BMJ Open Chronic rhinosinusitis: a qualitative study of patient views and experiences of current management in primary and secondary care

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To cite: Vennik J, Eyles C, Thomas M, et al. Chronic rhinosinusitis: a qualitative study of patient views and experiences of current management in primary and secondary care. BMJ Open 2019;9:e022644. doi:10.1136/ bmjopen-2018-022644

Prepublication history and additional material for this paper are available online. To view these files, please visit the journal online (http://dx.doi. org/10.1136/bmjopen-2018-022644).

Received 1 March 2018 Revised 11 January 2019 Accepted 24 January 2019



http://dx.doi.org/10.1136/ bmjopen-2018-022643



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ABSTRACT

Objectives To explore patient views and perspectives of current management of chronic rhinosinusitis (CRS) in primary and secondary care.

Design Semistructured qualitative telephone interviews as part of the MACRO programme (Defining best Management for Adults with Chronic RhinOsinusitis).

Setting Primary care and secondary care ear, nose and throat outpatient clinics in the UK.

Participants Twenty-five patients consented to indepth telephone interviews. Transcribed recordings were managed using NVivo software and analysed using inductive thematic analysis.

Results CRS has a significant impact on patients' quality of life, affecting their ability to work effectively, their social interactions and daily living. Patients seek help when symptoms become unmanageable, but can become frustrated with the primary care system with difficulties obtaining an appointment, and lack of continuity of care. Patients perceive that general practitioners can be dismissive of CRS symptoms, and patients often prioritise other concerns when they consult. Health system barriers and poor communication can result in delays in accessing appropriate treatment and referral. Adherence to intranasal steroids is a problem and patients are uncertain about correct technique. Nasal irrigation can be timeconsuming and difficult for patients to use. Secondary care consultations can appear rushed, and patients would like specialists to take a more 'holistic' approach to their management. Surgery is often considered a temporary solution, appropriate when medical options have been explored.

Conclusions Patients are frustrated with the management of their CRS, and poor communication can result in delays in receiving appropriate treatment and timely referral. Patients seek better understanding of their condition and guidance to support treatments decisions in light of uncertainties around the different medical and surgical options. Better coordinated care between general practice and specialist settings and consistency of advice has the potential to increase patient satisfaction and improve outcomes.

INTRODUCTION

Chronic rhinosinusitis (CRS) is a prevalent inflammatory condition of the mucosa of the

Strengths and limitations of this study

- ► The interviews permitted exploration of patient views of living with chronic rhinosinusitis (CRS) and helped to understand the treatment pathway from the CRS patient perspective.
- The study included patients from both primary, secondary and tertiary care, representing the views of patients at different stages of their CRS journey.
- It is unclear whether our sample of patients was similar in characteristics to the non-responders. It is possible that our primary care sample represents a group of patients with more severe or troublesome CRS symptoms.
- The views and experiences of the healthcare professionals responsible for the patient care are not included but are presented elsewhere.

nose and paranasal sinuses, in the presence (CRSwNP) or absence (CRSsNP) of nasal polyps. Prevalence rates are approximately 10% in the UK¹ and data from the Clinical Practice Research Datalink estimate that 1% of UK adults receive treatment annually in primary care.² With an estimated 120000 outpatient consultations and 40000 sinus operations per year in England and Wales,³ CRS contributes a significant burden to National Health Service healthcare resources.

Patients with CRS typically report symptoms of nasal congestion, nasal discharge, facial pain/pressure and anosmia which can have a significant effect on health-related quality of life.4 5 Research has found the impact of CRS to be equal to or greater than other chronic diseases such as congestive heart failure, angina and chronic obstructive pulmonary disease,⁴ and the extent of impact has been found to affect patient CRS treatment decisions.6

Treatment for CRS may include self-management techniques, topical and oral



medical treatments and surgery. However, patient expectations and experiences of CRS management have yet to be fully explored. Preliminary qualitative research identified patients' frustration with inadequate treatment and lack of coordinated care⁷; hence, further work is required to better understand the patient pathway in terms of patient–practitioner interactions, decision-making for treatments and indication for referral. There may also be differing views between healthcare professionals and patients regarding the severity and impact of sinus disease⁸ which needs exploring in light of its potential effect on the patient pathway.

This paper reports a qualitative interview study exploring CRS patients' views and experiences of living with CRS and aims to understand the treatment pathway from the patient perspective. Views and experiences of general practitioners (GPs) and ears, nose and throat (ENT) specialists are also explored as part of this work but presented elsewhere. This study is part of the wider National Institute of Health Research supported MACRO programme (Defining best Management for Adults with Chronic Rhinosinusitis) that the define best practice for treating and managing patients with CRS.

