

## **Long-term conditions: engagement report**

June 2016

### **Background**

The CCGs' Communications and Engagement team, working across the Portsmouth and south east Hampshire area, was approached to support the development of a new model for supporting people with long-term conditions.

The brief was broad. The only working assumptions were that the NHS was seeking to become more effective at supporting people to self-manage, and that – where appropriate – the overall direction of travel should be towards community-based (rather than acute-based) care.

The process of public engagement was to complement the other conversations which were taking place with clinicians working locally in primary, community and secondary care.

### **Approach**

It was agreed that public engagement should be conducted in two distinct phases.

The first stage was to be a quantitative survey, and the second stage would consist of qualitative 'focus-group' style sessions. The survey was intended to generate useful feedback in its own right, but also to highlight areas of interest which could then be explored further in the subsequent face-to-face discussions.

### **Phase 1: Survey**

An online survey was produced, to be made accessible to people living across the three CCG areas in question – Portsmouth, Fareham and Gosport, and South Eastern Hampshire. It was also made available as a 'hard copy', for those who could not, or preferred not, to use the internet.

The survey was promoted using traditional, digital and social media channels, and aimed exclusively at people who had at least one long-term condition themselves, or who cared for someone who did.

It was designed to give the CCGs some insight not only into the way that people were experiencing NHS care, but also to explore people's attitudes towards the way in which services could be delivered - for example, getting people to think about where they felt most comfortable receiving services, or how they wanted to be supported to manage their own care more effectively.

### **Phase 1: Survey results**

The survey generated 709 responses from people living in the Portsmouth, Fareham and Gosport, and South Eastern Hampshire CCG areas. In terms of current service usage, the respondents were most likely to visit pharmacies on a regular basis, followed by appointments with GPs or practice nurses. The group were least likely to have had contact with community nursing staff, walk-in services, and the out-of-hours GP service. Both A&E and the NHS 111 phone line were also seldom used.

The majority (59%) described themselves as feeling 'very' or 'quite' involved in decisions about their care – clearly, the fact that approximately four in 10 people did not feel able to make that claim suggests that there is more to be done in terms of communicating with, and involving, patients and their carers.

There was a similarly mixed picture when people were asked whether they felt their NHS care was 'joined up' or not. Almost 38% of respondents said that they would 'agree', or 'strongly agree' that care was joined up, whereas 35% said they would 'disagree' or 'strongly disagree'. (Of the remaining respondents, 23.6% said that they could 'neither agree, not disagree' that their care was joined up, with a small number who did not know.)

To gauge views on the **usefulness** – or otherwise – of potential service developments or changes, respondents were given seven options, and asked to rank them in order, from '1' (ie the most useful), to '7' (the least useful).

The options most frequently given a ranking of '1' were 'more information to help you do more to manage the condition yourself', and 'more convenient ways to consult with your doctor (eg email, online)'.

The options most frequently ranked as '7' were 'more hospital appointments' and 'more support from charities / voluntary groups'.

Respondents were also asked to give an indication as to **how and where they would like to receive their care** in the future. To do this, the survey offered four statements, and respondents were asked to choose a single option which most closely their feelings about the way they would like their long-term condition(s) to be managed.

The most popular option (chosen by 42%) was "I want to be able to get NHS support in GP surgeries or community facilities so that I only have to go to hospital when absolutely necessary..." The next most popular answer, chosen by 28% of the sample, referred to the

'reassurance' of having appointments in hospital, closely followed by 25% opting for "I want to get better at managing my own health..." Strikingly, fewer than 3% indicated that their preference was to get most of their advice and help from support groups, rather than appointments.

The survey also included 'open' questions, allowing respondents to record their views without using pre-determined lists of options. People were asked to explain what they felt were the best things about the NHS care they received for the long-term condition(s), the aspects they wanted to improve, and any other comments they would like to make.

In terms of the best element of their NHS care, respondents were most likely to praise the staff they encountered (both in general terms, and in terms of positive attitude), the ease of access (most commonly to specialist staff or teams), and the availability of regular checks and monitoring.

When asked to set out the areas where they felt the NHS could improve, respondents were most likely to cite difficulties of accessing support – most commonly this related to waiting times, although access to specialists (either knowledge, or staff) specifically, was also raised repeatedly, as was the desirability of access to GPs / other practice staff with specialist knowledge.

Observations about the timeliness, or availability of support, are perhaps to be expected and so straightforward comments relating to access were the most common. However, there were some other, less straightforward themes which also came up repeatedly.

