

NHS Long Term Plan

Survey Results

Bath & North East Somerset, Swindon and Wiltshire

whot

would you do?

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Executive summary

Background

This report contains the results analysis of two surveys conducted by Healthwatch Bath & North East Somerset, Healthwatch Swindon and Healthwatch Wiltshire (HW BSW) across the regions as part of the NHS Long Term Plan initiative:

- Survey 1 - people's general experiences of health and care services, and
- Survey 2 - NHS support for specific conditions.

Both of these surveys were available on-line from March - May 2019 as part of a national survey that had been created by Healthwatch England in partnership with NHS England.

In addition to this, HW BSW, in discussion with the local Sustainability and Transformation Partnership (STP) and the Clinical Commissioning Group (CCG) for each of the areas, identified local priorities for Healthwatch focus group engagement to be:

- Primary Care Networks (PCN)
- Frailty / Ageing Well

The STP also asked us to create a local survey to be completed at focus groups for Ageing Well / Frailty. The aim was to identify the main issues affecting older people, understand what helps older people 'age well' and understand what could improve people's experience of ageing well in each area.

Primary Care Networks form a key part of the NHS long-term plan, bringing general practices together to work at scale in order to provide a wider range of services to patients. The STP wanted to gauge how much people knew about PCNs and how they think they should work.

Swindon also held a Learning Disability focus group using the Easy Read version of the condition specific survey. This is a Swindon-specific priority to help inform the Autism Strategy. Wiltshire also held an additional focus group with Children and Young People to tie in with their work priorities.

In total we carried out ten focus groups across the regions. Reports on each of these can be found in the 'In Focus' section on pages 26 - 42. Details of our engagement plan can be found in **Appendix 5** (pages 157 - 159)

“Our focus on helping people in BSW to live well in the future and to make it easier for them to find and use local health and care services has been driven by priorities outlined in the NHS Long Term Plan and from discussion and engagement with our STP Executive and Clinical leadership boards. These priorities also reflect the expected future needs of our local populations.

The results of Healthwatch's engagement with focus groups on these priorities will provide invaluable insight as BSW develops its Five Year Plan for the future of health and care services across Bath and North east Somerset, Swindon and Wiltshire over the coming months.” - Dom Hall, BaNES, Swindon and Wiltshire Sustainability and Transformation Partnership



Picture: Healthwatch Wiltshire engagement at Devizes Market

The number of responses we had were:

- General survey responses quantitative data - **473/ 495***
- Condition specific survey responses for quantitative data - **156/ 196***

In addition to this we spoke to **95** people who attended focus groups.

** Extra surveys were received after the on-line survey had closed, which is reflected in the second figure. The quantitative analysis was completed prior to this. This is why the numbers used for the quantitative and qualitative data differ.*

The total population of BSW is approximately 905,000 and the breakdown of this in each area is as follows:

Region	Population
Bath & North East Somerset	188,700
Swindon	220,400
Wiltshire	496,000

Responses by Region - General Survey

The response rate for the Bath and North East Somerset region (B&NES) was significantly lower than the other two regions (12% vs 47% and 40% approximately for Wiltshire and Swindon respectively). Hence, any conclusions drawn in relation to responses from the B&NES region should be treated accordingly.

Region	N	%
Bath & North East Somerset	58	12.26
Swindon	191	40.38
Wiltshire	224	47.36
Grand Total	473	100.00

Responses by Region - Condition Specific Survey

The number of responses in this survey was lower compared to the first survey and half the responses came from one region (Wiltshire). As a result, any conclusions drawn from the data and comparisons between regions should be interpreted with even more caution.

Region	N	%
Bath & North East Somerset	42	26.92
Swindon	35	22.44
Wiltshire	79	50.64
Grand Total	156	100.00

There are 94 GP practices across BSW, as well as three hospital trusts, a mental health provider, an ambulance trust, organisations providing community services and many voluntary and charitable organisations.

A full quantitative analysis of all of the feedback we received can be found in **Appendix 1** (pages 2 - 74).

Key findings - General Survey (Full analysis can be viewed on pages 8 - 25)

The key findings were:

- **Healthy Lifestyle:** Most people realised that they should be leading a healthier lifestyle. Requesting advice on losing weight, knowing what food is healthy, managing stress, access to free gym use or affordable exercise was a high priority. Of the 473 respondents to this survey 66% and 27% said 'very important' or 'important' respectively when asked to rate having the knowledge to help prevent ill health.
- **Access to services:** Respondents said they would like better access to services. This was mainly to do with accessing an appointment with their GP when needed, but also included access to dentists and specialist support. Some people wanted to see a 'named' doctor, and most people would like their doctor to be local.
- **Independent living:** People wanted better facilities to help them lead a more independent and healthy life as they get older, including more support to enable independent living.
- **Technology:** When asked about technology some raised concerns that this would take away access to face-to-face appointments or that they would not have access to the technology itself. Others thought it was a good thing, citing text reminders and getting test results quickly as being positive. Some also want to see technology used to enable services to share data thus making healthcare provision more efficient.

Key findings - Condition Specific Survey (Full analysis can be viewed on pages 26 - 42)

- The conditions most people share their views on were:
 1. Long term condition eg diabetes and arthritis
 2. Mental health condition
 3. Cancer

- There was significant regional variation with Swindon respondents reporting much higher learning disabilities and autism (26% learning disabilities and 17% autism compared to 2% and 5% in B&NES and 5% and 8% in Wiltshire respectively). Note that the Swindon results include surveys completed at a Focus Group at SAM (Swindon Advocacy Movement) for people with learning disabilities. Wiltshire People 1st (self-advocacy group for people with learning disabilities) carried out surveys with their speaking group and young people's group in Wiltshire.
- Continuity of care was chosen by over half (54%) of respondents when asked what is most important during long term support. This figure was also reflected across all three regions.

Positive

- **Cancer services:** The overall feedback about cancer services was positive with reports of **swift treatment** after diagnosis and **exceptional care**. A consistent theme was that support tapered off once treatment had ended.
- **Other services:** Despite people telling us about misdiagnoses and delays in getting the necessary treatment, **once the support and treatment had been accessed experiences were often positive**.

Negative

- **Other services:** For the remaining respondents who provided feedback on autism, learning disabilities, long-term conditions, dementia, heart and lung conditions and mental health there was feedback about **misdiagnosis** and subsequently **long waits to get an accurate diagnosis**.
- **Long wait times:** This often left people feeling anxious, particularly where patients had been told they would be getting an **urgent referral** but then had **months to wait**.
- **Experts in their own care:** For those conditions such as **autism** or **Parkinson's disease** which can be **hard to diagnose**, patients and carers reported that they had to become **experts in their own care**. There was a feeling that they knew more about their own care than the healthcare professionals they were speaking to.

Who did we speak to?

General Survey

- About **two thirds** of the respondents were aged **over 45**.
- Approximately **one fifth** of respondents reported a **disability**.
- **One quarter** of respondents reported **at least one long term condition** overall.
- More than **two thirds** of respondents were identified as **female** across the three regions.
- More than **three quarters** of people were **White British**

For a full breakdown of demographics please refer to **Appendix 3** (pages 128 - 144)

Condition Specific Survey

The number of responses in this survey was lower compared to the first survey and half the responses came from one region (Wiltshire). As a result, any conclusions drawn from the data and comparisons between regions should be interpreted with even more caution.

- Almost **three quarters** of the respondents were **over the age of 45** years
- Almost **half** the respondents reported a **disability**
- **Two thirds** of respondents were **female**
- More than **three quarters** of people were **White British**

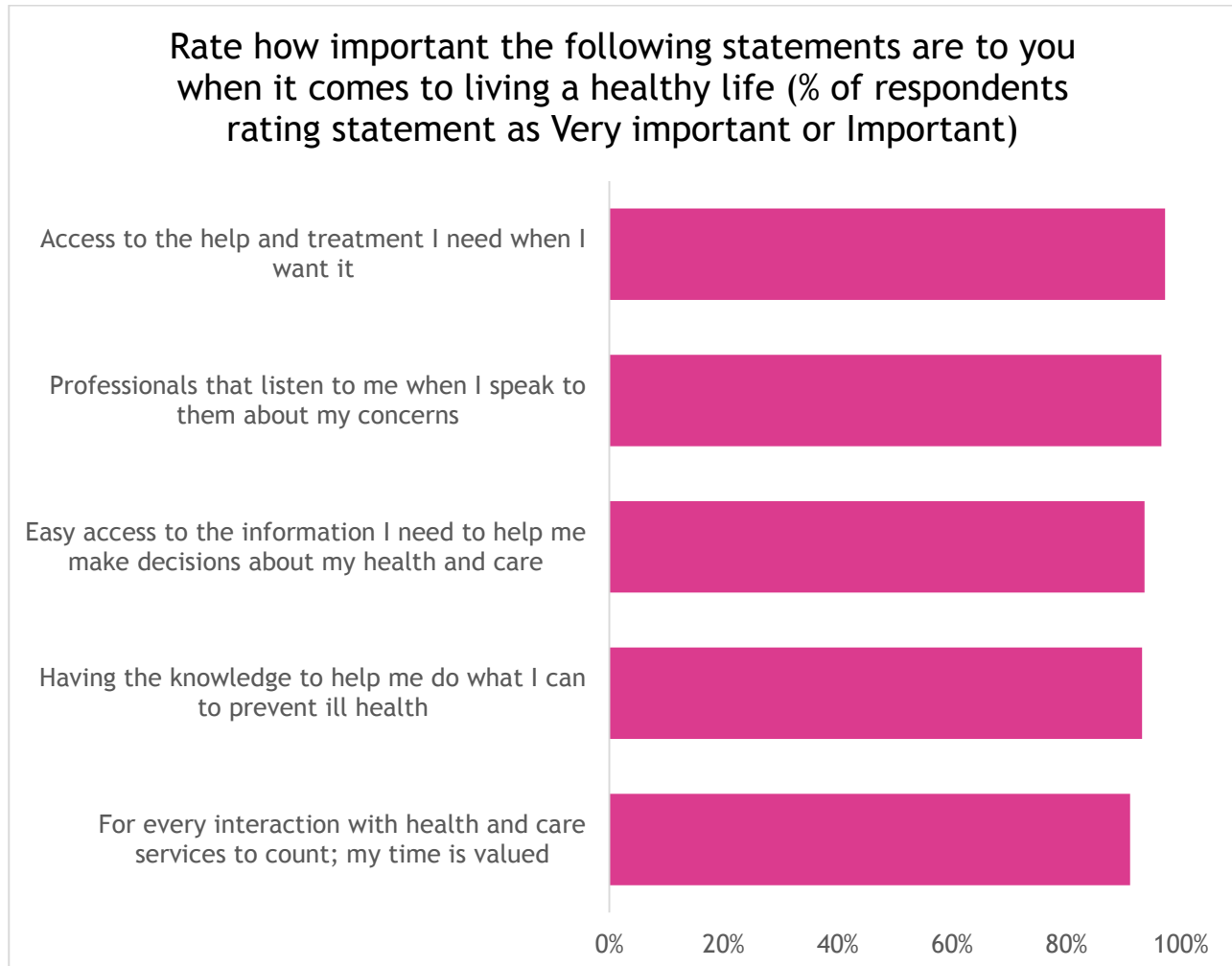
A full breakdown of demographics can be found in **Appendix 4** (pages 145 - 156).