METHODS Design

A qualitative interview study with a purposive sample of primary care and secondary care patients with CRS.

Participants and procedures

Patients with CRS were recruited through general practice and ENT clinics in the UK between January and April 2017. GP practices were purposefully selected based on practice demographics and geographical location to include rural and urban practices in the south and east of England. ENT clinics were recruited in similar geographical locations to identify patients who had experience of secondary care management in the same regions.

Primary care patients with a documented diagnosis of CRS were identified using a search of electronic primary care medical records. One hundred and five patients from three general practices were sent a study pack containing an invitation letter and information sheet, and 27 expressed their interest by returning a reply slip to the research team. Additionally, 23 secondary care patients with a diagnosis of CRS according to the European Position Paper on Rhinosinusitis and Nasal Polyps (EPOS) guidelines¹¹ from two ENT clinics were given a study pack during their consultation which resulted in a further 12 patients expressing interest in taking part. The reply slip also asked patients to rate how problematic their CRS symptoms were using a visual analogue scale ranging from 0 (not a problem) to 10 (worst thinkable). Patients were purposefully sampled to take part in a research interview using a range of characteristics including age,

gender, severity of CRS symptoms, symptom duration, self-reported polyp status and previous sinus surgery.

Interviews

Semistructured interviews were conducted by a trained interviewer (IV), each lasting approximately 25–55 min. IV (female) is a trained qualitative research fellow for the MACRO programme, who was not previously known to the respondents. Interviews were conducted by telephone to facilitate the inclusion of patients from a wide geographical area. An interview guide was developed through discussions with the wider MACRO Programme research team and piloted with a patient contributor (IS) (see online supplementary appendix 1). The guide was used to structure the interview but remained sufficiently flexible to explore unforeseen topics and concerns. Field notes were made during the interview to facilitate interpretation and contextualisation of the interview data. Verbal consent was given by each patient prior to commencing the interview.

Patients were asked to describe their experiences of CRS, explain how they sought help and treatment and describe their experiences of different treatment options available in primary and secondary care. The interviews were audio-recorded and transcribed verbatim in preparation for analysis. We took a pragmatic approach to research design and methods, and our epistemological position was one of subtle realism. New participant interviews continued until data saturation was achieved, that is, no new themes were emerging.

Analysis

Data management was facilitated through the use of NVivo V.11 qualitative analysis software, and inductive thematic analysis¹³ was used to analyse the transcribed data. The analytical process commenced with familiarisation and immersion in the data itself, by both rereading transcripts, listening back to the recorded interviews and reviewing the field notes. Initial ideas and concepts were noted. Sections of the data were then systematically coded using descriptive labels. Coding decisions were discussed at an early stage with another member of the MACRO team (CE). This brought an additional perspective to the analysis and provided the opportunity to settle uncertainties and reach agreement. Codes were then merged, grouped together, refined and relabelled resulting in a set of themes and subthemes which systematically and thoroughly explained the data. Data collection and analysis took place concurrently, and interviews continued until no new themes were emerging and thematic data saturation was achieved.

Patient involvement

A patient contributor from the MACRO programme management group provided input into the design of the study and contributed to the development of the interview topic guide. A second patient contributor (IS) helped to

Table 1 Participant characteristics	
	n=25
Male	14
Female	11
Age (median, range)	50 (20–74)
Ethnicity	
White British	22
White Latin American	1
Black African	1
Asian	1
Deprivation score (proxy measure using postcodes)	6.5 (3–10)
Recruited via primary care (National Health Service [NHS] trust/practice location)	n=17
NHS Cambridgeshire/rural village	9
NHS Lewisham/urban-major conurbation	2
NHS Southampton/urban city and town	6
Recruited via secondary care	n=8
Salisbury NHS Foundation Trust/urban city and town	1
James Paget University Hospital NHS Foundation Trust/rural town and fringe	7
Severity of chronic rhinosinusitis (CRS) (visual analogue scale 0–10) (mean,range)	7 (3–10)
Time with CRS (years) (median, range)	10 (1–40)
Nasal polyps (patient report)	
With nasal polyps (CRSwNP)	14
Without nasal polyps (CRSsNP)	11
Previous secondary care consultation	
Yes	21
No	4
Previous sinus surgery	
Yes	10
No	15

pilot the interview guide and reviewed and commented on drafts of this manuscript.

