NHS
Portsmouth &
South East Hampshire
Clinical Commissioning Groups

Your Big Health Conversation

Phase 2 findings

1. Summary

There has been extensive engagement activity – primarily face-to-face discussions with patients, service users and carers, but also including online feedback – across the three CCG areas in Portsmouth and south east Hampshire, seeking to generate feedback relating to four specific service areas: mental health care; frailty; same-day services, and support for those living with long term conditions.

Participants were encouraged to consider how services work currently, and also to express their thoughts about how care models could develop in future – particularly in terms of how community-based services could change, with a greater emphasis on early intervention, prevention and promoting independence.

Feedback was, of course, wide-ranging and varied but some of the key areas for consideration when new care models are being developed are below:

Community-based mental health care

- Flexibility: can services be more 'person-centred', designed to respond to individual need, rather than appearing to present a rigid, pre-set 'offer' which only meet specific, pre-determined needs and nothing more?
- Filling the gaps: can the NHS help to develop a system where early intervention and prevention are a greater focus? Can the NHS do more to prevent a crisis developing, rather than responding when it does?
- Accessibility: can services be easier to access, more available 24/7? "Out of hours" perceived to be a very long time.
- Compassion: can the NHS do more to include those with personal experience of mental health problems, to offer more understanding beyond medical care and treatment?
- Integration: can more be done to bring together not just social care and the voluntary sector, but also housing, police, probation, and all agencies involved in supporting patients?

People with multiple long-term conditions

- Continuity of care: how can the NHS deliver a system which makes the patient feel that they are being supported by a single, seamless system rather than a patchwork of different systems?
- Reducing the burden: how can the NHS make it easier to be a patient with multiple conditions – offering services which are designed to make life easier for the patient, not the system serving them?
- Easing access: how can the NHS enable patients to access not just any member of staff, but the right member of staff, quickly and easily?
- Holistic care: how can the NHS ensure that patients can access vital emotional, mental health and social support alongside medical care?

Same-day (urgent) care services

- NHS 111 and pharmacies: how can the NHS drive greater levels of awareness of these services, and a greater confidence in people to use them?
- Capacity: how can the NHS manage same-day resources in a way which encourages people to think help is available, rather than encouraging them to think that there isn't even any point trying to make contact?
- Access (1): how does the NHS balancing the need for efficient use of staff and resources with people's concerns over travel distance?
- Access (2): maximising the potential of new technologies, but ensuring that those without access to such technology, or who do not feel confident using it, are not disadvantaged
- Appropriate staffing: finding ways of protecting scarce GP resources so that doctors focus on the care they are best equipped to deliver, while avoiding any sense that other staff provide a 'lesser' service

Supporting frail patients

- Peer support and voluntary sector: not all support is clinical, and NHS needs to do more to put often isolated, vulnerable people in contact with non-medical support
- Capacity: how can the NHS provide community-based services which are organised and resourced in a way which feels like it provides a strong, comprehensive service?
- Carers: the need to make carers feel more informed, involved, and valued, not only because they would appreciate it but also because it would make them more able to play a more active role
- Proactivity: the need to address the enduring sense that the NHS steps in when something goes wrong, rather than planning ahead to avoid the crisis in the first place.

These questions and themes should be considered by commissioners from the earliest stage of service development, so that the perspective of patients, service users and carers are always to the fore, and can be balanced with other key considerations such as resources, workforce, and clinical best practice.

2. Introduction

Phase 1 of Your Big Health Conversation was intended to begin the discussion with local groups and individuals about the pressures and challenges facing the local NHS, and to start to gather feedback to support future decisions regarding potential changes to out of hospital care. At this, initial, stage, the issues covered were intentionally broad – exploring opinions on issues such as seven-day services, specialist centres, the balance between acute and community-based services.

The method employed for Phase 1 was also, again intentionally, broad. The overwhelming majority of responses were collected via an online survey, and respondents self-selected. This meant that the discussion and the questions were shared relatively widely (almost 2,000 respondents across the Portsmouth and south east Hampshire area, the largest sample size in recent years), but that the findings were considered to offer a snapshot of opinion, rather than a statistically robust measurement.

For Phase 2, a very different method was adopted. The intention was still to continue with what was essentially 'background engagement' – in that the feedback being collected was not designed to inform or endorse any specific decision, or the development of any specific clinical pathways – but the ambition was to initiate more detailed discussions, and so collect more informed and informative feedback.

