

## RESEARCH ARTICLE

# 'Lost time'. Patients with early inflammatory/rheumatoid arthritis and their experiences of delays in Primary Care

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**Abstract**

**Background:** Early referral forms a crucial part in early inflammatory/rheumatoid arthritis (EI/RA) recovery. Delayed decisions to refer can lead to severe incapacity and emotional distress for individuals and family and feelings of lost time. How patients with EI/RA experience early referral decisions in Primary Care is an under explored area and warrants further investigation.

**Aim:** To explore how patients newly diagnosed with EI/RA experienced their early contacts with Primary Care as they negotiated their journey through the referral process into secondary care.

**Design and setting:** Qualitative face-to-face interviews with newly diagnosed EI/RA patients.

**Methods:** In-depth semi-structured interviews were conducted to explore patients' experiences of referral from first symptoms to General Practitioner referral. All participants were interviewed within 2 weeks of being diagnosed in Secondary Care. Data analysis was conducted using interpretative phenomenological analysis.

**Findings:** All participants in this study described having experienced struggles with their navigation through Primary Care towards diagnosis and specialist EI/RA services. This struggle comprised five key elements: 'family persuasion', 'lack of continuity in care', 'pushing for referral', 'strained relations' and 'lost time'.

**Conclusion:** The delays experienced by patients when attempting to reach an early referral decision in Primary Care cause frustration for those presenting with EI/RA, partly because they do not feel heard. There is a significant impact on patients and their families when referral to specialist care is delayed.

**KEYWORDS**

delays, early inflammatory, patient experiences, primary care, rheumatoid arthritis

## 1 | INTRODUCTION

International guidance for early inflammatory/rheumatoid arthritis (EI/RA) recommends an intense, targeted approach (De Wit

et al., 2011; Deighton et al., 2009; Singh et al., 2012; Smolen et al., 2017). The 12-week time period between first symptom onset and treatment initiation for patients with EI/RA has been referred to as a 'therapeutic window of opportunity' (Van Nies et al., 2015). This

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- In as much detail as possible can you describe your journey from your first symptoms to when you were referred by your GP.
- *[explore patient feelings]*.
- In what ways, if any, have family supported you?
- How long did you have symptoms before seeing your GP?
- How many times to you go and see your GP? How many GPs did you see regarding your problem?
- What, in your opinion, were the factors that influenced the decision to refer?
- *Explore involvement in the consultation.*

TABLE 1 Interview guide

Note: The significance of italics were prompts that the interviewer may have wished to explore further with participants during interview.

'window' is considered the optimal time for prompt disease management: to achieve remission, improve long-term clinical outcomes and reduce risks of joint damage (Byrkerk & Emery, 2010; Stack et al., 2019; Van der Linden, 2010). The time it takes for a patient with early symptoms to navigate their way through Primary Care to a General Practitioner (GP) initiated referral to specialist rheumatology services is crucial in meeting this therapeutic window.

There are three key factors on which timely referral and meeting the window of opportunity are dependent (Sheppard et al., 2008). These include

1. Patient factors: the time it takes for a patient to consult with a GP.
2. Primary care factors: the time it takes for GPs to refer their patient to a specialist service.
3. Secondary care factors: the time it takes for a patient to be seen following referral.

Of these three key factors, the time it takes for GPs to refer their patient to a specialist has most recently been identified as the largest contributor to overall delay (Stack et al., 2019).

The National Clinical Audit of Rheumatoid and Early Inflammatory Arthritis report (2015) identified 20% of EI/RA patients were referred within 3 working days of their GP appointment, with 25% waiting more than 3 months.

'The State of Play in UK Rheumatology' (British Society of Rheumatology, 2015) identifies a lack of condition awareness amongst some GPs as a contributor in referral delay. There is also recognised disparity between clinicians and patient interpretations of shared decision-making (SDM), important in collaborative care. Delays are associated with avoidable complications, for example, unbearable pain, disability, anxiety and can negatively impact on patient-professional relationships (Deighton et al., 2009 & Murray, 2002). The National Institute for Health and Care Excellence (National Clinical Guideline Centre, 2012) clinical guidance (cg138), highlights that professional-patient relationships and patient-centred care are both strengthened by professionals identifying patient health needs, beliefs and preferences. SDM describes a therapeutic approach whereby two experts (patients and clinicians) make decisions collaboratively (Coulter & Collins, 2011;

Elwyn et al., 2012). It represents a middle ground between paternalistic approaches to health care decision-making (whereby the physician makes decisions) and informed choice approaches (whereby patients make decisions) (Charles et al., 1997, 1999; Elwyn et al., 1999). SDM has been assigned as an important collaborative approach to care for all adult NHS services for patients living with long-term conditions, including rheumatological conditions (Diederik et al., 2019; National Institute for Health and Clinical Excellence Guideline, 2018; Sanderson et al., 2019).

