healthwatch

NHS Long Term Plan

Sussex (incl. E Surrey)

Brighton & Hove, West Sussex and East Sussex

Executive summary

What would you do – a review of what local people told Healthwatch across three areas about their views on the NHS Long Term Plan?

The findings in this report have been drawn from responses to a country wide survey commissioned by Healthwatch England to stimulate public feedback on the NHS Long Term Plan.

It analyses local views gathered in Brighton and Hove, East Sussex, West Sussex and a small contribution from East Surrey residents (not statistical data) that reflects public opinion on priorities for the future of the NHS in Sussex; known as the Sussex & East Surrey Partnership Sustainability & Transformation Partnership (STP).

A total of **648** responses were received across the three local Healthwatch areas on what matters most to people about their care and support needs and perceptions that would help them to:

- Manage their support
- Live a healthy life
- The choice of support and their independence; and
- Their interactions with the NHS

Most people spoke about their individual experiences for NHS care and support, those people identifying as having a specific condition and answering for themselves were slightly lower. Those conditions most commonly declared were from people with:

- Long-term conditions
- Mental health; and
- Cancer diagnosis

What people said:

Consistent themes include:

- People's experiences accessing cancer services gave overwhelmingly positive responses
- People's awareness of diet and exercise in leading a healthy life and the need to for individuals to take more responsibility of their own health
- People spoke about a 'more holistic approach' to care and good examples were given highlighting the need and desire for more personalised care going forward; and
- People sharing views on mental health support received most of the negative responses

Themes around current views on the NHS included:

- Availability and timeliness of appointments
- Being able to see any medically appropriate health professional, whilst recognising the need for continuity of care
- More joined up understanding between physical and mental health; and
- Communication, Communication, Communication with patients, staff and organisations

> 'They addressed the medical symptoms only; they did not address any lifestyle changes I could make to improve my future outcomes'

The report also includes summaries of Focus Group activity with specific groups of people across the area i.e. young adults with learning disabilities (East Surrey) and people with experiences using mental health services (Sussex).

The need for preventative early intervention support was strongly communicated along with:

- Gaps in service area from primary mental health support to crisis support
- Parents of young adults with learning disabilities spoke in terms of 'fights' and 'battles'
- Referring into young people's mental health services remains a challenge; and
- The need for a trusting and respectful relationship between patients and mental health professionals

The views and experiences of older people are reflected in all the sections of the survey findings, together with the perceptions, where captured, of how the NHS should respond to the increasing elderly population of the area.

The statistical data and commentary included in this review provides valuable insight for decisions makers and should be referenced in the NHS plans for Sussex and East Surrey when they are published.

Background

NHS England and Healthwatch England commissioned local Healthwatch across the country to stimulate public feedback on the NHS Long Term Plan, published in January 2019. In Sussex, the national questionnaire was completed by residents from across Sussex and a variety of focus groups organised between February and May 2019.

This report covers the Sussex and East Surrey STP area, although only statistical feedback from Sussex is included. During the early stages of this process it was found that national survey respondents can only be identified by their county, so all East Surrey respondents for the Healthwatch surveys have been counted in the Surrey Heartlands STP area.

Some targeted focus group activity took place in East Surrey and it is likely that the East Surrey district will become part of the Surrey Heartlands STP later in 2019. The findings from this piece of work are shown in Appendix 1 on page 28 for information.

Purpose

The purpose of Sussex wide public engagement on the NHS Long Term Plan was to access local views on their priorities for the NHS going forwards.

Objectives

Our objectives are to produce a report that reflects public opinion on priorities for the future of the NHS in Sussex. We aimed to reach people in all parts of the STP area in both urban and rural areas. We also drilled down into the views of harder to reach groups through our focus group activity and by promoting engagement at various local events.

