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Information seeking behaviours and uncertainty around accessing primary care in the changing landscape of the COVID-19 pandemic: a qualitative study

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How this fits in
Throughout the pandemic we have become aware of the impact on vulnerable communities. However, we must understand what key issues contribute to this impact. This study has improved said understanding and identified key issues experienced by individuals which negatively impact their ability to access to primary care, likely leading to future health problems. This study is relevant and of interest to clinicians, as it provides insight into the issues experienced by patients, which can in turn be fed into practice**.**

Table 1: Description of demographic characteristics of the sample

Variable	N=34
Age (years)	
Mean	51 (11.3)
Range	20-67
Gender	
Male	4 (11.8%)
Female	30 (88.2%)
SIMD	
Quintile 1-2	10 (29%)
Quintile 3	8 (24%)
Quintile 4-5	10 (29%)
Missing	6 (18%)
History of chronic illness	
Yes	17 (50%)
No	17 (50%)
Shielding	
Yes	9 (26.5%)
No	25 (73.5%)
COVID-19 Vaccination	
Yes	24 (70.5%)
No	10 (29.5%)
Ethnicity as described by participants	
White	24 (70.5%)
British/Scottish	8 (23.5%)
Scottish Chinese	1 (3%)
European	1 (3%)

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ABSTRACT

Background

The COVID-19 pandemic has and will continue to have a disproportionate effect on the most vulnerable. Public health messaging has been vital to regulate the impact of the pandemic. However, messages intended to slow the transmission of the virus may also cause harm. Understanding the areas where public health messaging could be improved may help reduce this harm.

Aim

To explore and understand health communication issues faced by those most likely to be impacted by the COVID-19 pandemic.

Design and Setting

A qualitative study using online surveys. The area of focus was Fife, a local authority in Scotland, UK.

Method

Two consecutive surveys were conducted. Survey 1: N=19 support workers and Facebook group moderators, focussing on key issues faced by service users, as well as examples of good practice. Survey 2: N=34 community members, focussing on issues regarding access to and communication around access to primary care.

Results

Survey 1 found broad issues around communication and access to primary care services. Survey 2 emphasised key issues in accessing primary care, including, (a) the lengthy process of making appointments, (b) feeling like a burden for wanting to be seen, (c) a lack of confidence in remote triaging and consultations, and (d) not knowing what to expect prior to getting an appointment.

Conclusion

Clear issues regarding access to primary care were identified. Our new understanding of these issues will inform a co-creation process designed to develop clear, actionable and effective public health messages centred on improving access to primary care.

Keywords

SARS-CoV-2, Primary care, care seeking, health information

How this fits in

Throughout the pandemic we have become aware of the impact on vulnerable communities. However, we must understand what key issues contribute to this impact. This study has improved said understanding and identified key issues experienced by individuals which negatively impact their ability to access to primary care, likely leading to future health problems. This study is relevant and of interest to clinicians, as it provides insight into the issues experienced by patients, which can in turn be fed into practice.

INTRODUCTION

The COVID-19 pandemic has had a profound impact on the mental, physical and social well-being of individuals (1-3). Until the recent roll out of the vaccine programme, limiting the spread of the virus has been the most critical intervention available to reduce mortality and transmission of COVID-19. To achieve this, several public health measures and regulations have been put in place. These include compulsory face coverings, social distancing, shielding and self-isolation strategies. Messages to support these regulations were implemented, including the FACTS campaign (4) in Scotland (Face coverings, Avoid crowds, Clean hands, Two metres and Self isolate) and similar Hands, Face, Space campaign in England (5). Limiting the spread of the virus has been vital, yet some of the regulations and messages implemented to achieve this for example self-isolation/shielding also adversely impact the lives of the general population but more acutely the most vulnerable.

The pandemic has produced many challenges around communication in terms of reliability of the messages, trust in scientific research, reach of key messages and effects on behavioural outcomes (6-8). For example, there was some discontent and confusion from the public regarding some of these key campaigns, including the FACTS campaign, in that they struggled to remember what the acronym stood for (9), therefore making the messages unactionable. Confusion due to misinformation spread by the Government and mainstream media is also evident (10-13). Such confusion has been associated with increased mental health issues, including increased depression and anxiety (14).

