

Healthwatch England: Co-creating the future of Primary Care

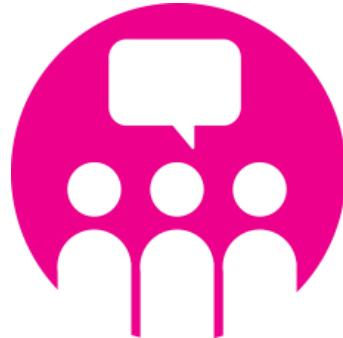
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healthwatch

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The logo for DJS Research. It features the letters "djs" in a large, dark grey sans-serif font. A small magenta circle is positioned above the dot of the letter "i". Below "djs", the word "research" is written in a smaller, magenta sans-serif font.

djs
research



This presentation summarises the detailed findings from two deliberative events to 'co-create' the future of primary care

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Executive Summary

A summary of the findings detailed
in this document

Executive Summary

Introduction

Healthwatch England (HWE), the national consumer champion in health and care, was seeking to understand what a 'person-centred' health and care model of the future would look like.

To this end, HWE commissioned DJS Research Ltd (DJS) to undertake a piece of research to canvas public opinion.

DJS engaged with a representative cross-section of the public to 'co-create' the future vision of primary care based on the future needs and preferences of service users and did so in a deliberative and qualitative manner.

DJS Research and HWE worked together to plan and carry out two consultation events (one in London and one in Bristol), each with 26-27 participants offering a representation from a range of demographic groups.

The events mainly comprised of interactive group based exercises to get participants to think creatively, and crucially, to not be constrained by the 'status quo'.

Executive Summary

Key Findings

There was a high level of realisation amongst respondents that at present there is a tremendous amount of pressure on the system. This is impacting on the care people receive and can make accessing care quickly (which is a key want/need) difficult.

Despite this realisation there was a real pragmatic understanding amongst respondents that a more people-centric approach does not necessarily equate to 'more money or more GPs' etc.

Instead, people were keen to take more of a role in their own care and a number of ideas were put forward for how this could be done, for example:

- *Self-referral – this held considerable appeal and was even seen as a 'win-win' as a means of improving the patient experience and relieving pressure on the system. At present GPs are often seen as 'gate-keepers' of referrals but this is seen slow down access, and 'self-referral' is seen as one means of addressing this.*

It should be noted however that this appeal is largely dependent on the condition being discussed. For instance, those with long-term conditions are more likely to view having control over their own care in positive and proactive terms whereas those dealing with serious, sudden or traumatic needs (e.g. finding care for an elderly relative) are more likely to need guidance and help navigating the care system.

Executive Summary

Key Findings

Choice is an area that is perceived to be lacking in many respects with respondents citing numerous examples where they have found themselves in a position that they had little control over.

Again, whilst the degree of control desired varied by condition, people want to be able to discuss their options 'now' and plan in advance knowing that they understand what is and is not available to them (i.e. the choice to go and access care where it is available most promptly).

Technology can play a key role here in reinforcing the importance of personal choice. Many respondents were clear on how technology could benefit the current system with numerous ideas being put forward (i.e. having access to their own healthcare information).

Executive Summary

Key Findings

There is a strong perceived need for more continuity and a more joined up approach.

Many respondents want to feel as though they are the most important patient being seen and this desire manifested itself in a number of interrelated issues:

- *In terms of continuity, the need to stop care and support 'falling off a cliff' was highlighted, particularly with reference to mental health where you are often allocated a set number of sessions (e.g. counselling) after which, you are left to your own devices – this does not constitute 'care' in many people's eyes*
- *At a fundamental level, people feel that sharing of information between the different healthcare professionals involved at different stages of care needs to be improved (again technology was mentioned as a means of accomplishing this)*
- *Many took this concept further and suggested a need for a caseworker or 'navigator' that would be a single coordinating contact through the process*
- *Some would like a more 'physically joined up' approach- i.e. health 'super centres' where they can access a range of expertise and services. Indeed, super centres were frequently mentioned in relation to providing prompt access to health and care which led people to question why walk in centres were being shut down.*

Executive Summary

Key Findings

People see potential to use technology to improve efficiency and streamline processes.

Use of technology to improve efficiency was a core theme across the discussions and in particular, people would like better means of sharing information and accessing it – both amongst the staff managing/delivering care and with the patient.

The appeal of technology varied according to respondents own views and comfort levels with using technology and according to the conditions being discussed (i.e. access to your own healthcare information was particularly valued amongst those with LTCs).

There is also a feeling that charities and companies could all play a role in taking pressure off health services.

For example, companies could provide convenient health checks in the workplace, charities could play a role in continuing care (e.g. mental health counselling) and supermarkets could be more proactive in providing preventative health information.

Based on the consensus from across the two events, we go on to present what the public would like the future model of health and care to look like.



The future model of health & care

Here we summarise what a future
'person-centric' model of health
and care would look like



Information, choice and ownership

- People are provided with information and advice to make informed choices about health and care – elderly care is a frequently cited example. There is an app or a (technological) means of accessing your own healthcare records.
- Those with LTCs (e.g. diabetes) in particular want to 'own their care' in this way.
- However, some people need more guidance than others – and in certain scenarios, help and guidance becomes more important than playing a proactive role.



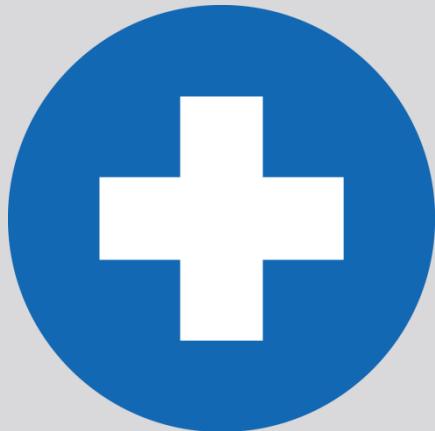
Joined up care navigation

- Technology is used to ensure a more joined-up process for sharing of information between healthcare professionals at different stages of the case process.
- In more distressing, complicated or serious circumstances a caseworker or 'care navigator' coordinates care and guides the patient through the process.



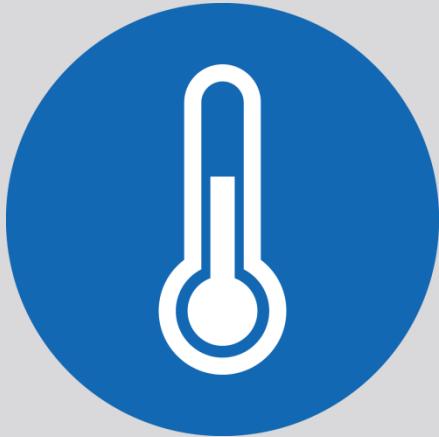
Super-Centres

- One-stop-shop health centres are available where patients can access a range of specialist expertise (e.g. specialist nurses, nutrition specialists) at point of access.
- These would also include more direct access to services and tests that are currently mainly available in hospitals (e.g. ultrasound, ECG).



Direct access to specialists

- In certain circumstances, patients can self-refer direct to a specialist at point of access (not necessarily a consultant, could be a nurse practitioner or GP with some specialist training).
- This is most relevant where getting a referral can take a long time, and where there is a perceived lack of specialist knowledge at the point of access (e.g. mental health).
- Also applicable to managing Long Term Conditions (e.g. diabetes) or preventative health issues such as nutrition.



Continuity of care

- Care continues for as long as required with as much consistency as possible; patients are not 'dropped off a cliff' after a set number of sessions or set amount of treatment.
- To alleviate pressure on the system, patients should at the very least be signposted to other organisations that can provide support (e.g. mental health charities).



Care at work and in the community

- To alleviate pressure on the system, other organisations are encouraged to take a role in health and care.
- Employers offer convenient access to health checks and preventative health advice in the workplace.
- Other relevant organisations such as supermarkets take more responsibility for providing preventative health advice.
- Charities help fill some of the gaps in on-going support (e.g. counselling and advice).



Improved efficiency through technology

- Fundamentally, technology is used to improve efficiency and care, particularly through joined up information.
- This should also include better use of technology for booking appointments, arranging prescriptions, accessing records (not very futuristic aspirations).
- In ten years we might be using Skype or Smartphones/Smartwatches to web-chat with care providers.
- However, the more basic improvements highlighted are more of a priority in terms of meeting patient needs.



Introduction

What we were trying to achieve and
how we went about doing it

Our objective was to build a vision for a *health and care model of the future* - outside of the constraints of the current system.

Understand what a 'person-centred' health and care model of the future would look like.

Specifically:

- 1** Ensure that future services are built to meet people's needs and are shaped by the people who will use them.
- 2** Examine which aspects of service delivery are important to patients so we know what to change and what to maintain for the future.
- 3** Identify what needs are not fully met by the current system and how these could be met.
- 4** Build from scratch a vision of what people want from the health and care system outside of the constraints of the current system.

DJS Research & HWE worked together to plan and carry out two consultation events, each with c.27 participants.

- ✓ We agreed a profile for each group to ensure representation from a range of demographic groups.
- ✓ DJS then arranged the events and recruited participants face-to-face, screening to ensure they were outgoing, creative and met certain agreed (demographic) criteria.
- ✓ We designed a topic guide to steer the discussions – it included a range of questions, prompts and interactive exercises to elicit views.
- ✓ Three moderators from DJS Research attended to facilitate discussions.
- ✓ Discussions were audio recorded for analysis.



Two events, one London and one Bristol, each with 26-27 participants

For each, we recruited specific demographic quotas as follows:

	Male	Female
Pre-family (no kids, aged 18 to 30)	4-5 (including at least 1 from BME ethnic group)	4-5 (including at least 1 from BME ethnic group)
Family (with kids at home, aged 30 to 55)	4-5 (including at least 1 from BME ethnic group)	4-5 (including at least 1 from BME ethnic group)
Empty nesters (no kids/kids left home, aged 55+)	4-5 (including at least 1 from BME ethnic group)	4-5 (including at least 1 from BME ethnic group)

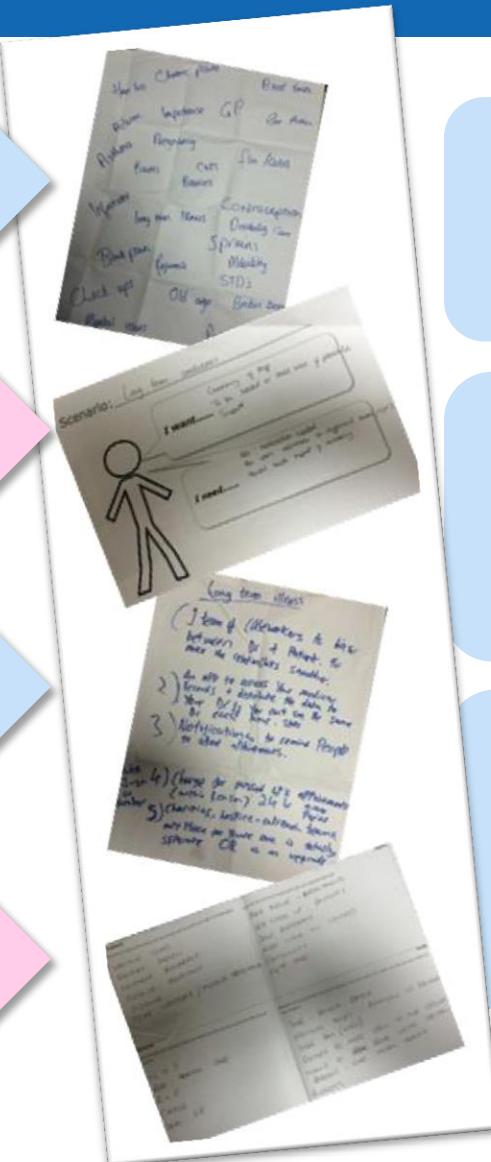
The events mainly comprised of interactive group based exercises to get participants to think creatively, and crucially, to not be constrained by the 'status quo'.

