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Abstract

Background. The COVID-19 pandemic has profoundly affected UK primary care, and as a result the route to cancer diagnosis for many patients.

Aim. To explore how the pandemic affected primary care practice, in particular cancer suspicion, referral, and diagnosis, and how this experience evolved as the pandemic progressed.

Design and Setting. Seventeen qualitative interviews carried out remotely with primary care staff.

Methods. Staff from practices that expressed an interest in trialling an electronic safety-netting tool were invited to participate. Remote, semi-structured interviews were conducted September 2020 to March 2021. Data analysis followed a thematic analysis and mind-mapping approach.

Results. The first lockdown was described as providing time to make adjustments to allow remote and minimal contact consultations but caused concerns over undetected cancers. These concerns were realised Summer and Autumn 2020 as our participants began to see higher rates of late stage cancer presentation. During the second and third lockdowns patients seemed more willing to consult. This combined with usual winter pressures, demands of the vaccine programme, and surging levels of COVID-19 meant that the third lockdown was the most difficult. New ways of working were seen as positive when they streamlined services but also unsafe if they prevented GPs from accessing all relevant information and resulted in delayed cancer diagnoses.

Conclusion. The post-pandemic recovery of cancer care is dependent on the recovery of primary care. The COVID-19 pandemic has highlighted and exacerbated vulnerabilities in primary care but has also provided new ways of working that may help the recovery.

Key words: General practice, cancer, COVID-19, remote consulting, early diagnosis

How this fits in

The Covid-19 pandemic caused huge disruption to primary care services and as the majority of cancers are first detected in primary care these changes would have impacted the normal routes to cancer diagnosis.

Our participants described how the initial decrease in patient consultations allowed them to reconfigure their practices, but also resulted in higher rates of late cancer presentations and diagnosis after the first lockdown.

During the second and third lockdowns, our participants described how they used all means available to them to get patients who had already experienced delays investigated.

The greater use of technology during the consultation was thought to help with streamlining some processes, but our participants were also cautious about how easily vital information could be omitted and prevent the GP from seeing the full picture of the patient's condition or make the use of clinical intuition difficult.

Our results illustrate how the balance was tipped in favour of reducing the risk of SARS-CoV-2 during the COVID-19 pandemic to the detriment of the assessment of cancer risk.

Introduction

The COVID-19 pandemic which was officially recognised by the World Health Organisation in March 2020 (1) has had a profound impact on health care in the United Kingdom (UK). The UK government managed COVID-19 through a series of lockdowns (2) (see Figure 1) which put substantial restrictions on activities of the public and businesses, and mandated a pause to all but essential healthcare with limited face-to-face contact (3, 4). The pandemic initiated significant changes in ways of working as efforts were made to maintain provision of care under these conditions (5). The impact on primary care in particular has been substantial as it provides 90% of clinician-patient contacts in the English National Health Service (NHS) through almost one million consultations daily (6, 7).

At the beginning of the pandemic, NHS England instructed all general practitioner (GP) practices to adopt a ‘total triage’ model where patient requests were triaged, the majority of consultations took place remotely, and face-to-face appointments were provided to those for whom it was deemed necessary (8) In April 2020 the British Medical Association and the Royal College of General Practitioners issued guidance on prioritising clinical activities using a red (should be postponed if prevalence of COVID-19 is high), amber (should continue if time and resources allow), and green (should continue regardless of prevalence of COVID-19) system (9). One ‘green’ activity was the assessment of new potential cancers, although it was also recommended that investigations were done remotely if possible and referrals made without seeing the patient.

GPs are central to cancer diagnosis in the NHS. In 2017, 62% of new cancers were detected through referrals made by GPs (10). However, only a small proportion of presentations to primary care result in serious disease diagnosis (11). Many patients later diagnosed with cancer present with non-specific symptoms making tools like clinical intuition and safety-netting, the practice of advising patients of what concerning symptoms to look out for and when to re-consult when there is uncertainty in the initial diagnosis, particularly important (11-15). These essential components of the consultation were markedly disrupted when face-to-face consultations were largely replaced by telephone or online alternatives to combat SARS-CoV-2 transmission (16).