To this end, the majority of activity during this phase was qualitative – face-to-face discussions. These discussions, supplemented by online feedback mechanisms, were based around generalised descriptions of how four key NHS service areas work today, and how they could develop in the future: community-based mental health care; same-day services; support of people who are particularly frail, and helping those who live with more than one long-term illness. In each case people were offered an outline of how out of hospital care could develop, and then discuss how the proposed direction of travel sounded positive, where they had concerns, and where they felt the local NHS may need to consider other factors which had not been reflected in the examples.

Wherever possible, engagement activity during Phase 2 sought to focus on people with lived experience of the services in question – hearing from people who were truly informed about the subject, and whose feedback would be informed by personal insight rather than assumption.

3. Phase 1 – what we learned

As stated, the intention behind Phase 1 was two-fold. Firstly, to begin a conversation with local people which set out more clearly than before the drivers for change – rising demand, staffing pressures, finite resources, advances in technology and treatments, and changing expectations. Secondly, the process was intended to begin to gather feedback which could inform future decisions about how those challenges could be responded to.

The Phase 1 findings, from a sample which was inevitably self-selecting, gave a broad sense that the respondents were largely aware that changes to local NHS services were inevitable, and constructive in their attitudes towards those changes. Some of the key findings were:

- The sample strongly agreed with the idea that patients could benefit from being cared for in larger, specialist hospital departments, even if that meant travelling further
- Less than 10% felt that fundamental change was unnecessary, with strengthened community-based services seen as the best way forward
- There was wide acceptance that pressure on GPs could be eased by utilising other professionals such as nurses and therapists

- Respondents appeared to accept that services were interconnected – most people felt that 'bed blocking' could be reduced with a greater focus on community-based care, even if that meant fewer acute hospital beds
- For mental health care, the focus was very much on access – not just in terms of waiting times, but also in terms of making it easier for people via approaches such as self-referral or drop-in facilities
- A sizeable minority (about a third) felt that a "seven day NHS" should mean all services being open, all day, every day.

4. Phase 2 – approach

For Phase 2 it was decided to focus on four areas – community-based mental health care, same-day (urgent) services, frailty, and supporting those with long-term illnesses. These four were chosen both for their importance (large numbers of people rely on these services), and also because they are certain to need to change to become both better, and more resilient.

For each area, respondents were given a sketch of how the NHS currently operates, and then an outline of how services may develop in the future. That outline was kept intentionally - and necessarily - broad, describing a future where different NHS, social care and third sector teams worked in a more integrated way, with a greater emphasis on early intervention and proactive support. Respondents were then encouraged to explain what they perceived to be the strengths and weaknesses of the current arrangement, and to discuss how weaknesses could be addressed.

For this round of activity, there was a conscious decision to try to focus very much on those with personal experience of services – both patients, and their carers. Over a period of several months that resulted in 24 separate discussions, which varied in size between just a handful of people, up to around 15 people in a single session, and 110 individuals contributing their feedback digitally.

5. Phase 2 feedback

5.1 Mental health

The feedback from users of mental health services produced some clear themes which were heard from numerous people. It was also notable that much of the feedback related to fundamental concerns about the very structure of the service 'offer' to people, and the adequacy of the NHS support available.

In terms of the way that services are currently organised, participants felt that NHS services were inherently inflexible. People often reported that they felt there was a large gap between the 'low level' interventions such as counselling, and the more intensive services such as inpatient beds or the Crisis Team.

This inflexibility was felt to have multiple, serious implications: people might feel that they were "too ill" for one service, but "not ill enough" for another, with the net result that they could receive no help at all; there was a perception that the gap in service meant that people whose condition was worsening had nowhere to turn until they deteriorated sufficiently (manifested either by hospital admission, or arrest) to become eligible for more intensive support, and there was a sense that people moving from one service to another (either transitioning from child to adult services, or moving geographically) could be delayed in getting the help they needed because they would be required to 'start from scratch', with little or no allowance for, or access to, their treatment history.

For those people who had presented themselves to NHS staff with conditions such as mild to moderate depression or anxiety, there was another sense in which they had met with an inflexible response. Typically, people reported feeling as if they had received a default "pills and/or counselling" option, with the perception

that this was a stronger reflection of the limited options available, rather than a considered assessment of their individual needs.