Moreover, rapidly changing recommendations and feelings that imposed regulations are "unreasonable" or "unnecessary" have led to advised behaviours not always being adhered to (15). Michie et al (16) suggest people are left feeling unsure about what to do when messages are not 'actionable' enough. There have also been many sources of misinformation, as currently seen in the context of vaccination safety, labelled the 'infodemic' (17-19). These communication issues have and will continue to lead to a variety of negative consequences, which will impact society for years to come. These consequences include increased risk from COVID-19, increased levels of anxiety and delayed health seeking behaviours - leading to an influx of serious health conditions further down the line and likely unnecessary mortality (3, 20).

Despite advances with the vaccination programme, it is likely that health messaging about transmission risk reducing behaviours will continue to play a key role in managing the pandemic (8, 16), to ameliorate the issues associated with the 'infodemic' and improve adherence to preventative measures(12). It is therefore necessary to ensure the messages are actionable and clear, particularly for those disproportionately affected by the pandemic. In Scotland deprivation is a key contributing factor to health inequalities and increased COVID-19 impact, with those living in more deprived areas more likely to be admitted to hospital with COVID-19(21). Other groups are also disproportionately impacted in the UK, including: older adults, people with lower income and those from South Asian and Black communities) (22, 23). Such disproportionate impact highlights and exacerbates current health inequalities (24), inequalities that must be tackled.

Throughout the pandemic the importance of communities and in particular the necessity for services and agencies to collaborate with communities to enable knowledge exchange and the development of services and solutions has been emphasised (25). People have turned towards and self-organised into community groups to support each other. This can involve finding relevant information and even collaborating to develop messages such as collating and providing information on available services in the local area (26). Local organisations, support workers and community Facebook groups have been key contacts assisting individuals and helping with the spread of information (27). In addition, Public Health Authorities globally have increasingly used Facebook for dissemination of messages and information during the COVID-19 pandemic, with varying levels of success (28).

In the constantly changing 'new normal', there are also constantly changing communication needs. The online community activity that has been observed provides an opportunity to purposefully make use of the insights that such groups have into key information needs within their own communities. Intentionally incorporating local experience can also encourage the development of messages that are relatable, relevant and actionable – essential to support behaviour change (29, 30). In addition, partnerships between community leads and public health authorities help to ensure that messages reach underserved communities (31). This is important as people who are disadvantaged by health inequalities and have less access to information are less likely to comply with public health recommendations (32).

The aim of this work is to gain insight into relevant and priority issues with health communication, to help determine the focus for a community-embedded co-creation process that develops clear and relevant messages to support vulnerable groups.

METHODS

Two consecutive online surveys were distributed amongst community groups and services. These surveys were undertaken with the aim that they would serve as the basis of a broader co-creation process.

Survey 1 aimed to gain insight into what information needs support workers observed amongst the communities they serve. The findings of this survey informed the aim of Survey 2: to get a fuller picture of communication issues around access to primary care from a diverse set of community members potentially at increased risk of negative outcomes from the pandemic.

The components of the Consolidated criteria for reporting qualitative research (COREQ) checklist(33) relevant to qualitative research using surveys (i.e., Domain 2-Study design and Domain 3-Data and analysis) were consulted to ensure best practice when describing the study.

Surveys
Survey 1: Support workers

Survey 1 consisted of seven open-ended questions exploring the observations of support workers about information-seeking behaviours in their communities, views on and examples of helpful communication and unmet needs of community members. Participants were also asked their views about channels other than Facebook where people found health information and support. The support workers views were expected to be a reliable representation of conversations in the community, as they were in contact with community members throughout the pandemic and had a unique opportunity to gain insight into issues experienced, both online and offline. This survey was developed and piloted with the wider project team, including representatives from NHS public health/health promotion, third sector interface, local council and a community representative, with feedback from the community representative playing a key role in shaping the questions to effectively capture possible issues. The outcomes of Survey 1 were also validated in Survey 2, ensuring reliability.

Survey 2: Community members

Survey 2 consisted of sixteen questions. These focussed on communication around accessing primary care including making appointments with the GP practice, attending remote/in-person consultations and picking up prescriptions. Questions alternated between closed responses on a 5-point Likert scale (ranging from 'not at all' to 'extremely' or when appropriate from 'very difficult' to 'very easy') and open-ended questions exploring responses to the closed questions. Data regarding the service/Facebook group the survey was accessed through, as well as the respondent's age,

gender, ethnicity, history of chronic illness, shielding and COVID-19 vaccination status were also collected. Demographic measures were self-report and open to participants interpretations, recommended practice to ensure the participant does not feel pressured to label themselves in a way that may not feel comfortable with. This survey was developed collaboratively like survey 1, with additional involvement of a user-experience researcher (KS), with the aim to extrapolate and validate the identified issues around primary care.