While some research has examined cancer diagnosis in primary care during the first English lockdown (17, 18), no study has reported on the how the situation evolved throughout the following year. In March 2020 we launched the CASNET2 study (19), shortly before the start of UK government’s measures in response to the COVID-19 pandemic were put in place. The purpose of the study was to trial a new EMIS-compatible electronic safety-netting tool in general practice. In light of the increased pressures on primary care from the pandemic, it was decided that the CASNET2 study would be paused to allow practices to focus on their COVID-19 response. However, we wanted to take the opportunity to speak to staff from practices who had already expressed a willingness to take part in research about their experiences during the pandemic. Staff from practices randomised to trial the tool as well as staff from practices who had expressed an interest but had not been randomised were contacted and asked if they would like to take part in an interview study. The aim of this study was to discuss the experience of NHS primary care staff throughout the three English lockdowns and explore how the detection of cancer functioned during the pandemic.

Method

Recruitment

Participants were recruited through their practice's participation in our CASNET2 study. The practices involved in the CASNET2 study were all located in England, and both randomised and non-randomised practices were invited as we were recruiting during a period where pressure on primary care was high and so a larger number of practices to recruit from would help us recruit a sufficient sample for this study. Staff were told that the interviews were to explore their experiences during the COVID-19 pandemic, particularly in relation to how patients presented, were investigated or safety-netted, and followed-up when they had symptoms that could indicate cancer. Any staff member involved in the care of patients or organisation of the practice could participate. All staff who responded to the invitation were interviewed.

Patient and public involvement (PPI)

CASNET2 has a PPI panel that has met regularly throughout the project. Before the interviews began, the panel met to discuss the project priorities and the areas of safety-netting and cancer care that were of interest to patients. This was considered when writing the interview schedules but the PPI group did not have direct input into them. Since the commencement of the interviews, the panel has met to discuss the findings and highlight important results from the patient perspective.

Interviews

Semi-structured interviews lasting an average of 43 minutes (range 30-57 minutes) were conducted by CFS between September 2020 and March 2021 (see Figure 1) either over the telephone (2 interviews) or over Microsoft Teams (15 interviews). CFS monitored the interviews for data saturation (20) and judged that it had been reached at the beginning of March 2021. Indeed during the analysis, see below, no new themes arose after interview 12. Any primary care staff, however, who volunteered to take part after this were still interviewed to gather additional support for and perspectives on the themes. Written informed consent was obtained from the interviewees, and was confirmed at the start of each interview. Interviews began with a discussion of the interviewee's career to date, and the size and make-up of their practice, before considering their experience of the COVID-19 pandemic and its impact on cancer care. The interview schedule is available in Supplementary File 1.

Analysis

The interviews were digitally recorded, transcribed verbatim and transcripts were uploaded into NVivo (version 12). Thematic analysis (21) was used to generate codes from the data and collate these into themes by CFS. Issues arising within the themes and links between the themes were mapped using a mind-mapping 'one sheet of paper' (OSOP)(22) method. A summary of the themes and the issues arising within them was produced by CFS and presented to the rest of the research team and the PPI group for discussion. Following these discussions, the summaries of the themes deemed to be of most interest and importance formed the narratives of each theme reported herein and informed our implications for research and practice in the Discussion.

Reflexivity Statement

Dr Claire Friedemann Smith is senior non-clinical primary care researcher. She has Bachelors and Masters degrees in psychology and a DPhil in primary care research. She is a mixed methods researcher and has spent ten years in cancer and primary care research and twelve years in research in total. She has conducted qualitative research with members of the public including adults and children, and with health care professionals.

[Figure 1 about here]

Results

Interviews were conducted with 17 primary care staff from 17 practices (see Table 1). Seven of the interviewees were women, ten were men, and they had been qualified for between one and thirty years.