Defining care
(without explicitly mentioning primary care)

Understanding fundamental needs across various care scenarios

Fleshing out needs and ideals in detail – the ideal way to reach desired care outcomes

Brainstorming and discussing the detail of how to achieve this vision



These techniques were generally very effective in getting participants to think creatively and not be constrained by the current system.

It was also surprising how quickly participants moved from speaking generally to citing their own experiences in areas ranging from family planning to mental health.

Getting people to think in this way is challenging, and there were some instances (albeit a minority of the time) where participants reverted to more obvious thinking – e.g. better parking at hospitals...



Detailed Findings

The research findings in detail



Meeting needs in specific scenarios

Participants discussed their wants and needs in a range of health and care scenarios, and went on to discuss how these needs would ideally be met in the future



What do people need/want... what is important to them?

The quality and availability of elderly care has come under some question in the media recently and as a result, the public want more information on how their elderly relatives are being looked after.

Educating the public about their entitlements and rights towards elderly care is key; many feel they don't know where they stand in this respect. Such education extends to providing **reassurance** to the public that their loved ones are in safe hands.

There is a feeling that there is a **lack of continuity** within elderly and domiciliary care. Having a consistent carer or key worker for the individual will encourage a caring and friendly relationship.

Regular checks and inspections on staff and care homes are important to build trust with families. Whilst there are systems in place to do this, such as the Care Quality Commission, they need to be more visible and accessible for the general public.



How could these needs be met?

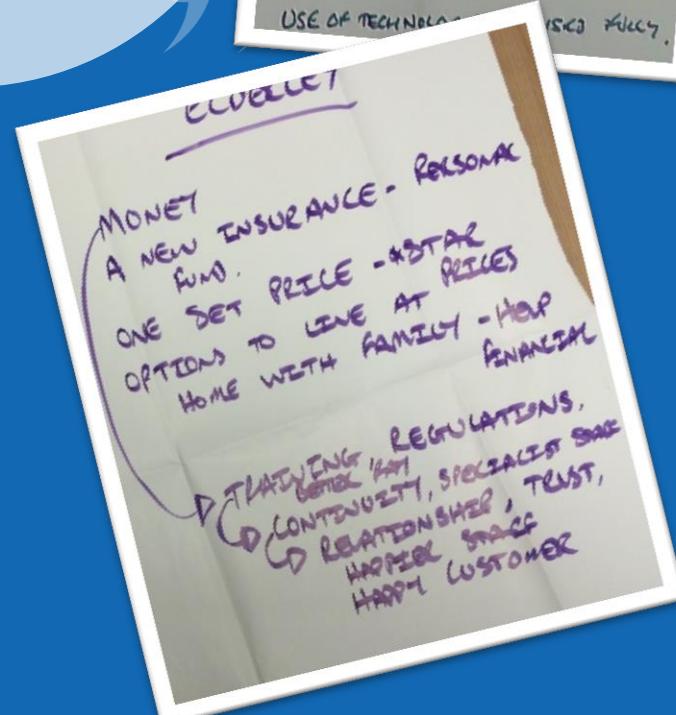
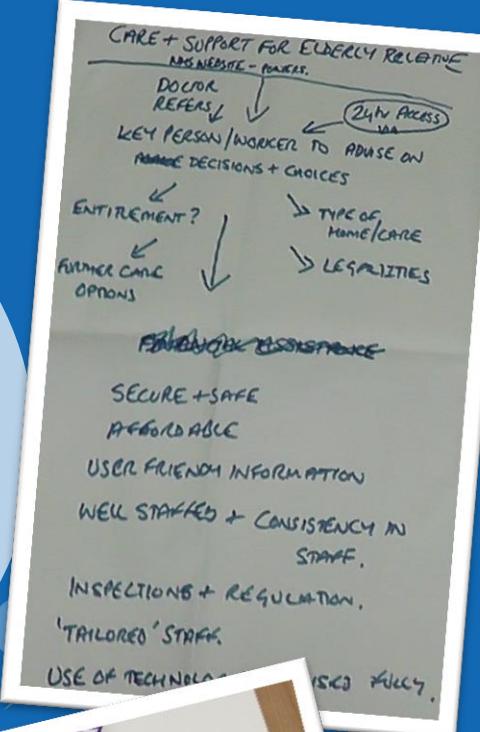
- Have a key worker assigned to your case – this person would help you with all aspects of the process. From explaining the whole procedure, any entitlements, to the choices that are available
- Strengthen the role of charities – increasing the role and visibility of charities within this area will help educate families about elderly care
- Better training – this will help refine the workforce and improve overall standards in care, providing the public with increased confidence in the services available
- Better use of technology – improving technology in elderly care will provide families with better access to their loved ones (e.g. the use of Skype)

Scenario: Elderly care

The family needs to be educated on what the elderly relative is entitled to. I wouldn't have a clue if we had to put somebody into care

There were different people coming in and out. She was old, confused and started getting scared. I'm not saying the people were bad, but she was ninety years of age

Access to better technology and also safety – a warden and an alarm, so if you're living in a community and you're elderly you've got an alarm and you've got a warden that would come directly to you and help you





What do people need/want... what is important to them?

Living with a long term condition can be a daily challenge; therefore it is vital there is appropriate support available.

Monitoring the condition is a key need for the public. **In-depth discussions** with **qualified specialists** in a particular area will help people understand their illness and manage it appropriately.

Consistency of staff as with many other healthcare scenarios is vital to maintaining confidence in services offered. Whilst many appreciate it is difficult to see the same healthcare professional every time, having a **collection of workers** who are familiar with the patient and their medical history is invaluable.

The role of **technology** can also play a large part in providing an efficient service. The sharing of information and medical records via the web or mobile app will help streamline process and help the staff who are managing and delivering the care.



How could these needs be met?

- Bridge the gap between hospitals and GPs
- Give patients full access to their medical records via a mobile app – this will give patients greater control
- An assigned case worker who can help with everything non-medical associated with having a LTC and speak to medical professionals on their behalf

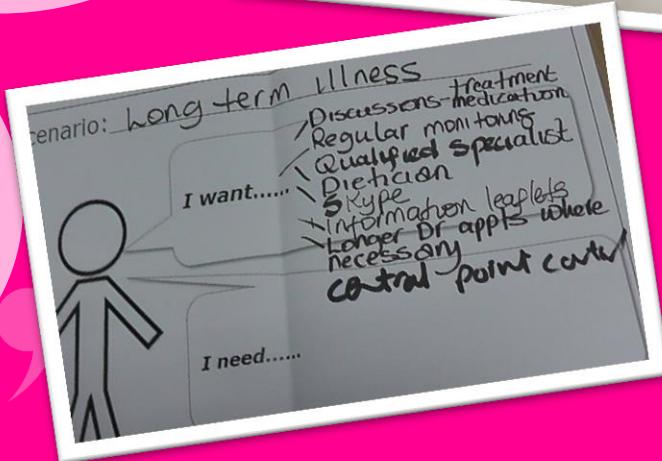
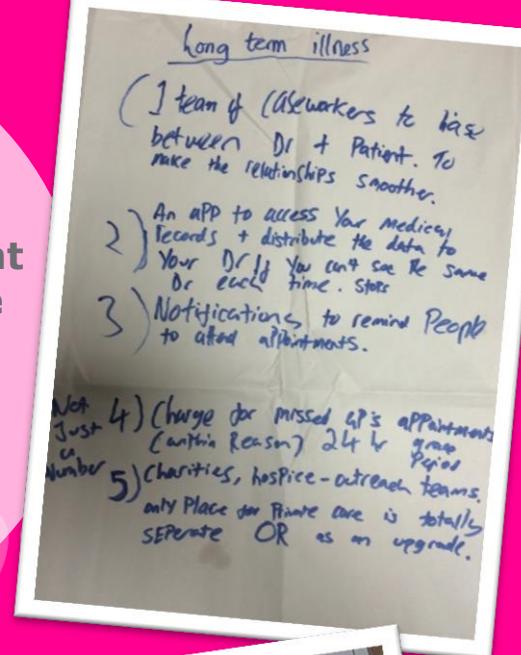
Scenario: Long term conditions

There should be one person that could point you in the right direction and coordinate all the people involved in the treatment of your illness

I think someone with a long term illness is going to want to have access to the information more readily and if they want a second opinion, get that easier

Consistency of staff, so seeing the same person every time, or a small selection of professionals

It's got to be one central coordinator





What do people need/want... what is important to them?

The public expects a **full dental service** provided within the NHS (including hygienist).

A **trustworthy and friendly** service is key. **Family appointments** should also be offered to those who request them.

As with many other scenarios, **continuity of staff**, specifically the dentist, is important. This is especially beneficial to those who are nervous patients as they will become familiar with the staff in the practise.