Our research plan contained the following components:

- Piggy-backing a wide variety of local and sub-regional events where we discussed the LTP, our engagement work and promoted the national surveys
- One south east regional Healthwatch event with senior system leaders from our STP and the Chair of Healthwatch England
- Organising a range of focus group activity with target groups
- Publicising the national survey on our Healthwatch websites and social media, including communications work with partners and external publications

- Publicising with partners at multi-agency meetings
- Local radio advertising
- Regular contact between local Healthwatch in the STP area to co-ordinate activity
- Regular contact with our STP Comms and Engagement lead to co-ordinate with engagement on our emerging STP Plan

Strategic context

The STP has been carrying out a period of significant public engagement around the NHS Long-Term Plan to help inform the development of the local health and care strategy that is due to be published by the autumn 2019. This engagement started in February and, up to April, almost 1,000 people gave feedback around the priorities of the NHS Long-Term Plan and the opportunities for change and challenges across the system.

From the engagement so far:

- 95% of respondents had a better understanding of the NHS Long-term plan and what it is trying to achieve.
- 95% of respondents had a better understanding of the challenges facing the NHS and need for change.
- 81% felt that they were able to contribute and get involved in discussions.

The demographic profile of the engagement so far has been:

- 79% of responders described their ethnicity as English / Welsh / Scottish / Northern Irish / British.
- 73% of responders were female, and 25% of responders were male.
- 100% of responders identified their sex as the one assigned at birth.
- 6% of responders described their sexual orientation as Lesbian/Gay Woman, and 2% of responders described their sexual orientation as Gay Man.
- 26% of responders had a health problem or disability.
- 46% of responders were Christian.

The insight provided in this report will feed into, support and be considered in parallel with the wider STP engagement work.

Summary of Findings:

What matters most to people in East Sussex, West Sussex and Brighton and Hove

Healthwatch East Sussex has coordinated the review of responses received from across the three local Healthwatch areas in Sussex and has analysed all the information from the national survey on the NHS Long Term Plan, as supplied by Healthwatch England.

Respondents were also asked to give some anonymous equality monitoring information to enable Healthwatch to see if a specific issue or issues affected demographics of people. The populations for each of the local Healthwatch areas was as follows (rounded):

	Healthwatch East Sussex	Healthwatch West Sussex	Healthwatch Brighton and Hove	Total
Population (rounded nearest '000)	552,000	852,000	288,000	**1,692,000**

East and West Sussex are similar in profile, with coastal populous areas of towns, mixed with large areas of countryside and more rural areas of habitation. Brighton and Hove is a densely populated mainly urban populous, and has closer communities sprawling from the main city areas.

Both East and West Sussex are seeing increases in population sizes of those aged 65+, while Brighton is seeing its biggest increase in those considered to be of 'working age'.

All three localities see White British as the ethnicity reported to be the highest, with 81% declaring this in Brighton and Hove, 89% in West Sussex and 92% in East Sussex.

The next section highlights who responded to the Healthwatch Surveys in more detail.

The questions asked respondents to tell local Healthwatch about their care and support needs and perceptions that would help them to:

- Manage their support
- Live a healthy life
- The choice of support and their independence and;
- Their interactions with the NHS.

Comments could also be left should someone wish to raise or highlight additional issues, and these are reflected in this report after the main findings.

Response rates for the two surveys for a) people's general experiences of their health and care services and b) for more specific conditions were as follows;

	Healthwatch East Sussex	Healthwatch West Sussex	Healthwatch Brighton and Hove	Total
General Survey	255	176	70	**501**
Specific Conditions	61	68	18	**147**
Total	**316**	**244**	**88**	**648**

Who did we speak to?

76% overall respondents to the general survey were female. 3% of respondents in Brighton gave ‘Other’ as their gender.

80% of respondents to the specific conditions survey were female. 5% of respondents in Brighton gave ‘Other’ as their gender.

22% of people responding to the general survey declared a disability.

Cancer, long term conditions and Mental health were the most declared conditions for the specific conditions survey.

Mental health respondents were equally represented across all age groups and featured consistently across all three Healthwatch areas.

Cancer was most prevalent in the West Sussex as declared. Long term conditions were also higher as responses in both East and West Sussex.

92% of respondents to the general survey declared that they were ‘White British’. Brighton showed the highest levels of diversity, with 21% of their respondents declaring other ethnicities.

‘White British’ was also the most commonly given ethnicity with 92% declaring this overall. 4% of respondents declared ‘Other’ or another non-white background overall.

38% of respondents to the general survey were 65+ with East Sussex having the highest rates in this age bracket.