The fundamental structure (and the sense of inflexibility) of the service was also felt to be a significant problem in terms of out of hours cover. On numerous occasions there was the observation that mental health problems are often linked to sleeping problems, making 'out of hours' a very long time indeed. Participants often described feeling that they didn't know where to turn (except the emergency services or the Samaritans) when they needed help at night or weekends. For some there was a sense that the services they needed just didn't exist, for others there was uncertainty as to whether they knew about the potential support on offer.

The 'talking therapy' counselling services were often described in critical terms by the participants – that dissatisfaction related both to the structure of the service, and the way it was delivered.

For many people there was a sense that there was a 'cliff edge' – right from the start it was known that the support was strictly time-limited, and there was the strong sense that the length of time you would receive counselling was dictated not by clinical need, but by the pre-determined constraints of the service. Others referred to being left 'high and dry' at the end of their course – again, that relates back to the earlier point about gaps between services. Service users seldom reported experiences where they had moved seamlessly from one referral to another, but instead reported long waits and bureaucratic handover processes which could often them without active care or treatment for prolonged periods of time.

Some of the difficulties in accessing services were felt to relate to capacity, rather than structure. There were several participants who told similar stories about how long it had taken them to get into a position where they could ask the NHS for help, only to then be faced with long waits before that help could be provided, and little perceived support that was available in the meantime. (More generally, this sense of a service which didn't quite appreciate how difficult it might be for people to ask for support, and how vulnerable they might be by the time they did so, came through frequently.)

One almost throw-away comment, which relates back to capacity, related to a family who were contacted by a 'trainee therapist'. Given that their child was, to their eyes, in a full-blown crisis, the fact that a trainee member of staff had been assigned to them undermined them, and suggested that their problems were not considered important enough to warrant a more experienced member of staff.

As well as discussions about how services were organised, there was also frequent feedback about the way in which services were delivered.

For mental health patients there was a strong sense of wanting support from someone who understood their experience, who had "walked a mile in my shoes". NHS staff were certainly seen as having a major role to play, but there were numerous references to the relative importance of empathy, understanding and compassion, as opposed to medical qualifications.

These observations were certainly raised with regard to talking therapy services, and crisis team staff as well. One ex-service user spoke powerfully of his experience with the crisis team: "I want them to know that nothing in this world makes sense, that I'm on the floor, and that all of the skills I have learned are no use – it is a crisis over which I have no control. What can they do? If nothing else they can sit on the phone and just be with you. It shouldn't be hard for them to just say they are listening."

The importance of a delivering a service which people feel comfortable with, and welcomed by, was also evident in the way that people described accessing NHS support. People spoke of the difficulty they had plucking up courage to contact their GP surgery, only to be told that they would be called back – but knowing that their anxiety meant they were unlikely to be able to answer the phone. Another family spoke of their teenaged daughter's distress at being allocated a middle-aged, male therapist – suffering acute anxiety

already, she simply failed to be able to engage with him, and then felt it she was considered to be at 'fault' for the treatment not working. (This sense of feeling blamed when treatment didn't work was another recurring theme – some people accepted that their illness made it hard for them to engage with people, but then described how this could end up with them having treatment withdrawn because of their 'difficult' attitude.)

One subtheme was that some participants were not convinced that NHS services were genuinely committed to getting feedback and using that feedback to drive improvements. One person, who was backed up by fellow group members, said: "At the end of the session you are handed a feedback form to rate your experience. But you have to fill it in there and then, in front of the person you have to see the following week. I've never filled one of those forms in honestly, never."

As well as the perspective of the service users, there was feedback relating to the actual provision of services in the future, as described in the engagement materials. There were some strong concerns (notably from Health Watch Portsmouth) that mental health staff working within place-based community teams must not become professionally isolated, and also reservations that the "care plan approach" – while right in principle – had not always worked in the past.

There were also questions regarding the deliverability of a more community-based model in the future. The questions included matters of capacity (would there be enough team to actually deliver care 'close to people's homes' or not), and also quality – would community teams be able to deliver the same standards of care that patients might receive in hospital settings? There were also references to the importance of ensuring that NHS teams were working closely with social care staff and the voluntary care sector, and also maximising the potential that these groups could offer. There was also a real sense that the NHS had to find better ways of bringing other agencies into decisions about patients – for some, getting the 'health' element right was only one element of a far bigger picture, and if someone was not being helped to face problems they may have with housing, money management, the justice system, or their family, then any proposed healthcare solutions were likely to fail.