Given the important role of both patient and Primary Care factors in relation to early intervention for EI/RA, the adoption of SDM within primary consultations could play a role in reducing treatment delay by facilitating open discussion of key concerns and a consultation outcome which involves full participation and agreement from both the patient and GP. However, to date, there is minimal evidence available exploring these Primary Care factors for referral delay, specifically from the patients' perspective. When considering referral from Primary Care to Secondary Care, it is generally acknowledged that patient involvement is important (Butterworth & Campbell, 2014; NICE, 2018; Sanderson et al., 2019). How patient and GP share in decision-making from the first contact through the transition towards a referral decision, potentially holds solutions to earlier referral into Secondary Care, improving the window of opportunity.

This research forms part of a larger, longitudinal PhD study which has been designed to explore SDM within rheumatology in Secondary Care across four time points (first contact, 3, 6 and 12 months). The focus of this particular phase of the study was to explore Primary Care factors in relation to early referral decisions to Secondary Care. This included exploring patient endeavours in seeking resolve for early symptoms, as well as their experiences in relation to seeking referral by their GP, including any factors deemed to hinder early referral.

## 2 | STUDY DESIGN

Given the lack of research currently available and the exploratory nature of the study, a qualitative design was selected. A semi-

TABLE 2 Inclusion/exclusion criteria

**Inclusion/exclusion criteria**

- Adults 18 years and over
- Individuals who were being referred into rheumatology department from primary care for the first time and subsequently diagnosed with EIA/RA.
- Individuals who were English speaking and able to provide written informed consent.
- Individuals who had not taken immunosuppressive therapies before, such as disease modifying anti-rheumatic drugs (DMARDs).

Abbreviations: EIA/RA, early inflammatory/rheumatoid arthritis; DMARDs, disease modifying anti-rheumatic drugs.

structured interview schedule (see Table 1) was developed and refined, with assistance from South Warwick Foundation Trust patient forum members, to guide the interviews, but they remained participant-led to allow material to emerge as relevant to participants experiences. Interpretative Phenomenological Analysis (Smith et al., 2009) was selected as the research approach and method for data analysis, given the priority placed on individual participant experiences and the role of the double hermeneutic. The double hermeneutic is applied when the researcher actively acknowledges the role of their own interpretations and experiences when seeking to uncover participant interpretations of an experience (Reid et al., 2005). The explicit role of the researcher in forming interpretations based on their own experiences assumed particular importance in this study as the lead researcher (Frances Chilton [FC]) is an experienced rheumatology research and clinical nurse specialist, bringing years of experience working with this patient population within a Secondary Care environment.

### 3 | METHOD

#### 3.1 | Sampling and recruitment

The study was granted NHS Ethics approval (*NHS Ethical approval reference 15/WM/0168*) as well as R&D approval within the recruitment site. Recruitment was conducted from within two hospital outpatient departments, based within a large NHS Acute Trust within the West Midlands region.

Prior to the study commencing, all six rheumatologists at the participant site agreed to identify potential recruits to the study. The lead researcher held an information session to overview the aims and objectives for the study, then provided copies of the inclusion/exclusion study criteria (See Table 2). These were available in all rheumatology outpatient consultation rooms as reminders.

Potential participants were identified and approached about the study towards the close of their initial consultation with their Rheumatologist. This involved sharing brief information about the study and asking for verbal consent from patients for the lead researcher to make contact by phone and provide additional study information. Contact was made by the lead researcher within 48 h of this consent to approach and confirm agreement to enter the study.