The need for greater integration of services – often either explicitly or implicitly linked to the need for better information sharing – was one such theme, echoing a frequently-heard frustration that patients still encounter delays, or have to repeat conversations numerous times, because of the ongoing operational separation of different elements of NHS care.

There were also comments expressing a desire for greater levels of routine monitoring and oversight, and for the availability of more information about the respondent's condition. Such comments, however, did not always make clear the motivation for such a desire – whether more information or oversight was felt to be medically necessary, or useful in terms of providing reassurance.

*The full results are at Appendix 1.*

## **Phase 2: Discussion groups**

Following the completion of the survey, and analysis of the results, a series of discussion groups were set up with people who have one or more long-term conditions.

The intention was to explore some key areas of interest in greater detail, and also to learn more about what may lie behind some of the headline survey findings. For example, a few

of the findings appeared to suggest that people with long-term conditions did not value the support that voluntary groups can provide – was that genuinely the case, or was that finding more a product of the way in which the question was asked? Or, similarly, is there really a significant minority who find it reassuring to go to major hospitals for their care, or was this apparent preference less an expression of an attachment to a particular setting, but rather an attachment to specialist staff?

For each discussion a loose structure was prepared to cover key themes, and to offer prompts to participants so that issues could be explored in detail. This structure, however, was never intended as a prescriptive script, and the degree to which it was followed varied considerably.

In general terms the intention was to explore the following areas: staffing, and questions of who was best placed to provide support; location, in terms of the most appropriate setting for support to be delivered; how the NHS can improve the information it provides to patients; how the NHS can better help people to ‘self-manage’ more effectively, and the issue of how technology could offer opportunities to better support people to stay well.

Although arranging a series of discussions which provides an entirely representative set of opinions is clearly difficult, the CCGs nonetheless sought to engage with people who have the most common types of long-term condition. Meetings were held with people with COPD (respiratory), coronary conditions, type 1 diabetes and (separately) type 2 diabetes, long-term mental health conditions, and musculo-skeletal conditions. The size of the group being engaged with varied widely, from three to more than 20.

## **Phase 2: Discussion groups – overall themes**

### *Emotional support*

A recurring theme was a sense that although the NHS was focused on providing *physical* support to help people stay well, or get better, there was little or no corresponding focus on the potential *emotional* impact of living with a long-term condition.

This perceived gap appears to be most acute in the period immediately post-diagnosis, but is not exclusively confined to that period. People reported experiencing extreme anxiety when, having been given a diagnosis, they then may have waited for weeks, or even months, before receiving fuller information about the implications of the diagnosis, their prognosis, and the way in which they may need to change their lifestyle. A number of people described feeling very vulnerable at this time, and troubled by their inability to know more about what was wrong with them, and what their prognosis was.

With a greater availability of information than ever before, allied to this potential delay in reaching a reliable NHS source of expertise and support, people are highly likely to immediately research their condition themselves. Given the abundance of potentially

unreliable information on the internet, and the potential lack of contextualisation, this presents a risk of avoidable distress. People reported reading lots of online information - relating to reduced life expectancy, the possibility of developing alarming symptoms or complications, the impact on fertility, for example – which although it may have been untrue, or at best unreliable, was the source of great anxiety due to the lack of an authoritative voice to guide them.

Most groups also reported that a) they received little acknowledgement from the NHS regarding the emotional impact of their illness, and that b) some form of support would be valued. However, it was not necessarily the case that people felt that the NHS itself should be the source of this support – for some that this was simply not the role of the NHS, but most commonly, *at the very least*, there was felt to be a role for the health service in acting as a facilitator, or as a signpost, towards appropriate support.

### *Speed of response*

Many people, across all condition-types, reported waiting for long periods before receiving any follow-up to their initial diagnosis.

As explained above, this was often felt to be emotionally difficult to deal with, but it was also felt to be a concern in terms of the management of the condition. People felt that they were unable to monitor themselves, manage their conditions, or be aware of the actions they could or should be taking. Such a gap increases the likelihood of people either seeking their own information (from sources which may not be reliable) or reacting in a way which is understandable, but not appropriate or useful – for example, being too apprehensive to exercise, or altering their diet in an unmanaged way.

### *Information preferences*

A recurrent theme whenever patients are asked about NHS care is ‘information’. People will frequently express the view that they would like more, or better, information about their condition – this is most commonly related to a desire to be better at managing their physical health, or perhaps to help them to feel more emotionally reassured.

During the group sessions there were efforts made to move past the generic desire for more information, and to explore precisely what that might look like. As was discussed at every group, the NHS produces lots of leaflets and other materials, but if those are not truly useful, what would be?