Some felt that having to pay for a check-up was often a deterrent for people regularly having their teeth checked which could lead to further more serious issues down the line. **Free check-ups should be offered.**



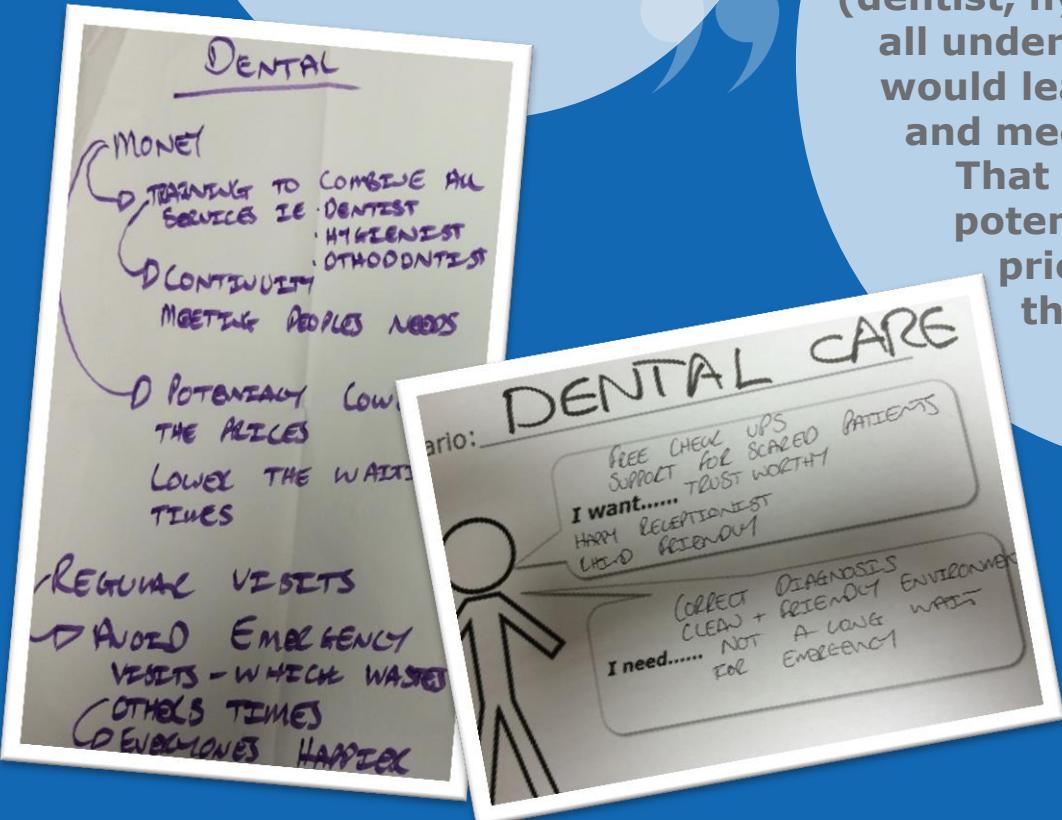
How could these needs be met?

- Better training – offering better training across the dental 'scope' will help combine services under one roof
- Such training will also lead to better continuity of staff (i.e. one dental practitioner for everything – dental care, hygiene, orthodontist etc.)
- Information on the quality of dentists in your area

Scenario: Dental Health

Participant comments

There were a few examples where you move area and try to choose a dentist and have no information about them and whether they're going to be any good or not



If there was more money in dental that could lead to better training to combine all the services, (dentist, hygienists, orthodontists) all under one net and then that would lead to better continuity and meeting people's needs.

That would then lead to potentially lowering the prices and lowering the waiting times



What do people need/want... what is important to them?

In order to lead a fit and healthy lifestyle, people need **appropriate advice** on how to do so effectively.

This advice can be delivered in a number of ways, be it **practically driven**, by offering **free appointments to health and wellbeing seminars and exercise classes**, or **information driven**, by providing appropriate links to websites with **advice and guidance**.

Regular health checks with your GP are a must, but in many ways, the burden must be taken by the public to ensure these happen in a timely manner.



How could these needs be met?

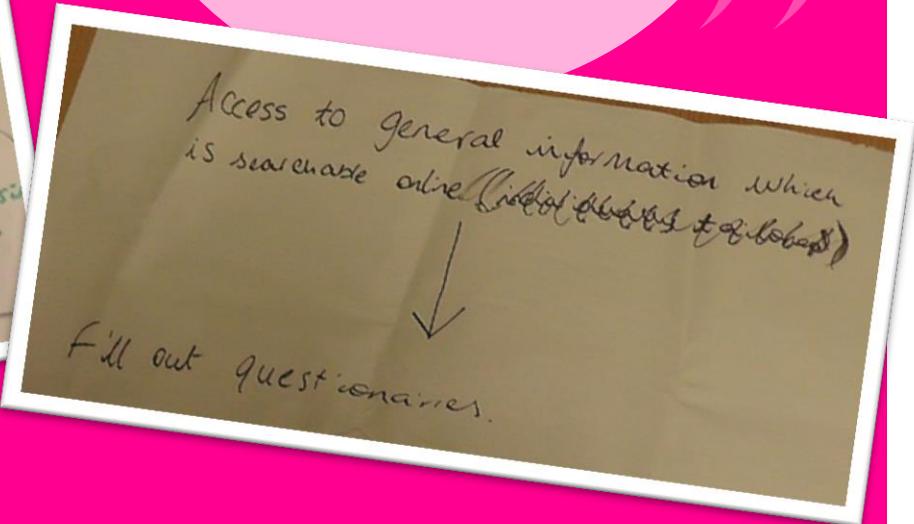
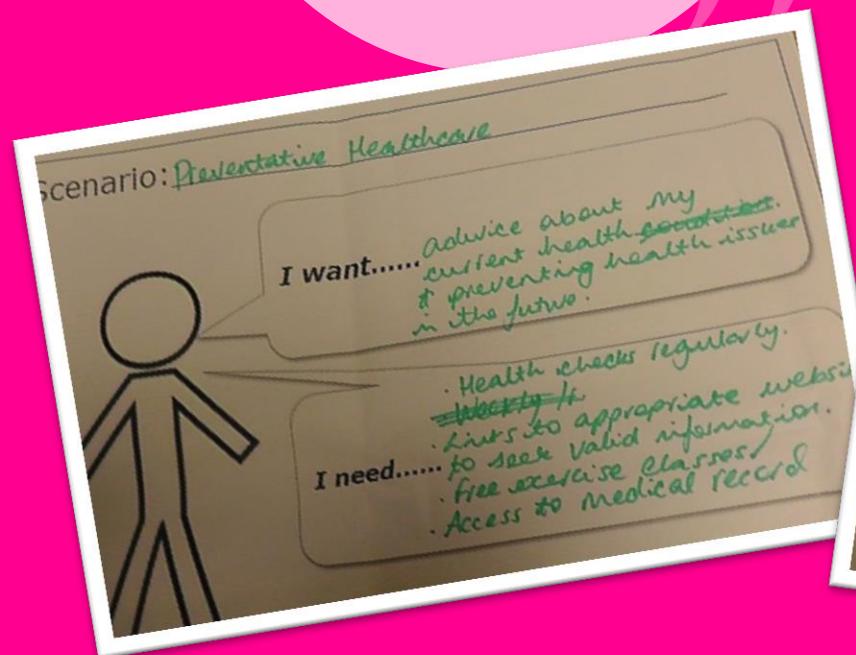
- Easily accessible information online (via appropriate channels such as Facebook and other social media)
- Online questionnaires and surveys to help educate on living a healthy lifestyle
- Health checks available at work, crèches or community centres (more accessible and convenient to the general public)

Scenario: Preventative health

Participant comments

NHS check-ups can come to you at work or the community centre or a crèche because that's just more convenient for people

I seem to remember not too long ago that children could swim for free. They cut it. Children can't swim for free. It just seems self-defeating





What do people need/want... what is important to them?

Mental Health is recognised as an area that has a certain amount of stigma attached to it and as a result there is a need for a shift in the way it is perceived – both amongst the wider public and within GPs surgeries.

People want to be listened to! There is a perceived need for **more understanding** at the initial stages of diagnosis. GP's were described as holding "the keys to everything" whilst not being specialised enough to adequately help and at worst were perceived as people who don't "believe" in certain mental health conditions.

Mental health requires quick and immediate care. The current system is seen to be **too restrictive and not responsive enough** – e.g. slow diagnoses and referrals.

Several people stated from experience that treatment can be completely inadequate - i.e. X amount of sessions that have an arbitrary cut off point regardless of the patients wellbeing.



How could these needs be met?

- Experts at point of access – prompt treatment would be more likely if there was specialist expertise at the point of access – either a GP with specialist training or, for example, a specialist nurse.
- Self-referral to specialists – this would help to reduce pressure on existing services *and* speed up the process of getting help. While some talked in terms of consultants, other felt that a specialist nurse would be more realistic.
- Offer walk in centres – enable people to bypass the GP and access specialists straight away at walk-in centres would give access to trained professionals who are on hand to see *you* about *your* condition (i.e. bouts with depression don't wait until a scheduled appointment!). At present the closure of many in Bristol has left participants feeling as though making cost savings was being prioritised over care.
- Help stops when you feel it can stop – not everyone's issues can be solved within a 'standard' amount of sessions with a specialist. Proactive follow up/ aftercare and 24 hour access to help is preferred rather than the current 'drop of a cliff' approach.
- Having a central co-ordinator of your treatment – having someone (i.e. counsellor, social worker, charities) that recognises that there's no one size fits all approach is important as they could help to co-ordinate bespoke treatment and "life support" (i.e. sign post to support groups, home visits, one-to-ones). Businesses too can take a greater role in employee well-being.
- Greater communication – using technology would be one way of enhancing communication across different departments/individuals. Too often treatment is disjointed.

Scenario: Mental health

Participant comments

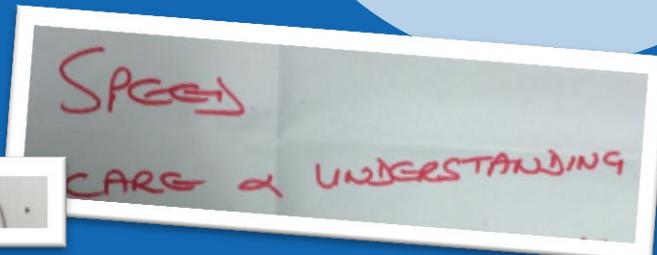
You cannot just go to a consultant. I think this is a big problem that you have to go to your GP. You can't ring up and say "Look I need to see a specialist" and if you do they say "Well sorry, no you have to go to the GP" ... "Well I can't get to my GP" ... "Well I'm sorry, then you can't see the consultant

Because GPs, as they say, they're general practitioners, so they are everything but not a lot of everything particularly. Jack of all trades, but perhaps master of none and I think, this is the problem

We would also reduce the burden on GPs which would mean appointments would be easier to make if you could go directly to a consultant and not waste the GPs time, to be referred back to the consultant

We felt that it was imperative this sort of illness is dealt with promptly. Basically quick appointments and access to specialists at walk in centres

Compassion + understanding.





What do people need/want... what is important to them?

If people require a prescription they often need it 'now' and don't want to have to wait for it – an all too common occurrence with certain prescriptions.

Similarly, people want to be assured that what they are going to be prescribed is attainable.

There is also an appetite for reduced cost of medication as there is uncertainty around why some medications are that are provided for free and others that are not.