Interviews were offered either at the hospital site or at home, according to participant preference. Although the interviews were

TABLE 3 Participant descriptors

Name	Gender	Age	Diagnosis (Sero positive +/-Negative -)
Alice*	F	50 years	RA+
Bev*	F	72 years	RA+
Carol*	F	59 years	RA+
Doris*	F	69 years	RA-
Eddy	M	70 years	EIA-
Freda	F	44 years	RA-
George*	M	71 years	RA-
Henry	M	61 years	RA+
Ian*	M	53 years	EIA+
Janice*	F	45 years	RA+
Karen	F	53 years	EIA-

\*Seven of the 11 participants experienced delays between Primary and Secondary Care.

conducted 1-2-1 (participant-interviewer), participants could be accompanied by a family member/next of kin if they preferred. All participants were interviewed for up to and no longer than 1 h, on the hospital site and three participants chose to be accompanied.

#### 3.2 | Sample

A purposive sampling approach was adopted to recruit individuals presenting with EI/RA symptoms for the first time in Secondary Care, with specific focus on exploration and interpretation of participant experiences. Fifteen patients were referred to the lead researcher. One of these did not fulfil the inclusion criteria and three declined to participate. Eleven patients consented to participate in the study (See Table 3 for participant descriptors). All are identified by pseudonyms. None of the participants attended the same GP surgery and so the participant experiences reflected eleven different GP practices.

As the study progressed, it became clear that a prominent aspect of EI/RA care was the experience of delays between Primary and Secondary Care. Seven of the eleven participants in the study described experiencing delays at this point of their care. The findings from these seven participants are highlighted through this study to enable an in-depth understanding of the perceived reasons and

impact of delay to patients and their family members. These participants are highlighted by \* from the whole sample in Table 3.

### 3.3 | Analysis of findings

Interviews were transcribed verbatim by FC, the audio recordings were then deleted as required by the relevant data management policy. All analyses were undertaken by FC, as per Interpretative Phenomenological Analysis (Smith et al., 2009) with support and confirmation from supervisory team. The first stage of analysis involved reading and re-reading the transcripts so as to become familiar with narratives. From initial notes, emergent themes were developed to reflect early understandings from the data. As analysis progressed, recurrent, interconnected subordinate themes were identified. At the final stage of analysis, a single 'master theme' was developed which reflected findings from the subordinate themes. The master theme was titled 'Navigational Struggles'.

**Findings:** The Master theme, Navigational struggles, reflects participants early contact with Primary Care as they negotiated their journey through the referral process into Secondary Care. Five subordinate themes encompass the master theme: *persuasion of family, lack of continuity in care, pushing for referral, strained relations and lost time* (See Figure 1). These will now be presented in turn.

### 3.4 | Persuasion of family

All participants considered their family and friends to have been influential in their journey to referral. They provided direction and support by influencing participants to confront their symptoms and persuaded them to seek medical opinion;

No, if it was up to me, I still wouldn't be here now. I'd still be taking the pain killers. Oh, everybody has influenced me, it's not just the family it's my customers (Ian).

This persuasion from family and friends appeared to be generated out of concern towards the symptoms being experienced by participants, which were commonly causing physical limitations and impacting on daily life. The impact of symptoms was not limited to participants, but impacted on their family members, a key reason why many family remained persistent when encouraging participants to seek medical help:

I've got a 15 year old daughter at home and obviously she does what she can for me but she has her own life. So, my main support has been my husband and he really helps me with everything (Janice).

When participants had consulted with GPs, family and friends continued to seek involvement and information about next steps and, where referrals had not yet been made, encouraged their family member to persist:

My daughter is a nurse in A+E...I kept her informed and she said I think a referral is asked for to be quite honest (George).

### 3.5 | Lack of continuity in care

All seven participants expressed frustration that they were often required to see a different GP at each visit, rather than a single, preferred GP. Participants shared their views that this disruption to