[Table 1 about here]

First lockdown

Impact of primary care generally

In general, the participants characterised the first lockdown as *"a very very uncertain time"* (P12, F, February 2021) of rapid change when being flexible was essential. The long quotation from P12 in Box 1 is representative of the experiences of our participants who described reconfiguring their Practice including the carpark and outdoor areas, the creation of 'hot' and 'cold' teams, and the introduction of enhanced hygiene procedures.

[Box 1 about here]

Participants said that during this initial phase of the pandemic there was a lack of strategies from administrative bodies that lead to anxiety amongst Practice staff, even *"blind panic"* (P16, M, March 2021), and confusion.

[at the beginning of lockdown 1] I think the PCNs [Primary Care Networks] were still working out a strategy for face to face, because the, even the practice was waiting on PPE [Personal Protective Equipment] and all those kind of things, to make it safer. But [with] video and telephone consultations, GPs were still working. (P01, M, September 2020)

The messaging that was directed at the public, however, was seen as highly effective at deterring patients from contacting General Practice. Participants described an initial dramatic reduction in the volume of patients requesting consultations. During this time, practices took the opportunity to prepare and get *"geared up for remote working"* (P07, M, December 2020).

The uncertainty experienced during this time also extended to patient care. Uncertainty was experienced regarding whether and when patients could be followed-up and what would happen once the patient was referred. These uncertainties had implications when cancer was suspected and are discussed in the next theme.

Impact on cancer diagnosis

During the first lockdown, participants described how the infrequency with which they saw patients meant that when and how they could follow-up a patient was uncertain if there was no immediate reason for the patient to be referred. This added difficulty to managing patients with non-specific symptoms where an undiagnosed cancer was a possibility, and required staff to balance the risk of cancer and the risk that either the patient or the staff member caring for them would catch COVID-19.

[I]t kind of felt like you were releasing them into the wild and might not be able to follow them up for a long time. (P05, M, November 2020)

[I]t's weighing up that risk benefit to the patient, […] how worried am I about this patient? Can it wait a little while? […] is it worth the risk for this patient, and the staff, […] if that phlebotomist went and caught Covid from that patient, could I justify doing that blood test? (P04, F, October 2020)

Under these circumstances, participants described how they might agree some next steps with the patient. These steps ranged from requesting updates or actively following up patients more frequently, to signposting and referrals to other healthcare professionals and could be facilitated by the new digital tools available to GPs and patients.

[I]t's so easy for them to keep me posted with the symptom now [referring to eConsult] […] you have a lot more tools at your fingertips (P05, M, November 2020)

With the decrease in patients presenting to primary care during the first lockdown, participants described a drop in suspected cancer cases which some perceived may have resulted in more advanced cancers presenting during Autumn 2020.

So last week in two days I saw three late presentations of melanoma, […] and they had been left from March, cos they'd first noticed them in March, but hadn't come in because of the COVID. (P03, M, October 2020)

Additionally, when patients did consult their GP, increased waiting times to access secondary care investigations resulted in suspected cancer not being investigated for extended periods.

It's made the diagnostics a little bit harder, sometimes to either access or knowing when you've referred, certainly in the first couple of months [of the pandemic], knowing that they're not going to, nothing's really going to happen. (P02, M, October 2020)

Second and third lockdown

Impact on primary care generally

Participants described a gradual change "*back to how things were*" (P01, M, September 2020) following the first lockdown where face-to-face consultations were reintroduced for pre-booked appointments. There was a sense of trepidation from participants interviewed in Autumn 2020 that the coming winter would be the hardest part of the pandemic.

April, May, June was a piece of cake, that wasn't an issue. Our issue I always felt was going to be this September, October, November, and leading up to Christmas, cos for all the obvious reasons, it was going to get busier, people were going to get more used to living with or because of COVID and, and adapting life around it […] just waiting for that, and everybody uses the term Tsunami, but just that massive wave to hit us. (P02, M, October 2020)

Participants also described a change in attitudes where, perhaps out of becoming accustomed to the pandemic or frustrated by having to delay consultation for their medical concerns, patients became much more demanding of consultations with their GP.

