations you have received about your shoulder problem ? *What were your expectations around physiotherapy ? What techniques did you expect ? What results did you expect ?*
HCP Influence
Who explained to you what was the cause of your shoulder pain ? How much do you think each professional influenced your choices ? How different would it be if the same advice had been given by another therapist ? Is it the same if it comes from a doctor, a physio, a specialised physio, a surgeon ? How do you think your therapists would react if you chose a treatment they didn't suggest ?

Conclusion

Thanks
Withdrawal is still possible after this interview
Feel free to contact me if you have questions about this study or your data.

Appendix 15: Data Analysis process

A characteristic feature of grounded theory is a concomitant data collection and analysis. The process involved the steps described by Charmaz (2014), and are succinctly presented here :

Initial coding:

The first step in the analysis process was the open coding of the interview transcripts. The transcripts were read multiple times to identify initial codes capturing the essence of the data; this was done using the “Commenting” tools of Libreoffice.

Focused coding:

The initial codes were then refined through focused coding and grouped into broader categories, capturing the most important themes and patterns in the data. This was done using the offline and open-source software Taguette (Rampin & Rampin, 2021).

Memo writing:

Throughout the coding process, the researcher engaged in memo writing to reflect on the emerging patterns and themes in the data. Memos were used during analysis but also generated new questions for the next interviews.

Theoretical sampling:

As described in the Recruitement section, theoretical sampling drove the recruitment of additional participants who could provide further insights and perspectives on emerging themes and patterns.

Theoretical saturation:

Theoretical saturation was reached after 9 interviews, where no new themes or patterns emerged from the data, and mostly brought confirmation. Recruitment and data collection then ceased as the analysis has reached a point of theoretical completeness.

Theoretical modelling:

The final stage of the analysis process involves theoretical modelling, where the researcher uses the emerging themes and patterns to develop a theoretical framework that explains the patient decision-making process and the contribution of healthcare providers to that decision.

Appendix 16 : Focus codes

Themes :	Occurrences
Medical History	**2**
↳Remote	**9**
↳Shoulder	**19**
↳Regional	**2**
Surgery	**31**
Treatment Choice	**71**
Communication	**47**
Treatment Matching Condition	**35**
Confidence	**18**
↳Duration	**1**
↳Physiotherapy	**45**
Initial Consultation	**9**
↳Abnormal	**3**
↳Symptoms Duration	**5**
↳Facilitators	**2**
↳Disability	**18**
↳Professional	**6**
↳Pain Intensity	**14**
Load/Capacity Understanding	**10**
Shoulder Load in Leisure activities	**2**
Shoulder Load in professional activities	**17**
Desire to continue	**20**
Natural Evolution	**21**
Imaging	**29**
↳Consistency	**15**

↳Exclude serious pathology	7
↳Anxiety	11
↳”To see”	10
↳Reassuring	6
↳”Nothing serious”	6
Treatment explanations	27
External drivers	20
Emotional drivers	20
Therapeutic gradiant	37
Uncertainty	8
↳Diagnosis	13
↳Evolution	6
↳Perceptions	10
Injections	27
Physiotherapy	48
↳Doubts	12
Natural	8
Osteopathy	4
Patho-Anatomical	55
↳Clinical Improvement	7
Prognosis	11
External realisation	5
Care	22
↳inflammation	16
↳Movement	18
↳Strengthening	25
Sleep	8
Specialisation	10
Injury	2

Appendix 17: Pathoanatomical statements by HCP

Many patients received statements that are susceptible to reinforce a pathoanatomical vision of their conditions.

Patient 1	“So, I've been told it's bursitis, so it's more likely to be an inflammation.”
Patient 2	“He told me that my tendon of the long head of the biceps had completely torn, it was going all over the place, it was in filaments. Every time he did something, the surgeon explained it to me and even showed it to me on camera, so that was good.”
Patient 3	“The surgeon warned me that I had an aggressive acromion.”
	“Suggest acromioplasty at least to relax the area.”
	“The aim, as I understand it, is always to try and lower the humeral head to relieve some of the tension in the area.”
	“According to the osteopath, my clavicle and humeral head are always too, too far up my shoulder.”
	“I'm thinking about decompression, and the physio will explain to me why I'm doing it, how it should be done and what it will do to my body. It's important to know. For me, after all, there may be people who don't try to understand more, but I always try to know more.”
Patient 4	“the liquid has to go to the place where you sting and not spread elsewhere”
	“the doctor tells you "it's no good". And there you are. We're naturally cheerful. You may have noticed. It's quite cheerful, very optimistic. And when we tell you that, you get a punch in the stomach and yes: "it's not good.... and?" So, these MRI doctors, they're certainly very competent, but they have a discourse that is absolutely not in the dictionary, or maybe in their own dictionary.”
	“a muscle that was damaged at the back, and that the third was tearing, and that there was one good left. He explained that to me.”
	"in any case, Mrs [Name]: I wear my patients down, you know, they come back because they’re not doing well"
Patient 5	“There are some fibres that we've had to get over or whatever. I don't know how you do it.”
Patient 6	“The doctor told me when he did the ultrasound that there's nothing wrong with the cuff, because there's also the possibility that... you never know, and there are no cracked or torn tendons, so that's already a good thing. It's comforting to say the least.”