RESULTS Participants

A total of 25 patients participated in a telephone interview. The median age was 49 years (range 20–74) and 14 (56%) were male. Included participants had a median history of CRS of 10 years (range 1–40); 56% of participants reported being diagnosed with nasal polyps (CRSwNP) and 40% reported previous sinus surgery. Patient characteristics are presented in table 1.

Themes

Thematic analysis identified four main themes relating to patient views and experiences of CRS management

Table 2 Themes and subthemes of the analysis		
Themes	Subthemes	
1. Recognising impact	Living with chronic rhinosinusitis Impact on work and social life Accepting and normalising	
2. Seeking resolution	Self-managing symptoms Medical treatment options	
3. Healthcare interactions	Primary care consultation Expectations of secondary care	
4. Surgical intervention	When surgery is acceptable Decision-making for surgery Anticipated outcomes	

(table 2). Quotations are presented to illustrate the themes and subthemes, with details of the participants presented in parentheses.

Theme 1: recognising impact Living with CRS

CRS was commonly described as annoying and frustrating for participants, especially if their symptoms adversely affect their daily life. Others report feeling depressed, sad and upset about their condition, which in turn can result in a feeling of lack of confidence.

I think the worst thing about it overall is if you don't keep on top of it, it can be amazingly depressing. (P25, male, CRSwNP)

Many participants described feeling embarrassed and self-conscious about their condition, especially when constant nasal discharge or nasal congestion affects ability to speak clearly in social or work situations.

In my job I have to talk to people and obviously when I have a blocked nose my words are not so clear. I'm a lecturer so I have to speak in front of students, it's uncomfortable. (P16, male, CRSwNP)

Impact on work and social life

Poor or disrupted sleep associated with CRS was commonly reported, leading to tiredness and fatigue, and consequently affecting ability to concentrate and be fully effective at work.

It's more like actually in my nose and up to the eyebrow area, but then it's also just mainly fatigue as well, that's a big part, feeling completely drained. (P20, female, CRSsNP)

Participants with a loss of smell and taste often reported reduced enjoyment in socialising and eating out.

Eating food was a necessity, not a nicety because there was no real pleasure. I could order the best steak on the menu, but I didn't have a scooby doo of whether it tasted it good or not. (P25, male, CRSwNP)

Others expressed concerns about potential risks and hazards of being unable to smell, especially being unable to detect gas leaks, burning or perished food.

There's also a danger element as well, you know, if something's burning, I cannot smell it so that's quite important for me. (P10, male, CRSsNP)

Accepting and normalising

Participants discussed ways of learning to live with the symptoms of CRS, describing it as just becoming part of their normal lives. Others described forgetting what it was like to be 'normal', or report moving to a 'new normal' of accepting that they are no longer able to smell.

I mean, I lost my sense of smell eight, nine years ago, so it's sort of - I've lived with it for a long time, and at the end of the day, I end up living with it. (P2, male, CRSwNP)

Participants described how they adapted to life with CRS, including always being prepared for symptoms to occur and taking preventative measures to reduce symptoms.

I can never leave the house without tissues, hankies, I've always got them, even in the summer time. (P11, female, CRSsNP)

Others with a loss of smell and taste described ways of managing their symptoms to prevent judgement by other people.

I have customers [as a waitress] that do ask me, 'What does that taste like?' I have to almost lie, ... I'm trying to learn and get to the stage where is it better to just pretend I can smell and taste. (P24, female, CRSsNP)

Theme 2: seeking resolution Self-managing symptoms

A number of methods for self-managing their CRS symptoms were reported by participants. Some use steam inhalation during acute exacerbations, often adding herbs and oils to clear congestion and sooth facial pain and pressure, although several expressed doubt about its effectiveness.

I find that helpful. It does relieve certainly the pain. My nose just streams. It's like I've got a stream coming out of my nose but it does relieve the pain. (P17, female, CRSsNP)

The use of over-the-counter medical treatments such as decongestants, pain relief and nasal sprays for symptom management was commonly reported with mixed results. Some participants sought relief with complementary therapies such as acupuncture and reflexology, while others used dietary modification but reported that this could be restrictive and difficult to maintain.

Certain foods seem to make it worse than others, and I've had a nutritionist for quite a while who, on three occasions, has sorted my symptoms out, but the dietary restrictions are so awful I end up lapsing and going back eating normal food again. (P9, male, CRSwNP)

Medical treatment options

Most participants reported using nasal steroid sprays, describing them as a rescue or maintenance treatment, which helped manage their symptoms. However, some reported difficulties in remembering to use regularly, while others stopped using the sprays if they did not see an improvement.

