NHS Long Term Plan



Bristol, North Somerset and South Gloucestershir



Executive summary

Background

This is the executive summary of a report that contains the findings of an engagement project carried out by Local Healthwatch in Bristol, North Somerset and South Gloucestershire (BNSSG) during April and May 2019.

You can find the full report at www.healthwatchbristol.co.uk

This engagement was part of a national project commissioned by NHS England and Healthwatch England. It focused on the NHS Long Term Plan and asked local people 'What would you do?' with the additional money that has been committed by central government to improve and enhance the provision of NHS services over the next 10 years.

This project was delivered through the use of **two surveys** created by Healthwatch England. One survey focused on people's general experiences of using health and care services, the other was targeted at people with long-term conditions and their experiences of receiving treatment and support.

Across the country Local Healthwatch gathered survey responses from over 18,000 people. Locally we gathered:

- 433 general surveys
- 183 condition-specific surveys.

Through discussion with colleagues at Healthier Together, the name for the BNSSG sustainability and transformation partnership, it was agreed that the local priority topics for this project should be **learning disabilities and autism**, and **cancer services**.

Local Healthwatch carried out **five focus group discussions** with local people on these specific topics, the results of which are captured in the report.

An overview of BNSSG

Almost one million people live in Bristol, North Somerset and South Gloucestershire (BNSSG), and similar to other areas of the UK, the local population is expected to grow significantly in the next few years (around 35,000 by 2020).

The area is relatively affluent and people's health is good, but there are significant pockets of deprivation - with around one in ten people living in a deprived location.

Some people within the area experience high levels of illness linked to low income, poor housing or disability. Average life expectancy varies between those living in the most and least deprived areas by around six years, with some places seeing a startling 15 years difference.

The annual BNSSG health budget is around £1.5bn. Funding for the NHS is growing year on year but it is not able to keep pace with current demand for services. Continuing as we are is not an option so local health and social care services are working together to try to build an improved health and care system that meets the needs of everyone that lives in BNSSG.



General survey responses by region

Please tell us where you live	No. of respondents	% of respondents
Bristol	141	33%
South Gloucestershire	88	20%
North Somerset	183	42%
(Blanks)	21	5%
TOTAL	433	100%

Key findings - General survey (433 respondents)

- Easier, more timely access to help, treatment and information when they need it. This was particularly pertinent to GP services, which consistently received negative reports of long waiting times, inconsistent/ unhelpful booking systems, and inadequate appointment length to enable full discussion of patients' concerns.
- Respondents recognised the need for individual responsibility when looking after their health and preventing illness, however there was a clear request for help to do this through increased investment in and availability of public health interventions and information.
- Respondents told us that they want to be listened to. They don't want to have to repeat their story multiple times with multiple providers. They would like services to be more joined up, and are open to the increased use of technology in order to support this.
- Respondents expressed a strong desire to be involved in making decisions about their care and treatment. They want to be informed about the options that are available to them including details such as waiting times, risks, benefits etc. and supported through adequate and timely discussion with clinicians/ health professionals in order to do this.
- Respondents want to live in their own homes for as long as possible, and hope that there will be community-based medical, social, emotional and spiritual support available to them to facilitate this.
- Respondents were open to the potential of technology in the health and care
 system particularly where it meant faster and more convenient access to services,
 such as GPs, and better communication between health providers, e.g. GPs and
 hospitals. However there were consistent concerns about data sharing, security and
 privacy of information, particularly if they were to manage/ access their own patient
 records via smart phones, tablets and PCs.



Condition-specific survey responses by region

Please tell us where you live	No. of respondents	% of respondents
Bristol	43	23%
South Gloucestershire	31	17%
North Somerset	95	52%
(Blanks)	14	8%
TOTAL	183	100%

Key findings - condition-specific survey and focus groups (183 respondents)

The greatest number of comments from the condition-specific surveys related to learning disabilities and autism (54 comments, 30%), and cancer services (36 comments, 20%).

We received 58 comments about long-term conditions, however once this was broken down into the myriad of conditions that people had, it made drawing any statistically significant results about experiences through the different care pathways very difficult.