Areas of challenge and suggested focus - mental health:

- Flexibility: being more 'person-centred', less rigid – responding to need, rather than retaining traditional models which are perceived to be inflexible and limited.
- Filling the gaps: can the NHS prioritise early intervention and prevention, instead of crisis response?
- Accessibility: can services be easier to access, more available 24/7?
- Compassion: can people with personal experience of mental health problems be more involved in service provision?
- Integration: can the NHS help to bring all agencies closer together to support patients, who will often have multiple needs beyond only health?

5.2 Long-term conditions

Much of the feedback relating to long-term conditions chimes with the views the local NHS has heard from multiple sources in recent years. However, it was particularly useful to hear directly from those either living with several long-term illnesses, or those who care for them, because it enabled some of those familiar themes to be explored further, and also allowed some issues to be discussed which had not been identified previously.

A very common refrain from people who are in contact with the NHS for a number of different long-term illnesses is that services are not joined up. Variations of this theme are heard time and again. Patients report experiences of services not talking to each other, IT systems which are not compatible, clinicians who are unaware of what other clinicians are doing, tests and checks being duplicated. It is noteworthy that such

comments were received so frequently, despite the relatively recent improvements in IT and information sharing in the local area.

For years patients have expressed their frustrations at having to tell their story more than once, and that message came through again loud and clear – both in terms of inconvenience, but also the sense that such a system undermines continuity of care.

Comments included: “Not having to explain to different people each time you see someone,” “Each patient must have a case manager. Too often each illness you suffer from is treated separately without reference to other illnesses,” “This isn't just about seeing different specialists and the time this takes. There is also a difficulty around seeing lots of different GPs… I saw a different GP each time who came into it part way through and had a different approach or angle, or each focused on a particular symptom.”

Continuity of care was seen as important both for the patient, and for clinicians. There were accounts of people feeling left in limbo because clinical staff from different departments had arranged various tests, but nothing was progressing while each team waited to hear news counterparts elsewhere. Or alternatively, frustration at GP practices organising routine, tests for people who were already receiving the same tests from the specialist departments caring for a particular illness. Such difficulties, participants felt, not only undermined their experience of care, but also made it more difficult for the clinical staff to be confident they were providing the best possible service as well.

A fragmented model of care was also perceived to undermine the idea of receiving ‘person-centred’ care: “I am not just my health conditions, I am me”, and “it needs to be holistic, consistent”.

For some, the solution to these difficulties is a single clinician to oversee treatment, for others it is greater co-operation and communication between different teams (“We need clinics… liaising with specialists to offer a one-stop shop”). For almost everyone, though, the answer had to involve a system which was more seamless for the patient, and which eradicated delays and inconsistencies. It has been apparent over several years that the traditional attachment to the idea of “*my* GP” is less strong than in the past, but people are still clear that they want a consistent service, even if the individual clinician cannot always be the same.

Another symptom of a system which people feel to be disjointed was a sense of burden that many patients reported. Just one discussion group generated the following comments: “The follow-up process isn’t great. You have a blood test and then you have to go back to them to get the results”, “They never call you back to tell you the results – you have to chase them”, “The nurses haven’t sent me the forms so I’ve had to chase”, “When I got in touch the results hadn’t been entered into the computer”. There was a cumulative sense from lots of feedback like this that people often feel that the system has lots of moving parts and interfaces which inevitably creates a high risk of mistakes and delays, and that the onus is on them to make things happen, rather than being served by a system which is designed with them in mind.

The attitude of participants towards the particular type and grade of staff they see is interesting. There is a considerable constituency who value specialist input above all else – this was clear both from this round of engagement, and from previous discussions. For respiratory patients, for example, specialist nurses were extremely highly thought of and much preferred over more generalist clinical staff. This is partly because some of this particular group can recall a previous service arrangement where they had good access to a team of specialist nurses, and so wish for a return to what they saw as a superior arrangement, but it also echoes some sentiments that are more broadly shared.

For some people with long-term illnesses, specialist staff are simply “a far better option for me”, or “I worry that GPs… just can’t give you the right care”. There is clearly an issue of confidence for some participants – non-specialists are thought to ‘not have enough knowledge’ to manage long-term conditions. This closely matches previous conversations with people living with Type 1 Diabetes, who expressed the clear view that

getting support from generalist staff was of limited use to them. One participant said: “Being able to trust the staff is key – that is more important than where you have to go.”

