Primary and Community Health Services

Community Priority Setting with Public Members in Kent, Surrey, and Sussex

This Community Priority Setting exercise with members of the public in Kent, Surrey, and Sussex (KSS) was conducted by the Primary and Community Health Services (PCHS) theme of the Applied Research Collaboration KSS (ARC KSS), and Public Advisors from three themes of the ARC KSS:

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Executive Summary

Primary and community care services are under strain following the COVID-19 pandemic. The Primary and Community Health Services (PCHS) theme of the Applied Research Collaboration in Kent, Surrey, and Sussex (ARC KSS) conducts research to improve health and community care services. As a theme, we support members of the public and providers of services to work together to inform and deliver service improvements, which offer better health outcomes and in turn economic benefit.

It is important that our research is connected to the needs of the local communities, so changes to services are informed by local people. The PCHS theme therefore conducted a Community Priority Setting exercise, which involved Public Advisors as collaborators. We captured the views of members of the public on areas of need in their local communities. This resulted in several themes, which can be used to shape future research and guide service improvements in Primary Care and community services. Here, we report these themes with contextual examples from our focus group discussions. We also discuss ways in which the themes can be used to guide future research and collaborations between researchers and providers.

We hope these findings will first help researchers in Kent, Surrey, and Sussex consider the impact of their research on the communities it serves. As a theme, we intend to use the results to guide our work, and to hold us to account regarding the usefulness of our existing research to local people. Second, we anticipate these findings will be useful to providers of health and community care services as they provide an overview of the kinds of challenges their users are experiencing. The Community Priority Setting results will be useful in guiding internal research and service evaluation, and we hope this report will spark further collaboration between the PCHS theme and providers of health and community services across ARC KSS, so we can continue to work together to deliver service improvements.

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Background

Primary Care services have faced years of chronic under-resourcing and were under strain prior to the COVID-19 pandemic. As the service at the front-line of patient care, Primary Care is under immense pressure to manage the needs of a growing and aging population, such as managing complex and poorly understood long-term conditions and multimorbidity (McKee et al., 2021). Prolonged under-funding has resulted in inadequate infrastructure to meet Primary Care demands, such as understaffing, and a lack of physical space and resources to provide sufficient patient care (Watt, 2019). The growing workload paired with a lack of resources in Primary Care has challenged the provision of accessible, comprehensive, and person-centred care (Levene et al., 2020).

The COVID-19 pandemic placed further pressure on a system already under stress. There have been additional challenges and changes to service provision, which have affected patient care and the wellbeing of Primary Care staff (Waters, 2022). Delivering the vaccination programme and dealing with patient back-log, as a result of redistribution of critical care to COVID-19 patients and years of patients delaying seeking medical help, are among some of the factors adding strain to Primary Care (Phillips et al., 2021). Rapid shifts towards online working also resulted in further disruptions to care in several domains (Carr et al., 2021; Gessa et al., 2021; Richards et al., 2020). Hybrid working and workforce retention issues have made managing and diagnosing complex conditions and multimorbidity even more difficult (Levene et al., 2020). Changes to the provision of standard and routine health services revealed new ways of working (i.e., digitisation), which have been seen as and opportunities for development and a potential way to manage some challenges facing the NHS (Reddy & Brahm, 2016). Digitisation, such as remote consultations, affords convenience, has workforce benefits, the potential to reach some clinically vulnerable patients, and scope to offer alternative approaches to care, which taps into the personalisation agenda (Casey et al., 2017). However, it has created greater layers of complexity for the Primary Care system (Sætra & Fosch-Villaronga, 2021), and risks worsening the digital divide, creating further barriers to healthcare for those without access to technology.

The substantial challenges facing the health care system will inevitably impact patients' experiences of health care (The Health Foundation, 2020). There is a risk that existing health inequalities will be exacerbated (Parker et al., 2021). The Primary and Community Health Services (PCHS) theme of the National Institute for Health Research (NIHR) Applied Research

Collaboration Kent, Surrey, and Sussex (ARC KSS)[1] recognise a need for contextualised understanding of the best ways to support patients and their carers/families within this changing landscape. We note the strengths of place-based approaches that complement the assets of the local community (Mullan & Stable, 2016). Therefore, we want to facilitate Primary Care service users and providers to work together, from the ground up, to inform the process of improving services, to fit local need, and encourage accessible, comprehensive, and person-centred care.