Picture: students from New College Swindon

What matters most to people in Bath & North East Somerset, Swindon and Wiltshire (BSW)?

Q1 Tell us what you think local services could do to help you stay well by rating how important the following things are to you when it comes to living a healthy life.



All five statements were rated as ‘very important’ or ‘important’ by over 90% of respondents. Access to help and treatment came out on top with 96% saying this was ‘very important’ and 11% saying this was ‘important’. Ratings against each statement were consistent across all three region. For a more detailed breakdown see [Appendix 1](#) (pages 2 - 74).

When people were asked ‘If there was one more thing that would help you live a healthy life, what would it be?’ we received the 288 comments.

Healthy Lifestyle

The majority of comments (109/ 38%) were about leading a healthy lifestyle and getting the right support to make that possible. There was a lot of feedback about the lack of affordability of exercise schemes and gym membership, and that this would be a barrier to exercising for those on low incomes:

- **Access to reasonably-priced exercise sessions led by a qualified, experienced and supported sports leader’ - Wiltshire**

The high cost of healthy food versus the cheap cost of junk food, thereby making it an easier option, was raised as an issue numerous times:

- **‘Cheaper healthy food, junk food is very cheap’ - Swindon**
- **‘The cost of healthy/organic foods are expensive at a lower cost it would encourage us more’ - Swindon**
- **‘Having healthier choices as more affordable and more accessible. At the moment the bad choices are the cheapest and easiest to make’ - Wiltshire**
- **‘More regulation of the food industry to reduce the exploitation of the sugar addiction it has created’ - B&NES**

There was an obvious desire from respondents to lead a healthier lifestyle but that this needed to be supported by more public health promotion, advice on nutrition, access to healthy recipes and less contradictory messages about what we can eat and drink. A small cohort commented on wanting cleaner air and better and safer cycle routes.

The message here was loud and clear across all three regions that healthy food and exercise should be affordable and, crucially, accessible to all. Without this those on low pensions would not have the ability to ‘age well’ in BSW. The STP should consider how to address this and diminish health inequalities.

Access to Services

49 respondents (17%) said they would like better access to services. This is mainly to do with accessing an appointment locally at a doctor’s surgery, but also includes access to dentists and specialist support:

- **‘More timely access to health services, for example 5 month wait for physio therapy appointment. Then a letter to see if you still require their service. Most people if able have spent lots of money on alternative treatment by then. That’s if you’re lucky enough to be able to pay yourself. What about those can’t afford to seek other therapies’ - Swindon**
- **‘Need to be able to get a routine appointment with a GP within a few days, not as at present a few weeks. My doctor is however very good at fitting me in for emergency consultations. Routine hospital appointments can often be months. This needs to be less so health conditions don’t get worse’ - Swindon**

Healthwatch know from feedback received that people have issues getting appointments to see their GP and these concerns are echoed consistently throughout the survey. We think that if people were aware of what preventative measures they could take to manage their own health better, as well as knowing what other services they could use, such as a pharmacist or minor injuries unit, it could ease pressure on primary care significantly.

The overarching aim of Primary Care Networks is to integrate care and to ensure that a wider range of services are available to patients.

Mental Health

A small number of people (13/ 5%), commented on mental health, and points were raised focusing on easier access to support, with one commentator saying:

- **‘Easier access to mental health support, particularly in the early stages. Many mental health services are focussed on the crisis point in a person's ill health and not in the preventative stage. We need more local services and supportive activities to catch those who are struggling before they get to crisis point’ - B&NES**

Regular Health Checks

Another 13 commented on the need for regular health checks, with suggestions for a ‘health MOT every 2 years’ and:

- **‘Regular health checks from a professional and feedback to guide towards a healthy life-style’ - Wiltshire**

The emphasis was therefore very much on preventative measures being implemented, to ensure that people, with the support of healthcare professionals, are able to look after their physical and mental wellbeing before reaching crisis point.

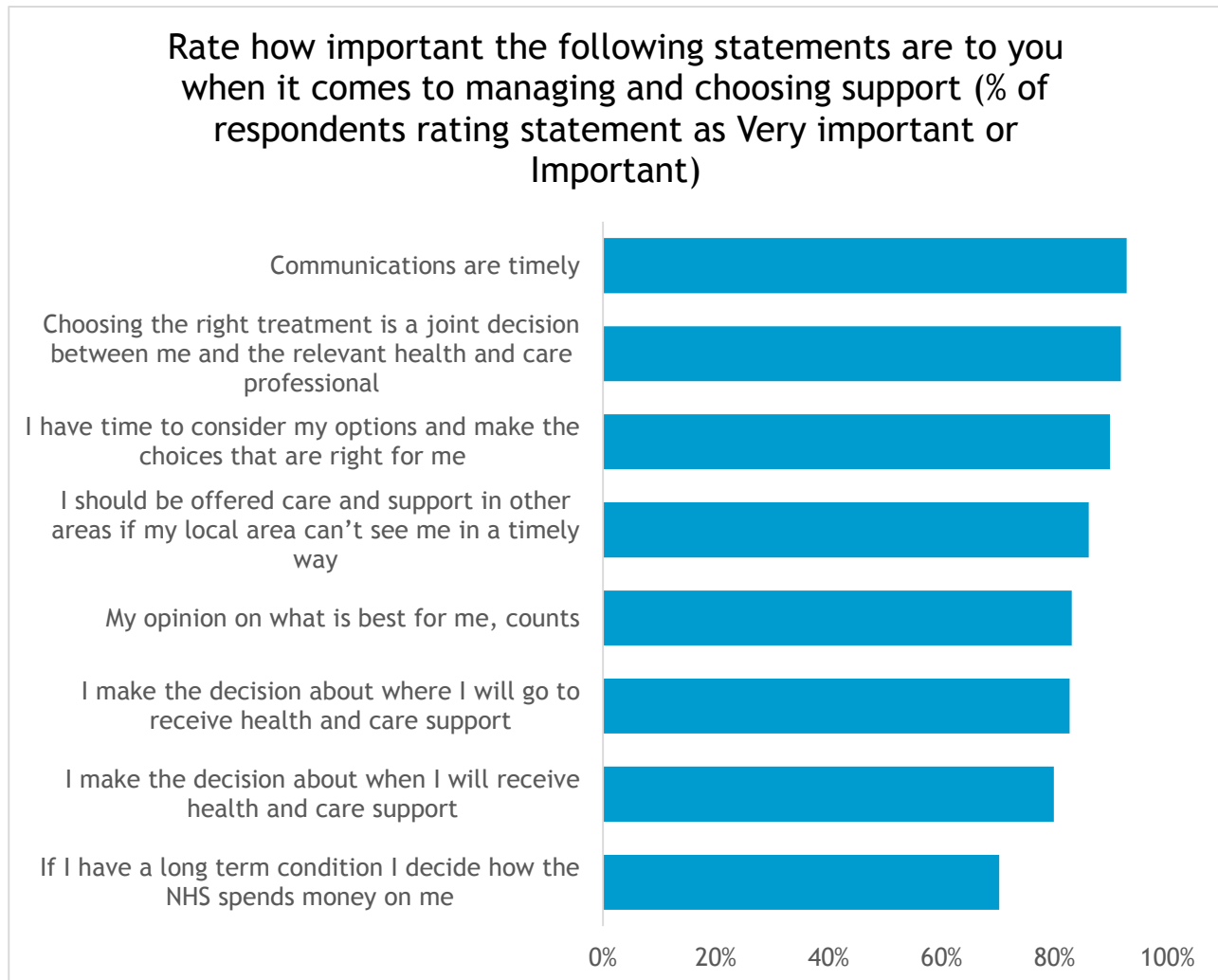
Continuity of care

Continuity of care would be an improvement for 12 people (4%). With pressure on services not only are people finding it difficult to get appointments when they need them, they do not always see the same doctors or nurses, resulting in having to repeat themselves each time they see someone:

- **‘I would like the professionals who deal with our many problems to have time to listen properly to what we are telling them and to have some continuity of care i.e. being able to speak again with the same doctor or nurse who is already familiar with us and our problem, rather than seeing a different person each time. - Swindon**
- **‘For doctors or nurses too read a small paragraph on long term health problems of the patient before appointment or phone consultation call’ - Wiltshire**

Data sharing would also help to alleviate this issue, enabling different health providers to access patient record and do the ‘homework’ suggested in the second of the two quotes above.

Q2 When you are unwell and need support or treatment for your condition you need to be properly informed to make choices about what works best for you. Rate how important the following things are to you when it comes to managing and choosing the support you need.



The ratings were fairly consistent across all three regions. Getting timely communications was considered either ‘very important’ or ‘important’ with a combined rating of 92%, followed by being involved about decisions about treatment at 91% and having the time to consider options at 89%.

When people were asked ‘If there was one more thing that would help you to manage and choose how the NHS supports you, what would it be?’ we received an additional 348 comments.

Access to services

The majority of respondents (61/ 28%) cited once again that better access to appointments and doctors as being the 'one thing' that would improve how the NHS supports them. This was a mixture of offering more flexibility around appointments, better booking systems and of course quicker access to appointments.

The development of Primary Care Networks should alleviate some of these issues with the introduction of, for example, social prescribing. The STP should consider how the suggested changes and improvements will be implemented and communicated to the public. Healthwatch thinks that a clear communication strategy and improved signposting to other services would be solutions to consider to ease the pressure on practices and staff.

Better communication

19 people (9%) said they would like better communication, this could be about a specific condition, to be more informed prior to making decisions, better communication between services or accurate communication.

The case studies below highlight when this is not done well. The first one also reflects the respondents desire to be listened to and to be involved in contributing to the care they receive.

Case study 2 - Swindon

Communications are truthful and note taking is accurate...only about 15% of the letters that I have ever received from my local hospital actually reflect accurately what was said at my appointment.

It feels like I am listened to but not heard and the notes and dictation that happens after I leave reflects this. I ended up having unnecessary surgeries because one consultant wrote down that I was post-menopausal in my notes, when this was not the truth, not what I said to him and I was still having active periods! Unnecessary surgery resulted because the consultants I saw after this believed that the bleeding I consequently had was post-menopausal and should therefore be investigated.

I did not realise this until some years later when I found out what had been written at the appointment where this misinformation started! As patients we need to be listened to...we know our bodies better than anyone...and this active listening should be reflected in accurate note taking and letter dictation.

I have lost count of the number of times I have had to ring the hospital and correct information contained in a letter that is supposed to represent the appointment I have had and the information I have given that is supposed to contribute to my care!!!

Case Study 2 - Swindon

Better administration in the NHS. At the moment the admin at GWH is a disgrace. HERE ARE SOME EXAMPLES:

- Attending the Eye Clinic for a pre-op appointment and being asked "What are you here for? (No notes available)
- Having all pre-op tests and then being told on the day that I hadn't had one of them
- Discovering in Day Surgery that I had been listed for the WRONG operation
- When my consultant says I have to be seen in 4 months' time I never get an automatic letter appointment. I always have to phone, and never get one on time

My own surgery is pretty good on appointments, but I have to wait a while to get one with my own doctor. Older people particularly want to see the doctor they have been seeing for years, not an unknown doctor

We feel this is a good example of when communications and administration go wrong, the adverse impact this has on the patient and illustrates the additional, unnecessary work it creates for the service provider.