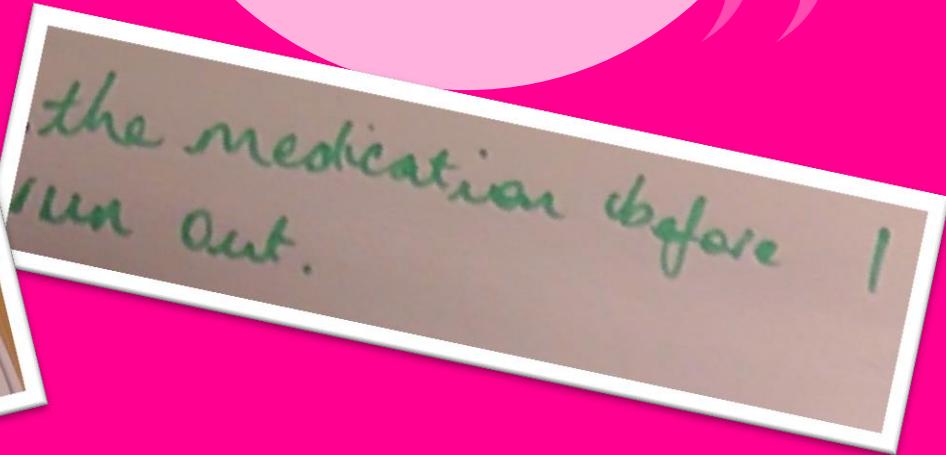
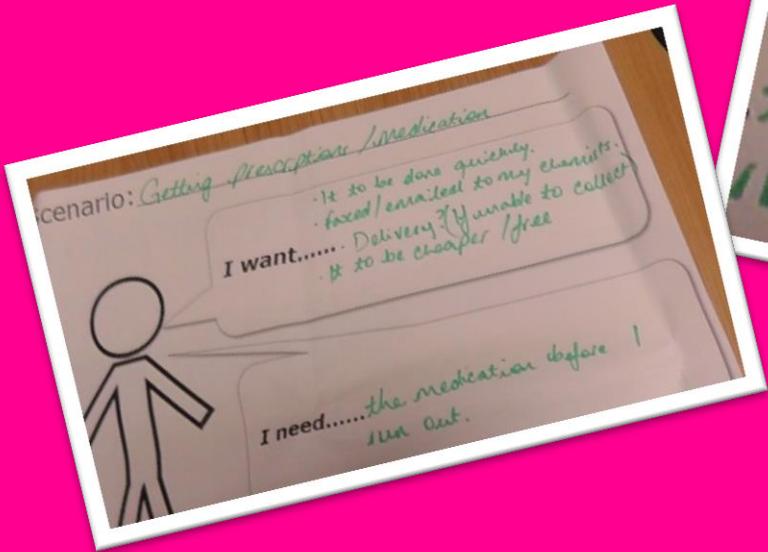
How could these needs be met?

- Advance ordering – if you need the medication it would be best to have it pre-ordered before you run out, having it faxed or emailed to the chemist ready for pick up. Offering a delivery service should you be unable to pick it up yourself would also help meet this need.
- Greater joined up communication – people have experienced being prescribed medicine only to find that it is no longer being manufactured and therefore stocked. Greater use of technology should be incorporated to ensure that there are good levels of communication between patient, prescriber and stockist (i.e. using Skype or email to order medication and have regular consultations to judge whether new / continued medication is required).
- Frequent consultations via Skype/FaceTime to keep people informed about new and alternative treatments so that people can be more informed on the choice available.
- Offering reduced price medication or greater information on why some prescriptions are offered for free and others are not would be appealing.

Scenario: Prescriptions

If you need the medication you want it before you run out and it should be done quickly. Faxed or emailed to the chemist. Possibly with delivery if you're unable to collect it

Why will somebody with a thyroid problem get free medications when somebody who has asthma doesn't? Why is there such a difference as to who can get free prescriptions and who can't?



Participant comments



What do people need/want... what is important to them?

On the whole, there was a feeling that provision of services relating to family planning and sexual health was quite well catered for as it is.

Still, discussions around family planning, sexual health and contraception can, for some, be an embarrassing subject to discuss. Finding ways to alleviate this anxiety is one area that could be improved.

Choice is also an area where improvements could be made so that people feel as though all options are available to them from which they can pick the most relevant and suitable.



How could these needs be met?

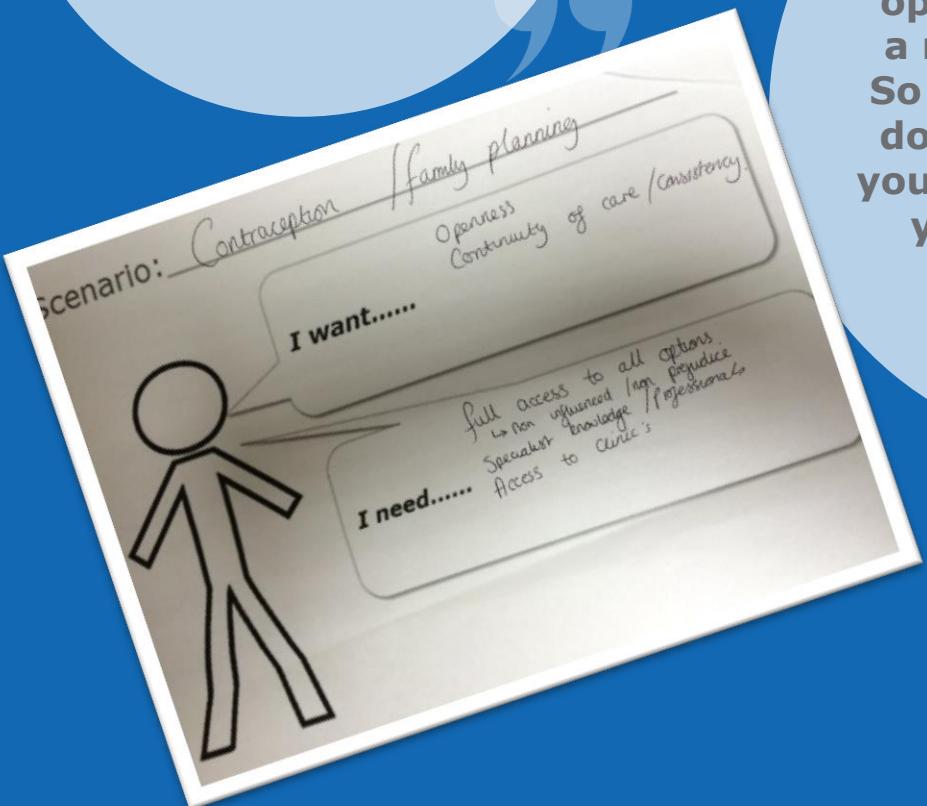
Consistency/continuity – a big need in relation to this sensitive topic is **consistency of care**. Having the same professionals available helps to create an atmosphere of reliability and familiarity.

Manner of care – the manner of care needs to be **unprejudiced** and **unbiased** as people want to feel comfortable having discussions around these topics. Frontline staff need to understand and reflect this at all times.

Scenario: Family planning & sexual health

We want consistency of care so when you go for your check-up to see the same nurse or the same doctor

You need full access to all the options; particularly in a non-prejudiced way. So no matter what your doctor thinks, he gives you the options and then you're able to make a decision



Participant comments



What do people need/want... what is important to them?

There is a desire for quick and immediate referral and care. The current system is seen as slow and inefficient.

Many participants felt as though there is a great importance to be placed on continuity of care as the process of being diagnosed and referred is a very emotive and uncertain time. Participants felt that, all too often, patients can receive an initial consultation with a GP only for them to 'wash their hands of them' once referred.

A lack of available information is a frequently cited source of frustration and worry – something that participants would like to be rectified.

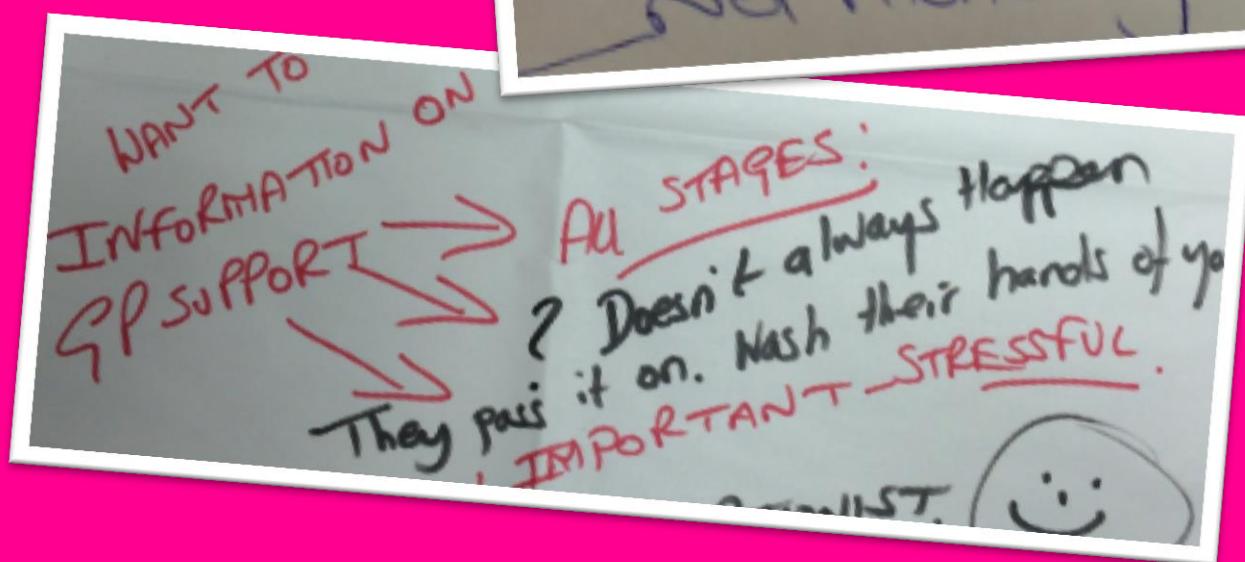
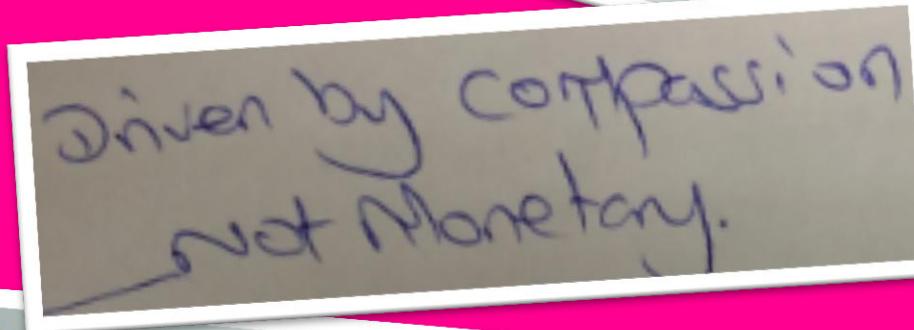
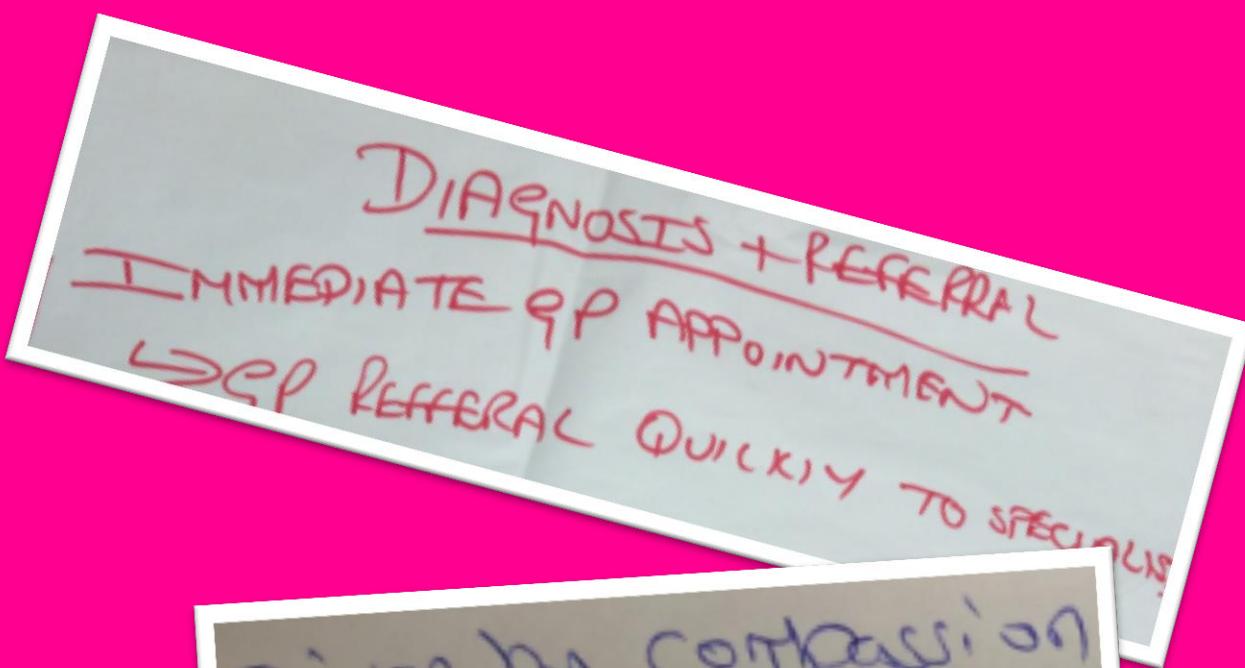
Anything that can help to build a sense of familiarity into the process would prove appealing.