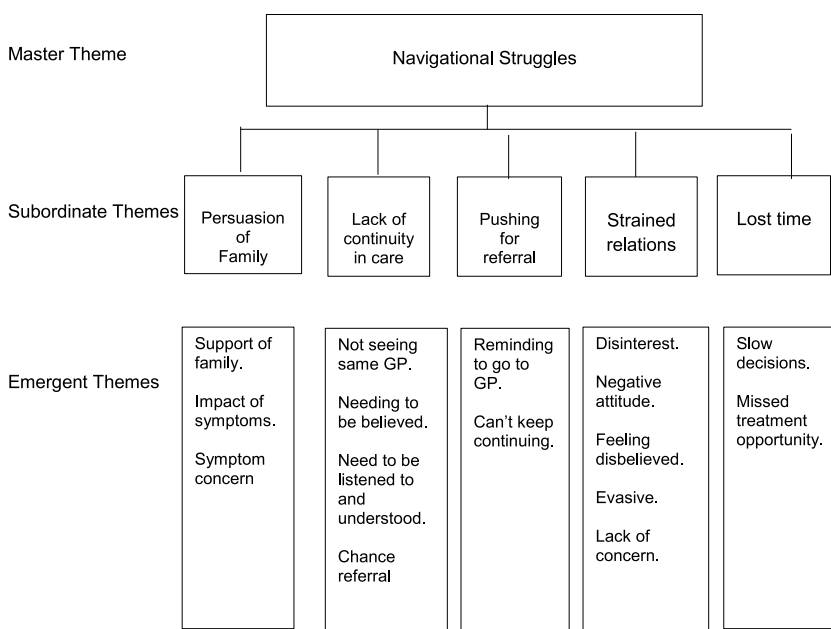


FIGURE 1 Process of analytical development

continuity of care had prolonged their journey to referral and caused them to make multiple appointments in an attempt to resolve their ongoing symptoms and resulting in different medical decisions and suggested diagnoses which prolonged their journey to referral:

I saw three different GPs at different times and they did blood tests and sent me for an x-ray. They didn't seem to come up with much and then on the final time that I saw someone my wrist was also beginning to swell and be painful and he decided to refer me to the clinic. .... (Bev).

I suppose the first time you hope it will just go, that was the first time they puffed up and I had the pills and thought oh that was it., it didn't improve really did it erm, the second time I don't know really...but by the final one (GP)we found a bit more than we were looking for you know we found the answers a bit more I think by Dr Cxxx (George).

This led to participants reporting feelings of confusion, frustration and anxiety in relation to their ongoing symptoms. For some, anxiety and frustration were caused by symptoms worsening, for others, they felt their symptoms were being dismissed and they were perceived to be a 'nuisance patient'

so I felt a bit off mentioning it, that I was a bit of a nuisance and you know...their time is precious and I was totally unimportant (Carol).

We were going back and forth oh, 2-3 weeks in between, probably on a weekly basis because we knew something was wrong because at our practice you can't see the same Dr unless you make an appointment 3 weeks/4 weeks ahead, and we weren't seeing the same person (George).

### 3.6 | Pushing for referral

Not feeling listened to, often despite worsening symptoms, was a key cause of frustration for participants and their family members;

I think if I hadn't been referred when I was then I would have pushed for me to be referred because I felt that I had gone long enough with trying different things. ...I felt frustrated because I could see that it was spreading and getting worse, YES, and my husband was as concerned really because he could see, that things were progressing and not getting any better... (Bev).

Through this journey, participants were required to remain persistent in seeking help, given the ongoing nature of their symptoms;

I did say I ache all the time, I'm tired all the time, which I'd been to the Drs for many a year and I'd been saying this sort of thing. In the end the condition just got worse and worse and all my joints were aching and I was staring to not function properly (Carol).

I had to push for it (referral) because I kept on since last year I was suffering with these symptoms, which have been going on now for over 1 year, now, so I do have to constantly keep going down to the Dr's with the same symptoms and because my left ankle and right hand were swollen that's when he referred me (Alice).

There was little evidence of meaningful patient participation through this process, with participants feeling marginalised through the referral decision-making process;

So I went to the Dr and I asked if it could possibly be Rheumatoid Arthritis, So she did the blood tests and they came back negative and so that was negated, I just couldn't understand it (Doris).

### 3.7 | Strained relations

Participants who expressed a lack of continuity in care, reported indifferent responses from their GPs which included disinterest and negative attitudes. Responses included reports of not being taken seriously;

I'd been to the Drs before and they had picked out swelling that I'd got on my joints and a different Dr would say oh, that's just arthritis in a way that was Oh... that's just not taken seriously (Carol).