Case Study 3 - Wiltshire

1. Returning emails for example when I email for a repeat prescription i do not get an acknowledgement that it has been received and then have to follow up to see when it is ready (St James surgery).

2. Confirmation of feedback following appointments for example I saw a physio and he was going to refer me to a dietician. I've never heard anything and don't know if it was because he didn't make the referral, the Go felt it wasn't necessary or if I just haven't waited long enough to get.

Better communication and integration of services was also commented on:

'Better communication between health professionals involved in my care. I have had to photocopy letters from the hospital consultant which haven't been sent to my GP and also given copies to a hospital consultant who didn't receive the information because two units who saw me at one hospital functioned separately from their own different hospitals with separate notes' - Wiltshire

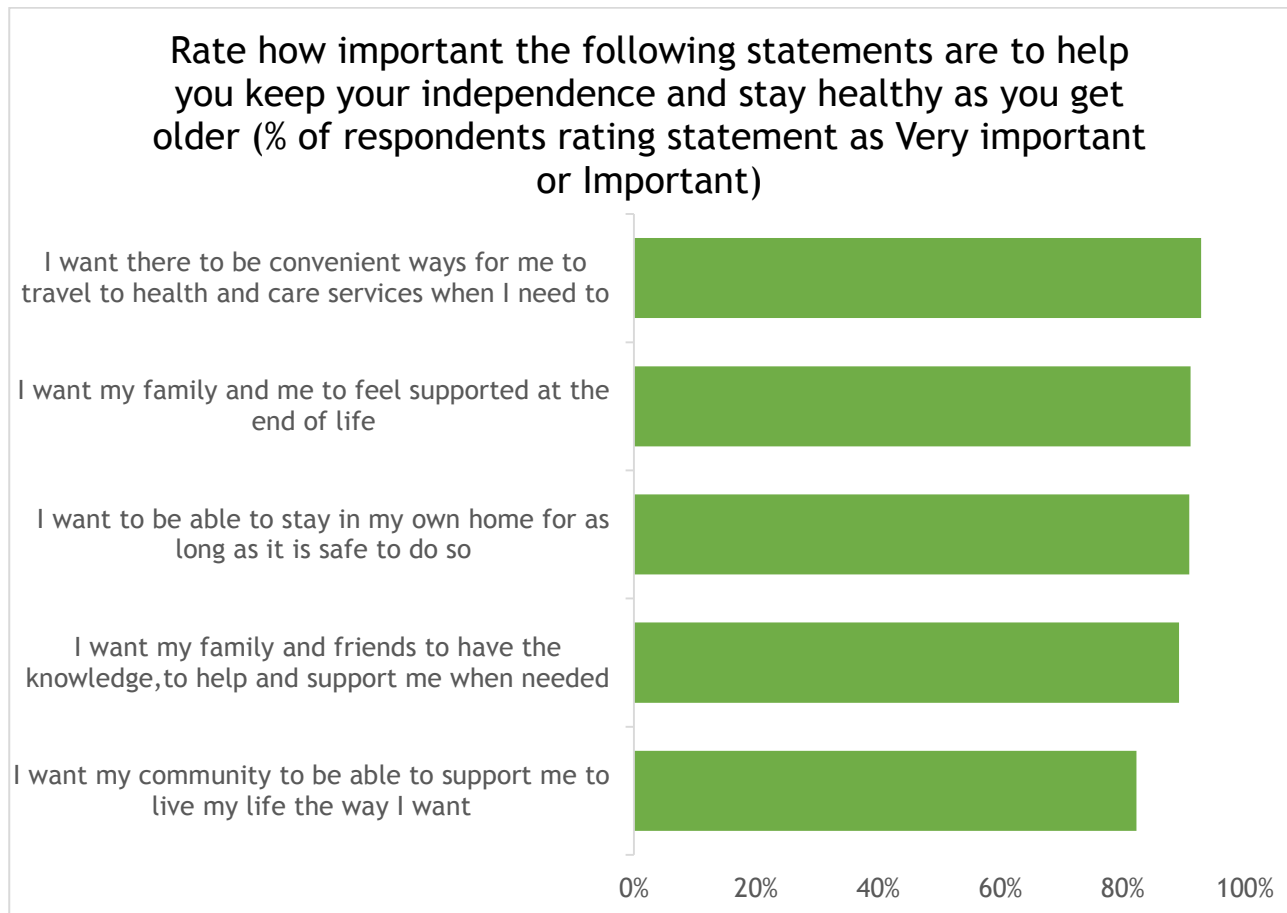
Communication and how this is delivered needs to be reviewed and addressed. This will reduce negative experiences of patients, ensure they receive timely and correct treatment and make service provision more efficient.

Funding

Funding was also mentioned by 14 people (6%). People were grateful for the NHS and the hard work of its staff and therefore wanted to see more funding allocated:

- 'Ensuring there is sufficient support out there - so often departments are stretched or posts put on hold or closed for budgetary reasons. This is costly in itself as staff get overloaded, go off sick or leave. Regular changes of provider are also very costly and disruptive' - B&NES

Q3 Our ageing population is placing greater demands on the NHS. We know that people want to be able to look after themselves for longer, and the NHS wants to help you to do that. Rate how important the following things are to you when it comes to keeping your independence and ageing healthily.



All statements rated highly but the top three were convenient travel to health services (93%), end of life support (92%) and the ability to stay in one’s own home (91%). Again, regional variation does not appear to be substantial.

When asked ‘If there was one more thing that would help your independence and live healthily for as long as possible, what would it be?’ e received a further 212 comments

Better Care Facilities

21% (44 people) stated that better facilities would help them lead a more independent and healthy life. This was not only better care homes, but better care when in social care and more provision for support for independent living in their own homes, including better pay for carers. People also said that although they may not necessarily need ‘care’ in their own home, they would like someone to drop in for a ‘chat’ to make sure that they are not isolated and to help with small tasks in the home.

- ‘To know that I will be taken care of and being there when needed. Services integrated to look at the person more holistically rather than departmentally and by NHS department administration in isolation.’ - B&NES
- ‘Stop cutting funding to carers who help provide support to those who need help to stay in their homes’ - Swindon
- ‘To be able to do the things I like in the care home without being restricted. I am unable to go outside as the care home won’t let me. I am physically able to but the carers refuse to take me outside. To live healthier, a carer/chaperone to assist me outside to walk and get fresh air’ - Wiltshire
- ‘Strong outgoing community services to help stop isolation’ - Swindon

Funding was also cited as an issue and the lack of it being an impediment to providing vital community support:

- ‘I want my community to receive the necessary funding / resources it needs to support people - not to have to rely on well-intentioned individuals who are trying their best but not receiving the resources those individuals / organisations need to be able to do a good job’ - Wiltshire

There was a sense in some of the comments made around funding that this would give short term benefits but that in the long run it would cost more money:

- ‘I think the services to enable this this have been stripped back to the bare minimum. Not just medical services, but those services that promote and encourage positive mental health. So a huge injection of cash put into the NHS and services that support the NHS. Surely the cutting back of vital services, will increase the strain on the NHS, costing the Government more money in the long run’ -Swindon

Healthy Lifestyle

27 people (13%) spoke about the need to adopt a healthy lifestyle with regular exercise, a good diet and plenty of social interaction:

- ‘Home help, support groups, communication and staying in touch, being kept up to date, social events, getting out and about, having hobbies’ - Swindon

There were several comments about providing exercise classes aimed at disabled people:

- ‘Things to be cheaper that are healthy and more exercise for the disabled’ - Wiltshire

There was an awareness that people also needed to take responsibility for their own health and take preventative measures to manage their wellbeing, but with access to information about how to go about doing this:

- ‘Taking responsibility for my own health as I currently do, with the support of GPs. If I say I need a DEXA scan in order to monitor bone density due to being on anti-cancer medication, I expect the GP to have enough knowledge to agree to that. Not smoking and a healthy diet so as not to be overweight will also contribute. Of course, patient who never see a GP in person will not be able to be given advice about healthy diet, Active Health initiatives, and help to stop smoking. Then people will get Type 2 diabetes for example and cost the NHS more money, whereas if more money was spent of actually SEEING patients it would cost less’ - Wiltshire

This mirrors earlier comments in the report about respondents’ desire to be healthier. More information needs to be provided so that people are aware of the array of groups - be it support, exercise or social - are available in their area. More public health information also needs to be

available with clear advice on healthy eating. People felt that there was too much conflicting advice in the public realm. There were also more requests for screening and regular health checks to pre-empt health issues.

Transport

11% (29 people) said that transport in their area was an issue. This is particularly pertinent for those in rural areas:

- ‘Public transport is critical, especially in a rural area’ - Wiltshire
- ‘Making sure there is good transport links with disabled access’ - B&NES

Hospital parking is also problematic due to cost and lack of available spaces:

- ‘The bus pass is only valid from 09.30. It would be really good if transport were automatically free for people with an early morning hospital appointment. I use the bus both because it is sometimes difficult to find a parking space and because of the level of parking charges’ - Wiltshire
- Taxis (GWH) cannot drive up to the front door, so people like my mother, who has difficulty walking or standing, have a really difficult time getting to and from appointments She also can’t go out to the kerb to wait because there is nowhere to sit - Swindon

Case study 1 - B&NES

One respondent suggested using technology to negate the need to take a lengthy and, in this instance, unnecessary trip to collect test results:

Access to advice electronically e.g. Skype rather than lengthy and involved bus and train journeys (there are 4 buses a day in my village) and after my stroke I wasn't allowed to drive for a month).

My daughter recently took 1.5 hours each way by public transport to get to hospital in Bath to get her post biopsy results which took 2 mins and were clear/negative.

My husband drove her to Bath for her earlier biopsy appointment but was unable to find anywhere to park at the hospital (as usual) and had to drop her off, go elsewhere and return for her later. We really wanted someone to be with her for this surgery but had no choice but to leave her to it.