How could these needs be met?

- A number of ways to meet each need were offered, these included:
 - Offer more ways to book appointments – many participants can only book within a strict pre-9 o'clock window. Having to get through between 8-9am is difficult and leads to many missed opportunities to see a GP. Using (or promoting the existence of) technology to enable people to book appointments online would help to alleviate this problem.
 - Improve the continuity of care – people want to see the same faces throughout the course of diagnosis, referral and eventual treatment. This helps individuals to feel as though they are being treated by a dedicated team.
 - Self-referral – being able to self-refer to specialists could help to unburden the current structure and speed up treatment – there was high demand for this.
 - Joined up approach - many were realistic about this though and understood that different health care professionals will need to be seen but this only strengthens the desire for a more joined up approach. Sharing records electronically with different services/professionals or even having specified individuals whose job it is to navigate the patient and their families through the process would be appealing here.
- Enhance the 'human touch' at all stages – the diagnosis and referral process is something that should be led by compassion. One way of achieving this is having staff at all touch points (i.e. receptionists, nurses, GPs etc) trained to show a certain attitude that espouses empathy. This goes beyond initial contact and includes aftercare at every step of the journey so that people do not feel alone. One way of aiding this was through offering remote meetings with key personnel (meetings with GPs over Skype and FaceTime etc).
- The diagnosis itself – drawing on the points above, people want to be able to feel as though they are the most important person that will be seen that day. Making the time to have a dedicated Q&A session following a discussion is a simple step that can help to convey this feeling of importance.
- Offer more information – offering information in various formats to make it as easy to access as possible to understand what is going on is crucial in combatting people's uneasiness. Pamphlets, leaflets, books, web content on *their specific condition* is important in making them feel informed. Similarly, allowing patients to access their own information can help to tackle the lack of information and uncertainty that many people feel (i.e. should they require a second opinion they can get one if they choose).
- Choice, choice and more choice – being able to pick and choose where you will be referred to and eventually treated is something that is currently lacking and implementing this would enable people to feel in control of their own care.

Scenario: Diagnosis & Referral





Core wants & needs

Here we detail a number of key cross-cutting themes that emerged very strongly across the deliberative workshops.

**People recognise
the pressure on the
system, and many
want to do more 'for
themselves' to help
relieve it –
a 'win-win?'**

Many people were keen to take more of a role in their own care as a means of improving the patient experience and relieving pressure on the system.



Participant comment...

“...they are under pressure, we have to accept that they are. But when you go your problem is the biggest thing in your life. And you want it sorted quickly. You don’t want to wait”

1

There was widespread recognition of the pressures facing the NHS, and how this conflicts with the need for prompt access and care.

2

When people were encouraged to think creatively, their suggestions for better meeting needs and a more people-centric approach were pragmatic and not based on ‘more money, more GPs etc.

3

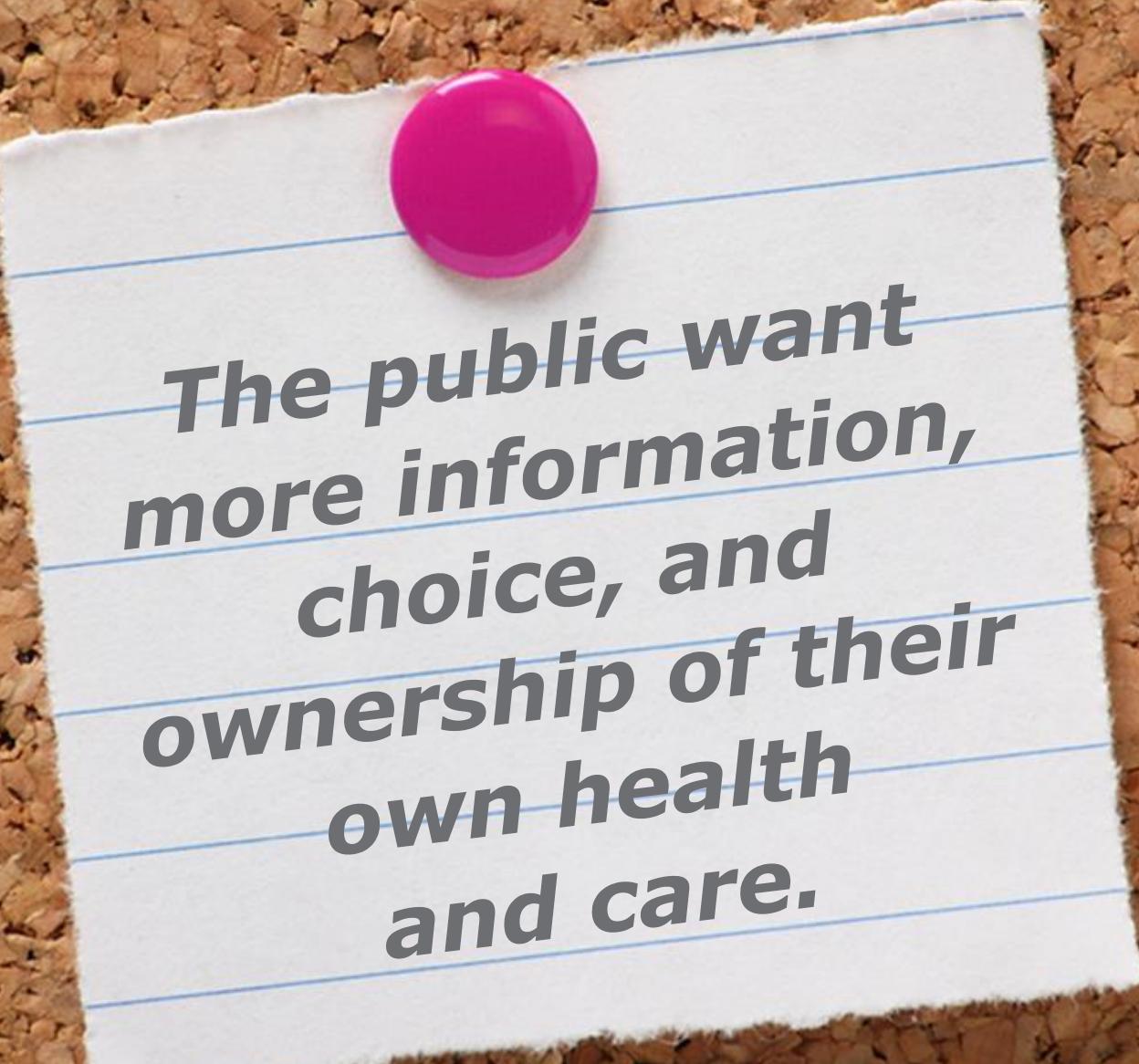
In particular, many people were keen to take more of a role in their own care, and ideas such as self-referral were suggested as ‘win-wins’ to improve the patient experience and relieve pressure on the system.

This was a theme across the discussions, in particular in terms of patients having more control of their own access to resources and information.

More direct and that way you would then be going to a specialist, a consultant or whatever, or it could be a nurse practitioner... urology, oncology or whatever. But it means that there's not this wait, because it appears that in all we've discussed, our main discussions have been about delay of time ...To add to that point, we would also reduce the burden on GPs which would mean appointments would be easier to make if you could go directly to a consultant and not waste the GPs time, to be referred back to the consultant.'

The premise of this, is you can access your information and be able to transfer that information, again because we're looking at the kind of situation with the government and everyone saying that "oh we're spending too much in the NHS". If we can relieve some of that burden on to the patient, that way you have that information at hand. It means that there's less chance for things to go wrong.

Participant comments



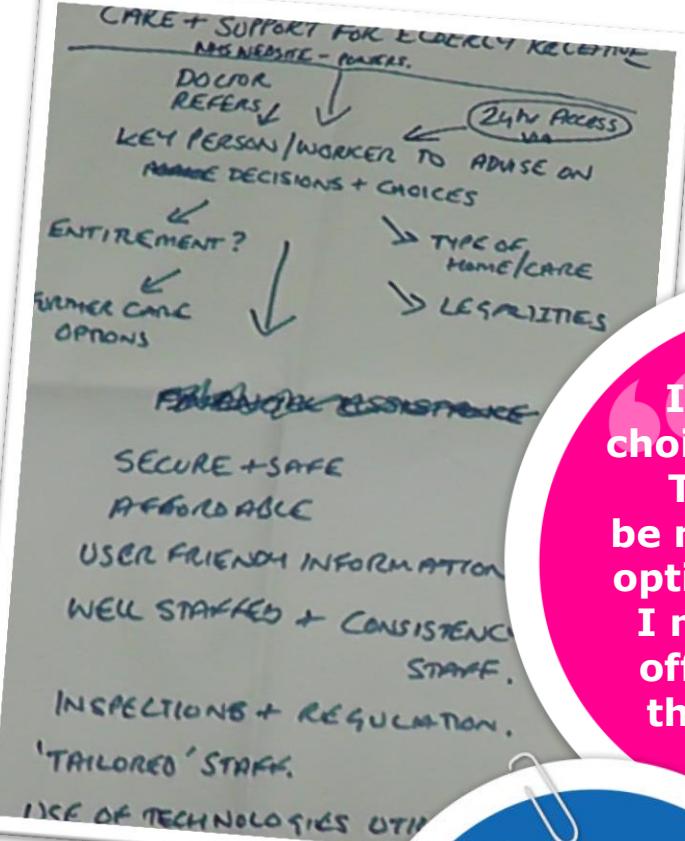
The public want
more information,
choice, and
ownership of their
own health
and care.