Opinions on what ‘good information’ looked like varied considerably, and were often difficult to pin down. Often, the discussions quickly moved towards a consideration of clinical information and monitoring data, rather than information *per se*.

However, the overall preference was clearly for face-to-face, prompt communication in the early days following a diagnosis. Some people did express a preference for written

materials, or for web-based resources, or for phone lines, but those other suggestions tended to be in the context of additional or supplementary options, rather than as a main source. The way in which people absorb information tends to be quite specific to the individual, of course, and so a range of preferences is to be expected. However, the value of a face-to-face encounter with someone who had knowledge of the field was clearly the most popular suggestion, with very few people feeling that such an option was not valuable.

### *Specialist input*

Some of the 'free text' comments submitted as responses to survey questions at Phase 1 suggested some fundamental differences in what people wanted from the NHS, in terms of managing their long-term condition. One group of people prioritised access to specialist support – either in the form of a consultant, or nursing staff, or a GP with a specialist field - above all else, whereas others felt that they wanted someone who could offer a more holistic view of their health – someone who could see them as a person, not a particular condition or set of symptoms.

During the Phase 2 group discussions, it was evident that the majority of people who were spoken to fell into the former category. Access to specialist support (the definition of what this meant varied – there was no consensus that 'specialist' equated only to 'consultant') was very widely prioritised above access to general practice. The degree to which this was the case varied from group to group, but the overall message was that people felt that staff with the relevant specialist area of expertise were of far more use to them when it came to the management of their long-term condition, than those working in general practice.

It is important to stress again that the particular value given to specialist staff was not necessarily connected to medical consultants. In fact, specialist nursing staff were clearly very highly valued, and respected, and frequently this group was seen as the best option not just in terms of monitoring and advice, but as the first point of contact. Similarly, GPs with a relevant specialist interest were also prized. When talking about the more routine aspects of care – monitoring, advice, reviews – very few people felt that consultants, specifically, had a role to play, or that they needed to be more readily available. A very small number of people did specifically talk about wanting better access to consultants, but then tended to find it hard to express specific reasons for that wish, or to explain the specific circumstances in which that improved access would have been necessary.

### *Location preferences*

In the Phase 1 survey, one question gave respondents four choices regarding their preferences for how care should be delivered, and asked which one most closely matched their preferences.

One of the possible answers was: "I find it more reassuring to have appointments at hospital, and would prefer that to continue." Although the received wisdom tends to

suggest that almost nobody wants to go to hospital unless absolutely essential, a notable minority (28%) of the sample chose that option.

During Phase 2 this issue was explored with all groups, to test out what might lie behind that result. Almost without fail, the participants felt that precisely *where* appointments were held was essentially secondary, compared to the *expertise* of the person they were meeting. In some cases that view accompanied a sense that appointments in general practice were under particular time pressure (or indeed hard to access at all), and that specialist teams might be able to spend more time with the patient.

The conclusion appears to be that there was *not* felt to be anything inherently reassuring about travelling to a hospital building *per se*, but rather that hospitals were associated with specialist staff. In short, people did not seem at all concerned regarding where they could access specialist staff and knowledge - as long as that access was available.

There was less easy consensus regarding precisely what, or where, services should be located if not in hospital. For some the natural alternative would be their local GP surgery, but for others there was an acceptance that it may not be feasible to provide all services, for all people, in all locations. Generally, there was tolerance of the need to travel for routine appointments but this tolerance varied, and – perhaps – reflected the fact that the majority of participants were able to control their condition at least moderately well.

### *Peer support*

The Phase 1 survey produced some interesting – and surprising – findings regarding the apparent value or otherwise of non-NHS support, whether that was through charities and/or the voluntary sector, or peer support.

Although a common assumption would be that many people would find reassurance and strength from being able to spend time with other people who face the same challenges as themselves, the survey results did not support that assumption. Support from charities, and peer support, appeared to be given very little value by respondents. Given this surprising, and slightly counter-intuitive, finding, it was important to test this area in the face-to-face discussions of Phase 2.

A slight caveat to what comes next – most of the people we spoke with during Phase 2 were part of support groups themselves, and so would naturally be expected to value such a format.

This was an area which was brought up with all the discussion groups, and the response was very consistent and clear.

Almost everyone who voiced an opinion during the discussion groups testified to the value of peer support networks. This is despite the fact that not all of the groups worked in the same way, or appealed to the same groups of people. For example, the strengths of some

groups very much lay in the emotional support, and reassurance, they were able to provide to members, whereas others were most valued for enabling members to access information and expertise on a regular basis.