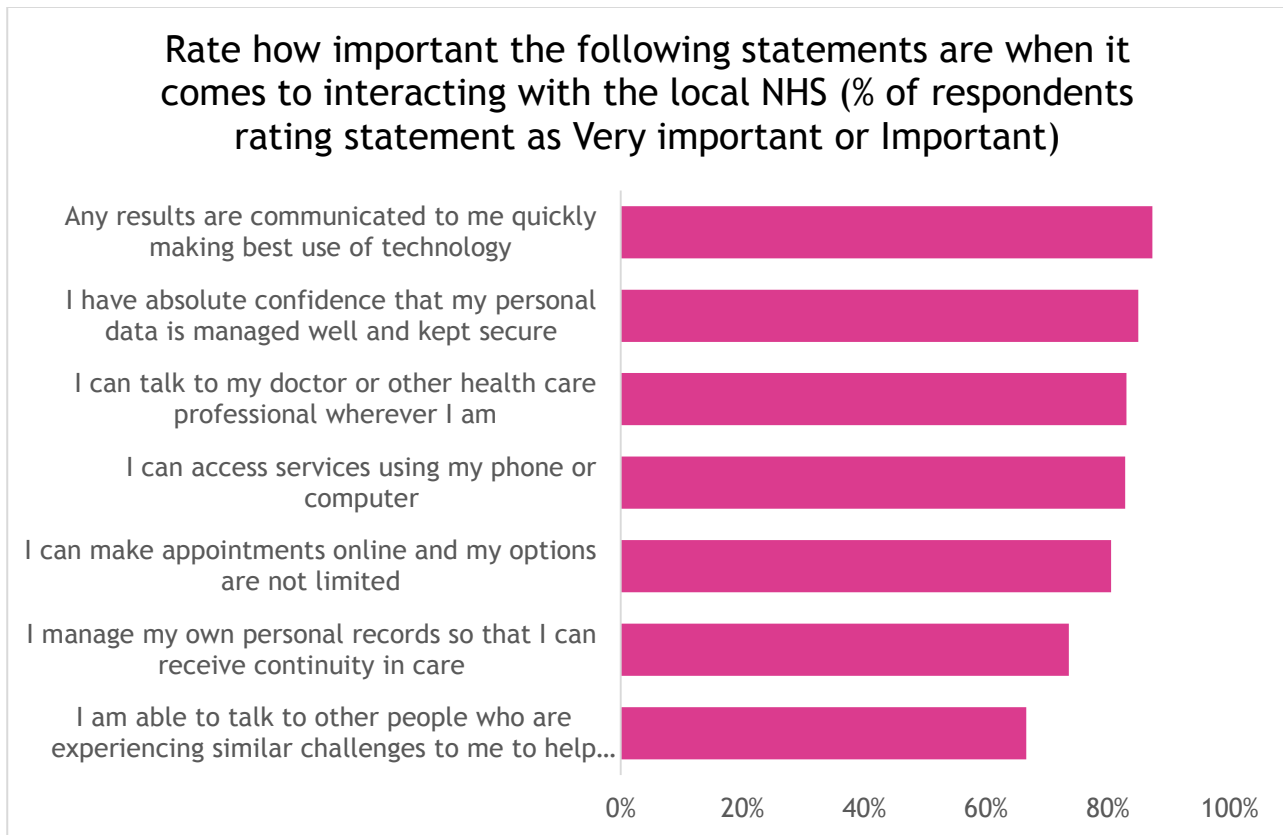
Equipment - Mobility Aids

For our ageing population and those with mobility needs getting information about aids and services was important. 17 people (8%) said that access to free mobility aids and house adaptations would help them to lead a more independent life:

- ‘Readily available information on how to get help with mobility aids and services’ - B&NES
- ‘More access to grants or cheaper access to mobility aids such as chair lifts or lifts in the home’ - Swindon

Ageing well and frailty are a priority area for BSW and good provision of mobility aids and services will provide vital support to older residents.

Q4 The NHS wants to adapt to make it easier for people to access support they need, when they need it. Rate how important the following things are to you when it comes to keeping your independence and ageing healthily.



Although there is support for all seven statements, the variation is rather higher in this question compared to the previous. Support ranges from 87% (using technology to communicate results quickly) down to 67% for the ability to talk to other people who are experiencing similar challenges. Some regional variation appears to exist, with Swindon respondents showing higher preference for managing their own personal records and making appointments online.

When asked ‘If there was one more thing that you think needs to change to help you to successfully manage your health and care, what would it be?’ we received 176 comments.

Access to Services

Access to services came out on top once again with 59 people (35%) providing additional commentary about this:

- ‘Invest in primary care services! Trust is destroyed when people are asked to ring at 8am when they are unwell and can’t get through. Trying to get an appointment should not make you ill. Less phone consultations. Conditions are diagnosed and prescribed for over the phone and I think this is inadequate care often in and of itself. It should not be a crime to ask for a home visit either’ - B&NES

Use of Technology - Negative

25 people (14%) said that the use of technology was a negative thing. They were worried that this would take away their access to face to face appointments with their doctor. Others had expressed concerns that they would not be able to use the technology or even have access to it,

so an over-reliance on this should be avoided. Older people or those on lower incomes may be most adversely affected by this and their needs must be factored in to planning around the use of technology to ensure they are not excluded from services:

- ‘More appointments with human beings with less emphasis on digitalisation of communication’. - Swindon
- ‘Can’t use a mobile phone or computer - not interested. Should not be restricted to on-line- Swindon

Positive use of technology and shared data

Ten people (6%) would like more access to technology. Nine people (5%) would like to see data sharing across the services to enable a more joined up service that meets their needs:

- ‘It’s 2019 for goodness’ sake - we have the technology but it’s not used!’ - B&NES
- ‘Easier access to health records and better communication between hospital departments who do not communicate if you have more than one condition to manage’ - Swindon

The frustration in having to supply a list of medication, treatment and other information at every appointment was palpable from this respondent. They were advocating the use of a card with all their medical data available. For someone who has to visit multiple services or who has multiple or complex health conditions the use of technology and the sharing of data is vital.

Case study 1 - B&NES

- Support groups are very useful to convey information and become aware of services on offer, etc.
- Use of online media to access medical services 24/7/365 if possible and credible.
- Text reminder of an appointment the day before the appointment is extremely useful.
- More data and information on services and waiting times within and outside local NHS authority

We have used these comments from one respondent as a case study to illustrate how technology can be put to good use. There is also a useful comment about the benefits of support groups and their ability to signpost and provide information about other services available.

Technology, therefore, has a key part to play in managing communication between services (shared data) and between services and patients (appointment text messages and receiving test results). If used to its full potential it has the ability to streamline service provision, easing pressure on services and making more appointments available to those in need of them.

Other comments were made around better training for receptionists and for them to not to be the ‘gatekeeper’ to services. More access to information available on how to keep healthy and better continuity of care.

Health Inequalities - feedback from specific groups

What did they tell Healthwatch?

For the purposes of this report we have split further findings into condition-specific sub-categories with key themes which have emerged and our recommendations.

Autism

In total 17 people who responded to the survey had autism. Three people said their experience was positive or very positive, five people said it was average and nine people said it was either negative or very negative.

Key themes which emerged in the feedback we received were as follows:

- The condition is generally poorly understood and there is not enough support provided by services.
- Misdiagnosis and the lack of support leads on to mental health issues. In one case a respondent said they attempted suicide as help had not been provided despite numerous requests.
- Health care professionals getting autism confused with a mental health condition.
- Early intervention is crucial for a child with autism, yet this is often not forthcoming and in some cases patients' / parents' concerns have been dismissed by the health care provider they have been speaking to. Once targeted help, such as a paediatrician or speech and language therapists, has been received people's experience can transform from being negative to positive.
- People have been left to struggle to find other sources of support, with one parent saying: **'really it has been down to me as mum to become an 'expert' and to educate others'** due to the lack of help available.

Our recommendations

- It is well-documented that support for those people with autism can be non-consistent, hence issues arising such as misdiagnosing with a mental health condition. We recognise that people with autism are on a spectrum and that the condition is complex. Commissioners should, however, consider reviewing service provision and invite patients and parents as **'experts by experience'** to help guide this. One respondent suggested **'There should be an experienced older parent on every team, NHS, Social Services, GP units, to help and support younger parents.'**
- The emphasis should be on early intervention to give those diagnosed with autism the best possible chance of progressing and leading a life of independence.
- There needs to be a focus on creating more joined up services that can refer people on quickly and easily to support groups etc. Often people are left to their own devices and stumble upon Early Bird courses or access to respite - **'Services actually working together would have been really helpful as then I could have got the help I needed without a battle in my darkest days'**.
- The benefits of specialist services, such as Wiltshire Autism Diagnostic Service (WADS) and other peer support groups cannot be overstated. They offer much-needed advice and support, not only to patients, but can reduce pressure on primary and secondary care services. More awareness and support of these services is crucial and commissioners should consider how best to achieve this.

Cancer

In total 20 people with a cancer diagnosis responded to the survey and the feedback was overwhelmingly positive which was encouraging to read. Ten people reported very positive experiences, eight positive and two very negative.

Key themes which emerged in the feedback we received were as follows:

- One respondent said that there was a lack of choice in terms of having to travel from Swindon to Oxford for skin cancer treatment. Another was very dissatisfied with their treatment from start to finish at their local hospital and would like more choice in where to go in future in order to avoid going there again.
- Two respondent suggested that more research into ovarian cancer was necessary, as well as consistent access to trials and testing: **‘It’s a very finite set of approaches for this cancer and not a hopeful prognosis. Lack of funding into research or lack of clinical trials put the UK way behind other countries in terms of survival’.**
- People reported receiving a quick diagnosis and then being treated swiftly. They reported very positive feedback about their experiences of care: **‘Could not have been improved. It’s been excellent’.**
- Overall respondents felt that, once the initial diagnosis had been made and treatment administered, that the level of care tapered off: **‘When the diagnosis was terminal and discharged from hospital there was a lack of communication between hospital/GP and hospice and, in consequence, there was a period of 10 days where there was no support and no effective pain medication. It’s very important that other health care professionals are alerted once the oncologists can do no more.’**

Our recommendations

- More focus on developing after care support and ensuring that services are ‘joined up’ and talking to each other, particularly once a patient is discharged.
- Some very negative feedback was received from one respondent about the oncology department in one hospital. Treatment after diagnosis was slow - **‘There is no cohesion of services and oncology waiting times and follow up are very poor. I had to wait over six weeks to find out if I required chemotherapy, as nobody wanted to answer the question!’** There was a catalogue of other issues experienced by this respondent, such as seeing a different nurse every time preventing the ability to build therapeutic relationships, appointments being cancelled with no explanation, telephone numbers to the oncology department on letters were incorrect etc. This issue could well be exceptional but is a good example of what happens when things go wrong. We will take this back to the service provider in question.
- Overall the feedback was extremely positive. Services should continue to provide what appears to be an excellent service to patients with a cancer diagnosis across the region.

Dementia

Eight people with dementia, or responding on behalf of someone with the disease, responded to the survey. The sentiment of the responses were mixed, with three people reporting average experiences, and one person responding negatively, positively and very positively. In addition to this one person said ‘don’t know’ and another left the response blank.

There was a limited amount of additional commentary provided by these respondents but key themes which emerged in the feedback we received were as follows:

- There were reports that it took a long time to get a diagnosis of dementia, despite there being warning signs and symptoms long before.
- One respondent felt that there was a distinct lack of empathy from the healthcare professional they were dealing with and that: **‘Dementia patients are treated as being inferior and not valued’** and another felt that an illness such as cancer is given priority over others, such as dementia. This respondent also paid for other services themselves to provide support, but felt that this should be provided for free on the NHS.
- People suggested that longer domiciliary care visits were necessary, the availability of more day centres, community support and more regular GP visits. Where additional support has been provided patients and carers benefited hugely from this.

Our recommendations

- More support available to those with dementia and for their carers. Again it is imperative for services to work in a more joined up fashion so that people can be referred on to additional support they may need, rather than struggling to deal with matters on their own.

Heart and Lung Disease

Nineteen people with heart and lung conditions responded to the survey. The sentiment was predominantly positive with four people reporting very positive experiences, another four saying positive, five saying average, four saying negative, one saying very negative and one person saying ‘don’t know’.