Ethical approval was granted by the University of St Andrews, School of Medicine ethics committee (Approval code: MD14931).

Recruitment
Research location: Fife
Fife is a county in Scotland with a population of approximately 370,000 (34). Its demographic characteristics are broadly similar to that of Scotland as a whole. However, the percentages of older adults and younger people are greater, and the level of deprivation is slightly higher than that of Scotland as whole, increasing the population's risk from the impact of COVID-19 (35). The majority of the population of Fife (over 90%) are described as white, indicating limited ethnic diversity in the region (36).

Survey 1: Support workers
Survey 1 was sent via email to a small number of community learning and development, social work and health links, linked to the planning group, as well as to moderators of Facebook community/support groups – both through existing contacts with NHS Fife. This pragmatic sampling method did now allow for calculation of a response rate but was chosen to increase the likelihood of recruiting participants at a time when support workers were under a great deal of pressure.
17 support workers from community services, housing, social work and voluntary organisations and 2 moderators for local Facebook groups responded (June-September 2020).

Survey 2: Community members
To recruit to Survey 2 a distribution list maintained by NHS Fife of Facebook moderators of community groups and service leads was used. This survey was completed by 34 community members from 10 Facebook groups and local community services (March-April 2021). To improve the likelihood of a diverse representation, participants were also recruited through equalities and faith groups. The resulting set of participants represented a diversity of people with respect to age, Scottish Index of Multiple Deprivation (SIMD: Deprivation scores -for each area of Scotland based on a variety of factors(37)) and history of chronic illness. Four men and 30 women responded. Nine of the 34 participants had been shielding during the pandemic, while 24 had received their COVID-19 vaccination. The majority described their ethnicity as white (70.5%). The remainder described their nationality instead of ethnicity, being Scottish/British (23.5%), European (3%), Scottish Chinese (3%). For a full description of demographics, see Table 1.

Analysis
Survey 1
Data collected was extracted to Excel and analysed thematically (38), with each key issue identified representing a theme. A summary of each key issue was created with appropriate evidence from the survey attributed to these. Issues were often explicitly stated by the support workers and so minimal interpretation was required. The outcomes of this survey were discussed and validated with the project group to prioritise the scope of the second survey.

Survey 2

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Data collected was extracted to Excel. Qualitative data was analysed thematically (38). This process involved identifying key themes, representing issues and/or examples of good practice experienced when accessing primary care. To identify and develop these themes data was first read and re-read by MvB and LB. The data sheet was annotated denoting potential issues experienced and examples of good practice, drawing on both deductive (results from the previous survey) and inductive means (new knowledge from the survey as interpreted by the researchers). These points were then discussed to condense where possible. Finally, a coding table was created denoting each of these themes and associated evidence.   Descriptive statistics and frequencies were conducted to enable description of the quantitative data collected.

RESULTS
Survey 1: Support Workers
The surveyed support workers served a wide range of individuals including older adults on low income, young people, lone parents, vulnerable families, young carers, people in adult basic education and groups affected by drug and alcohol use, homelessness, trauma, mental health issues and unemployment. Information-seeking behaviours and information needs within these groups were captured in three themes, in order of descending frequency, information on: 1) accessing health services, 2) COVID-19 transmission and protection, and 3) mental health support. As accessing health services was the most dominant theme and issue, it was agreed this would be the focus of Survey 2 (Community members).

### 1.	Accessing health services
Information was sought on what services were open, in particular access to primary care, appointments, waiting times, referrals and medication review. In addition to *"confusion around [the] new way of working in primary care"* (Support worker), other services that were mentioned in this context were mental health services, harm reduction around drug and alcohol-use, pharmacies and crisis support.

### 2.	COVID-19 transmission and protection
Another common need in the groups was for information on COVID transmission and on mitigating risks. Specific topics were information on social distancing, advice on masks and Personal Protective Equipment (PPE), COVID testing, safety of children and safety as part of the shielding group or carer.

### 3.	Mental health support
Several responses specifically mentioned mental health support, including self-care such as diet, exercise, sleep and coping with stress. In this context, tackling loneliness and sharing details of contact groups for support were also mentioned.

Message delivery
Support workers noted examples of good practice regarding messages on domestic abuse, harm reduction around alcohol and drug use, and support services in mental, sexual and physical health. Community-driven spreadsheets of available services and contacts, listing available services, and overviews of essential contacts were mentioned as helpful formats. A respondent pointed out a need for NHS messages to be publicised and shared, while another said there was already too much information. A need for consistent, simple messages across platforms was described as desirable, as well as continued promotion of the core public health messages (e.g. FACTS guidance) and clarity on differences around the UK and Scottish Government advice.