For some participants, seeing primary care clinicians was simply an unnecessary barrier, either because they felt they knew their condition better than a GP, or because they knew that specialist involvement would be needed in any case: “Seeing general staff is wasteful, because they only end up contacting specialist staff anyway,” and “Get a specialist opinion in earlier! This is not fashionable, but it can stop people with multiple chronic problems living with deteriorating health (and) having multiple appointments.”

The reluctance of some (although not all) to have their condition managed via primary care is also influenced by issues of access to care. Timely access is almost always raised as an important issue by all groups of patients, but for people who are in such frequent contact with the NHS – and especially those who have conditions with a risk of rapid deterioration – it is hugely significant.

Many people reported the difficulties they had in getting primary care appointments – that was an issue both in terms of how they perceived the service working now, but also in the future: there was a degree of scepticism that any new model based within primary care could succeed because of concerns over capacity and access. “The example (quoted in the engagement material) given sounds great, but at the moment with GPs and specialist nurses stretched to the limit I don’t see how it could happen.” This reflected a widely-held sense that any model could only work if it had the capacity to enable good, speedy access. It is also noteworthy that complaints about access to specialist staff (as opposed to GPs) were relatively rare.

Capacity was not just an issue in terms of length of wait, although that was a major concern for many – this group also felt that a traditional GP appointment simply did not offer them the chance to have their illnesses managed effectively. Comments included: “You really need one appointment to cover all your illnesses”, “10 minutes just isn’t enough”, or “doctors are under pressure to resolve something in very tiny spaces of time”. Short appointments were not just seen as inconvenient and dissatisfying – they were also felt to inhibit discussion and questioning, undermine good decision-making, and inhibit the ability of patients to self-manage conditions effectively.

Healthwatch Portsmouth also posed a series of questions relating to capacity, more broadly – querying whether a new model would have sufficient staff, facilities and sites to make it work, how staff might operate within new structures, and asking to what extent such an approach might involve additional travel for patients.

The role of the third sector (either formal charities, or more localised peer support arrangements) was raised by various groups. Given the nature of the participants (many of whom would attend support groups) it is hardly surprising that such services are valued, but opinion vary as to how and why such groups are most useful. To some, non-NHS support can provide essential social and emotional support (previous engagement work has suggested how important this can be, especially in the early days following a diagnosis), while for others there is a more practical benefit – the ability to learn more about managing a condition, without being limited to short appointment slots.

There was also feedback from Healthwatch Portsmouth, highlighting the importance of the third sector in designing services, as well as providing support (both for patients themselves, and for their carers). Questions were also asked regarding how the NHS might be intending to fund and support the third sector, if such organisations were having more asked of them.

Areas of challenge and suggested focus – long-term conditions:

- Continuity of care: how can the NHS help patients feel they are supported by a single, seamless system rather than a patchwork of different systems?
- Reducing the burden: how can the NHS make it easier to be a patient with multiple conditions?

- Easing access: making it easier to contact the right member of staff, quickly and easily.
- Holistic care: the importance of helping patients access vital emotional, mental health and social support alongside medical care.

5.3 Same-day (urgent) services

This topic has already attracted a great deal of feedback in recent years, with extensive engagement activity having taken place to understand more about people's experience of same-day services, and their views about potential changes. This topic is also the one where it is hardest to identify a target audience because all elements of the population may require urgent care support at any time.

Past engagement activity across Portsmouth and south east Hampshire has generated a picture of a population who, on the whole, feel that the current system is overcomplicated and in need of simplification, and who have a sense that pressures on primary care capacity are one of the key drivers for A&E attendance. When presented with a broad picture of how community-based same-days services could work in the future, some of those themes were very much in evidence again.

Before examining what *was* said by participants in this latest round of engagement, it is worth noting what (usually) *wasn't* said. Given the growing attention and energy being given to 'talk before you walk' messages promoting the NHS 111 telephone service, and the potential for pharmacies to play a greater role in managing demands for urgent care and advice, it was noteworthy that both of these service still do not appear to have gained stronger resonance with people. Without prompts, the 111 service and pharmacies tend not to be cited by respondents very often at all – almost all comments referencing existing services are instead primarily directed towards primary care access, walk-in centres and A&E. This enduringly low level of awareness is significant, given the clear direction of travel both locally and nationally towards a greater emphasis on self-care, and the use of 111 and pharmacies to manage a greater proportion of the demand for same-day support.