Key themes which emerged in the feedback we received were as follows:

- Some respondents said they had to wait for a long time for their diagnosis, operation or were misdiagnosed, with some stating they had to wait two to three years to be operated on. One respondent was repeatedly told by GPs and respiratory nurses that he had asthma but after having paid privately for a consultation was told he has interstitial lung disease (ILD) and has since been referred to a specialist clinic.
- One person felt that there was ageism and inconsistency in the health system. One GP said that after 70 they were no longer eligible for an operation, only to be referred for the requisite operation by another GP.
- Transport was named as an issue for several respondents with one individual in particular from Bath and North East Somerset saying: **‘Due to a lack of vision, I cannot get to hospital for physiotherapy. Now there is no transport. Told [by non-emergency patient transport provider] that as I can get into a car that I can get there’**. Whilst this is only one comment we know from focus groups Healthwatch Bath and North East Somerset have run on this particular topic (this was one of their work priorities for 2018) that accessing Non-Emergency Patient Transport is an issue. A report on this is due to be published. Living in a rural area (in Wiltshire) was also cited as an issue for getting to appointments.
- More support was suggested by another: **‘A little more individual support, generally have to do your own research then push for the service’**.
- Several comments were made about the need for more investment in rehab and diet and exercise programmes, as well as helping people to give up smoking. **‘The opportunity to have post op rehab including getting back in to exercise was invaluable I now at 70 attend the gym regularly’**.

Case study 1 - Swindon

To illustrate when care works well and services are ‘joined up’, including across different local authorities, we have used a case study from a Swindon resident. The respondent has provided

detailed information about their care pathway, commenting on what works well and with some suggestions for improvement:

I had a heart attack in 2007, the ambulance arrived within 5 minutes of our 999 call. With a follow up ambulance quickly following. The first responder persevered and decided to take me to hospital despite being told that my electrocardiogram (ECG) was ok. She was right, my actual heart attack occurred in the ambulance. Emergency department was fully prepared to receive me and my pathway through the hospital lead to a double bypass. Only blip was my wife being told to take me home 5 days post op on a train. Needless to say that didn't happen I refused to leave. In my opinion I was supposed to be in an end to end process and transport back to Swindon should have been provided. To save my wife further arguments and distress I let my youngest son drive me home. I don't think that was a suitable conclusion.

I was admitted kept in hospital until a slot for a cab was available for return from Bristol Royal Infirmary. The Great Western Hospital rehab pathway and access to safe rehab and exercise was excellent.

As above all went well except the stress caused by trying to get hospital transport home. Post op care after Intensive Care Unit was poor and the food in Bristol was appalling.

Subsequent to my heart attack I have regularly seen my cardiologist 2007 to date 2019. I have also been afforded scans and echos during that time, which have been very reassuring to both me and more importantly my family. This should be common practice. The not knowing what's happening inside is torture for a spouse in particular. I believe that scan angiograms should be carried out at say 5 year intervals.

The opportunity to have post op rehab including getting back in to exercise was invaluable I now at 70 attend the gym regularly and try if you will to justify the investment made in me by the NHS, by staying fit and well.

Our recommendations

- Investigate why it is taking so long to diagnose and refer some patients on for operations.
- More emphasis is being placed on prevention and this should continue. The benefits to introducing a healthy diet and exercise are well-documented and more investment in this area is recommended. This ties in with local STP work around prevention and self-care.
- Review Non-Emergency Patient Transport for those in need of it. The current system in places such as Bath and North East Somerset can be uncompromising, leaving patients in genuine need of this service stranded.

Long term conditions, for example, arthritis/ diabetes

Sixty four people with a long term condition took part in the survey. There were mixed responses to this but with more people responding with positive or average experiences. Twenty people said their experiences were average, seven said they were negative, eight very negative, 19 were positive, seven were very positive, two said 'don't know' and one person left this blank.

Key themes which emerged in the feedback we received were as follows:

- Reports of late diagnoses, particularly for more poorly understood illnesses such as Chronic Fatigue Syndrome (CFS)/ ME and Parkinson's disease. This can also lead to doctors not noticing that different health issues might actually be caused by the same condition: **'It is almost impossible to get effective support with more than one issue at**

a time, even when they are all caused by the same underlying condition. In my experience this has improved slightly in the last couple of decades but nowhere near enough and, while it is certainly the case in primary care, it is even more so in secondary and tertiary/acute settings’.

- Long wait times reported even for so called ‘urgent referrals’. This can leave those experiencing ‘scary symptoms’ feeling anxious about a potentially worsening condition.
- Varying service levels depending on where you live and if there have been cuts services are likely to be sub-optimal leaving patients to languish. An example of the difference in service provision for patients with Parkinson’s disease can be seen in Swindon (good) and Wiltshire (sub-optimal).
- Respondents would like to see more continuity of care and ongoing support to help them manage their condition better: **‘I want an NHS that takes my desire to be responsible for my own health seriously and provide me with advice and support to enable me to do that - preferably earlier in the disease cycle to be preventative rather than acute treatment’.**

Case study 1 - Swindon

We have used a case study to illustrate multiple points raised throughout the condition specific survey, such as late diagnosis, getting the wrong advice, the benefits of accessing specialist support, doctors not joining the dots, what happens when things go wrong and what happens when an area has good service provision. It should be noted that this respondent stated having an overall ‘positive’ experience when accessing healthcare.

I have had Parkinson's (PD) for 16 years. When first diagnosed, it was by a Chinese doctors who first noticed it. My GP arranged for me to see a neurologist at the Ridgeway as work provided private health. I was given the completely wrong advice to stay off medication for as long as possible. A few years later after ‘nagging’ by my wife I phoned the Parkinson’s UK help line and spoke to a desk nurse there. After going through my symptoms and being asked what meds I was on, she was horrified when I said none. It should have been the sooner you get on meds the better.

One problem also is people go to their GPs over time with a string of different symptoms. GPs are slow to put, 1, 2, 3, 4 etc. together and send the patient to see a neurologist specialist in PD who is the only one who can diagnose it. This leads to late diagnosis, generally in mid 50s. As Chair of a local PD branch, I see a lot of this.

Carers are very much neglected and often become prisoners in their own homes. I hear of so many horror stories. For example, a small 80 year old lady with a tall 80 year old husband who has PD. On entering the room he had moved, which he had never done before, to a very low seat. She was unable to get him up. Phoned the help line she pays for and told because he was not on the floor they would not come out. She waited till the lady who helps get him to bed came and both of them could not move him. On phoning the help line again, they still refused to help. She was told he would have to stay there till the morning. He was also incontinent. They tried 999 for an ambulance but because of more urgent calls none came till the morning. He was there 22 hours incontinent.

As a Branch we now fund a free respite service. Provide a free 5 day exercise programme with 7 options, including special seated for those unable to stand to dance, walking football, Tai Chi, Balance and Exercise. The hospital refers their patients to us.

In Swindon we are lucky to have a dedicated Parkinson's Services including, consultants, 2 PD nurses, physios, OC Health, Speech & Language and get looked after well.

Case Study 2 - Wiltshire

We have used this case study to enable comparison of service provision in Swindon and Wiltshire

Parkinson's care within Wiltshire is poor. This is the only county in the UK that has no dedicated Parkinson's nurses. Parkinson's UK recommend one nurse per 350 patients. There are more than 1200 persons registered with Parkinson's in Wiltshire and so we should have four nurses. As a comparison, Swindon has two dedicated Parkinson's nurses plus a team of specialist physio and occupational therapists along with speech and other support services. We in Wiltshire have been badly served by our CCG and have asked for urgent attention to our plight.

Our recommendations

- A more holistic approach to care is needed so that healthcare professionals join the dots in managing patients' health, particularly for those with complex health issues.
- Involve patients in training. Some people feel that they are more informed about their condition, particularly if the conditions are complex or poorly understood, than the healthcare professionals they are speaking to: **'Local healthcare professionals could benefit from further training [in treatment of rare skin conditions]. We often feel we are doing the training.'**
- Where wait times for appointments and referrals cannot be reduced manage patients' expectations around this so they know what to expect and why. Advice needs to be given about what patients can do to manage conditions themselves if there is going to be a lengthy wait and signpost to other services which can offer further support.
- Once again the value of support groups cannot be overstated. Future commissioning and funding strategies should therefore ensure that the value of some providers are not ignored.

Mental Health

Forty people with a mental health condition responded to this with ten people reporting an average experience, six people reporting a negative experience, six saying very negative, twelve saying positive and six saying very positive.

Key themes which emerged in the feedback we received were as follows:

- Mental health service provision for children and young people needs to be improved: **"GPs need more training in mental health issues in young people, they need to understand referral routes and that telling a young person to get help at college is not OK. CAMHS need to not discharge someone from care at critical times in their lives such as exams, starting college, starting uni etc. CAMHS are not recognising Autism during assessments but diagnosing anxiety instead"**.
- There were mixed responses about wait times with some people saying this was satisfactory and others saying they have had to wait a long time. In one instance someone who was suicidal had a lengthy wait: **'We were not seen by a specialist for at least two months after our initial consultation which as my husband was suicidal was too slow'**.
- Once services were accessed some people felt that the treatment was too broad and not long enough or that they were not comfortable going to group therapy (when accessing IAPT services) whilst others said that once they accessed counselling it was good. Some respondents also wanted to be offered alternatives to medication.

Improve Understanding of Mental Health

9% of those completing the Condition Specific survey would like to see a better understanding of mental health with 2% saying they would like to see better access to 1:1 counselling:

- 'Whilst the staff at Lift Psychology are great for general classes, it's hard to get to see anyone 1:1' - Swindon
- 'GP said it was normal for teenagers to feel depressed/anxious/self-harm and said to access support at my college and take up rugby' - Swindon
- 'Mental health services in Salisbury for younger people are over stretched and over a year's waiting list, also a lack of funding' - Wiltshire
- 'Mental health services for young people need to be better. Currently long waiting times for counselling at school' - B&NES
- 'When asking for help it took me to harm myself and to put myself in hospital before I got any help because I nearly died. I also have mental health issues and a learning disability' - Swindon
- 'Never a one stop place to go! Never the same doctor twice! Lack of insight and training into Specific Learning Difficulty (SpLD), Autism, Sensory Issues, Pathological Demand avoidance and acute Anxiety! Just chuck drugs at it attitude! Social Services Community Care appalling! No safeguarding! No insight, not listening to loved ones, all this exacerbated the Anxiety until one failing from Community Living team triggered acute anxiety, section 3 at age 43!!! There should be an experienced older Parent on every team, NHS, Social Services, GP units, to help and support younger Parents.' - Wiltshire
- 'The Social Prescribing/Community Navigator Service hadn't started when I became ill. It would have really benefitted me. My depression at the time was treated well via counselling and short term medication' - Swindon

Our recommendations

- Look at more training for GPs and other first line services in mental health.
- Encourage GPs to look at alternatives to prescribing medication, where appropriate.
- Look at improving wait times to access mental health services, particularly if someone is in crisis, and empower people to help themselves whilst they are waiting to prevent conditions getting worse and then finding themselves in crisis.
- Look at ways more nurses can be funded whilst in training to encourage more staff in mental health.
- Look at access to talking therapies and social prescribing.