30% of respondents to the specific conditions survey were 65+. The highest single age group for this survey were 55-64, with 29%.

18% of respondents to the general survey said they were a carer.

Respondents who said that they were a carer in the specific conditions survey were higher, than the general survey, with 27% indicating that they fulfilled some kind of caring responsibility.

88% of respondents to the general survey declared that they were heterosexual. Brighton showed the highest levels of diversity with 22% responding with different preferences.

76% of people responding to the specific conditions survey declared themselves as heterosexual.

Overwhelmingly, respondents told local Healthwatch about their individual experiences for general NHS care and support, with **96% (473 people)** declaring 'Yourself' when asked who they were responding to the survey for.

Numbers of people identifying as having a specific condition and answering for themselves was slightly lower at **76% (124 people)** overall. Where respondents said that they were answering for someone else, most identified as living in East or West Sussex **23%** (**33 people**), with **4** living in Brighton and Hove. **1** person did not answer this question.

The specific conditions survey identified those declaring as having a long-term condition, Mental Health and Cancer diagnosis most commonly where respondents wished to give their experiences.

Sussex & East Surrey STP area demographic headlines

Population of 1.8 million people

Annual healthcare budget of £2.7bn

Children and young people:

- We have more children and young people smoking at the age of 15 than the national average – Brighton and Hove is double the national average with 15%.
- 15% of our year six pupils are obese and there are higher rates in deprived areas.
- We have higher rates of hospital admissions for self-harm of children and young people aged 10-24 compared with rest of England, particularly in Brighton and Hove and Hastings.

Adults

- We have 250,000 smokers on GP registers, with high rates in Brighton and Hove and Hastings.
- We have over 155,000 adults with depression on GP registers, which is 10% of patients.
- Physical activity rates vary across the area, with 78% in Brighton and Hove and 27% in Eastbourne.

Older people

- We have over 18,000 people on the dementia register and many more are not diagnosed.
- We have over 183,000 carers, with 15,000 carers aged 65 and over.
- We have over 110,000 older people who live alone.

Mental health

- Severe mental health is 5% higher than the national average, which is around 25,000 people, and we have 25% higher rates than the national average for people with dementia.

Large numbers of older people live in the STP area compared to other parts of the country, where dementia prevalence is 25% higher than nationally. Improvements needed to mental health services are recognised as a key priority for the STP, severe mental illness is 5% higher than nationally in Sussex and East Surrey. Our STP recognises Cancer as the number one priority disease.

What did they tell Healthwatch?

Ranked Questions – General Survey Responses

Respondents were able to rank their answers in response to some areas of the surveys and pick one theme which they felt was the most important to them in the future.

Unsurprisingly, respondents to the general survey when asked to rank how important it was to them in each of the area for questions within the four topic areas, there was an overwhelming response that it was either ‘Very Important’ or ‘Important’ to have the choices presented to them, in most instances this a response rate of over **80%** across all the local Healthwatch areas.

Other responses were mainly given as ‘Neutral’ to some questions, indicating that this may not be an issue directly impacting upon a respondent at the time of completion.

Commentary

Respondents could also leave comments after each section of the survey, to provide some further views and information, should they wish to do so. Shown below are the main themes emerging from these comments in each of the four topic areas for the survey.

Healthy Living - what would you change?

Many comments received indicated an awareness of the ***importance of access to information and support to help a person maintain a healthy life***. These included references to:

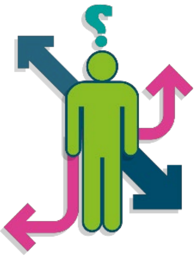
- Better information about nutrition and healthy eating
- Access to exercise and facilities where people could go to exercise on a regular basis
- More holistic therapies being made available – such as Tai Chi
- Prescribing medication should not always be the first thing a health professional should turn to when supporting an individual to maintain a healthy lifestyle
- Other types of support being made available through other pathways, not just GPs

> “more specific information on healthy eating, across all age ranges, importance of maintaining a healthy weight and physical activity”

People also commented on a need for better coordination between health professionals and health providers within the health system, including better access to GP services and longer opening times surgeries, as well as shorter waiting times for assessment and diagnosis.