It should be a daily thing, but I'll forget or I'll think oh, I'm all right, I don't need to take it, but maybe then I don't know if it just needs to be part of a normal routine for me to do it all the time. I do miss days. (P19, female, CRSsNP)

Some concerns were expressed about not using the sprays in the correct way, resulting in the spray remaining in the nose and not reaching the sinuses. In some cases, the nurse or GP were helpful in describing or demonstrating how to use the sprays correctly.

Now, my trouble with that is getting it into the right area. My doctor has kind of told me how to do it, but it's awkward. It is difficult, and I'm not in any way convinced that I've actually got it in the right area. (P9, Male, CRSwNP)

A number of participants reported using nasal irrigation on recommendation from ENT specialists, and while some found it beneficial in clearing nasal passages, others found the technique awkward or time-consuming.

To be honest, I don't think I would do that because for work days, I get up at quarter to six, and sitting there then with that nasal douche thing going up one nose and down the other, I haven't got time for it. (P19, female, CRSsNP)

Most participants had some experience of antibiotics for their CRS, describing their potential benefits when symptoms were severe or when there was a possibility of an underlying infection. Some concerns were raised about associated side effects, with reports of stomach problems associated with some antibiotics, while others reported concerns about emerging antibiotic resistance.

The only thing, my concern is with the antibiotics because I know my stomach is very sensitive. I know with antibiotics then I have stomach problems so that's why I told you that I wasn't a fan of antibiotics. (P3, female, CRSsNP)

Theme 3: healthcare interactions *Primary care consultation*

Participants reported consulting the GP when their symptoms of CRS worsened or became unmanageable with self-management or prescribed medical treatments.

However, participants often described difficulties getting a GP appointment.

It's very hard to get an appointment now and our doctors, especially at the moment, it's that we're low on doctors and I think that that's such a shame because you are stressed at home and you want to see somebody (P24, female, CRSsNP)

However, when participants do consult in primary care, some described not prioritising their CRS especially if they had other health problems. Others described not wanting to burden the healthcare system by booking multiple appointments.

But to be fair, because I've got a lot of other health problems, they kind of outweigh that, and you know you're only allowed to see the doctor about one or two things. (P1, female, CRSsNP)

Participants often described frustration about not being listened to by their GPs, or the GPs being dismissive or disinterested in their symptoms of CRS and not understanding the full impact on the participants' lives.

So that would be nice, for people, or doctors, to actually recognise that it actually is as painful as you're telling them it is. (P11, female, CRSsNP)

Participants often report difficulties in seeing the same GP at subsequent visits which could result in a lack of continuity of care. Others suggested that multiple visits were often needed before getting the right treatment or onward referral.

It was a long process because you keep going back to the GP over a period of months and months, probably a year or so, to finally make them realise. (P22, male, CRSwNP)

Expectations of secondary care

Consultation in secondary care is described as important to understand what is causing their symptoms, especially if symptoms have been present for a long time.

Seeing as it has been going on for so long now, I really think that I should be referred to the hospital and investigated to actually see if there's anything else going on up there that's causing it. (P1, female, CRSsNP)

Participants recount undergoing a series of tests and examinations for the specialist to make a diagnosis of CRS. However, some expressed the view that specialists do not always take a 'holistic' approach to CRS especially if participants have asthma and allergy, and are not always open-minded to other causes or treatments for CRS.

I have felt sometimes specialists should be able to see the problem in a wider context. (P16, male, CRSwNP)

Some participants feel rushed through the consultation without being given time to ask questions and have them answered satisfactorily. Others were frustrated with the

time between clinic appointments, and also reported a lack of continuity due to follow-up with different specialists (eg, consultants, registrars, staff grades, etc). This contributed to reduced satisfaction with the secondary care system.

I would be sent off to try something for three months but it would be 11 months before I saw them again. (p21, male, CRSwNP)

Theme 4: surgical intervention When surgery is appropriate

Some participants described an expectation for further medical management when consulting the ENT specialist for the first time and often wanted to try additional medical options first prior to being considered for sinus surgery.

To be honest with you I haven't really thought about surgery, I don't like being put under to be honest. That would be my really, really, really last resort. (P11, female, CRSsNP)

However, others had a high expectation of surgery and considered surgery to be offered too late in the patient journey.