Picture: Healthwatch Wiltshire engagement at Springfield

In focus

Primary Care Networks - Swindon Specific with additional comments from Bath and North East Somerset

A focus group, was held by Healthwatch Swindon with 21 members of the Patient Participation Group (PPG) Forum. The focus during the meeting was the development of primary care networks (PCN).

A key part of the NHS long-term plan will be on primary care networks, bringing general practices together to work at scale. This was picked up by Bath and North East Somerset, Swindon and Wiltshire Sustainable Transformation Partnership (BSW STP) who subsequently asked its local Healthwatch to speak to people about this as part of the engagement on the NHS Long Term Plan.

The objectives of the forum meeting were to:

- Ensure members of the PPG were aware of PCNs. Information from the Kings Fund was distributed prior to the meeting, along with an infographic showing a timetable of required action by GPs.
- Make members aware of changes already happening in Swindon regarding this.

What we did and what we heard

It was explained to the 21 members who attended the meeting that it was understood the three groupings of GP practices in Swindon (Integrated Medical Holdings (IMH), also known as Better Health Partnership, Wyvern Health Partnership and Brunel Health Group) had been following the expectations from NHS England and preparing to establish PCNs within the terms set out in recently received documentation. The expectation was that PCNs would cover a population of between 30,000 to 50,000 people it was likely that the Brunel group would establish two or three PCNs whilst IMH and Wyvern were within the prescribed population range.

Discussion followed about the two outlying IMH practices of Eldene and Phoenix surgeries and how they would relate to the rest of the IMH group of Abbey Meads, Moredon and Taw Hill. Two other practices were not within the existing three groups and it was understood they were likely to be encouraged to join up because of the financial incentives and potential benefits to patients.

Whatever the organisation of GP practices, members felt the following would be vital to ensuring the successful development of PCNs:

- Communicate to patients clearly and well in advance of changes. IMH was cited as an organisation that had failed to do this when introducing its call centre.
- That patients understand that they may not (need to) see a GP and that other clinicians may be most appropriate.
- That reception staff are known and understood by patients to be trained to an appropriate degree in order to ask (the right) questions and respond to callers.
- There was mixed views on the options of travelling between different surgeries for services, those with transport were willing to travel, whilst those reliant on public transport would prefer not to.

- There was a general acceptance that PCN's, in principle, are a good idea to improve access to services. However, in Swindon there has already been issues with IMH and the implementation of a 'hub' which is managing the 'back office' activities. This includes a call centre that has been inefficient for the last 8 months. There has been a general lack of communication to the public from both the practices, IMH and CCG with any changes that have or will take place. There is real concern that this would continue to happen. At the moment there seems to be no clear accountability for the issues.

There were questions about the availability of home visits, extended hours, out of hours, weekend appointments and whether nurse practitioners were able to refer people to secondary (hospital) care.

By way of example of developments and improvement encouraged by the NHS Long Term Plan, it was explained that the Brunel Health Group had already started to recruit two paramedics who would undertake some home visits to patients of practices in the group. The intention was also to recruit some mental health practitioners, similar to a number of practices in Swindon which already have one.

PCNs were required this year to recruit social prescribers, similar to Swindon's existing [community navigators](#). People felt that this was a good idea and were aware of the existing provision of the community navigators.

There was brief discussion about the work of PCNs with other organisations in their locality and the development of integrated care systems, as well as about the challenge of recruiting GPs to Swindon - albeit some practices were training practices and might be able to retain the services of doctors at the conclusion of their training.

For this forum the debate about arrangements for PPGs within and between PCNs was important and would be the subject of continuing consideration as the PCNs emerge.

An additional meeting in Bath generated the following comments:

- **Having read the attached information and watched the videos, how do you feel about Primary Care Networks?**
Initially it appears to be a good plan, but with reservations, who will be monitoring and have governance of them?
- **What do you think is positive or negative about them?**
The positive is that everything will be local, and hopefully they will take on best practice. Also with a group of GPs there's a chance of some speciality in each practice. The negative is if they pay a 'CEO/Director' for the network.
- **How do you feel Primary Care Networks could affect people's care and services locally?**
Hopefully to more specialised GPs, also equipment that can be accessed across the network.
- **Do you have any thoughts as to how Primary Care Networks might affect your own care and experiences, or those of the people you care for?**
Being positive; easier access to services and specialists. Negatively: more pressure on GPs/therapist resulting in even longer waiting times to be seen.
- **Do you have any questions or concerns about Primary Care Networks?**
Will it be as promised or a pipe dream?

Primary Care Networks - Wiltshire Specific



Pictures: Healthwatch Wiltshire's meeting about Primary Care Networks

What we did

Further to the British Medical Association GP (England) committee and the NHS England agreement to develop and rollout Primary Care Networks, Healthwatch Wiltshire were invited by the Clinical Commissioning Group (CCG) to undertake a focus group and gather the views of the patient participation groups (PPG's) in the Wiltshire area. The PPG's are made up of a group of volunteer patients, the practice manager and one or more of the GP's from the relevant surgeries.

33 people took part in the focus group and all areas of the county were represented.

An information session was hosted by the CCG regarding PCN's and the attendees were given an opportunity to ask questions which were answered during the discussion.

Healthwatch Wiltshire volunteers then facilitated table discussions around the following questions:

1. What do you think of the concept of Primary Care Networks?
2. What opportunities and benefits could working together have?
3. Are there any potential barriers or difficulties?
4. How can Healthwatch and the CCG engage with you and the public about this?

What people said

Overall, those taking part in the discussions saw PCN's as a positive thing and a great concept:

- "Great concept - great potential"
- "Concept is good - joined up thinking"

The opportunities and benefits of working together included reduced waiting times, appointments handled by more appropriate health professionals resulting in freeing up GP time. This would allow for "the most appropriate intervention at the right time" and "more opportunities for individual care." Other benefits included "better connections between Primary and social care with less waiting times, less paperwork and fewer people falling between the cracks." Money for new posts was seen as a huge benefit and the ability to "share" staff between surgeries, including back office functions was also considered a positive thing.

- "Freeing GP's to focus on complex patients"
- "See most appropriate care at the right time"

Potential barriers or difficulties included transport issues in rural areas, managing the expectations of patients and sharing medical records. Transport, especially in rural areas, was deemed to be a huge barrier especially for those who do not have access to a car. In many

villages in Wiltshire there is a limited bus service making referrals to other practices problematic.

For those patients who opt out of data sharing this was seen as a huge issue which would need to be resolved quickly by reassuring people about the security of their data and making them aware of the dangers of opting out.

Other issues such as the physical accommodation of staff and additional IT equipment was another potential problem, as was the timescale of July 2019 with many asking if this was enough time to roll out PCNs. Another difficulty that could arise was the question of how CQC inspections would work and problems with communication/working between practices and other agencies. One of the main difficulties that people envisioned was getting the message out to the patients.

- “May be more challenging for rural practices“
- “What plans for IT equipment? - not fit for purpose at the moment and no plans in place”
- “The public needs educating about who/when to see”

Overall, those attending the focus group agreed that Healthwatch Wiltshire and the CCG would be best positioned to assist with the rollout by informing and educating the public. This could be carried out by using a variety of media including social media, apps, websites and a national campaign.

- “Word needs to go out - A5 leaflet/electronic boards/press release - national campaign”
- “Ensure the public understand that being directed to a nurse/paramedic/pharmacist is not a lesser step than seeing a Doctor”
- “We have to get past the point of needing to see the Doctor for everything - we need to be prepared to see others”

In focus

Frailty / Ageing Well - Swindon Specific

Healthwatch Swindon worked in collaboration with Mervyn Webb Sheltered Housing and Age UK Wiltshire, when it attended its 'Fitness and Friendship' session in Swindon, and ran two focus groups with both organisations on frailty and ageing well in April 2019. This formed part of the work Healthwatch England was commissioned to carry out by NHS England to ask people's views on the NHS Long Term Plan.

Frailty and ageing well was an area identified by Bath and North East Somerset, Swindon and Wiltshire Sustainable Transformation Partnership (BSW STP) that it wanted local Healthwatch to focus on.

The objectives of the focus groups were to:

- identify the main issues affecting older people,
- understand what helps older people 'age well' and
- understand what could improve people's experience of ageing well in Swindon

What we did

We spoke to 36 people in total. We had 23 attendees at Mervyn Webb Sheltered Housing and 13 attendees when we visited Age UK Wiltshire. The focus groups were arranged in a relaxed and informal setting where we asked the following questions:

1. What does the term 'ageing well' mean to you?
2. What do you think might enable or prevent someone from ageing well?
3. Describe three wishes for your future in terms of ageing well.
4. What do you understand by the term 'frailty' and how do you think people who are frail can be supported to live as well and healthily as possible?
5. What do you like most about living in Swindon and why?
6. What do you think are Swindon's strengths as a place to live for older people?
7. How do you feel about growing older in Swindon and why?
8. What do you think about opportunities for social, cultural and physical activities in Swindon?
9. What would encourage you to attend more of these activities?



Picture: focus group with Mervyn Webb Sheltered Housing

What people told us:

Ageing Well

More than half of respondents cited the need to keep fit and active in order to age well, as well as having a healthy diet, giving up smoking and drinking less alcohol. Mobility issues, lack of

social contact, financial difficulties and loneliness came up consistently as things that would prevent people from ageing well. Concerns about poor healthcare provision also came up:

Comments Received

- **“Fearful that resources are overstretched to meet my needs, especially GP appointments/hospital appointments. My church provides for many of my needs.”**

When asked to ‘describe three wishes for your future in terms of ageing well’ some of the comments received were:

- **“Good accessible health support. Enough to live on. Good transport services which are affordable.”**
- **“Health body with no pain. Able to get out and about. Live in a sociable community. Volunteer”**
- **“Good health, mobility, support from family/healthcare.”**
- **“Concerned about the use of IT, I have no access and it’s more and more on-line.”**

Frailty

When asked to share their views on what people understood by the term frailty people felt this meant less mobility and independence, diminishing physical and mental health and weakness.

They were also asked how they thought people who are frail could be supported to live as well and healthily as possible. Lots of people said that ‘maintaining outside connections’ such as support from family and community was important, as well as:

Comments Received

- **“An improved social care service, good access to healthcare, healthy lifestyle”**

And

- **“Proactive involvement by the primary care system and adequate funding to provide necessary support.”**

Ageing well in Swindon

When asked about the benefits of living in Swindon for its older population there was a mixed response with some people feeling that ‘opportunities for social, cultural and physical activities in Swindon’ were limited or poor or very poor and not enough knowledge about what was available. Others commented that they were good or very good, with particularly positive comments made about green spaces and access to the countryside. Another theme which emerged was that there are ‘plenty if you are active, mobile and can access them and can afford them’.

It seems therefore that better information about what is available in Swindon is required, as well as ensuring activities are affordable and easy to access. There was, however, a general feeling during group discussions that cutbacks were too severe for non-emergency transport.

Other things people said

Access to GP surgery was an issue with wait times of two weeks. All at this focus group attend Hawthorn Surgery. Most appointments were gone by the time they had got through on the phone. Most people had signed up for text reminders for their appointments. When asked if anyone would be happy for a skype call with their GP surgery everyone answered no as they felt this was too complicated. Only one person from the focus group was online.