Participants commonly felt dismissed within Primary Care and left with the perception that their symptoms were considered trivial;

He just wasn't interested. Erm..... No. It was one of the Drs at the surgery he just said nothing wrong, change your pillows and your 10 min is up go. That's the sort of feeling you get with some of them and even then, I can remember, my ankles had started to swell (Doris).

These experiences led to participants feeling their relationships with GPs were becoming strained. The changing nature of symptoms and the current appointment system within many GP practices (same-day appointments only for the most urgent cases) meant that appointments were often held after symptoms had temporarily resolved, aggravating the perception held by participants that they were not believed by their GPs:

So I went and showed him. I insisted, because he didn't really want to see me. Too busy of course, then I said I desperately need to see you and he said, well can't we do this over the phone, and I said, well I really want you to see this because every time I tend to go, by the time you get the appointment it's gone down hasn't it (Ian).

All of the participants recalled feeling that their GP had been evasive about the possible cause of their symptoms, which could cause a great deal of anxiety and frustration;

I turned up there [GP surgery] after telling him the symptoms on the phone and he got a little book out and started reading it and he'd got a list of the things that it could possibly be and he said I can't tell you what they might be because I'd worry you to death, and I thought Christ, what, just tell me. I mean, I felt like getting the book off him and having a good look see. You know if you start doing that, you start imagining things that are wrong with you (Ian).

yes and I'd just had that one blood test back and I went to see him and he said they had picked a little something up. He was very cagey, he wouldn't say anything; he just picked up a little something up, but this is alright, and that's alright but there's a little something, and but the other levels are fine you know. I felt like saying just tell me then (Carol).

For some participants, their eventual referral was described as a chance event, by seeing a GP with whom they formed a good relationship, or who was keen to listen, or who just happened to have more experience in relation to patients with RA;

so that's when I started to see Dr Jxxxxx by chance and she was, you felt that she listened to you, you know, and understood what you were going through and erm (Doris),

but really you're in the lap of the Gods a little bit aren't you, (George).

### 3.8 | Lost time

When reflecting on their journey to referral, some participants felt that action should have been taken more quickly within Primary Care and were left with a sense of having 'lost time' struggling with their symptoms:

Slow in from the GP point of view, yes, I should have been referred sooner (Alice).

I suppose on hind sight we (wife and George) hoped it would have been picked up a lot quicker and by now the process would have been to start the medication. I think we have lost nearly 2 months probably (George).

Well, they (GPs) should have referred me a lot sooner. They should have really insisted. That I think you have got this and you should have a test at the hospital. That's what I'd do to be fair (Ian).

## 4 | DISCUSSION

Experiences shared by participants with EI/RA in this study, highlighted several challenges faced within Primary Care. These challenges are not exclusive to patients but extend to family members as well. Findings revealed that family and friends offer an important hidden, influential shared network in guiding and encouraging participants in the very early stages of their decision making to seek professional help, as well as providing essential ongoing support at times of concern and frustration.

Seeking support from family and friends when experiencing early signs of EI/RA has also been reported (Sakalys, 1997; Shaul, 1995; Stack et al., 2012). It offers insight into the shared and naturalistic decision making (Klein, 2008); participants in this study used during personal uncertainty pre-consultation with their GP. As such, family and friends become important partners in the journey to referral and could provide support in reducing delays to early referral.

Participants in this study had to remain persistent in order to achieve a referral to specialist services. Their ongoing and often worsening symptoms provided some urgency and motivation in encouraging them to continue to seek help from their GP. This was despite their experiences of feeling disbelieved or dismissed by their GPs. Although personal urgency has been previously identified as a precursor to help seeking in other RA research (Bykerk & Emery, 2010; Diederik et al., 2019; Molbaek et al., 2016; Simons et al., 2017; Stack et al., 2012; Van der Linden, 2010); there has been little recognition of the impact feeling disbelieved or dismissed has on individuals attempting referral. Unlike other RA studies that have reported reluctance by participants to seek help (Kumar et al., 2010; Raciborski, 2017; Sheppard et al., 2008; Stack et al., 2019; Tiwana et al., 2015), this study indicates a key feature of delay is a lack of GP knowledge and apparent triviality assigned to participant reported symptoms. This has only been identified by participants detailed relational aspects of their experiences describing their persistence to have symptoms resolved. Whilst previous studies indicate patients attend GPs from four and up to ten times seeking help, before being referred (Bykerk & Emery, 2010; Diederik et al., 2019; Stack et al., 2019; The King's Fund, 2009), this study revealed how participants, who experienced symptoms for some time, reported repeat visitations to GPs seeking answers in what became a joint endeavour with family to resolve ongoing pain and incapacity.