In terms of the accessibility of the available health messages, guidance from governing and organisational bodies was perceived as helpful, but sometimes too long. Easy-to-read information, roadmaps and simple messages were suggested instead. Posters, social media, TV/radio and

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signposting via workers over phone were mentioned as channels that work well to help spread and reinforce messages. Opportunities were identified to address digital barriers and at the same time increase engagement on Facebook through infographics and videos.

Survey 2: Community members

Results indicated that while 41% of the respondents were not at all hesitant to make a GP appointment, 35% were 'very-extremely' hesitant. A key factor appeared to be the difficulty of actually getting an appointment – almost one third did not find this process clear at all. Two respondents commented on the use of online forms to obtain an appointment: one felt uncomfortable explaining the reason for their appointment and the other was dissatisfied with having to wait for a response after completing the online form. However, most issues related to making appointments via the telephone. The main concern for people was the total length of the process: in the first instance to get through from the answering system to the receptionist, then to triaging and finally to be allocated an appointment:

> *"…waiting to get through can be frustrating. I recently took 48 attempts to get through. (…) if you don't keep trying there are no appointments left."* (female, 50 years old)

However, others found themselves unable to get through or dismissed:

> *"Had the phone hung up on me as my appointment request was not urgent"* (male, 20 years old)

These respondents expressed their frustration with this process and trying to make an appointment was described as pointless. Another barrier that various people experienced was feeling 'unwelcome', or *"your (sic) made to feel like a burden… for expecting to see your GP"* (female, 40 years old). Confusion around when it is appropriate to contact the GP was apparent: "*Adverts say see your GP. Local info and that from surgery say no"* (female, 54 years old). As a result of this message, some respondents described putting off making appointments to avoid burdening resources. A third reason that was provided for not making an appointment was the (perceived) difficulty of being referred for follow up care.

One respondent also mentioned mental health concerns as a reason for feeling hesitant. However, another mentioned the manner in which their mental health concerns had been dealt with as the reason they did not feel hesitant at all:

> *"Whole process of keeping in contact (about mental health) and changing medication went very smoothly"* (female, 50 years old).

Finally, respondents mentioned being "scared… (to) catch COVID", as well as worried about the outcome of an appointment, for instance, "finds something like…cancer" (male, 60 year old), emphasising fear as barrier to health seeking behaviours. Although there were concerns about catching COVID-19, others mentioned being satisfied with the COVID-19 safety measures in places, leading to reduced hesitancy around making and attending appointments.

More than half of the respondents considered attending the consultation easy "*once you get an appointment*" (female, 54 years old). Most (29%) had received a phone consultation, while a further 29% had received both a phone and face to face consultation, 12% face-to-face only and none had received a video consultation. A recurring issue mentioned was not getting a fixed time for the appointment but rather a time range. Some indicated experiencing stress due to not being able to see their regular GP, as they struggle to talk with other health care professionals. There was also

dissatisfaction around not having a choice in the type of appointment. While some described phone consultations as easy and comfortable, others felt a lack of confidence in remote appointments and triaging:

> *"My problem is something that needs to be seen not described. I was asked to send a photo but it's not showing on the photo. I just want to see someone and I can't. I am having to wait over 2 weeks just to speak to someone and this is not acceptable to me when I'm in pain."* (female, 51 years old)

This confidence was also questioned in light of prescriptions by two respondents, with one saying that "*I seem to have had a prescription given by a receptionist and pharmacist but haven't spoken to a doctor.*" (female, 55 years old). However, overall the process of picking up prescriptions was said to be very to extremely clear (71%), with the integrated process between GP and pharmacy being mostly unchanged.

While just 12% experienced their appointment as 'very difficult to attend', 27% felt it was not at all clear what they could expect from attending an appointment. Most people found information on how to access their GP practice on the practice website or over the phone (56%), while a further 9% used social media, 3% got information from their family/friends, 3% from a leaflet and 3% from a maternity app. 24% of respondents used a combination of these mediums to find information about their practice. It was suggested that information on the consultation could have been emailed or sent in between making the appointment and receiving the consultation.

DISCUSSION
Summary
This study aimed to gain insight into information needs present in the community as observed by support workers and local Facebook support groups. The results show that access to primary care continues to be a relevant and urgent problem, even this far into the 'new normal'. The main barriers for people to contact their GP appear to be the lengthy process of making appointments, feeling like a burden for wanting to be seen, a lack of confidence in remote triaging and consultations, and not knowing what to expect prior to getting an appointment.