> “For my body to be considered as a whole, rather than 'dissecting' it into parts i.e., prevention and treating the whole unified person by one team not lots of different fragmented ones”

Choice of Support - what would you change?



> “I recognise there is a balance between what I want/think is best for me and what health professionals with their expert opinion believe is best for me, so I do not believe that patients should always have the final say: we need to be able to trust and rely on the advice being given to us so it's

> essential that the range of options is made clear and that often isn't the case currently"

Responses from across the three local Healthwatch areas were again consistent, where comments were made on this part of the survey. Respondents talked about the need for a ***more holistic, joined up service that works for them***, with easy access to information and support that would provide them with the confidence that the choices they made, or the choices made for them, were appropriate and helped them remain as independent as possible.

References were also made in this area for professionals to share information where necessary, to prevent delay and provide better and more coordinated pathways within health and care, with appropriate methods of communication with individuals also being referenced.

> "Shared communications between different NHS elements - primary care, acute, hospitals, nursing. Experience of having to repeat information numerous times and notes/test results not being shared between them or appointment conflicts as they don't share information"

Feeling listened to by health and care professionals, to enable a person to feel part of the process, as well as access to local services in a timely way – with less waiting times – all emerged as themes as well, indicating a desire for respondents to feel part of a 'person centred' approach to their support.

Remaining Independent – what would you change?

Respondents commented on the need to maintain or increase levels of support to enable a person to remain as independent as possible. Comments included the need for ***more and better trained care and support staff***, ***easier access to residential care or home adaptations***, including funding, and appropriate and dignified choice for end of life care

> "To live an independent life with the support of family and the community if possible. However, if I am unable to maintain my independence I would like to be kept informed at all times about my care"

There was a clear acknowledgement of the strain the care sector is under, especially in staff levels and funding, with references also made to the need for a clearly defined pathway between health and care sectors. Community assets such as District and Community Nursing and Health Visitors were referenced as being important to ensuring some could maintain a level of independence within their own homes.

Linked to healthy living there were continuing references to the importance of maintaining a healthy lifestyle and the positive effects this would have in maintaining independence.

> "Better information on healthy eating in older age and the benefits of maintaining a healthy weight as you grow older"

Interaction with the NHS – what would you change?

Availability and timeliness of appointments were commented upon frequently in this section. With communication, access to information – including individual medical records – and joined up systems to ensure that a person's records are accessible between providers all featuring prominently.

Respondents want to feel in control of their interactions and how their information is used as part of this. They want to feel confident that their information is being used appropriately. Some felt that the move to less formal interactions, for example call centres and automated systems, left them feeling less valued as a person.

> "I do not understand why hospitals cannot access your doctor's records of you. This is ridiculous. We should all have one health record that anyone in the NHS can access"

Access was also mentioned in commentary. This included physical access to local services being needed or more local services being provided. It also includes appropriate language being needed to allow people to understand their diagnosis and better access to GP appointments, including out of hours access.

Underlying these findings are some comments on the recognition that integration or digitisation of systems was not universally adopted. This may lead to some of the issues for communication and holistic provision of services that have been highlighted previously. Conversely, some people welcomed innovations such as Skype appointments.

> "It would be helpful to be able to Skype or face time appointments which are really not necessary to be in the room with my epilepsy nurse. Sometimes these are just reviews - and travelling all the way to Hove poly clinic is a pain and it would be more suitable to face time"

A common theme was the lack of available GP's impacting upon many aspects of a person's interaction with the NHS, meaning lack of confidence and trust in some cases where continuity of contact is not readily available.

Tell us what is important

People were also asked to pick one statement from the preceding ranked question set which they felt was the most important to them at the end of the survey. Results from these questions follow.

Access to the help and treatment that a person needed when a person wanted it

53% (253 people) stated this as a preference. This was a common response across all the local Healthwatch areas.

Choosing the right treatment that was a joint decision between the person and the health and care professional

The highest response, both overall and across all the local Healthwatch with **48% (230 people)** who responded overall stating this as a preference.

Be able to stay in their own homes for as long as possible

55% (259 people) answering overall chose this response. Again, this was consistent across all local Healthwatch.