Participant comments...

I want more choice in my care. There might be more than one option for me but I might not get offered both of those options.

Personal choice is very important



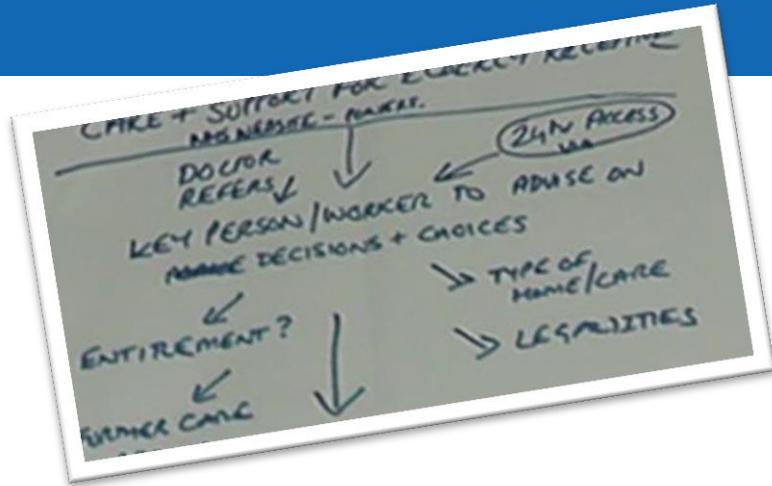
People want to be provided with information to make informed choices about health and care

Those with LTCs (e.g. diabetes) in particular want to 'own their care'

People would also like more discussion and choice of care options for elderly care (for example discussion and planning options when younger, before they are needed)

More generally, people want information and choice, and some would like a (technological) means of accessing their own healthcare information

Elderly care was felt to be an area where information, advice and choice is lacking.



Ideally the doctor would refer you immediately to a key person or worker again but would advise you on your decision ...things like the entitlements that you can get help with, further care options, the types of care that is actually available and the legalities as well and stuff.

Some participants suggested people should discuss and choose their future care when relatively young – i.e. before they need it

We should be able to discuss our options now and plan it in advance, choose what we want, a bit like funeral plans.

Participant comments

**There is a strong
perceived need for
more continuity
and a more joined
up approach**

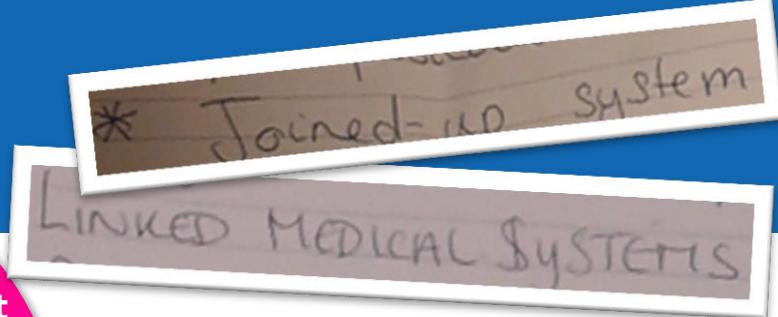
The desired 'joined up' approach comprises of a number of interrelated issues

In terms of continuity, the need to stop care and support 'falling off a cliff' was highlighted, particularly with reference to mental health

At a fundamental level, people feel that sharing of information between the different healthcare professionals involved at different stages of care needs to be improved (possibly using technology)

Some would like a more 'physically joined up' approach'- i.e. health 'super centres' where they can access a range of expertise & services

Many took this concept further and suggested a need for a caseworker or 'navigator' that would be a single coordinating contact through the process



Participant comment...

You have got loads of technology out there. But when I go into the Royal Free and my doctor's don't even know I have been there... That's why we wanted it so it was linked so whoever was involved in the process knew what was going on"

Many comments make reference to a perceived need for a central coordinator to help patients navigate their way through the care system/process.

"I think also one person that could sort of not control it all but point you in the right direction and coordinate all these people involved in the treatment of your illness. It's got to be one central coordinator."

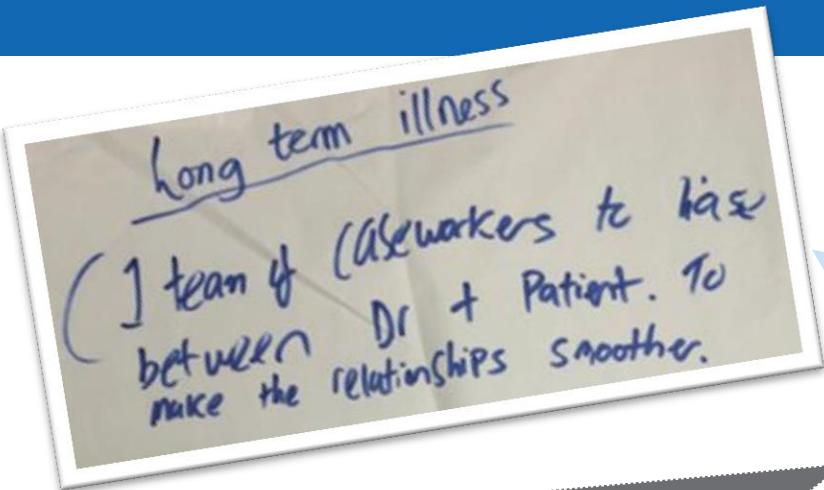
Participant comments...

"On an individual needs basis and again it's about having key people to coordinate the relevant help for you. Because what might be good for you might not work for somebody else. That's what they need to understand."

"Often it's left to the person who's ill and they can't cope with it and their families can't cope with it. They don't know where to turn. We've just been in a situation like that with a family member and it's horrendous. That was my biggest bugbear. Why is there not just one person? ...I just think one localised person to say, 'We've got a dietician.' And then to check up that it's all been done so that ill person can be ill."

"Okay so one person managing your care but then we were discussing well who would that one person would be on this sheet, and we were saying it would probably rest first and foremost with the GP or a key worker that would be based in the practice."

Most thought that a care 'navigator' would not need to be a clinician, but more of a 'medical liaison officer.'



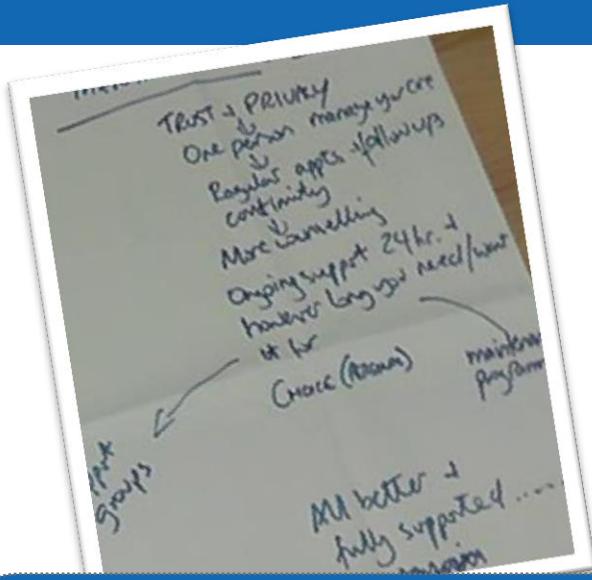
"We said there should be like medical liaison officers, like you have with police, you know if there's been a crime and they assign you specifically your family liaison officer to your case. That should happen in the medical profession."

"A brief background of kind of the way the NHS works, is actually being knowledgeable on the intricacies and the bureaucracy of modern medical care would be much more beneficial than being able to offer medical advice which is available."

However, when reverting from creative/future thinking to recent experience some thought the role should rest with GPs

Participant comments...

There is also a strong feeling that care (particularly for mental health issues) should not have an arbitrary cut-off point where people are left to fend for themselves.



“...the maximum amount of counselling was 12 sessions to deal with some real bad abuse as a child. Well that's just not enough and what he's been given afterwards, "Well we'll give you some confidence building courses." It's not enough - and he was told "You're lucky you've got 12 because most people get 6." ...Things need to change in that area big time..”

“I think it's governed by the cut off point - you are allocated a certain amount of support and then you have used it up and that's the end of it. So if you actually feel you want more or you think you need more or even if your counsellor thinks you need more, it's irrelevant and you are on your own... it should be an ongoing process.”

“Follow ups and continuity and more counselling and ongoing support 24 hours. However long you need it for rather than just getting your treatment and then disappearing off the radar so to speak.”

“Even maybe like a support group if you need it – it's always there for you to dip and out of and that's why we talk about support groups and walk in centres and... maybe that's where the charities come in.”

Participant comments...

**People want to
address access
issues through
direct/self referral
to specialists**

Direct access and self-referral to specialists is seen as another potential means of reducing pressure whilst improving (access to) care.



Participant comment...

“More in depth discussions about treatment. Qualified specialists in any area – a dietician or of things of that nature.”

1

Currently, getting a referral can take a long time, and some feel there is a lack of specialist knowledge at the point of access. Mental health was an example cited several times.

2

People suggested solving access problems by facilitating direct access to specialists at point of access.

3

This is not necessarily about specialist *consultants* – this could be specialists from a range of disciplines – e.g. nutrition, diabetes, mental health.

4

Another suggestion was self-referral to specialist nurses at ‘super centres’.

The pressure on GPs as the 'gate-keeper' of referrals is felt to slow down access, and 'self-referral' is seen as one means of addressing this.

"It's self referral isn't it...going to see a nurse, see the nurse so you're not wasting the surgery's time...We want specific information on our diagnosis and we want a fast track referral, for certain things you can get now. What we need, is we want a dedicated team around us, nurse, specialist, anaesthetist, a consultant. We want a consultant who is expert in whatever we've been diagnosed with, not a generalist, more of a specialist. We need not to ever feel alone and we want after care through each stage that we go through."

Family planning and sexual health was cited as an example where the lack of need to constantly return to the GP, and self-referral to the appropriate resources works well:

"I think first off with contraception and family planning, we felt it was actually well provisioned as it is. The system of going to the GP once every 6 to 12 months for a health check up, that aspect of it is good and then actually being able to either go to the pharmacy to actually pick it up - we didn't see any flaws in that really."