Aims and Objectives

The PCHS theme focuses on supporting the users and providers of health care services to work together to create services that fit local need and offer holistic person-centred care. The PCHS theme has three sub-themes, which direct and guide research activity:

1. Sustainable care for Marginalised Groups
2. Service redesign and the provision of integrated care to support people to live well with chronic conditions
3. Promoting and evaluating new models of 'left shifting care'

The sub-themes were developed before the COVID-19 pandemic to reflect the landscape of Primary and Community Health Services. They were developed with a consideration of the challenges of the sector and are constructed to direct research activity that is sensitive to the needs of marginalised, or seldom-heard groups. However, we must consider whether the sub-themes remain appropriate given the changes and challenges to Primary Care in light of COVID-19. Involving stakeholders in research is essential to reduce health inequalities, and to ensure research is impactful and relevant for the communities it serves (Altman et al., 2020). Stakeholder involvement typically occurs during the development of research and during implementation (Harrison et al., 2018). Involving community stakeholders in the entire research journey, including during priority setting, ensures research is guided by the needs of the community, supports and empowers the user, and helps direct resources towards public need. This may aid the effectiveness of research implementation and improve the value of research activity for the local community.

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[1] https://arc-kss.nihr.ac.uk/research-and-implementation/primary-and-community-services

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Purpose of the Community Priority Setting exercise

The purpose of this exercise was to refine the research priorities of the PCHS theme and to help us operationalise the sub-theme aims. We involved members of local communities across KSS to ensure our planned research activity aligns with local needs and to employ locally appropriate understandings of the best ways deliver on our broader theme aims. We intend to use the results of this exercise to guide our research activity, hold us to account regarding the impact of our existing work, and enable the voice of the user to be amplified. We held focus group discussions to hear the views of the public regarding their priorities for research. By doing so, we endeavoured to engage communities in the entire research process and foster ownership, support implementation, and achieve sustainability of research outcomes.

Objectives of the exercise:

- Engage with local communities in Kent, Surrey, and Sussex (KSS) to provide an opportunity to share their views on what research activities should be carried out within the PCHS theme in the ARC KSS

- Develop an understanding of the lived experiences and main concerns of members of the public in KSS

- Identify key areas for future research within the PCHS theme

- Determine how the current research activity of the PCHS theme maps onto local needs and concerns

The Community Priority Setting Approach

We took a co-production approach and used Public and Community Involvement and Engagement (PCIE) throughout. As there is no standardised definition of co-production, we have adopted the guidelines[2] developed by the co-production theme of the NIHR ARC KSS. The co-production guidelines highlight that co-production involves collaboration with intended beneficiaries of the research, in this case members of the public in Kent, Surrey, and Sussex. We invited ARC KSS Public Advisors[3] to co-produce this work with us. The Public Advisors were involved in the conceptualisation phase, preparation of a protocol, the creation of the topic guide for the focus group discussions, the facilitation of the focus groups, the analysis of focus group data, and the development of this report.

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[2] Involving and working with patients and the public to produce relevant research.

[3] ARC KSS theme public advisors

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Method

The Community Priority Setting exercise used elements of co-production and Public and Community Involvement and Engagement (PCIE) to define research priorities and inform service delivery. This therefore does not require ethics approval as recommended by the Health Research Authority (HRA)[4].

Public Advisor Involvement

Prior to the exercise, we created a briefing document for the Public Advisors, and they were offered to be paid for their time via payroll at their standard hourly rate for the ARC KSS. At each phase of the exercise, we tailored our meetings and avenues for engagement to suit to needs of the Public Advisors, such as using a combination of email, video meetings, and phone calls for feedback. We also involved the Public Advisors in meetings where the Community Priority Setting exercise findings were presented, such as theme forums and the ARC KSS research symposium, ensuring their contributions were highlighted.

Participants

Focus group participants were members of the public and were reimbursed for their time at a standard rate of £20, via a gift voucher, for their time/participation in the discussions. In line with the ARC KSS definition, we define members of the public[5] as: *"patients, carers, and people who use health and social care services, people with lived experience, people from organisations that represent people who use services or members of the public with an interest in research".*

Participants were recruited in each locality (Kent, Surrey, and Sussex) by the research team and the Public Advisors, who shared study adverts with their networks. Twenty-seven participants took part across three focus groups (see Table 1.). Of participants who disclosed their gender, most were female (*n* = 11), and of those who disclosed their age range, the most common was 46-60 years (*n* = 7).

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[4] https://www.invo.org.uk/wp-content/uploads/2016/05/HRA-INVOLVE-updated-statement-2016.pdf

[5] Terminology and PCIE (nihr.ac.uk)

Table 1.

Demographics of participants who took part in the Community Priority Setting Focus Group Discussions

	n	Gender (M:F)	Age range (*n*)
Kent	5	1:2 *2 did not disclose*	30-45 years (3) *2 did not disclose*
Surrey	6	1:5	18-28 (2) 46-60 (2) 61-75 (2)
Sussex	11	3:4 *4 did not disclose*	30-45 (1) 46-60 (5) *5 did not disclose*

Procedure

We held three online focus groups with members of the public. One group was held in each region: one each for Kent, Surrey, and Sussex. We advertised specifically for each locality using methods described above. The focus group discussions were conducted online via Zoom, which is reported

to be an accessible video conferencing software for online research (Gray et al., 2020).