In terms of the feedback, it was unsurprisingly clear that access was a hugely significant factor – whether in terms of physical distances involved, opening hours, or getting through to the service people needed to contact. This was closely connected to an often-expressed scepticism regarding whether, in terms of same-day services, the NHS has the people or money to do the job properly. There were repeated references to a lack of suitably-qualified staff, the difficulty in getting appointments, or even getting through to a practice in the first place. Given the earlier reference to how previous engagement has suggested that pressures on primary care are seen by some people as a key driver of pressures on A&E, this perception can have tangible, problematic consequences – if people believe that getting hold of a GP surgery is difficult, it increases the likelihood that they won't even try. Unlike the other three topic areas, for some people the way to secure better same-day services was essentially simple: more money, and more staff.

Comments regarding capacity and access included: "There are currently too few staff being pushed beyond what is safe", "it would be great… if there would actually be appointments available in the near future", "there is no belief that you will get a same-day appointment", "my concern is that there isn't any same day care happening", and "NHS is too understaffed to allow the system the chance to be a success."

A notable subtheme of access concerns regarded the available *means* of getting hold of services, particularly GP services. Some typical comments included: "More incoming phone lines to reduce queues", "do away with appointments, the system used to work perfectly", "have a number for urgent care, and another for appointments", "rid the NHS of queuing telephone systems… they are expensive, time-consuming and exclude patients on low income", and "For surgeries to answer their phones and provide more effective triaging – not to tell everyone to phone at 8am!" One participant added: "Trying to get hold of a practice by telephone in the morning is basically impossible – you might as well just go in person."

For some respondents the answer to such access frustrations was to provide better, or better resourced, traditional forms of communications. For others, the answer lay in the use of new technology. For example: “At our GP surgery you can send them a message online, and they respond within 24 hours – that works well”, or “If you can get real-time online consultations… that would be fine with me.” A related point is that some respondents felt that a centralisation of services was only viable if it was backed by good IT systems which enabled clinicians to access the patient records of everyone using the facility, regardless of where ‘their’ GP surgery was based.

For everyone who talked about the possibilities of new technology, there were always those who wanted to raise their concerns. In a few cases there was discussion about the reluctance that some groups (generally, but not always, relating to age) may have regarding technology, but such concerns tended to be cited as a plea for recognition of those who might struggle, rather than as an argument against modernisation: “You have to remember that not everyone has a computer. You need a diversity of provision.” Few people are hostile to the idea of using technology per se, except those who see it as inferior to the ‘personal touch’, but more were worried that it could produce groups of patients who would feel at risk of being left behind if traditional methods were abandoned.

This engagement once more demonstrated that, for some, the ability to be able to see or contact a GP remains of paramount importance. Unprompted, the default setting for such conversations remains about getting a “*GP* appointment”, or “seeing a *GP*”. For many people, there still some distance to go before they think in terms of getting a same-day *primary care* appointment, which may be with a nurse, a therapists, or a paramedic. As before, though, there is clearly a sense amongst others that they are receptive to the idea that an alternative member of staff not only could help them when they need help in a hurry, but also that this other professional might actually be the best person for them to see.

These quotes highlight the difference. On the one hand you would have a respondent saying that the most important thing is: “To get an appointment with a GP on the day, not see a nurse nor have a GP phone patient or their carer.” Alternatively, another participant said: “It doesn’t have to be a doctor – if you got advice from a nurse it would put your mind at rest. I would be confident getting advice from a nurse – I’d be happy with that.”

There were some participants who also referred to opening hours, in terms of how this negatively affected access (“You need longer opening times”, or “Must be open for longer – no-one works 9-5 anymore”), but this was not a common theme. Previous engagement has suggested that there has been a lag in terms of people’s reported experience not reflecting recent changes in opening hours for primary care, so it will be interesting to see whether there is a growing awareness of enhanced access arrangements and out of hours services.

In this scenario, participants were offered a general sketch of a future where a greater range of services might be available in a local area, but that not all services would necessarily be available in all GP surgeries. For some the notion of ‘hubs’ was welcome but there was an unsurprising concern: travel distance. Several participants made reference to the difficulty of travel, especially when someone is ill, and there were also multiple references to the potential unfairness for people who do not have their own transport: “By centralising staff, the people that need the services most can’t get to them.”

Such concerns were particularly evident in online responses, when people were asked to focus on their concerns over how services could change.