"It's almost like your GP is the one, like the security guard of the gate that makes the decision. I've had loads of issues with my daughter and basically it took me a year of seeing loads of different GPs until one of them actually referred her."

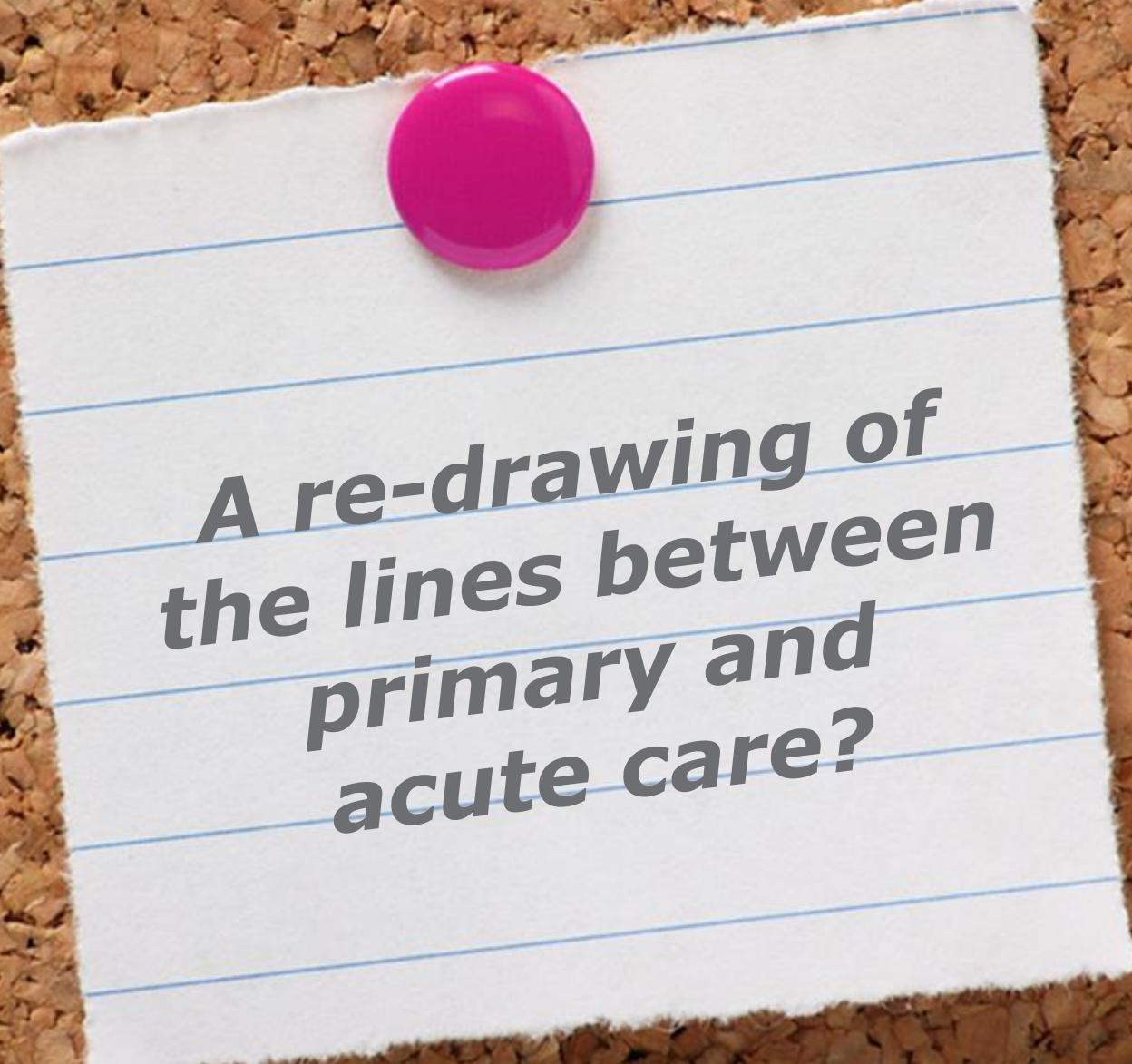
Participant comments...

At both Bristol and London events, participants were surprisingly open in illustrating their points using their own experiences of mental health issues.

For example, I'm a widow, I was widowed when I was thirty and I asked for counselling. I had to wait nine weeks to get any sessions. And then it was restricted. It was certain days and the days I was allocated aren't the days you feel like talking to somebody. I never had a mental illness, that was all stress, but I can imagine if you asked somebody that is battling with depression or suicidal thoughts, that time is crucial. That's my own personal experience"

"From my own experience, someone very close to me was at a real dark place and went for help and it took us three GPs to get someone who referred him to the mental health."...I think you should be able to... Like a walk in centre, you walk in, "I need help, I'm feeling this low, blah-blah." They shouldn't have to go to a GP, wait for that, then get referred to the mental health team, you're then on the waiting list of I think 15 weeks... That really needs improving; big time."

Participant comments...



A re-drawing of
the lines between
primary and
acute care?

Some groups expressed a need for more integrated care – in particular some things available in hospital and acute care could be more effectively if integrated into primary care.



Feedback on how wants and needs could ideally be met suggests a **perceived need for more integrated care to improve access**, convenience and efficiency.

There is a view that some things available in hospital and acute care could be **more effectively delivered if integrated into primary care**.

Some would like to **move the boundaries of primary care to enable immediate and direct access** to things like diagnostic tests.

Walk-in or super-centres in the community were also mentioned as potentially meeting a need for improved access in this context.

The direct access and 'closer to home' issues were mentioned in a number of scenarios, often in relation to the concept of a 'one stop shop' (or walk-in centre).

Participant comments...

"Long term conditions. ...to be treated in the local area if possible. I think with things like dialysis or chemotherapy, again, people in rural areas, had to slog out three hours to get to your hospital...."

"Shorter waiting lists and the one-stop-shop, but they'll say "Well that's just impossible because you can't see somebody, have your x-ray and the results all on one day." Well there should be a way of doing that because what it actually reduces is that you're not going back twice or three times, so they're not using their resources for repetitive visits, they're investing it in doing it in a one-stop-shop."

Super centres were frequently mentioned in relation to providing prompt access to health and care which led people to question why walk in centres were being shut down.

Across both workshops there was a strong desire for walk in centres to be recognised for the important role that they play in health and care today.

At present this doesn't seem to be happening (in London and Bristol at least) and a degree of frustration was apparent around the closure of walk-in centres.

Recognising that this is in direct opposition to most people's desires is key in crafting a health and care system.

"They're closing walk in centres in Bristol. They're closing them now. It's crazy! They're shutting them left, right and centre. We had so many and they've all closed. There's one or two I think that are left and that is it!"

"With things like depression, anxiety, stress we feel that it is imperative this sort of illness is dealt with promptly. Basically quick appointments and walk in centres."

Participant comments...

The proximity issue is nuanced however a need for greater flexibility of where you access care was also stressed (i.e. the choice to go to where it is available most promptly).

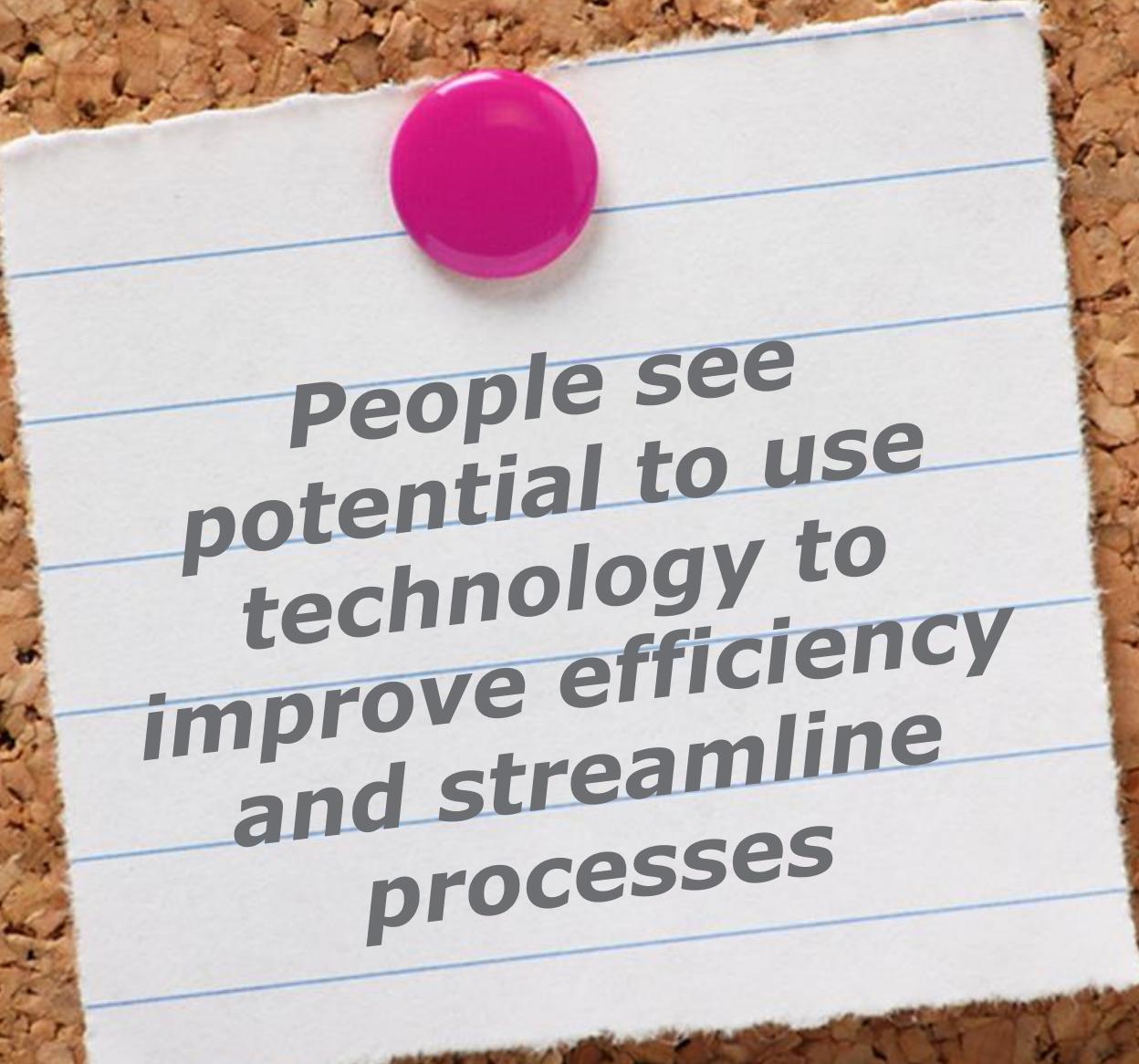
"I had a situation where I was seen at St Mary's hospital A&E and they gave me a card to have...an ultrasound...I then went to my local hospital...and they said, 'We can't see you here.' I said, 'This is a medical card from the NHS saying I need an [Ultrasound].'