The focus groups were facilitated by three members of the research team and the Public Advisors for the Primary and Community Health Services (PCHS) theme. The discussions were semi-structured with questions around three areas relating to Primary Care: The Primary Care services, the users of Primary Care, and the needs of the users who access Primary Care. The groups lasted between 79 to 88 minutes (*M* = 83 mins 34 secs). The agenda and the questions were sent to participants ahead of time to enable them to prepare their responses ahead of the discussions. Audio recordings were trimmed to ensure participants' details were anonymised and the reduced recordings were sent to a professional transcription company (Essential Secretary[6]) for transcription.

Data analysis

Following familiarisation with the transcripts, one researcher analysed the data using Thematic Analysis and following Braun & Clarke's (2006) process, as outlined below. A second researcher and the PCHS Public

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[6] https://essentialsecretary.co.uk/

Advisors were involved in steps 4 and 5. The Public Advisors were also given the opportunity to review the final report produced from step 6.

- Step 1- Data familiarisation: 1 member of the Community Priority Setting research team independently reviewed the transcripts (GG) from each focus group.

- Step 2- Initial coding: The same researcher generated initial codes (meaningful units of the data) within each transcript.

- Step 3- Generating themes: The same researcher created potential themes from the initial coding ready for review with the public advisors.

- Step 4- Reviewing themes: 3 members of the research team collaboratively reviewed the themes (GG, DG, KFS).

- Step 5- Defining themes: Then, 2 researchers and 2 Public Advisors reviewed the themes together to ensure the finalised themes were representative of the Public Advisors' experiences of the focus groups, and to define and label the themes and subthemes (DG, GG, HR, KT).

- Step 6- Producing the report: The 2 Community Priority Setting team members (DG, GG) generated the resulting report, which was shared with the Public Advisors (HR, KT) for feedback, and whose comments were incorporated into the final report.

The thematic analysis used an inductive or 'bottom-up' approach, meaning that the codes and themes are derived from the data, rather than pre-existing concepts and ideas held by the researcher (Braun & Clarke, 2012). Microsoft Excel was used to organise the data into codes, themes, and sub-themes.

Results

Through an explorative thematic analysis, we identified three primary themes: *improving the 'front-door to the NHS'*, *addressing problems in the healthcare system*, and *further developing patient-centred care*. Each theme had three-four sub-themes (*figure 1*.). A list of specific medical conditions and populations that were mentioned throughout the focus groups was also identified, which represent a list of seldom heard groups in research. In the next four sections, we describe and illustrate each theme and present the list of seldom heard groups mentioned throughout the discussions.

Figure 1.

The final primary and sub-themes generated from the Thematic Analysis.

1. Improving the 'front door to the NHS'	2. Addressing problems in the healthcare system	3. Further developing patient centred care
1.1 Accessible and practical booking systems	2.1 Funding that meets patient need	3.1 Encouraging and improving engagement by reaching out
1.2 Meeting patients' physical accessibility needs	2.2 Addressing waiting times	3.2 Additional support in alternative settings
1.3 Consider increase in technology on patient access	2.3 Relations between practitioners and patients	3.3 Personalised care
		3.4 Joined up care with services/family/carers

1. Improving the 'front door to the NHS'

The first theme primary theme broadly concerned participants' experiences of accessing and obtaining an appointment with their Primary Care provider.

1.1 Accessible and practical booking systems

Several participants discussed their experiences of trying to navigate the booking system for their GP surgery. In the UK, many GP surgeries offer same day appointments, which typically requires telephoning at 8am and can result in a busy queuing system. This system has become the norm for many surgeries, even for less urgent appointments. For several participants, this is impractical. One participant highlighted the impracticalities of trying to get an appointment at 8am as a mother to school aged children. Another noted that whilst the availability for same day appointments is necessary for some people, in some circumstances, it would be more practical to have an appointment in the future, but these are now harder to obtain.

> *"I would rather be able to phone at any time of day and say, my situation is not urgent, I would like to make an appointment for next week or a couple of weeks' time. And that option just doesn't seem to be there anymore."*

> *"But generally, if you need an appointment, it's a case of this whole waiting on the day and I don't think anybody quite appreciates when you're a mum to three children, 8 am, trying to get them ready for school on the day, it's just not practical."*

During the COVID-19 pandemic, there were substantial changes to the availability and delivery of consultations in Primary Care. Telephone appointments were normalised, and patients were encouraged to send photographs of their problems to the GPs rather than attend the surgery. Our participants expressed frustration and concern regarding the increased difficulty of seeing a GP in-person. One participant also highlighted the value in establishing rapport and connection with a GP.