Yes, surgery obviously is always looked at as a final thing, which I disagree with because it was the best and the only thing for me and if they had done that 11 months earlier I think it would have made everyone's life a lot easier. (P20, male, CRSsNP)

Participants were variously concerned about the risks associated with surgery, including the general anaesthetic, discomfort, and the possibility of making things worse. Surgery also requires time off work which was not always possible for participants. However, most would only consider surgery if it resulted in a significant improvement in symptoms and was more than just a temporary solution.

Whilst I accept there might not be a total cure, if it wasn't a very significant improvement, then frankly in my opinion, it probably wouldn't be worth it. (P7, male, CRSsNP)

Decision-making for surgery

Participants reported relying on the ENT surgeon to decide whether surgery was the best option for them. However, participants who reported having nasal polyps often described being advised by the specialist for early surgery.

They often say, 'Well, no, it's your choice', and I'm like, 'Well, hang on, you are the expert... They know the potential benefits. I don't, so I go with the doctor and if the doctor thinks I should have surgery, I'll have surgery. (P9, male, CRSwNP)

Participants with nasal polyps described a good understanding of what surgery was trying to achieve; however, participants without polyps were less likely to understand the purpose of sinus surgery.

I don't know what they could do for me, when I don't have polyps and I don't have a blockage. (P24, female, CRSsNP)

Anticipated outcomes

Sinus surgery was often described as a temporary solution, with expectation that symptoms would return and further surgery may be required.

I presume I'm likely to need at least one more, two, three more operations before my lifetime, and as and when the symptoms get bad then yes, I don't really see there's much choice. (P15, male, CRSwNP)

Many participants described acknowledging that there is no definitive answer for their CRS and recognised that they would require ongoing treatments to manage their symptoms.

I have been told that it is chronic; I have to take nasal sprays all the time which was a bit inconvenient for me. They said there's no quick cure for it, even surgery doesn't solve the problem. (P16, male, CRSwNP)

DISCUSSION Summary

CRS has a significant impact on patients' quality of life, affecting their ability to work effectively, their social interactions and daily living. Patients seek help when symptoms become unmanageable but can become frustrated with the primary care system, with difficulties obtaining an appointment and with lack of continuity of care. GPs can be perceived as being dismissive of CRS symptoms and patients often prioritise other concerns when they consult. This lack of acknowledgement and communication can result in delays in accessing appropriate treatment and referral. Adherence to intranasal steroids is a problem and patients are often uncertain about correct application. Nasal irrigation can be time-consuming and difficult for patients to use. Secondary care consultations can appear rushed, and patients would like specialists to take a more 'holistic' approach, by considering CRS management in the wider context of the patients' overall health and well-being. Surgery is often considered a temporary solution, appropriate when medical options have been explored.

Comparison with existing literature

Previous work has identified that the impact of CRS can range from a minor inconvenience to having significant implications for patients' social activities and employment. While our study described similar effects on patient quality of life, it also identified that patients were

often embarrassed and upset by their symptoms, and this could affect their confidence in social situations and ability to work effectively. Zhou $et\ al^{15}$ found a strong association between sinonasal diseases and depression symptoms, while a study by Erskine $et\ al^{16}$ found that depression and anxiety were significantly more common in patients with CRS compared with healthy controls. Patients in our study also described depression and anxiety associated with their sinonasal symptoms and the impact on their daily lives.

The chronic nature of CRS means that patients often accept and normalise their symptoms, and our study found that patients do not always prioritise CRS when they consult their GP, especially if they have significant comorbidities. However, when patients do consult, GPs can be dismissive or underestimate the impact of the symptoms. A study of 100 physicians in the USA similarly found that ~30% underestimated the impact of allergic rhinitis on patients' ability to work, ¹⁷ although it could not be established whether this affected treatment decisions.

Maximum benefit from medication is best achieved if patients use their treatments correctly and for the prescribed amount of time. Intranasal steroids are an important and established treatment for CRS 1920; however, compliance can be variable. In Our study highlighted that intranasal steroid use can be suboptimal in primary care either due to incorrect use of nasal sprays or premature discontinuation of treatment. Patients described being uncertain about correct use and reported limited information or training from healthcare professionals.