For those living at the Mervyn Webb Sheltered Housing Scheme their experience there was positive and the consensus was that it eased loneliness and that everyone looked out for each other. There was also awareness within this group that not all sheltered housing schemes have as much social activities and not all wardens encourage social interaction. The warden here is very proactive in organising trips and transport. There are 60 sheltered housing schemes in Swindon with approximately 3,000 residents, so the statistical significance of our findings is limited.

We visited the 'Fitness and Friendship' group run by Age UK Wiltshire and the general feedback from the attendees about their own experience of ageing was positive. The group here paid a £4 fee for going to the group and organised their own transport - so finances and access were not an issue. They were all aware that for other older people this would be an issue and that the lack of vital social contact would result in loneliness.

In focus

Frailty / Ageing Well - Wiltshire Specific

The aim of these focus groups was to explore opinions on how people can be supported to live and age well. We wanted to find out more about what aspects of care and treatment had been useful to people, what could have been better and any support that they thought was missing. We also wanted to find out about people's understanding of the term 'frailty' and of how support might enable people to live as well and healthily as possible.

What we did

We visited two services in Wiltshire who provide support to older people and those who have experienced 'frailty'. We spoke to 18 people, 6 at care home in north Wiltshire and 12 at a community centre in east Wiltshire. We spoke to people either in one-to-one interviews or in small focus groups. Our discussions were aimed to be informal but were based around the following questions:

1. Can you tell us about any help and care that you have received?
2. What has gone well?
3. Is there anything that could have been improved? If so, what would could have been done differently to have made things better?
4. What information were you given information to help you make choices or understand your options for treatment and care? Is there anything else that would have been helpful?
5. Are there any other ways in which you would like to be supported?
6. What do you understand by the term 'frailty' and how do you think people who are frail (including younger people) can be supported to live as well and healthily as possible?

What people told us

About care and treatment

All of those we spoke to had experiences of receiving health and care services and they were happy to share these with us. Overall most comments were positive about the quality of services they had received.

People highlighted aspects of their care that had worked well for them. Most of these comments focussed on things that had aided recovery. They included physiotherapy, provision of equipment and enabling services such as the Home First service. We were told "they helped me get back on my feet" and "the physios gave me exercises which helped". Other things that were mentioned were services to support people more long term such as emergency call bells and carers. One person mentioned that the information given to them by their dietitian and follow up appointments had been valuable in supporting them to manage their diabetes.

There were a few comments about what could have been improved, one person would have liked to have seen their GP more frequently throughout their treatment, one person felt that hospital staff had not listened to them, and one person said that they thought agency domiciliary staff needed more training around manual handling.

Most of those we spoke to felt that they were given the information they needed and involved in their care. However, it was evident from our conversations that some people didn't know about services that might be of benefit to them, for example home adaptations.

About ageing well

People shared their views with us on what they thought would help people to be as healthy and well as possible.

Eating regularly and having a good diet was frequently mentioned, we were told “it’s important to eat the right food” and “people need a proper meal”. Several people mentioned that they thought that this was something that they had needed support with following treatment and said that they thought being provided with this support had enabled them to make a good recovery.

Keeping active was mentioned as something that people strongly believed would help them remain healthy. A wide range of examples were given including “doing as much as you can for yourself” walking, running, golf, tai chi, keep fit and gardening.

Social activity was also mentioned as being an important feature of what people thought was important for people to age well. The value of being able to attend a community group, going on an outing or joining in an activity were frequently mentioned as being something that had increased people’s sense of well-being. We were told “I like the social aspect I have made friends here”. Some people also told us that they would like to go on more outings and some people said they would like more company at home as well.

About ‘frailty’

People told us that they thought that the term ‘frailty’ to mean that someone was physically in poor health. Words used to describe people experiencing frailty were ‘not very strong’ ‘poorly’ ‘weak’ and ‘at risk of accidents’. Frailty was not always viewed as being permanent but rather as a stage during illness or following treatment. Although most people frailty as generally associated with older people, it was recognised that younger people could also experience ‘frailty’, particularly if they had a long-term condition.

It was thought that those experiencing frailty needed care and support. For example, people said “they need a lot of help”, “they need people to give them time”, “need a lot of help and care, physical care, rest and food”. Other comments also mentioned that support would need to be individually tailored and that it was important that people were treated with respect. In most cases people thought that the right care could enable people to recover, although it was recognised that this might not be the case for people with serious illnesses. Of the people we spoke to most of them could identify times in their lives when they had been ‘frail’ but only a few of them thought that they were currently experiencing ‘frailty’.

Other things people said

Most comments about the approach of health and care workers were positive with them being described as “nice people”, “kind” and “they were all great”.

People talked about the support they got from their families and it was evident that this varied greatly.

The people we spoke to told us that they would want to help and support other people who were experiencing frailty as much as they were able to.

Healthwatch Swindon have also produced two other impact reports on ageing well earlier in the year, the results of which echo our findings from the focus groups:

[Swindon Polish Catholic Mission Survey](#)

[Age UK Wiltshire Survey](#)

In focus

Learning Disabilities - Swindon-specific



Picture: Healthwatch Swindon speaking to the learning disability focus group

What we did

Healthwatch Swindon held a focus group with service users of Swindon Advocacy Movement (SAM). This was to gather the views of services provided in Swindon for those with a learning disability, high functioning autism, Asperger's or mental health condition. We spoke to 14 people, 5 male and 9 female, aged from 18 - 59. At this group 9 people completed the condition specific survey, all but one person responded themselves. There was some difficulty explaining some of the questions.

The objectives of this was to:

- identify the main issues affecting people with learning disabilities,
- understand what could improve people's experience of using health services if they have a learning disability.

What people told us

Travel

Travelling to appointments seemed to be an issue, with people wishing to remain independent and not having to rely on someone else to get them to appointments.

Four respondents commented on the need to be close to services to enable them to get there on their own without having to ask for help:

- 'I can't travel to appointments anywhere out of Swindon I prefer local appointments nearby'
- 'If I can't get there on the bus or walk I have to wait for someone to take me'
- 'All appointments need to be close to where I live in order for me to be independent, otherwise I need a supporter to help get me to the appointment. They then tend to speak on my behalf, which I don't like. We need a better services, more doctors, and the receptionists not to be grumpy and be able to understand different conditions.'
- 'I need to walk to appointments otherwise I have to have someone to help me, so they need to be close by, because I don't want anyone to help me.'

There was a clear desire from those attending the focus group to retain their independence. We recognise it may not always be possible for people to get appointments close to home, but where this is possible we feel that every effort should be made to facilitate this.

Diagnosis / Training

There was sometimes frustration at the length of time it has taken to get diagnosed with some conditions and the understanding of certain conditions.

- ‘I am autistic. I don’t think there is enough training for the NHS on dealing with people with autism’
- ‘I nearly killed myself because of the time it took’

One of the quotes was around staff attitudes and the need for those delivering services to be more understanding of different conditions. We recognise the statistical limitations of these responses, however ongoing concerns about premature deaths of people with learning disabilities is well-documented - [see University of Bristol report](#). We feel that reviewing staff training is therefore imperative.

There were also some positive comments:

- ‘I have always felt well supported’
- ‘I want to understand my support, better and make it easier and clearer for me to help myself understand better’
- ‘No jargon to be used, make things easy to understand. I need someone to explain things to me’

When asked what the NHS do to help people stay healthy or manage any conditions they have, one respondent suggested:

- ‘I am partially sighted so not everything is easy to read. It would be good if we were easily identifiable, with a coloured lanyard perhaps’

Healthwatch Swindon felt that this was an excellent and simple suggestion to make identifying someone with additional needs easier by staff so that they can then make reasonable adjustments for those particular patients. With the implementation of the Accessible Information Standard (AIS) in 2016 health services by law have to provide information to patients who request it in a way that is easy for them to understand. We are aware that a number of NHS services are still not implementing the Standard and measures must be taken to address this.

Healthwatch Swindon have also undertaken Enter and View visits to nine GPs and dental practices with volunteers with learning disabilities. We are seeking further funding to continue with this piece of work as we feel that these provide valuable insight to service providers about their service delivery from the perspective of someone with a learning disability. Our final report about these visits can be read [here](#).

In focus

Children and Young People - Wiltshire - specific

What we did

Wiltshire Youth Union is a group of young people who meet regularly to discuss what is important to them and is made up of members of the Youth Parliament, local schools and colleges, Healthwatch young listeners and children in care council. As part of the Wiltshire Youth Union meeting on 7 March, Healthwatch Wiltshire were given a 30-minute time slot to conduct a focus group around the Long Term Plan.

Twelve young people took part in the focus group and all areas of the county were represented.

After a brief reminder of who Healthwatch Wiltshire is, and how we work, we showed them a short video from Healthwatch England - *The NHS Long Term Plan: What would you do?*

We asked the young people to take part in two activities the first of which was to find out about their experiences of children and young people's health and care services. Based on their personal experiences we asked them to tell us what really worked for them, what was ok and could be improved, and what really didn't work for them.

They were given green, orange and pink post-it notes and asked to record their experiences using the green to say what was good about the experience, orange to say what was ok and would have been easy to improve and pink to say what really didn't work.

The second activity was asking the young people for feedback about what matters most when improving services for children and young people. We put them into small groups and asked them to discuss, and give feedback on, specific questions around how the NHS should provide future services.

The questions asked were:

1. Who should assess/diagnose/treat/support you?
2. Where would you expect this to happen?
3. How far would you travel?
4. Would you prefer to travel to see a specialist or receive support locally?
5. What type of care would you be prepared to wait for if the service was exceptional?
6. What additional information would help you to make choices? Is there enough information?
7. Who should provide information? Where and how would you like to access it?
8. How can communication be improved?
9. In what other ways would you like to be supported?

What people told us

The young people spoke about a range of services including Accident and Emergency, GP surgeries and the school nurse. Overall their feedback regarding these services was very positive. In response to the first activity the main points, when asked what was good about their experience, were that the staff were very helpful and the level of care provided was good.

- **'Listened to with no problem and received good treatment.'**

In answer to the question 'What was OK and would have been easy to improve' the majority stated waiting times as the main issue. One young person told us that the out of hours GP had to come out to them twice 'not knowing what was up.'

- **‘GP Surgery/Out of hours - Nobody told us why our appointment was late, we were sat waiting for quite a while but not told why after it was a lot later than our appointment.’**

Waiting times and accessibility of services was also the main concern when asked what really didn't work. One young person said that there was no follow up with teams that they said they would refer them to and another said that the vaccination specialist wasn't confident when providing information to them.

- **‘I waited for four hours for a booked appointment.’**
- **‘NHS Direct - 6 calls later; appointment 30 miles/1 hour away’**

The second activity was asking the young people for feedback about what matters most when improving services for children and young people.

When asked who should assess/diagnose/treat/support you they felt that they should be fully qualified such as a nurse or doctor and this should depend on the level of severity. Where they would expect this to happen were GP surgeries, walk in centres, hospitals, out of hours surgery, at home or an online diagnosis (which is not always suitable).

- **‘Anyone who is qualified and should depend on the level of severity’**

There was a mixed response to the question how far would you travel, with one group stating that it depends for the best level of care. The other groups said 5 miles or no more than a 30 minute drive as most are dependent on someone taking them. The majority of young people were prepared to travel for the best treatment but within reason and providing it was in the patient's best interests. Only one group stated that they would like to receive support locally.