> *"Getting a face-to-face appointment is becoming a real issue, for … my children as well. I've got a problem that needs to be seen by physical eyes, and if I'm honest, I'm getting quite sick of having to take pictures to send them… it's been hard to get face to face appointments because the wait times are really long..."*

> *"…it's almost impossible to get an appointment"*

> *"… if people feel they need to see the doctor, they should have that right to see the doctor, physically going … just makes people feel they've actually-- that just seeing the doctor can help them really, just having a chat … and just the way they're interacting with the patient, I think that's so important. If we end up having that disconnect like that, it's almost like being robotic. It's a bit of a worry."*

1.2 Meeting patients' physical accessibility needs

Participants highlighted services did not always meet physical accessibility needs of patients. One participant noted some GP surgeries lack even wheelchair accessibility. This may be indicative of other physical accessibility considerations such as creating inclusive spaces, or the availability of necessary adaptations for hard of hearing, blind or visually-impaired communities or, as noted by another participant, housebound patients.

> *"I registered at a surgery that didn't have wheelchair access. It just didn't occur to me that you wouldn't have wheelchair access in a service"*

> *"The problem is with some of those community services, where you then see someone their access sometimes is worse because of the locations…that aren't accessible by public transport"*

Additionally, the community infrastructure is an important consideration to determine the accessibility of essential Primary Care and community services to ensure inclusivity and support patient access. It was highlighted by one participant that due to being in more rural areas, some services are not accessible by public transport and would therefore rely on people having a car to attend the service, which creates barriers to accessibility.

"I can't get to the appointment, so for some people who are housebound or not close to… [services are inaccessible]"

1.3 Consider the effect of the increase in technology on patient access

The COVID-19 pandemic sparked an increase in the use of technology-mediated interactions in Primary Care and community services. There was a necessity to shift a range of services online, with telephone appointments, e-consultations, and video calls becoming common modes of interaction between patients and consultants. For some participants, this was seen as a welcome and innovative development. Not only does this innovation enable continuity of care for patients with potentially infectious illnesses, the greater availability of alternative appointment formats also made accessing services more convenient. For some it improved accessibility by removing physical accessibility barriers to an in-person appointment.

"It depends on accessibility requirements, I can't get out of the house, having a digital phone call is much easier for me to attend an appointment."

The increasing reliance on digital methods of communication, however, comes with some risks. The participants noted the potential to exacerbate a digital divide. Several participants were concerned about the accessibility of services for those without the skills or resources to access services

digitally, including the necessary physical technology as well as the time and space to meet clinicians privately in their own homes.

"Yes, I'm a bit concerned that with all the more and more asking you to do it through the internet, doing it digitally, how many of those appointments are going to be left for people that can't…"

"I think there is need to pay due regard to marginalised groups because with some sectors of the mental health population who … have trouble accessing good quality health especially in the context of Covid where people, with so much contact was required to be digital inclusion and the impact on the digitally excluded wasn't really gauged. That's not really a question of whether or not someone has access to apps and Wi-Fi, it's also whether or not they have access to the privacy, to actually access whatever therapy or interaction with the clinician, in private."

The quality of the interaction using digital tools was also a concern for some participants, particularly considering conversations around mental health, or for isolated patients, for whom experiencing a connection with and receiving reassurance from a practitioner can considerably support their recovery and/or well-being. One participant emphasised how some patients can find it difficult to express themselves online, which can be intensified when the interaction is mediated by a screen. However, several participants highlighted the value in a hybrid model of care, where people have a choice

about how they access support. They stressed the need to continue adoption of innovative developments with a balance that supports inclusivity and is driven by clinical need and patient choice.

> *"We want a hybrid model… some people for other social, environmental reasons can't do it [use online services]."*

> *"…there's something here about choice isn't there? That for some people kind of the move to digital and the ability to access support has been better. …there something isn't there, about you know, ensuring that when we come out of this kind of Covid period, that the new things that have been adopted, we don't just assume that suits everybody. You know, there's a balance."*

2. Addressing problems in the healthcare system

The second theme included perceived systemic issues within the wider network of health and community services and addressing the impact they had on patients.

2.1 Funding that meets patient need

Participants expressed frustration regarding funding issues in healthcare and the resulting impact on the capacity of services to provide appropriate care. Some specific examples of resource issues linked to COVID-19 were discussed, including a lack of beds and a blood-tube shortage. However, there was a recognition that systemic funding issues are not unique to the COVID-19 pandemic, with cuts to healthcare funding over the last 10 years resulting in greater pressure on community services and affecting patients' access to necessary services.

> *"… there is that wider systems issue as well… about this blood tube shortage, and that actually affects the capacity of the Primary Care facilities to provide the services that they would normally provide. And that's in addition to the existing strain on the NHS system currently… that is influencing on access to the services."*

> *"The other problem I think is that you know, the NHS certainly see the voluntary sector as being something they're going to use to fill in their gaps."*

While participants noted the problematic reliance on the community sector, they also recognised the value in community organisations and roles embedded into local areas to support the health and well-being of communities. One participant noted that with requisite and sufficient funding, such roles can foster a sense of community and facilitate behaviours that prevent ill-health, as long as appropriate and sustainable training and support is available. Despite this potential, another participant expressed concern that community support is being cut without consulting

the service users, possibly due to a lack of understanding and awareness of the value that it holds in the wider system.