Of the people we spoke with it was noticeable, for example, that people with mental health conditions, and those with Type 1 Diabetes, appeared to gain socially and emotionally from their groups, whereas people with cardiac conditions, and MSK, particularly valued the opportunities their groups gave them for education and information.

Given the stark difference between the perceptions of non-NHS support during the survey phase, and the discussion phase, it is probably useful to make a few points regarding the relative strengths of the findings. An obvious caveat to the views of the support groups is that – of course – the participants were members of such groups themselves, and so would naturally be expected to value such a format. On the other hand, people who have not experienced such charity/peer support themselves may not be aware of the benefits such help can bring, and so would naturally be more inclined to express a preference for the structures of support they are most familiar with.

Both sets of findings tell us something, although it is probably significant to note that the survey questions relating to this area were asking for a judgement on non-NHS support *relative to other forms of support*, rather than in absolute terms. During the discussion groups, these conversations were far more absolute in nature - people were simply encouraged to talk through advantages and disadvantages, without being forced to make a definitive choice.

### *Self-management*

Although a key focus for the NHS, both locally and nationally, is to improve the way in which patients can be supported to help manage their own condition more effectively, it proved difficult to engage people over the specifics of what that improvement should look like. 'Self-management' may be widely discussed within the NHS, but at present it is not a term people relate to readily and so the question often had to be asked numerous times, in different ways – even then, groups were seldom able to provide many substantive answers to the question of how the NHS could better help them to manage their condition more effectively.

This is partly, presumably, simply down to human nature – it is hard for most people to envisage something they have not previously experienced. It would be reassuring to conclude that the difficulties in getting much feedback on this issue was because the local NHS is already doing everything that could be expected of it. However, it is important to note that such an interpretation is not always supported by a wealth of positive references to the support people are receiving – given the frequency of references to the difficulties

people experience when trying to access information and support, this would probably not be a sound assumption.

Such specific 'self-management' references as there were tended to relate to potential technological aids, or the improved availability of particular staffing groups, but there was very little in terms of specific suggestions.

## **Phase 2: Discussion groups – condition-specific themes**

### *Mental health*

Talking with a small number of people living with long-term mental health conditions (bipolar disorder, depression, anxiety, in particular) it was very clear that this group of people had very different needs, and expectations, from the other groups we met with.

Although there was a sense that GPs and/or psychiatrists had an important role to play, the group actually felt that this role was limited. One described it as giving them “chemical, or medical stability”, before the patient themselves began the longer road to recovery.

**Peer support** was valued *extremely* highly within this group – more than any other discussion, there was a premium put on the need for the person supporting the patient to be able to directly relate to the experiences that patient was going through. The sense that the person helping you had “walked a mile in my shoes” was seen as utterly essential. The overriding impression was that they felt that only someone who had lived through mental illness could help someone else with mental illness.

This judgement was not necessarily delivered with any tone of criticism, or bitterness – the people really felt that the NHS could not be expected to deliver the ongoing emotional, and psychological, support that they needed. The long-term conditions being discussed were considered to place more of an onus on the patient themselves to take an active part in ensuring a long-term recovery, rather than relying on external third parties.

The full write-up of the mental health discussion group is at Appendix 2.

### *Type 1 diabetes*

Talking with a small group of people who had Type 1 diabetes, there was a very marked preference for specialist input – although most groups we spoke with indicated how important it was for them to be able to **access specialist expertise**, people with Type 1 diabetes prioritised this beyond others.

There was a very strong sense that advice from generalist medical staff was not received well – it was either felt to be potentially wrong, potentially upsetting, or occasionally dangerous. Routine testing and checking could be done in community-based settings, it was felt, but access to specialist expertise was key – albeit not necessarily physically in a major hospital. One person said of visiting the specialist team in an acute hospital: “Even the

receptionists there know about your condition, and understand it”, and made that statement to highlight that this had not been their experience in general practice. There was a stronger sense of the importance of **exclusivity** (in terms of their condition being distinct from others, and treated as such) within this group than elsewhere.

Perhaps unsurprisingly (given the relatively young age of the participants) the potential of **technology** was more important than in discussions about other conditions. People were positive about technological advances, both in terms of monitoring, and communication.

This group also exhibited a strong sense that the NHS could do more to facilitate **emotional support**, as well as physical treatment. There was a need for support both in the early days following diagnosis, but also to deal with the daily reality of living with the condition – the phrase ‘burnout’ was used frequently, and was clearly an issue of major importance to the group. Peer support was seen as crucial in helping combat this.