[P]atient attitude changed probably after about the first two months, to actually "I want everything sorting," even my cataract, I don't care about COVID, and I, I would say that's stayed. [P04, F, October 2020]

The sense that workload was increasing remained into the Autumn and Winter of 2020/21. Participants stated that the second lockdown in November 2020 had little or no impact on the numbers of patients presenting, and additional activities to "*catch-up*" (P10, M, January 2021) kept the workload high. Lockdown 3 was in force in England from the end of December 2020 to March 2021 and was described as the worst part of the pandemic. During this period, a slight drop in routine presentations was described, but was offset by much higher cases of COVID-19, staff administering vaccines, and a perception that chronic and mental illnesses were reaching crisis point.

[T]hat sort of six weeks after January was as bad as anything I've ever seen […] everything that was kind of prophesised it happened […] and was everything kind of that we feared it was going to be. (P16, M, March 2021)

Some participants mentioned the increasingly stressful working environment in primary care, which some believed would decrease staff retention as it had already begun to.

I think in contrast to where we were in April last year where people were clapping for, for health professionals and care workers, it does feel like there is more aggro in comparison to that. (P16, M, March 2021)

The impact on cancer diagnosis

Despite the return to more normal patterns of consulting, many of the participants said that they believed the pandemic's full impact on cancer diagnoses had not been seen yet and were anticipating that the impact would be very bad for patient outcomes.

There's bound to be some delay in diagnoses, there's bound to be some though we, we all know that's going to come and kick us up the backside at some stage, but we don't know when. (P06, M, December 2020)

Some participants spoke about increases in their rate of referrals to two-week-wait pathways; urgent referral pathways where the patient should be seen by a hospital specialist for cancer investigations within two weeks. They explained that this was often because delayed presentations meant that the time for watchful waiting had passed or patients' symptoms had developed to the point where they met referral criteria. Participants reported that their thresholds for referral also lowered, partly because of a reduction in direct access testing meaning that two-week-wait referral was the only route to investigation for these patients.

[T]here are just more people coming with, with histories that fit a two week criteria, […] and you know the two-week is the only access really that we have to, for example CT scans […] So, I have a lower threshold now I think than I did before because before we had direct access scanning. (P11, F, January 2021)

[I]n GP we use time as a kind of tool, [but] when somebody's come to you with like six months of symptoms, you can't really use that anymore. (P14, F, March 2021)

There was a mix of opinion on how secondary care had coped as the pandemic progressed. A minority of participants said their local hospitals had "*coped really remarkably well"* (P11, F, January 2021) but most described tightening referral criteria which led to increased referral rejections, and backlogs in two-week-wait investigations which meant that waits routinely exceeded two weeks. This was described as being especially true when the specialty was one that could not easily make use of remote consulting.

I think dermatologists were very good, the colorectal gastro weren't very good at all. And they're still not. A two-week referral for gastro probably still waiting four months. Colorectal four or five weeks. And that's now [January 2021], the system didn't work for bowel cancer or GI. ENT's not much better either actually. (P10, M, January 2021)

One GP who worked shifts in his local emergency department described how he was seeing the consequences of delayed presentation and investigation as an increase in the number of emergency diagnoses of cancer.

I think I've probably anecdotally seen more [cancers diagnosed in A&E] in the last six months than I probably would have in the period before for a couple of years. (P16, M, March 2021)

Remote consulting and cancer suspicion

There was a mix of experiences of the impact of remote consultations on cancer suspicion. For some participants, the absence of a physical examination when dealing with specific symptoms did not substantially change how they would practice since the patient's history and knowledge of their own body were sufficient grounds to make a referral. Prior knowledge of patients and information gathered during previous visits also supplemented the remote consultation. For others, the lack of physical examination along with reduced continuity of care meant that remote consultations increased the risk that cancer would be missed.