> *"There used to be a thing they used to do it at school... to support children with ASD... one year that just got-- it's just got stripped away. So, I think there's little things like that that probably were of more value than was maybe realised when the people top down were making these big decisions."*

2.2 Addressing waiting times

Waiting times were consistently highlighted as an ongoing issue within GP surgeries and A&E as well as specialist services. Participants reflected that this may be a result of COVID-19 pressures on services; however, it may also be indicative of wider systemic issues.

> *"I took him [partner] to A&E and we had to queue outside, and he had pneumonia. It really is very, very difficult at the moment to get A&E help and yet if I phone the GP, he says take him straight to A&E,.. We were [there] eight hours before we were seen by a doctor. To me that is unacceptable at the moment. I know there's Covid, but they are not using new ideas, new routines, and new plans. They're sticking to the same old ones they've done for the last 20 years. With Covid they need to rethink it."*

> *"He said I should ring the GP. Well, I tried, I think it was three times, bearing in mind I've just lost my mum, I think it was a week later and I'd tried three times and each time I couldn't get hold of them."*

It was highlighted that longer waiting times cause greater deterioration in patients, thus requiring more resources. Due to the severe worsening of waiting times as a result of the COVID-19 pandemic, participants noted services may experience a backlog for the next few years, which will potentially impact the health of future generations.

> *"...what about these poor children who need orthotics for their growing feet. I do really feel that's a huge issue. Then we have issues with teeth, huge issues with gum disease. It's not because of lack of cleaning, it's actually the tissue. Everything like that, eyes, ears, everything, so all the outpatient appointments for people, particularly gastrointestinal issues...[were] delayed."*

> *"In terms of actually having to wait, it affects your quality of life, and... that has knock on effect on other things, in terms of your mental health and your wellbeing, and so there's something about actually that quicker treatment. And yes, I guess there are the wider issues around workforce and blood tests, and you know, all the things that we're finding we've got shortages of. But yeah, just that kind of what can happen as a consequence I suppose."*

2.3 Relations between practitioners and patients

It is possible that the systemic issues discussed so far have impacted the relationship between clinician and patient. With the clinician working on the front-line, issues within the system are often seen as issues with individual practitioners, who may be under great strain. For instance, some

participants expressed a lack of trust in their clinician's capacity to provide appropriate care, particularly in cases of mental health difficulties or in instances that patients feel require more specialised care.

Some stated they felt their GP wasn't willing to put the time in to work out what was wrong with them. On the other hand, others were pleased when their GPs were honest in stating that they didn't know what was wrong with them and referred them to more specialised care.

> "I find when you go to a GP, coming from a mental health standpoint there's a lack of confidence on who they should treat you and deal with you… when I was younger and I'd go to the GP because that was advised, they would just send me to A&E or they would just give me antidepressants without anything alongside that. You can pick up when there's that lack of confidence."

> "I was lucky with my GP, with the trouble with my diabetes. He said you're too complicated for me … I leave that to the specialist."

> "If you maybe have certain … maybe repeating themselves in a three-month pattern, then you need to look a bit deeper into it and sure that takes time, it means you have to analyse a bit more, you have to scratch your head a bit more... I fully accept that maybe not everybody is fully trained on being a specialist in everything but then being free enough to say, okay I passed you on."

3. Further developing patient centred care

The final theme identified ways in which Primary Care and community services can work together and consider patients' individual differences to improve personalised, tailored support and move towards left-shifting models of care.

3.1 Encouraging and improving engagement by reaching out

Our sample highlighted the potential for the burden of responsibility to shift from the patient to health and community services. Several participants recognised the difficulty some patients have in engaging with services and the problems this can cause with regards to their health and well-being. They mentioned the importance of identifying groups who may experience barriers to accessing support and "reaching in" to encourage engagement.

> "It's about reaching into communities and not expecting them necessarily to come to you."

> "...the key point of this is capturing statistics and capturing data because you can't really forward any planning in terms of design, research or anything if you're not actually capturing data on any of these marginalised groups"

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" …I just feel sometimes that GPs would have records of patients that haven't engaged for a long time and things like that. Maybe there should be a way of community care, Primary Care reaching out and just checking on those people, maybe they're not engaging for lots of reasons, but maybe in some way we need to just look at everyone and just check everyone's okay or give them an easy way of engaging just in case they don't know how to."

Some participants also noted the necessity for services to tailor their support for marginalised groups. While some services do reach out to support the engagement of their patients, this isn't always in line with the needs of marginalised groups. The resource and systems issues can also make such pathways difficult to maintain. The participants noted that engagement activities such as supporting with healthcare education, supporting understanding of, and confidence to access the services, or offering follow-up care, can enable successful early intervention.