Participants faced difficulties when seeking consultations in a timely manner with their preferred GP. Access to preferred GPs was not always possible and often resulted in them being seen by unfamiliar GPs. This study identifies how a lack of continuity contributed to inconsistencies in medical decisions and subsequent delayed referral. Participants often attended an appointment with their GP after symptoms had resolved, so the GP had to rely only on their description/recollection of symptoms. There was a sense that GPs were reluctant to refer until they had seen physical evidence of symptoms (e.g., joint swelling) and would not refer on the basis of patient description only. This could be contributing to delays in referral, reducing opportunities for patients to see a specialist Rheumatologist during the important 'window of opportunity' with potentially longer-term consequences for joint damage. In addition, this delay prolonged the amount of time participants in this study had to continue to live with their symptoms, often as their symptoms worsened. The inconsistency in medical decisions, due in part to lack of GP continuity, led to uncertainty and frustration for both participants and family in seeking a resolve to their pain and disability.

Being listened to, believed and understood are fundamental requirements of patient-centred care which did not appear to be consistently experienced by participants in this study. Participants perceived poor interpersonal relationships, unsympathetic attitudes, behaviour and apparent limited understanding of their presenting symptoms as barriers to being believed and understood. Participants believed these barriers played an important role in delaying their referral to specialist care. The recognition by participants of the 'lost opportunity' of an early referral is a cause for concern. As patients learn more about their condition, their sense of dissatisfaction in the care received within Primary Care could grow. The limited reports of any shared discussions between participants and their GPs in relation to a referral decision suggests that attempts towards SDM were minimal. Preliminary findings (not yet published) indicate by adopting a SDM approach within Primary Care could reduce or prevent such referral delays. Therefore, it is important to recognise those patients attending the surgery several times with unresolved symptoms and expedite referral for specialist opinion.

In this study patient symptomology was reported by some patients as *horrendous*, *life changing* and recognised as *lost time*. Some reported symptoms ongoing for over 12 months despite seeking medical assistance on several occasions. Whilst there is recognition of the factors influencing delay and the frequency patients visit their GP, there is limited evidence on the effects that a lack of GP continuity has on communications and sharing in early referral decisions for patients presenting with EI/RA.

## 5 | STRENGTHS AND LIMITATIONS

Whilst this study cannot be representative of patients with EI/RA in the wider rheumatology community, it has to be recognised, there were as many medical practices as there were participants. Patients

would have been happy to have been interviewed longer than 1 h. However, the limitations of interviewing participants no longer than 1 h were respected as stated in ethics application. If interviews had been extended, it is possible more detailed narratives may have been collected.

## 6 | CONCLUSION

This study highlights the experiences of seven EI/RA participants who experienced delays in referral from Primary Care into Secondary Care. Participants reported that they didn't feel listened to, believed or understood and they associated this with their delays to referral into Secondary Care. The consequences of this delay extended from patients to their families, as patients relied on support from their family members in order to pursue their referral. Participants reflected on this as a period of great frustration and perceived that this impacted on their relationship with their GP. Given the physical impact that delays to referral can have for those with EI/RA, additional training and awareness raising amongst GPs about the physical and psychological needs of this group, is recommended.

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## CONFLICT OF INTEREST

Authors declared no competing interests.

## ETHICAL STATEMENT

This manuscript and data is neither submitted nor published elsewhere.

None of the authors have any conflicts of interest to declare.

All co-authors meet criteria for authorship.

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We obtained informed consent from our patients. All patients were informed at time of consent if they were happy to answer some questions relating to this project that would hopefully be published. All patient data have been kept anonymous.

## AUTHOR CONTRIBUTION

The study's research question, study design and analysis plan were conceived by F Chilton as part of PhD thesis with E Bradley and T Mitchell. Data analysis was conducted by F Chilton with support from supervisory team. All authors contributed to the preparation of this manuscript.

## DATA AVAILABILITY STATEMENT

The authors confirm that the data supporting the findings of this study are available within the article.

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