[F]or example patients who had scans cancelled because of the first wave, weren't brought in for face-to-face examination, had multiple consultations with different doctors, turned out to have for example ovarian cancer, and, […] it's just like that, that Swiss cheese effect, there's just lots of things that unfortunately happened, because of lockdown, [that] I think in normal times wouldn't have happened. We wouldn't have tried to manage somebody with pelvic issues over the phone. (P11, F, January 2021)

Regarding safety-netting, some GPs described how they had become more careful with the advice they gave patients, bearing in mind that it may be difficult for patients to contact their GP. Participants also spoke about how the increased use of technology was changing their processes for safety-netting and making digital safety-netting tools more convenient than other methods.

I would say I'm using more of the online safety-netting […] than when I see patients face-to-face yeah, I would say it's increased. (P12, F, February 2021)

We're already thinking what can we do to safety-net better, you know, if someone's on the phone for a problem more than twice how do we flag that up and bring them in? (P17, M, March 2021)

One of the drawbacks of remote consulting was described as the lack of subtle cues which "*make your antennae twitch*" (P07, M, December 2020) and facilitated cancer suspicion. As such, a number of participants described having to be more careful for fear of missing something that could indicate a serious underlying condition.

[W]e are missing the face-to-face clues, so if someone comes in through the door, and I can tell whether they're unwell or not the minute I see them, but over the phone you've got to go through a lot more cautious stages to get all the information to document they're okay. (P03, M, October 2020)

While a number of the participants described the benefits of patients being able to use their smart phone to take and send images of suspicious skin lesions, a greater number expressed concern at the quality of the photographs or missing a crucial detail. P17 gave two examples of patients where detail missing from a photograph delayed a cancer diagnosis.

[W]e've had a few, well a couple of patients […] who had a, something in her axilla, a rash, we thought it was an infected cyst, it certainly looked that on the photographs […] she had a couple of courses of antibiotics and then, so we thought we're going to have to see her and so she came in […] she had a full fungating breast cancer that we hadn't seen in the photograph […] and one of the other doctors mentioned someone who had an ear infection, that we just treated over the phone, when he actually came in, he had a skin cancer on his scalp […] and so you know phone and camera is not, it's not safe. (P17, M, March 2021)

Discussion

Summary

During the COVID-19 pandemic, a balancing act was necessitated between reducing the risk of SARS-CoV-2 transmission and appropriately assessing the risk of undetected cancer. During the first UK lockdown, General Practice used the quiet period to rapidly reconfigure services to provide remote and minimal contact consulting. Our participants reported that this quiet period caused delays to cancer diagnoses as patients refrained from consulting which they began to see in the summer and autumn of 2020. During the second and third lockdowns as numbers of patients consulting returned to normal levels, our participants described how they used all means available to them to have patients who had already experienced delays investigated. Our participants described lowering their risk threshold for referral, using two-week-wait pathways to access investigations, and modifying their diagnostic approach. Information gathered in pre-pandemic face-to-face encounters facilitated clinical intuition but assessing risk digitally and using 'gut-feeling' nevertheless remained difficult.

Strengths and limitations

The strength of this study is that we were able to gather experiences of the pandemic that spanned the three UK lockdowns and the winter period of 2020/2021 and so are able to report on how practice staff saw the situation evolve, and how concerns raised early on in our data collection played out. Another strength is that the sample was drawn from across England with geographic spread including participants based in both rural and urban practices, and in areas with varying prevalence of COVID-19.

The participants were, however, all based in England and so these findings may not reflect the experience of staff working in the other UK nations, especially as the devolved governments did not always follow the same timeline for lockdowns (23). A second limitation is that although we present how the views of GPs on consulting and cancer suspicion evolved over the pandemic, we did not follow-up with our initial participants which would have given a more direct account of changing experiences. Finally, this study does not include patients' perspectives on the changes in primary care or the challenge of having non-COVID symptoms investigated. We know from recently published research that the public were reluctant to present to primary care even when experiencing red-flag cancer symptoms during and shortly after the first UK lockdown (24), but there is still a need for research to explore how attitudes changed as the pandemic continued.