Asking people to travel further for care wasn’t only seen as a potential inconvenience, or barrier – in some cases people felt it may even affect people’s decision-making: “The geography of the services and how patients may go 'a little further' for care - if this is not easy… then patients are still likely to go to ED.” Clearly,

for some, getting that balance between a comprehensive service and a local service wrong risks producing the behaviour the NHS is trying to avoid.

Feedback from Healthwatch Portsmouth suggested some key considerations, most notably the importance of any same-day service having access to patient records, and being able to deliver timely care. There were also questions regarding resources in terms of having enough locations to facilitate an effective service, having enough appointment slots, and having enough staff. There was also an interest both in whether any new model of care could provide a broad enough range of healthcare professionals to meet patient needs, and also a concern as to how people would respond to being triaged towards 'non-GP' staff – would people be satisfied with this?

Areas of challenge and suggested focus – same-day services:

- NHS 111 and pharmacies: how does the NHS raise awareness of, and confidence in, these services?
- Capacity: coping with high levels of demand, and the perception that services simply cannot cope.
- Access (1): the need to balance efficiency of delivery, with people's concerns over travel distance.
- Access (2): maximising the role of new technologies, without risking 'digital disadvantage'.
- Appropriate staffing: how to enable GPs to focus on patients who need their skills, without creating a sense that other services are less valued or valuable.

5.4 Frailty

Purely in terms of engagement activity this topic has perhaps received less attention in recent years locally than some of the areas already discussed, above. And given the vulnerability of the patients in question, in is not surprising that some of the feedback is very particular to this group – particularly around the role of carers. It is not uncommon to hear people making the case for better support of carers whenever local services are being discussed, but in the case of supporting those who are particularly frail this theme comes through loud and clear. This subject was also more likely to generate discussion about social care – often in terms of shortage of capacity, or a lack of integration with NHS teams.

Some of the carers who participated in this project described systems and staff caring for them well, but more often they recounted experiences where they felt either unsupported, uninvolved, or uncared for themselves. One carer recalled a time when a GP had taken time to check how they were, as well as the patient – just that one gesture was deeply appreciated, partly because it was a rare example in their experience. More typical was the participant who spoke of "shouldering a huge burden… without much appreciation or support".

A sense of not being included came through strongly. For example: "As a carer it would have been nice to be given information about what needs to happen, and where you can go for help", and "Communication is key… It's like being sent home with a new baby and no instructions."

There was little sense that people felt that their role as a carer was seen as centrally important, let alone as a key player in helping vulnerable people to maintain their independence. A few participants clearly felt that this sense of exclusion was made worse by the attitude and tone of some staff, but for most it was more about the way services operated rather than being the result of the attitude of a few members of frontline teams. "You need everyone working together, and the carer involved".

Not everyone felt excluded though – there were also conversations about what really good practice felt like: "My mum sees a consultant for another condition, and he's brilliant. He talks to me, allows me to accompany her, allows me to be there when she comes out of treatment – he understands and accommodates. He takes the time to involve the carer and let them play a role."

There were numerous references to the fact that fulfilling a carer role can place a strain on the person's health and wellbeing, and no real sense that the NHS fully appreciated this fact. "You are 'flagged' as a carer, but that is it" was one verdict, and another person said: "if one person is carrying the sole weight of care it can destroy that person's health." Another said: "If you, as a carer, want an appointment for yourself, it is really hard – you're really limited in when you can go out but the practice can't accommodate you. Instead, you might be trying to have a telephone consultation when the person you are caring for is wandering around, or you might be put on hold for ages. You're treated as though caring is easy!"

There is also a strong perception that support is in short supply for the patient, as well for the carer. A significant number of participants made reference to the issue of capacity – feeling that there was fundamentally a shortage of community-based support which needed to be addressed. Several people referred to the difficulties they had getting hold of their GP surgery and how challenging this was for frail or vulnerable people, and others referred to a sense that they were dealing with staff and services who were hard-pressed and who struggled to give them time.

Related to this point, there was some (although not common) feedback which negatively highlighted the role of private agencies in providing home-based care. A few participants felt that such agencies meant that people received excessively brief visits which were of little value.

"Employ more district nurses and home carers", "more investment in community nurses", and "adequate staffing in the elderly care sector" all summed up that sense of a stretched service, and there were other references to a perceived lack of appropriately and usefully trained staff, or weekend cover to give people support outside normal office hours.