The key themes that emerged were:

- Waiting times to access services and support were highlighted as an issue, with
 respondents reporting waiting times varying from two weeks to two years plus. This
 was deemed particularly problematic where it was felt that a quicker assessment or
 diagnosis may have prevented circumstances from deteriorating. This was
 frequently raised in relation to mental health services.
- Support works best when it is joined up and person-centred. Again respondents told us that they don't want to have to repeat their stories and they wished services spoke to one another. Some respondents said that they feel they "are their condition" and have to continually champion their cause in order to prompt assessment, monitoring and diagnosis.
- Respondents expressed a desire to receive more information about local support options, particularly those that are located in or near to their community

Based on response rates, we took the decision to focus our detailed analysis of the condition-specific surveys on learning disabilities and autism, and cancer services. This approach meant that the quantitative data gathered through the surveys could be cross-referenced with the rich qualitative feedback that was received through the focus group discussions. This has enabled us to pull out more themes from the focus groups and provide a clearer view of what people are experiencing.

Healthwatch North Somerset asked some additional questions in both the general and the condition-specific surveys covering topics specific to North Somerset. To ensure that the feedback shared by local residents is captured and used effectively, these findings will be pulled into a separate report and published during the autumn.



Local services in focus

Cancer services

- Overall feedback was positive. Focus group attendees reported positive experiences of assessment, diagnosis and treatment.
- From the survey results, 64% answered yes to having received support that met their needs when they first tried to access help with 79% describing their overall experience of getting help as 'very positive' or 'positive'.
- The positive trend continued with 66% describing the time they waited to get an initial assessment or diagnosis as 'fast' or 'very fast'.
- When asked about ongoing support, 59% said they found it 'very easy' or 'easy' to access ongoing support post-diagnosis or assessment.

Learning disabilities and autism

Unfortunately the findings from the surveys and focus groups presented a less positive picture to that reported of cancer services. Some of the themes emerging were as follows:

- Diagnosis is not always followed by support and support for carers needs to be improved.
- The length of time taken to get a diagnosis impacts on both the individual and those caring for them.
- There is a lack of joined-up services for people with multiple conditions. Having more than one condition was considered to make things harder and could mean people missed out on care.
- Changes to benefits are impacting on individuals and carers abilities to access services. Increased stress and difficulties accessing the system is exacerbated by the increase in one-off and cyclical assessments, and the short periods support is available for.
- Workforce issues including lack of available staff, poor information sharing, handover and silo working by services make accessing and using care services difficult and at times led to failures in care provision. Appropriately trained staff were not always available.
- Difficulties in getting adequate support were common with a lack of support highlighted in mainstream education. Two people mentioned children being unlawfully excluded due to their autism. Positive experiences were reported of specialist providers.



Key findings - Engaging people in health service delivery

This short section collates feedback received through focus group discussions regarding how people would like to be involved and engaged in the delivery of health services in the future.

What people expect during their treatment journey

 Feedback should be asked for on a regular basis and as a minimum at the end of a piece of support/ discharge from a service. Respondents highlighted that this didn't happen regularly.

What people expect during service change and transformation

- Service users and carers need to be involved from the beginning before the "first draft" so that their involvement can be meaningful.
- Co-design was seen as the gold standard with change starting from what users need rather than what the service thinks they need.
- Reasonable adjustments shouldn't come after they shouldn't be needed as they should have been built in from the start through co-design.
- Services need to use the feedback, reports and insight already provided. Checking back on what has come before. It was felt that the same questions and ideas are put forward in cycles with many of the solutions already having been identified by previous engagement and consultation.

What will happen next?

Feedback from this project has been shared with Healthier Together, the local sustainability and transformation partnership, in order to help them to develop a Five Year System Plan. This will be coupled with feedback from insights from the Healthier Together Panel - a representative sample of 1,000 people from across the BNSSG area who are invited to take part in surveys, and feedback from staff who work across the 13 health and care organisations that make up the Healthier Together partnership.

Healthier Together will carry out a second phase of more detailed public engagement, including a public survey, further conversations with staff and in-depth conversations with the public and key stakeholder groups on particular topics.

Acknowledgements

We would like to thank colleagues within local health and social care organisations across BNSSG for their help in promoting the project to local residents.

We would like to thank the voluntary, community and social enterprise sector across BNSSG for helping to share and promote this project to their clients and service users.

We would like to thank the residents who took the time to complete the surveys and attend focus groups for sharing their views, experiences and being so willing to talk to us.