Appendix 18: Desire to continue

Wanting to keep on living their lives and working was common to many participants, here are relevant quotes:

Patient 1	“As a result, the stress had somehow anaesthetised me and it was only when I became aware of the problem that I really started to realise how uncomfortable it was.”
Patient 2	“Then, as I never pay attention to myself, “it'll pass, it'll pass”. We take what we can get from the pharmacy and treat ourselves as best we can.”
	About her occupational doctor: “then I told her: you're not going to disqualify me, are you ? So she put restrictions on me.” And later: “In fact, I didn't really listen to her, and when she told me that, I thought to myself "what nonsense is she talking to me about", I said to myself "anyway, we won't be able to keep the restrictions and I don't care", and that was it, off we went again.”
	“in any case, we were already short-staffed. So, for me, in my head, it was no, you're not going to stop. Because if you stop, there's nobody left.” And later : “For me, I had no choice.”
Patient 3	“You see, just lifting a weight was triggering very sharp pains in my weights. That's why I sought help. More than... Otherwise I wouldn't have gone to the doctor, I'm not basically a softy.”
Patient 4	“In your head, you always play it down. You know it hurts, but you always say to yourself "there are worse people than me". Well, as far as I'm concerned, it's a bit like that.”
Patient 6	“well, I regularly have little problems, whether it's sports, I've had tendonitis quite often. Well, I always managed to... And I said to myself, well, I'll wait, it'll pass.”
Patient 9	“I'm really able to cope with pain, fever, all sorts of illnesses, and I avoid taking medication.”

Appendix 19: Surgery was inevitable

Patients went to surgery as a last resort, but are convinced there was no other option.

Patient 2	“it's a repair job, like breaking a car.”
	“No. I don't know what he could have... given that the tendon was all part of the long biceps, it went in all directions... the acromion, I don't know what he could have done, if we hadn't gone there mechanically.”
	“I think it could have been a bigger rupture. I think the repair might have been more complicated, more complex.”
Patient 3	“I was relieved that he suggested the operation, which is what I wanted anyway.”
Patient 4	“And then, after a while, you have to go back, because when the pain, the painful episodes, the episodes of intense pain, you could say, come back, it's really physical.”
	“my doctor, who saw me during the painful episodes, told me "there comes a time when you have to go"
	“So there was no choice, it was straight to surgery. In any case, I think that given the state, from what I understood from the MRI, given the state of the shoulder, there was really no choice.”

Appendix 20: COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	16
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	16
3. Occupation	What was their occupation at the time of the study?	16
4. Gender	Was the researcher male or female?	16
5. Experience and training	What experience or training did the researcher have?	16
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	14-15
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	14-15, 17
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	16-17

Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	13
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	14
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	14
12. Sample size	How many participants were in the study?	17
13. Non-participation	How many people refused to participate or dropped out? Reasons?	15
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	16-17
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	16
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	16-17; 62

Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	16-17; 88-89
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	16-17
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	16
20. Field notes	Were field notes made during and/or after the inter view or focus group?	15-16
21. Duration	What was the duration of the inter views or focus group?	62
22. Data saturation	Was data saturation discussed?	17
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	38
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	17
25. Description of the coding tree	Did authors provide a description of the coding tree?	91-92
26. Derivation of themes	Were themes identified in advance or derived from the data?	17
27. Software	What software, if applicable, was used to manage the data?	17

28. Participant checking	Did participants provide feedback on the findings?	38
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	18-30
30. Data and findings consistent	Was there consistency between the data presented and the findings?	18-30
31. Clarity of major themes	Were major themes clearly presented in the findings?	18-30
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	25;35