Nasal irrigation was only rarely used in primary care, while more commonly recommended by ENT surgeons. Patients generally found the technique time-consuming and uncomfortable, although some patients reported it to be acceptable if they were shown how to use it correctly. This is consistent with a recent primary care study²² which found nasal irrigation to be an acceptable procedure that could relieve symptoms in patients with recurrent or chronic rhinosinusitis. However, detailed and clear patient information, together with perseverance with treatment, may be required to improve uptake and usage over the longer term which has been shown to be poor at the point of referral to secondary care. ²¹ There may be an important role here for pharmacists, who are accessible to patients for advice and support without requiring an appointment. Community-based pharmacists have been shown to significantly improve inhaler use for patients with lower respiratory disease, a technique which similarly requires good instruction and technique training.²³

Despite valuing the secondary care consultation, patients can become frustrated with a lack of understanding of their CRS symptoms, the extended time between appointments and a perceived lack of holistic approach especially if they had comorbidities such as asthma. These findings are consistent with previous qualitative work which reported that CRS patients can be dissatisfied with the lack of an integrated approach to upper and lower respiratory conditions.²⁴ The coexistence of CRS and asthma

and allergic rhinitis is well documented^{25–27} which has led to the concept of a united airway disease. This may necessitate the use of coordinated care strategies to better address these different manifestations of airways disease, with the view to providing better overall management and improving patient satisfaction and compliance with treatment.

Patients in this study reported mixed views about sinus surgery for their CRS, which appeared to be related to previous surgical procedures, severity of symptoms, polyp status and effectiveness of medical treatments. Additionally, many patients report wanting to explore medical treatment options prior to being considered for surgery. While other work has explored patient views about the impact of CRS and its management, this is the first study to specifically explore patient views of treatment options and referral pathways for CRS and will help to understand the decision-making process from the patient perspective.

Implications for practice

Patients perceive that clinicians do not always appreciate the severity and impact of CRS and can become dissatisfied with management. Better recognition of CRS and the impact it has on patients' lives has the potential to improve early management in primary care and enhance the precision of referral. Patients also perceive that they do not get enough information and find some things difficult. Better communication between patients and clinicians and involving patient in treatment decisions have the potential to increase patient satisfaction and improve compliance with treatment options. More efficient delivery of care (eg, appointment viability, reductions in clinic waiting times) also has the potential to improve patient-perceived barriers and causes of frustration and delay.

Strengths and limitations

A key strength of this study was the recruitment of patients from primary, secondary and tertiary care, from urban and rural parts of the UK. This allowed us to capture the views and experiences of patients at different stages of their CRS journey, from a range of locations with differing local services and referral pathways. It would be interesting to explore whether views and opinions differed between demographic groups, but this was not the focus of our evaluation.

Our sample included patients with both CRSsNP and CRSwNP who had experience of a range of self-management techniques, medical and surgical interventions. However, it is unclear whether the demographics of primary care sample was similar to the non-respondent group. There are many reasons why patients do not respond to invitation letters for research; however, it is possible that our primary care sample represents a group of patients with more severe or troublesome CRS symptoms.

The MACRO study is situated in the UK, and it is possible that CRS patients' experiences in different countries and

healthcare systems may vary from those reported in the UK. Although we feel that our findings are likely to be relevant to countries with similar patterns of CRS management in primary and secondary care, replication in other settings would be required to confirm this.

Rigorous methods were employed to ensure credibility and trustworthiness of the findings of this study, including constant comparison techniques, multiple coders and a transparent audit trail.

CONCLUSION

In summary, our qualitative study identified that patients can become frustrated with the management of their CRS, and impact on quality of life is not always recognised. Better coordinated care between general practice and specialist settings, with evidence-based treatment options and a clear, integrated care pathway, is needed to optimise CRS patient management across both settings. The MACRO programme also included a qualitative study exploring primary and secondary care clinicians' views of CRS management, which has recently been published.⁹ These two qualitative papers should ideally be considered in conjunction, and their findings have helped inform the trial design in MACRO. Together with the trial findings, they will help to formulate new recommendations for the management of patients with CRS across primary and secondary care.

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Acknowledgements The authors would like to thank the CRS patient participants who contributed and made this study possible.

Contributors The protocol was developed by CE, MT, CMP, CH, AS, PL and HB. IS helped to pilot the interview guide. JV led the data collection and analysis, with academic contributions from CE, MT, CMP and CH. IS provided a patient perspective during analysis and interpretation. JV drafted the manuscript and coordinated the revisions from the authors. All authors read and approved the final manuscripts.

Funding This paper presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research (PGfAR) Programme (Grant Reference Number RP-PG-0614-20011).

Disclaimer The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health

Competing interests None declared.

Patient consent for publication Not required.

Ethics approval The study was given ethical approval by the Health and Social Care Research Ethics Committee A (HSC REC A) on 22 September 2017 (Reference number: 16/NI/0197).

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data are available.

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