- **‘Depends for best level of care’**

Elective procedures or non-emergency care was the service that most were prepared to wait for with the preferred waiting time of between two and six months. One group stated that for all services they should not be waiting long at all.

- **‘Travel to see specialist providing it was within patient's best interests’**

When asked what additional information would help them to make choices they responded that all options should be mentioned when assessed and from people who are aware of their case. Online options were also another way that they could make choices. This information should come from GP practices, pharmacies, easy to use websites and/or the doctor or nurse that is seeing you. Communication could be improved by having more 111 staff, advertising campaigns and more information in pharmacies. Being told about cancellations would also help to improve the waiting times for appointments.

- **‘More 111 staff and information in pharmacies’**

Finally, when asked in what other ways young people felt they would like to be supported they answered through pharmacies, better GP consults, mentors and Mental Health services.

In a separate group we wanted to find out more about which areas of mental health services local people felt we should focus on and to gather some initial feedback about experiences of using mental health services.

We designed a short survey which asked people to choose one area they thought we should focus on, and to tell us the reasons for their choice.

Key messages

- Access to services was chosen by most respondents as a priority and there was concern about long waiting lists.
- Difficulties with access due to stringent criteria and complicated access pathways was reported.
- There was concern about quality of mental health services.
- Crisis support was thought to be crucial to provide support in difficult times.
- It was thought to be important to maintain people's mental health so that they are supported to remain active in their local community.

Engaging people in health service delivery - Wiltshire Specific

Feedback from Healthwatch Wiltshire Volunteers

What we did

Healthwatch Wiltshire volunteer support and development day conducted a focus group around the Long Term Plan.

Fifteen volunteers took part in the focus group and all areas of the county were represented.

We asked the volunteers to take part in two activities, the first of which was to find out about their experiences of health and care services. Based on their personal experiences we asked them to tell us what really worked for them, what was ok and could be improved, and what really didn't work for them.

They were given green, orange and pink post-it notes and asked to record their experiences using the green to say what was good about the experience, orange to say what was ok and would have been easy to improve and pink to say what really didn't work.

The second activity was asking the volunteers for feedback about what matters most when improving services. We asked them to discuss in small groups, and give feedback on, specific questions around how the NHS should provide future services.

The questions asked were:

1. Who should assess/diagnose/treat/support you?
2. Where would you expect this to happen?
3. How far would you travel?
4. Would you prefer to travel to see a specialist or receive support locally?
5. What type of care would you be prepared to wait for if the service was exceptional?
6. What additional information would help you to make choices? Is there enough information?
7. Who should provide information? Where and how would you like to access it?
8. How can communication be improved?
9. In what other ways would you like to be supported?

What people told us

A range of services were discussed which included GP surgeries, hospitals, dentists, pharmacies and ambulance services. Overall the feedback regarding these services was very positive. In response to the first question the main points, when asked what was good about their experience, were that the staff were very helpful and the level of care provided was good.

- 'Spa Medical Centre, very friendly, direct service, good explanation of procedures.'
- 'Visit to my local pharmacist...very helpful and informative and pointed me in the right direction where to get help next.'
- 'Practice nurse calling back promptly to assess symptoms and making urgent GP appointment.'

In response to the second question the majority felt that waiting times, trying to get an appointment at their surgery, the provision of information and communication from staff could all be improved.

- ‘Quick medication but wasn’t given any information on these meds, for example, side effects.’
- ‘Long wait for ENT consultation for my adult daughter. Non-urgent but chronic condition no better after two years.’
- ‘Could have been given all local options (dentist).’

Waiting times, lack of communication and information as well as cancelled appointments were all raised as concerns when asked what really didn’t work.

- ‘Impossible to get GP appointment after 50 phone calls.’
- ‘Some aspects of my mother’s stay in hospital - largely due to lack of communication and information.’
- ‘Lack of ambulances - 3 hours wait for 999 call.’
- ‘Cancelled appointments for NHS surgery.’

The second activity that the volunteers took part in was asking for feedback on how the NHS should provide future services. In groups of five, the volunteers were asked to discuss specific questions relating to the provision of future services.

When asked who should assess/diagnose/treat/support you the group felt that it should be someone appropriately qualified but was also dependant on the nature of the medical need.

- ‘The right person at the right time.’
- ‘Triage system.’
- ‘Health professional.’

Where they would expect this to happen was also dependant on the situation and medical need and included their own home, local health centre, GP surgery or via phone/digitally to a triage administrator.

- ‘As close to home as possible.’
- ‘Community health centres - more of these for each town.’

There was a mixed response to the question how far would you travel with one group suggesting within a ten mile radius or thirty minute drive. Concerns raised about travelling included the accessibility of public transport and where, and when, the services were being provided.

- ‘Depends on the accessibility and availability of public transport/transport links.’

“Concern for elderly people and those who don’t drive as well as the issue of driving when feeling unwell.”

All groups were united in their response to the question would you prefer to travel or receive support locally with all electing to receive support locally.

- ‘Would prefer to see locally but would be prepared to travel. Specialists should travel for people who can’t or don’t drive. A choice of different sites would be useful.’

Non-life threatening or non-urgent/specialist surgery was deemed the type of care that the volunteers were prepared to wait for if the service was exceptional, however, they also felt that all care should be exceptional including urgent such as cancer or a broken hip.

- ‘You would need a lot of information to be able to make a decision about this.’
- ‘Specialist surgery unless in acute pain.’

When asked what additional information would help them to make choices one group responded that availability of treatment, the doctor’s specialisms and changes in care were important. One group felt that there was enough information already but people needed to know where to find

it and the last group felt that any information should be delivered by people but backed up with written information that was easy to understand.

- **‘Information delivered by people and backed up with written information easy to understand.’**

They felt that information should be provided by a relevant professional and delivered face to face, however, access to all options should be available from the beginning of the journey. Other options for providing information included easy read leaflets, NHS website, surgery newsletters and trained volunteers.

- **‘Relevant professional; face to face; trained volunteer in appropriate circumstances with support available to manage the message.’**

In answer to the question, how can communication be improved, the message was that this should be timely and with the person given the care. There should be a holistic approach, it should be jargon free and patient centred. Centralised/available medical records were another way that communication could be improved as long as consent was given. Informing families and carers was also a good way to improve communication.

- **‘Available medical records to all who need access if consent given.’**
- **‘Being patient centred. Holistic approach. Services should be linked up better.’**

Finally, when asked in what other ways they would like to be supported they answered by using common sense, treating people as individuals and staff being able to act on their own initiative rather than being driven by “processes” and “the system”. Knowledge of non NHS support services and using community co-ordinators was another way that people could be supported.

- **‘Treat people as individuals.’**
- **‘Community co-ordinators.’**
- **‘Knowledge of non NHS support services.’**

Next steps

Dom Hall from Bath & North East Somerset, Swindon and Wiltshire Sustainable Transformation Partnership has said in response to our findings:

Experience of, and access to, services is currently being explored as part of the B&NES, Swindon and Wiltshire's (BSW) Our Health, Our Future campaign which continues until 31 July. Together, Our Health Our Future and the Healthwatch campaign provide an opportunity to strengthen partnerships and build a common understanding of local issues and collective priorities. We will use the findings from both, alongside other engagement work we have already conducted, to shape our local system's five year plan. More information about Our Health Our Future is available [here](#).

The findings highlight a number of issues such as lack of awareness/understanding of autism spectrum disorder and dementia and poor patient experience of using services. However in order to identify key areas of focus, we first need to share and discuss the findings with senior leaders and commissioners in our partner organisations.

The Healthwatch findings will be considered alongside feedback gathered through Our Health, Our Future campaign and will be used to help inform the development of our five year plan. This includes using the Healthwatch results to help shape our approach to support a number of system-wide and local priorities including mental health, supporting people to age well and primary care. The role of local people in shaping and developing primary care networks is being explored by CCGs and practices and the Healthwatch findings will play into this piece of work.

We are working to timescales set out by NHS England/Improvement which will see a draft five year plan produced by the end of September 2019. Between November 2019 and January 2020 we will publish our full plan, alongside a shorter, accessible summary.

Our first priority will be to share feedback we receive from our campaign, and insights gathered from Healthwatch engagement, directly with commissioners, and communicate back to the public how we will use their feedback to shape and develop health and care services. Then, on an ongoing basis over the next five years, we will work together as a system to engage with the public, staff, community groups and other key stakeholders on our progress against the plan. Further discrete pieces of engagement or consultation - related to specific services - will be carried out where necessary and with the full involvement of those in our communities who may be affected by the proposed changes.

Recommendations

- Provide more public health information on healthy eating and exercise - there is a clear appetite from the general public for this and this ties in with STP prevention strategy. Information should be clear and not contradictory with tips on how to eat healthily for less and access to affordable exercise groups.
- The use of technology, without excluding those that are not online such as older people and those with low income and no access to IT should be prioritised. This could transform healthcare provision, helping services to communicate better with each other and providing patients with quick access to information and test results.

- A review of service provision for conditions such as autism should be carried out. It is clear from feedback received that health inequalities are experienced, with patients and carers not accessing vital services and interventions.
- Communication with the public needs to be clear, honest and open and without any jargon or acronyms.

Methodology

Bath and North East Somerset, Swindon and Wiltshire Healthwatch ran two surveys on their websites. This was supported by the STP and CCG's in each area. Healthwatch gathered relevant evidence to answer research questions to meet the objectives.

- A test survey was carried out on Healthwatch volunteers.
- All staff and volunteers of Healthwatch BSW receive training during induction to ensure that information gathered is not biased. Some blinding will be introduced - for example, those who gather the feedback will not analyse the surveys and survey responses will not be analysed at the same time as the demographic data. Findings / conclusions will be reviewed by a third party staff member to control for confirmation bias during analysis.
- An external data analysis was commissioned to carry out the quantitative data analysis.
- Various methods were used to gather information including on-line and paper surveys in regional hubs, as well as online sampling in order to attempt to reach a representative sample of the population. Gaps were pre-empted and addressed where possible (e.g. proactively approaching younger people who may traditionally be less likely to engage with Healthwatch). Swindon ran a session at the local college, which is reflected in the age spread of responses in Swindon.
- Focus groups were targeted at specific groups to obtain the information that we needed.
- We considered making use of translation services if practical and required.

Data Management:

- Most feedback was collected directly through the Healthwatch England URL. For individual focus groups we used our own survey monkey questionnaire. Any paper copies of surveys were entered onto the system and shredded.
- Individual feedback was noted and recorded within the individual reports. Consent was agreed before any information was recorded. All was anonymous.

Analytical process and techniques - We have a track record of research using robust analytical processes. We will clean data before using it, removing blank survey forms / survey clearly submitted multiple times in error. We will introduce a degree of awareness of statistical significance when drawing conclusions (i.e. not making claims based on statistically insignificant data). We will avoid applying findings across boundaries when there is no strong rationale for doing so, particularly qualitative feedback. We will demonstrate an understanding of the differences between how we can use quantitative and qualitative feedback.

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Dom Hall, Communication and Engagement Manager, BSW STP.