Links to existing literature

The wholesale reconfiguration of primary care during the first lockdown, creation of 'hot' and 'cold' zones, practices, and teams, repurposing areas for activities such as decontamination, and the spacing out of appointments have been previously reported (18, 25). Additional demands from the vaccination programme at a time when COVID-19 was reaching its third peak may have contributed to the increased rates of GP burn-out that were mentioned by our participants and others (26). The changes were not all negative though, with both our participants and others describing how the pandemic facilitated a rapid uptake of technology that normally would have been met with resistance (27). The successful uptake of technology, however, cannot be equated to its improving patient outcomes. A number of our participants mentioned technology could hinder the detection of cancer for example through poor image quality, and gave examples where not being able to see the wider picture of the patient's health may be harming outcomes. Neither the successful uptake, nor the suppositions of potential harm are evidence of the impact of these new ways of working on patient outcomes, however, and this remains to be seen.

Studies have reported reduced rates of consultation for cancer symptoms and of cancer diagnoses during 2020 (17, 28-31). Our participants also reported longer waiting times for secondary care investigations and they are not alone in this observation (17, 32, 33). Reduced rates of consultation began to disappear following the first lockdown (34) and our participants found this was accompanied by an influx of patients who had been experiencing symptoms for some time. For these patients further delay was not felt to be appropriate, and this led to an increased number of referrals later in the study period which was reflected in a report by Cancer Research UK in May 2021 (35).

Implications for research and practice

The message of stay home to protect the NHS was highly effective during the first part of the pandemic as evidenced by the period of very few consultations. The intention of this messaging was clearly not to prevent patients with potentially life-threatening conditions from seeking medical help, nevertheless this was the result (24). Balanced messaging and improved public understanding of risk are needed, and how both of these could be achieved should be established. As pandemics are set to become more frequent (36), it is important that we learn from COVID-19 to avoid creating a situation where a crisis of non-communicable disease, as we may see with cancer, follows every pandemic.

Clinicians modified their diagnostic approach as consultation format and consulting behaviour changed throughout the pandemic. The COVID-19 pandemic has indicated some ways of working that could streamline services, for example through remote consulting and removing the need for physical examination before referral. These modifications could, however, harm the use of other longstanding tools such as clinical intuition. Research is needed to establish the circumstances in which modifications to clinical practice may be effectively used to improve care and whether approaches such as electronic safety-netting tools (19) may mitigate some of the risk.

This study is one of a growing number that have reported the immense pressure that the pandemic has put on primary care. Increasing demand for appointments alongside GP burn-out and declining numbers of GPs were an issue even before the pandemic and the experiences of the pandemic period have done nothing to ease these issues (37). As GPs are central to the diagnosis of cancer (38) the smooth running of primary care has implications for the post-pandemic recovery of cancer care. Despite pledges to increase GP workforce by 5,000 by 2020 and then 6,000 by 2024, these targets have been missed and are on track to be missed respectively (39). If NHS primary care is to recover, the chronic under resourcing of services, which is central to many of the reasons that GPs give for leaving the profession, must be tackled directly and with urgency (39-41).

Conclusion

The COVID-19 pandemic has had and continues to have a profound effect on primary care and the wider systems that work to detect cancer. Some of the changes will have been a positive step forward in the modernisation of practice, but it is apparent that the net impact of the pandemic on the detection of cancer has been negative and that the full effect on stage, treatment intent, and survival may not be fully understood for some time. There is an urgent need to investigate how changes in diagnostic approaches might affect the patient pathway to diagnosis especially if the changes reduce the GP’s ability to use some of their clinical tools, or act a barrier to help-seeking for patients. The pandemic period has not been easy and so it is important that as we build back we use the hard-learnt lessons to build a more resilient health service.

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Ethics

Ethical approval for the CASNET2 study was granted by the North West—Greater Manchester West National Health Service Research Ethics Committee (REC Reference 19/NW/0692). The need for additional ethical approval for this sub-project was assessed by the University of Oxford’s Medical Sciences Division Interdivisional Research Ethics Committee (ref: R71351/RE001) but was deemed to be an evaluation and so not requiring additional approval.

Competing interests

The authors declare no competing interests.

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