The full write-up of the Type 1 Diabetes discussion group is at Appendix 3.

### *Type 2 diabetes*

The importance of **face-to-face communication** was clear in this group of patients – many of whom had very positive experiences going through the DESMOND educational course. This was connected to very positive assessments of specialist nurses – and an absence of the sense that greater access to medical consultants was required.

This large group also placed a higher premium than others on the availability of **practical, day-to-day advice**. For some, there was a sense of frustration at the difficulties they found when interpreting food labelling, and for others there was an appreciation of the benefits of education days – for example, on better foot care.

This group viewed peer support as a key means to address this lack of advice from the NHS – meeting with other people who had diabetes was seen as a way to remain informed, and access advice, rather than simply to find reassurance and emotional support.

As with a few of the groups, there was criticism of the NHS for not being more able to **signpost** patients towards voluntary/third sector support. There was an acceptance that GPs and practice nurses could not reasonably be expected to be aware of all of the support available locally – and so a corresponding acceptance that the charitable/voluntary sector would be better placed to do that – but there was nonetheless a frustration from participants that, as they saw it, staff did not even have basic information to hand.

The full write-up of the Type 2 Diabetes discussion group is at Appendix 4.

### *COPD*

A large group of respiratory patients were spoken to, and there were a few themes raised which appeared to be specific to them, or at least of particular importance.

The need to recognise the **emotional impact** of a diagnosis was particularly important for them – several participants reported a long delay between being diagnosed and getting anything other than rudimentary training in the use of inhalers, and this was clearly an upsetting, difficult time. Several people testified as to the damaging emotional consequences of the way their diagnosis was handled, and speeding up access to the first contact with specialist staff was seen as critical in mitigating this.

A related point, the patients reported that any deterioration in their condition could be extremely frightening. As a result, the ability to make instant, **emergency contact** with a specialist (nurse or consultant – the specific grade was not important, rather the ability to help) was felt to be hugely important. There was a greater emphasis than elsewhere on the role of the GP, although even amongst this group the preference was very much for ongoing support and management to be delivered and co-ordinated by those with specialist knowledge. Access to GPs (this particular group was based in Gosport, where primary care access is particularly challenging, and is perceived as such) was felt to be very difficult.

**Rehabilitation** classes were felt to be very valuable, primarily in terms of the physical benefits they bring, but there also appeared to be a secondary benefit in terms of the associated social interaction.

The full write-up of the COPD discussion group is at Appendix 5.

### *Cardiac*

The large group of cardiac patients we met with were already receiving a large proportion of their care in **community-based settings**. This was felt to be a strength of the local system of care – people were entirely comfortable with the idea of care being delivered outside traditional hospitals, with the only caveat being that the appropriate levels of expertise, and equipment, must continue to be available.

This group was more likely than most to emphasise the **value of GPs** as the central point in their care, as the best-placed person to be able to see the 'bigger picture'. Levels of trust in GPs were also high, although access to primary care – and consistency of primary care in particular - was clearly felt to be a problem which had grown notably worse in recent years, and this appeared to be having an impact in terms of the quality of the relationship people had with 'their' GP.

The full write-up of the cardiac discussion group is at Appendix 6.

### *Osteoporosis / MSK*

The small group of MSK patients we met felt that **voluntary/charity group support** was vital, but more in terms of practical advice rather than emotional or social support. Such non-NHS sources of information and expertise were highly prized because of the opportunity they afforded people to find out more about managing their condition, without

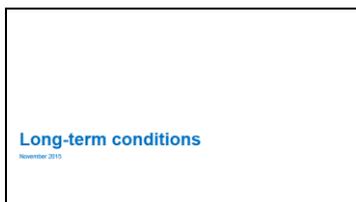
feeling they were taking up scarce NHS resources in doing so. There was a strong sense that participants did not see the role of the NHS as extending to the provision of advice and support for self-management – it was felt that this was neither an appropriate, or practical, use of NHS resources.

The group was very impressed with the **phonenumber** facilities open to them, which were both accessible and trusted. Convenient access to specialist nurses for non-emergency advice and support was felt to be tremendously useful, and the nursing teams were felt to be the most valuable resource for patients needing support to manage their MSK condition.

The full write-up of the osteoporosis/MSK discussion group is at Appendix 7.

## Appendices

### Appendix 1: Survey results



### Appendix 2: Mental health discussion group



### Appendix 3: Type 1 Diabetes discussion group