"They may even feel they're not ill enough to engage or something like that. Some people don't want to bother people. … especially people who live on their own, people need advocates, people need people to help them navigate the system, if you don't know the system then you don't know how to engage."

"And it's actually building confidence is hard, so that people feel like they can come forward. Don't ask me how to do it, because I have not a clue (laughs), but it just really needs to be done."

There was also recognition that some environments are not inclusive or comfortable for some patients or patient groups, which can prevent necessary engagement. Some participants voiced a need for discovering ways to foster supportive and comfortable environments for a range of individuals and groups.

"It's about creating situations where those different communities and specifically the marginalised groups that we've been speaking about, making situations where they feel comfortable in coming and sharing their opinion and their experiences and the issues that they're facing."

3.2 Additional support in alternative settings

The focus group discussions demonstrate an acceptance from our participant group of left-shifting models of care. Several participants expressed a sense of social responsibility and a desire for positive community connections to build an ecosystem to prevent ill-health. They emphasised the potential in our communities, and the possibility to harness skills of local people, working together to build a new model of care.

"The old role of the community centres, the hubs, actually used to try and do some of that work, in bringing people together… And actually, could contribute if they didn't come to receive help, they came to do something they were good at, and they could help other people with.."

"It's back to that … community where we were all giving and taking, but it's kind of a mutual beneficial kind of experience … having more places that people could come together, just to connect with each other and share experiences and support each other. Rather than medicalising problems."

Participants also discussed how some patients require additional support to identify difficulties. The discussed the value of embedding support into existing organisation structures, such as schools. The reflected that underlying issues cannot always be identified during consultations, for example, and supporting patients holistically and in alternative settings may help identify areas of need.

"The role that schools perhaps have to play, around supporting children again, rather than kind of, again it's medicalising kind of yeah, problems isn't it, or making you know, deciding this child is difficult, when actually it might just be about you know, what support they're getting in school."

3.3 Personalised care

Participants expressed the need for Primary Care to be more individualised and to consider individual differences when providing care. This was particularly evident for those with long term conditions as it can be quite frustrating to have several tests done when there are abnormalities that may be normal for the individual but are flagged up on the system as being a cause for concern.

"This is what I do every day and everyone who manages my care knows this, yet, at the same time I'm told by the system that I have to do this annual review in order to require the medications I need to stay this well."

"Yeah, and also what we were saying earlier on actually, about taking a personalised approach, not putting everyone into a box, not one size fits all, actually is a good way to start thinking, going forward"

3.4 Joined up care and communication

Several participants emphasised the impact that poor communication between services can have on the quality of treatment and accessibility. Participants expressed frustration at repeating conversations with services they felt were connected. They also noted the safeguarding risks of poor communication, such as in the case of discharge from acute settings.

"One of the big things to ensure is that it [support] is sufficiently individualised."

"You tend to find that these things aren't joined up, and that you'll get messages through various apps and then they're not followed up when you go from the GP and to the pharmacy, things like that. If they're developing services, they need to be joined up, they need to be communicating with each other."

"A lot of discharges around our area have to be done because of the bed pressure from what I've gathered, but the communication has to be done properly… proper assessment before discharge and the pathways have to be established…Everybody involved has to bear in mind safeguarding issues."

Participants in our sample stressed the importance of connecting with the wider support system of their patient, particularly family carers. Carers can offer valuable insight into the patient's needs, particularly at crucial moments in a patient's healthcare journey, such as at discharge from acute settings. Some participants also noted that by increasing meaningful engagement with carers during patient appointments, carers may describe their own need for support; this provides a means of reaching out to members of this underserved group.

The discussions also covered the benefits of an integrated health and social care system. They reflected how services within both the health and community sectors can work disparately, with gaps between the health and voluntary and community sectors. One participant shared the system that was adopted in Kent and the benefits it had in lowering hospital admissions and potential for higher quality of patient care and smoother referrals.

"The plan was that all of the referrals would go to the same place…. From that it would go to the most appropriate team. Is it working? Yes, it is working… [but] at the moment we still have an us and them fighting sometimes… there is a long way [to go] … there's a lot more work to be done but with the integrated teams."

"The voluntary sector has been doing a lot of work, expected to do a lot of work, by the government, by the NHS. But the voluntary sector is, say, disparate and not very well pulled together, so half the time the voluntary sector don't know what each other are doing, and what they provide."

4. Seldom-heard groups in research

Part of the focus group discussions centred on the users of Primary and Community Health Services. This resulted in discussions about the diversity of users of services, and consideration of the needs and experiences of different groups. There was discussion around the terms used to describe these groups, and the participants we spoke to felt the term marginalised was stigmatising. Most indicated a preference for terms such as 'hard-to-reach' or 'seldom-heard'. We extracted terms relating to seldom-heard groups mentioned in the discussions, to create a list of groups that are potentially excluded or underserved in primary and community care services delivery, underrepresented in research, and whose voices may be less likely to be heard by services and commissioners (*figure 2.*). All demographic groups and conditions listed in *figure 2.* were identified as equally in need of representation in future research.