Strengths and Limitations
Using online surveys - a practical result of the pandemic - likely excluded those who experience barriers to accessing technology. The effect of this was mitigated by surveying support workers who work with these groups. Moreover, it was not possible to ascertain the number of individuals who were sent and/or interacted with the survey. Regardless this was the best suited recruitment method due to the broad net cast at a time when recruitment was generally difficult. This enabled the involvement of vulnerable populations and follow up work in a timely manner. This study looked at local information needs in a relatively small group, the sample is not necessarily widely generalisable. However, with the demographic characteristics of Fife being broadly similar to that of Scotland, some careful extrapolations can be made.

Despite attempts to recruit a more ethnically diverse population, the majority of participants described themselves as white. Measures were employed to recruit a more ethnically diverse sample, yielding limited results. Yet, the population recruited is similar to that of the area of Fife more widely, with over 90% of the population being white (36). Also, a number of participants reported their nationality as opposed to ethnicity, leading to a number of missing data points. However, self-report demographics were recommended to ensure participants felt comfortable responding, key in collaborative work. Moreover, this study was successful in reaching those living in areas of high deprivation, a contributing factor of negative impact from COVID-19 in Scotland (21).

Comparison with existing literature

A significant increase in serious health problems is anticipated as a result of people's changed health seeking behaviours since the start of the pandemic (20). Recent campaigns have been attempting to target these problems, for example the campaign to create awareness of lung cancer symptoms (39). However, public messages such as *"GP practices are very busy, so before deciding to contact your practice, please think whether you can manage your problem yourself"* (40) may feed into people's concerns about 'burdening' their GP, rather than empowering people with potentially serious health problems to seek out support.

This fear of contracting COVID-19 when accessing primary care services in particular, has been highlighted in mainstream media, as well as previous research (41, 42), and this study. Therefore, it is necessary to ensure future messages support access to primary care, alleviating this sense of burden and worry, and in turn reducing the anticipated "tsunami of demand". A recent campaign by NHS England, "Help us to help you" aimed to encourage individuals to access healthcare services, with the first phase focussing on contacting their GP (43). However, the key phrasing of "Help us to help you" may continue to put some people off, as it places the onus and burden of responsibility on the patient without much guidance.

Various studies have looked at the use of telehealth and consequences on patient uptake of appointments. In the past telehealth has often been adopted by remote communities, the pandemic has led to a widespread adoption of telehealth systems (44). It is expected that even after social distancing regulations are relaxed this new way of working will play an important role in general practice (45). However, this study shows that there is still work to be done to help manage patients' expectations around such consultations and ensure they are confident in accessing services.

In addition to the increase in telephone consultations, practices have seen a significant influx in calls to schedule appointments. The issues observed in this study around the process of making appointments are likely to vary from practice to practice. Regardless the study does emphasise the important role of GP practice receptionists as the key contact point for patients, and the potential need for additional resources and support to help them manage patients' expectations of the consultation process. Over the years, various work has pointed out the often overlooked but essential role of these front-line administrative staff (46-48).

Furthermore, the results of this study corroborate the findings of a recent HealthWatch report, highlighting the benefits of telehealth for some and the difficulties it poses for others (45). The difficulties emphasised revolved around the consultation itself but also included access to primary care, indicating that many feel services are not "open for business"(45). This also highlighted how patients can feel like a burden on the NHS, so choose to avoid making appointments, consequently leading to visits to A & E and advanced illness (45). It is clear from this study's results that these issues are still prevalent, and work is required to develop means to educate and inform individuals, through messaging, about access to primary care services. Improved communication in this area could reduce the future burden on the NHS and reduce the anticipated increase in health inequalities.

Implications for research/practice

Access to primary care is a continuing issue that potentially vulnerable groups could benefit from supportive communication for the foreseeable future. These issues include: (a) the lengthy process of making appointments, (b) feeling like a burden for wanting to be seen, (c) a lack of confidence in remote triaging and consultations, and (d) not knowing what to expect prior to getting an appointment. The findings from this study will be used to inform an online, community-embedded

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co-creation process to create messages to support access to primary care for the community and provide communication guidance for practices.

Ethical approval

Ethical approval was granted by the University of St Andrews, School of Medicine ethics committee (Approval code: MD14931).

Competing interests

There are no competing interests to be acknowledged by any of the authors.

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