And this perceived lack of support wasn't always talking about the number of staff available – for some people, too many staff didn't seem to show enough care and compassion. "Treat the frail and elderly with care and respect, and listen to them if they have fears", "teams must have a caring nature and understand that frail folk are often frightened", and "treat people as individuals". That reference to being frightened also linked to others who spoke of how frailty can easily lead to loneliness, and to isolation from friends and family.

There was also some feedback to the effect that patients and carers were facing a health and care system which was not joined up – in much the same way that people with long-term conditions often experience. With frail patients often coming into contact with multiple NHS and social care teams, there was a strong need for those contacts to be co-ordinated and clear.

Just some comments relating to this issue included: "A single point of contact is important", "unless it is clear who is in charge, there can be sloping shoulders", "you need one organisation – you can work it through as a team process, with links into all the services that that patients could need."

This apparent lack of co-ordination also chimes with another theme – a desire for more proactive, planned care which supports people, rather than the emphasis on stepping in when people are in crisis. For example: "Mum's NHS care is very fragmented, and only responds to emergencies."

A lack of co-ordination and clarity can add to the burden of care – like those with long-term conditions, being put into a position where the patient or carer is expected to assume responsibility for making things happen is felt to be very onerous. "It's frustrating. If you've been discharged back to your GP and then need more help, you need to get a whole new referral." Other people found similar frustrations when the person they were caring for moved closer to them: "When she moved nearer to me, the systems in the different areas didn't 'talk' to each other, so she was told she needed a new assessment. That would be traumatic for her, and her condition hadn't changed. We couldn't just pass prescriptions across, either, and her notes didn't come through."

Although most discussions centred on the role of the NHS (and also social care, in some cases) in care of people who are particularly frail, it is clear that for some, at least part of the answer lies outside the NHS and in the realm of the third sector and/or peer support.

"I had to find out about support groups myself – why is that?" was the plea of one person, while another said: "Staff should be pointing you towards support groups". Similarly: "I have learned a lot from support groups – support from other people is so important. We are all on the same journey, but at different points."

Feedback from Healthwatch Portsmouth supported the proposed overall direction of travel towards integrated, proactive care planning, but members clearly had questions relating to the detail of how a new model of care could be delivered.

There were particular queries regarding how well NHS staff as a whole are currently able to provide holistic care to people, and how a larger, more multidisciplinary team would function. The group was also keen to stress the importance of involving other sectors, most notably the voluntary/third sector, and council services.

Areas of challenge and suggested focus – frailty:

- Peer support and voluntary sector: how to successfully help isolated, vulnerable people to make contact with vital, non-medical support?
- Capacity: how can the NHS provide community-based services which are organised and resourced in a way which feels like it provides a strong, comprehensive service?
- Carers: how to make carers feel informed, involved, and valued?
- Proactivity: finding ways to move away from need to address the enduring sense that the NHS steps in when something goes wrong, rather than planning ahead to avoid the crisis in the first place

6. Next steps

A high-level summary of the findings has already been shared with participants and key stakeholder groups, and publicised on the CCG websites in Portsmouth and south east Hampshire, and using social media.

This more detailed report will be shared with CCG Governing Boards and bodies, commissioning teams, transformation teams, local neighbourhood teams, key external groups, and the public.

'Phase 3' will be developed with a view to making it locally flexible, and will prioritise the growing need to communicate changes clearly to local populations and stakeholders – both in terms of the specific changes themselves, and also the wider agenda to develop new models of care.

Although the overall objectives of system reform across the Portsmouth and south east Hampshire area are largely shared, there are still significant degrees of local variation in terms of the particular steps being taken to achieve those objectives - both in terms of specific service models, and timings. This local variation, as organisations increasingly move from the planning stage to piloting and delivering change, suggests that moving from 'system wide' to 'local' would be appropriate – albeit accepting that there will nonetheless be areas of work which are still best considered across a larger area.

The new phase of communication should also clearly reflect how the results of engagement activity to date are influencing the numerous service developments which are currently underway. Decisions are increasingly being taken in the context of a considerable amount of feedback from local patients and residents being available, and future materials should make that connection clear.

As services are tested, and established, it also makes sense for the nature of the engagement activity to also change to reflect that shift. There should be a new emphasis on capturing the views of local people regarding their experiences of the new services, and using those views to inform the ways in which services are modified, or extended, in future. As services become established, this more experiential engagement should replace the predominantly 'background engagement' approach which has been to the fore until this point.