Participants in the current Community Priority Setting exercise noted that people in seldom-heard groups can face several barriers to accessing and using the services that they are entitled to. One sub-theme identified above (*3.1. Encouraging and improving engagement by reaching out*) illustrates participants' perception of the need for services to recognise the potential barriers for these groups and places the emphasis on services to make changes in order to engage users from seldom-heard groups.
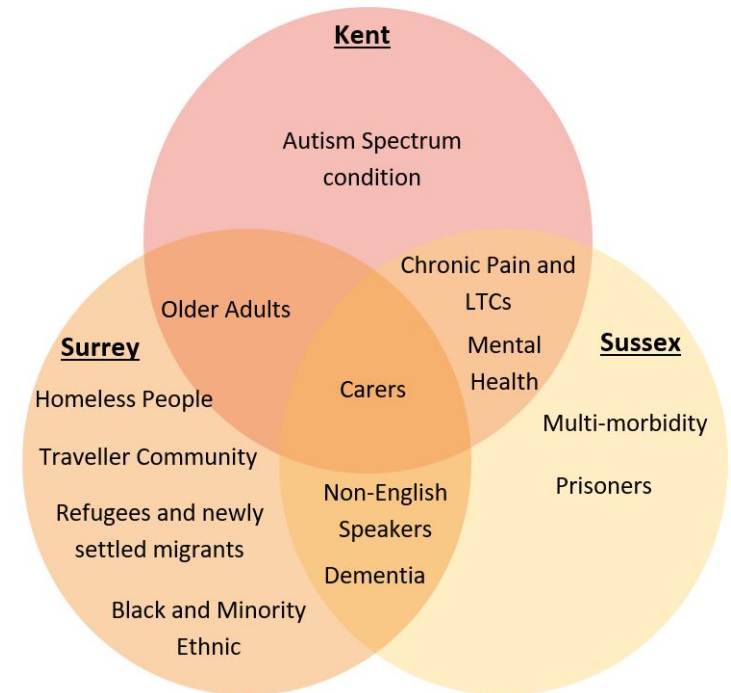

Figure 2. Seldom-heard groups and conditions identified by focus group participants in each geographical area

Summary of Findings

This Community Priority Setting exercise revealed the experiences and views relating to Primary and Community Health Services (PCHS) of members of local communities across Kent, Surrey, and Sussex (KSS). The themes have been identified as research priorities for the Primary and Community Health Services theme of the Applied Research Collaboration for KSS.

The findings highlight issues with patient access and satisfaction with the current delivery of seemingly disparate services across Primary Care and the voluntary and community sector. The increased digitisation of booking systems and delivery of services has been a benefit for some patients, however, the introduction of technological innovations in Primary Care has been complex and may result in access issues for some patients and should be driven by clinical need, with clarity and choice for patients regarding digital access.

Primary Care and the NHS more broadly are facing immense pressure, with the British Medical Association[7] stating the current health service is unsustainable. Our participants noted the strain is having consequences for patients' access to safe and timely care. They reflected how wider systemic issues are reducing patients' trust in their practitioners and the wider system. Participants emphasised the need for a system that is individualised with smooth integration across teams, and which offers creative solutions to engage and support health and wellbeing. They also noted the particular importance of tailoring support for and empowering seldom-heard groups, especially the hidden workforce of unpaid carers.

Implications

Several themes generated from the focus group discussions align with the aims and objectives of the PCHS theme. For instance, the theme aims to deliver projects that support sustainable care for marginalised groups by investigating new approaches to enable patients and carers to take control of their care. This addresses several of the community priorities summarised by theme 3, *Further developing patient centred care*, where participants highlighted the need to reach out to marginalised, or seldom-heard, communities and for care to be adapted to the needs of the individual and of communities. The findings illustrate the need for creative approaches to engaging seldom-heard groups, from addressing access barriers, to

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[7] https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/an-nhs-under-pressure

developing a more expansive understanding of potential settings where support and health-focused conversations could occur.

The concerns noted by participants also highlight the need for cross-theme collaborations across the ARC KSS. Several areas of need identified here also have relevance to other ARC KSS themes. The importance of support for carers and emphasis on joined-up working with other community and health and social care services indicates a need to for PCHS to work more closely with the Social Care theme, for example.

Several concerns raised by our participants reflect the widespread workforce shortages we are currently seeing in the NHS (Alderwick & Charlesworth, 2022). Reducing patient waiting times, practitioners' capacity to provide tailored care, and the time to engage with and build connections with complementary organisations require a full and thriving workforce. Patients are understandably recognising the impact these issues are having on their care, which may account for the reduction of trust in their practitioners. It is therefore crucial that researchers address the impact of their work on the Primary and Community Care workforce.