But they said, 'That's a different trust'...'What? I don't care. I'm part of the NHS. I'm entitled.' If I'm dying in South London I need to be treated in South London...Too much bureaucracy. I thought that was ridiculous. They actually said, 'Go back to St. Mary's.' 'But I live here.'
..."

"I think it's more important for GPs to actually offer people a choice of going to see a consultant at another hospital, even if it's hundreds of miles away, because they can get an appointment quicker than they can in their local area. The system does exist because I have used it myself. I think if GPs told people more about this rather than just saying, 'You need an appointment...."

"If you need an MRI why would you need to wait eight weeks to go to your local hospital when you can get an appointment next week at another hospital. An MRI is an MRI regardless of where you do it...."

Participant comments...



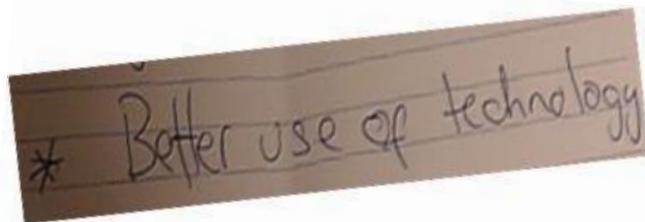
**People see
potential to use
technology to
improve efficiency
and streamline
processes**

Use of technology to improve efficiency was a core theme across the discussions.

In particular, people would like better means of sharing information and accessing it – both amongst the staff managing/delivering care, and with the patient.

There were also various suggestions for things that are (or should be) available now – such as online appointment booking and online repeat prescriptions.

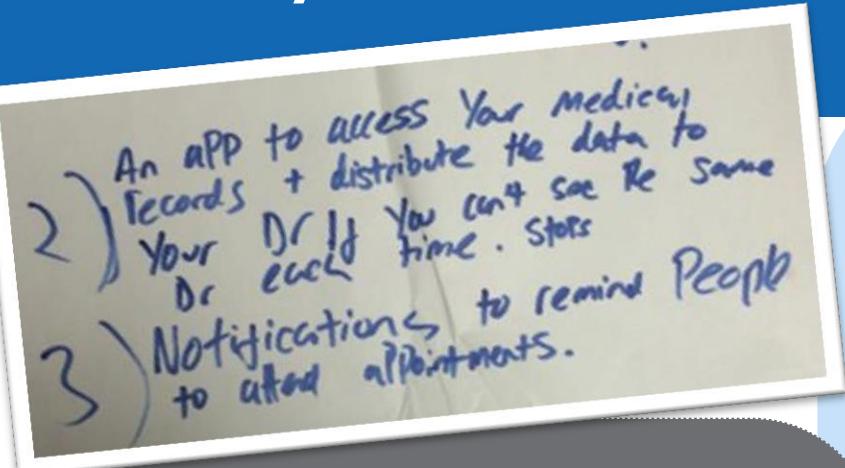
This suggests work to do in improving awareness and access to what already exists.



Technology

Another means of improving efficiency, reducing pressure and taking ownership?

Access to your own healthcare information would be valued, particularly for those with LTCs.

- 
- 2) An app to access your medical records + distribute the data to your Dr if you can't see the same Dr each time. Stays the same.
 - 3) Notifications to remind people to attend appointments.

"I think someone with a long term illness is going to want to have access to the information more readily and be able to, if they want a second opinion, get that easier. They'd be able to, not having to go to your GP to apply for that information, to ask them to give you details on your own health conditions...We all felt that an individual could perhaps take a bit more responsibility to lighten the burden, although it shouldn't be forced upon them."

"We thought what's actually really important up here, kind of bridging the gap between hospitals and GP. We're quite split on this table between technophiles and technophobes. The technophiles were quite keen on patients being able to have completely full access to their own medical records as a patient, via an app and then storing it on your telephone and then if either the GP or your consultant or you nurse practitioner is having issues getting the relevant information you'd be "Don't worry...I'll get that information.."

Participant comments...

Technology could help solve frustrations with old fashioned aspects of the current system – in particular appointment making with pieces of paper!

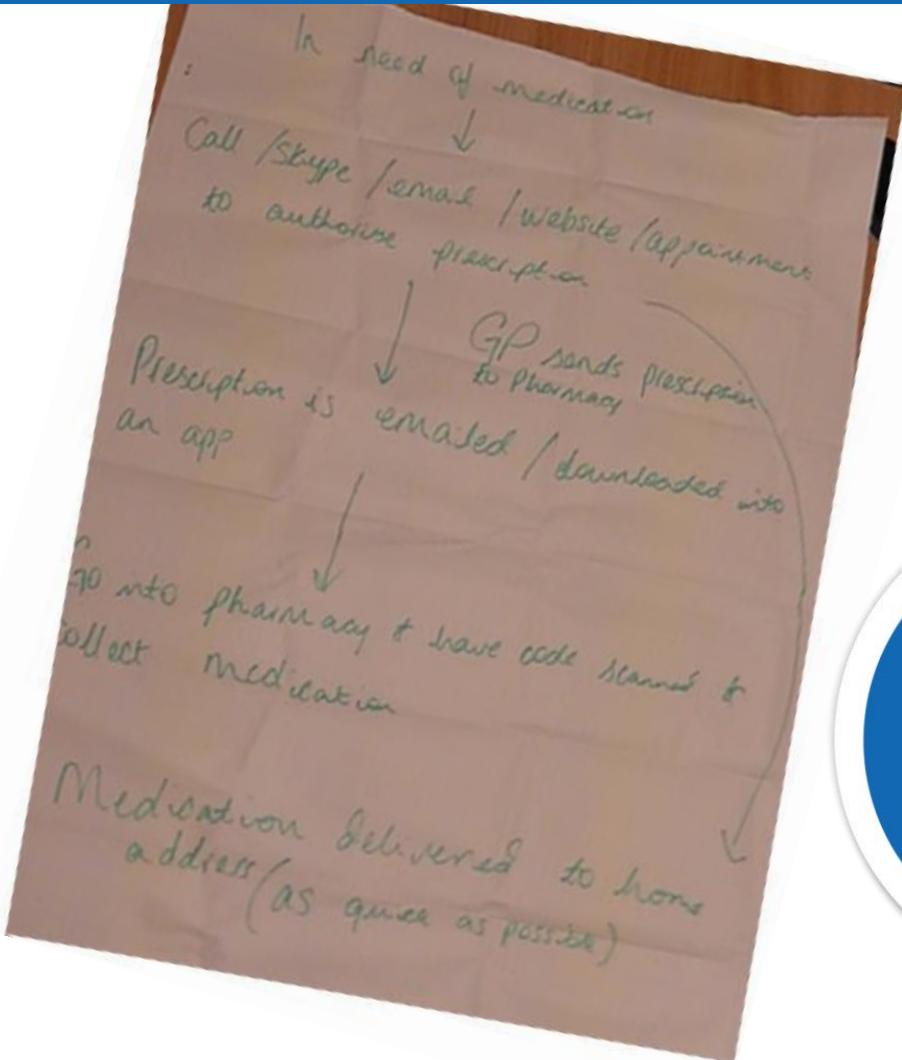
"The other thing that we also discussed was that once the patient goes out, the consultant actually gives them a piece of paper saying "Go and give it to the receptionist for your next appointment which will be in six months time or twelve months time." They don't even mention that you've got to go and see the receptionist, just to give a paper, expecting that they go and book their appointments and again, in this day and age why shouldn't themselves put a link on the computer to book them in for the next six months time. You shouldn't expect the patient to go out and do these sort of things. Again, it would be automatically done."

"In this day and age they should be at the point of communications whereby the appointment is done for you, rather than having to sort of rely on paperwork passing and the paperwork gets lost and nothing happens from then."

"If you don't book it with the receptionist you will never get another referral for a long period of time. You can slip up on that system in there; it's all about getting the right communications to the right people."

Participant comments...

Other technology based suggestions included more efficient access to prescriptions and monitoring of the elderly.



We like the technology part and if you are in need of medication you can call by Skype or email through the website and then use it. This would then be sent to the pharmacy and they would have it delivered to your own street or you could go to the pharmacy and get the code scanned.

Recording and monitoring of the elderly when they're living in the home on their own.

Participant comments...

**Individuals, charities
and companies could
all play a role in
taking pressure off
health services**

There is a feeling that individuals and various organisations could all play a role in taking pressure off the current system whilst improving access and care.



- 1** People don't want to re-invent the wheel. Current staff and services are valued (but stretched).
- 2** However, individuals and organisations could all play a role in taking pressure off the current system.
- 3** One suggestion was healthcare in the workplace – more of a role for employers, which would enable convenient access for busy workers.
- 4** There was also a feeling that other organisations such as supermarkets should take some responsibility.
- 5** Charities could fill some of the gaps in on-going support (e.g. counselling).
- 6** More of a role for specialist nurses, non-specialist 'navigators', pharmacists?

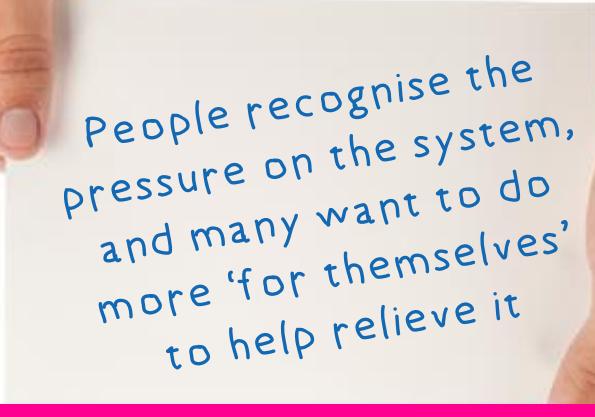
It was felt that individuals, employers, charities and the private sector could all play a role in relieving pressure and improving care.

We said companies that had enough funds so maybe like big banks could provide health checks for their employees - you know to be responsible and to help them - because they're busy people. We thought maybe if there was a health campaign you could have that on TFL it could give up some of its advertising space because that's quite an effective way to bring things to people's attention."

"A lot of individuals are managing their own or their families' health, who can help them?

Well, the community could play more of a role... All the big supermarkets they have a lot of information if you use a Clubcard, on what you buy and what people in that shop buy. There's just all this information out there, a little pool, it just needs somebody who pulls it together and that's working with the supermarket companies, working with the travel companies

Participant comments...



People recognise the pressure on the system, and many want to do more 'for themselves' to help relieve it



The public want more information, choice, and ownership of their own health and care

A 'win-win' formula for relieving pressure on the system whilst improving access and care?



There is a strong perceived need for more continuity and a more joined up approach



People want to address access issues through direct/ self referral to specialists

A re-drawing of
the lines between
primary and
acute care?

Access
'closer to home'

A 'win-win' formula for relieving pressure on the system whilst improving access and care?

Individuals,
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People see
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