Additionally, the theme 'addressing problems in the healthcare system' highlights how wider systemic issues can impact service delivery and patients' outcomes and experiences of healthcare. Several participants

noted that systemic issues, such as funding issues or workforce difficulties, can have a substantial emotional impact on patients, further exacerbating health problems. They recognised that when Primary Care is in crisis, patients end up in crisis as preventative and ongoing support is not available. Our sample emphasised the importance of identifying innovative ways to mitigate the impact on patients.

These findings demonstrate an acceptance of 'left-shifting' models of care from communities across the KSS region. The PCHS theme aims to promote and evaluate new models of care, which harness the power of local community assets to support patients to live well with chronic conditions, and to foster healthy communities. Participants observed the value of the voluntary and community sector, reflecting that pressure on NHS services could be reduced if community services and roles were well funded and if their value to the health of the community was recognised.

The use of technology in Primary and Community Health Services has grown considerably in recent years, accelerated by the necessity for online work during restrictions to in-person activity (van Hattem et al., 2021). The PCHS theme recognises the developing digital ecosystem across primary and community care. However, as discussed, the sudden influx of digitisation seems to have resulted patchy implementation that is not well received or appropriate for all patients or conditions. It is important that services and

practitioners are empowered to use technology to their advantage while tailoring its use to individual patients or patient cohorts (Jefferson, 2022). However, implementation of digital tools will be most successful when informed by research with stakeholder involvement and strong Public and Community Involvement and Engagement (PCIE) components (Garmann-Johnsen et al., 2020).

The increase of digital tools in our health and community services raises questions around digital security. The participants in this exercise highlighted the desire for more connected care across different organisations. However, this comes with challenges surrounding data sharing and accountability. Considering these themes as connected matters is therefore essential to ensure appropriate and sustainable service improvements.

Methodological Reflections

The novelty of this Community Priority Setting exercise was the involvement of members of the public as Public Advisors at every stage of the process. The co-production allowed their valuable insight to be garnered to inform future research, which we hope will help direct limited resources to areas of priority for local communities.

A particular strength was the involvement of the Public Advisors during the focus groups. Their support with facilitation enabled natural and open conversations, which helped reveal the most salient challenges communities face with regards to their experiences of Primary and Community Health Services. There was value in additional human resources to support different aspects of online focus group discussions. For instance, the ability to respond synchronously in the chat function as well as continuing the flow of verbal conversation allowed different avenues of expression for participants. Participants also reflected at the end of the session in Kent, that the group of size five helped everyone to feel welcome and have a chance to speak. They also remarked that it felt like a productive and constructive discussion.

While the online method allowed for some flexibility with how participants engaged in the discussion, the purely online format could have limited the range of views we collected. As discussed in theme 1.3 of the results, switching to digital communications has the potential to omit those who are already isolated or digitally excluded. It is possible that those who might not be able to engage with online focus group discussions are those with the greatest challenges. Therefore, we represent a limited collection of patients views and experiences of health and community services. Nevertheless, the

results do provide insight into the kinds of issues faced by the public when accessing health and social care.

Additionally, the online format limited the full participation of some participants who were able to attend. For example, some were unable to turn on their videos. Facilitators also experienced technological disruptions, which highlights the need for more human resources and contingency plans during online engagement with the public. This observation connects with our findings regarding the need to consider how the increase in technology has affected patients' experiences of health care. The participants in this exercise are likely to be a self-selecting sample, who are motivated to engage with and improve services. Given the difficulty some participants had fully participating, the ability to sufficiently connect with and attune to a practitioner online may also be reduced.

Concluding Remarks

With this Community Priority Setting exercise, we aimed to engage members of the public and provide the opportunity for communities across the KSS region to share their views and experiences of primary and community health services. We hoped engaging with local communities would enable the identification of community priorities, which could help

guide our research activity as a theme and hold us to account regarding the impact of our existing projects.

The resulting themes provide a basis for the conceptualisation of future research. Using these community priorities as a guide to project development will help direct limited resources to areas of community need and will enable us conduct research that will have a positive impact for community beneficiaries. The Primary and Community Health Services theme in the ARC KSS will use these findings alongside their theme-generated aims and objectives to guide our future work and collaborations with researchers and health and community services across the region.

The exercise has the potential to underpin the future work of the PCHS theme during the final phase of commissioning of the ARC KSS and to inspire targeted collaborations with health and community care services in the region. These findings are significant for the wider health and social care system, as they provide some clear areas for improving patient access and experience. We therefore expect the community priorities to augment the conceptualisation and methodological development of future projects within the ARC and between the ARC and front-line services. They will be of particular utility in strengthening rationales for research funding and collaborations with service providers. Alongside project specific PCIE, using

these community priorities to develop funding applications demonstrates responsiveness to the needs of local communities.

We intend to disseminate our findings through existing working links with the respective Integrated Care Boards across KSS, publish in a number of academic journals, and use outputs as citizen-centred needs articulation to inform innovation within the changing Primary and Community Health Services ecosystem.

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