Being able to talk to a doctor or health care professional wherever someone is

This was the single highest, with **33% (153 people)** overall choosing this statement. This was the same for all local Healthwatch. Nearly all the other statements had a **10% to 18%** response rate between them, indicating a ***wide range of feeling about how people wanted to interact with the NHS*** in their lives.

Living with a specific condition (or conditions)

People living with a specific condition or multiple instances of conditions were asked to tell local Healthwatch about their experiences in the following areas;

- Diagnosis, assessment and treatment
- Provision of ongoing support
- Travel to and from support
- Expectations of care

The survey asked about a range of conditions, including mental health, cancer, learning disability and long-term conditions, such as diabetes/arthritis. Respondents were asked to complete the survey with a view of their experiences of one of these conditions (even if they suffer from more than one). A total of **165** responses were given to this survey across the three local Healthwatch areas.

Shown below is a table indicating the levels of response for each condition identified by their local Healthwatch.

	Healthwatch East Sussex	Healthwatch West Sussex	Healthwatch Brighton and Hove	Total
Autism	3	8	--	**11**
Cancer	6	19	--	**25**
Dementia	4	2	--	**6**
Heart and lung diseases	10	6	3	**19**
Learning disability	6	2	--	**8**
Long-term condition e.g. diabetes, arthritis	20	24	3	**47**
Mental health	17	19	13	**49**
Grand Total	**66**	**80**	**19**	**165**

Those with long term conditions featured prominently in East and West Sussex, while people wanting to talk about their experiences of cancer treatment were high in West Sussex. East Sussex had the highest response rates for those indicating heart and lung disease as a condition.

Respondents indicating that they were suffering with a mental health condition were consistently reflected in the three local Healthwatch areas and were the highest representation for respondent in Brighton and Hove.

58% (83 people) indicated that they had lived with their condition for longer than three years.

> "It started 25+ years ago and was very available and useful. Over the years it has stopped for a while and then become very hard to access, there is a definite worrying lack of REGULAR psychiatric help with NO CONSISTENCY"

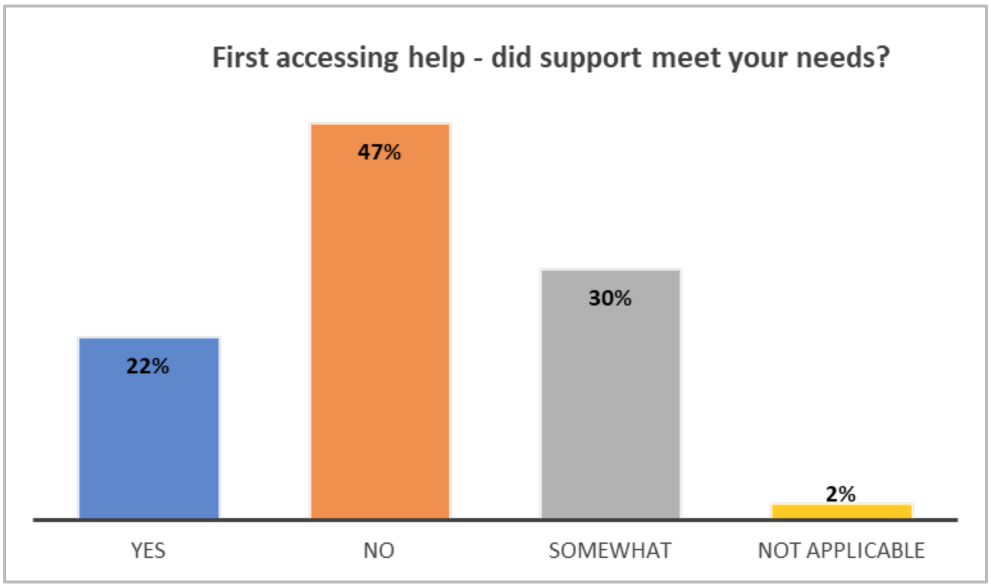
In East Sussex at least 6 responses were received from young people who identified as having a learning disability and completed Easy Read versions of this survey.

Assessment, diagnosis and treatment

Respondents were asked to tell us about their experiences of accessing help and support and, if having more than one condition, whether they felt this impacted on them positively or negatively.

Their experiences of initial assessment and diagnosis were also sought including the waiting time between assessment and diagnosis and onward referral.

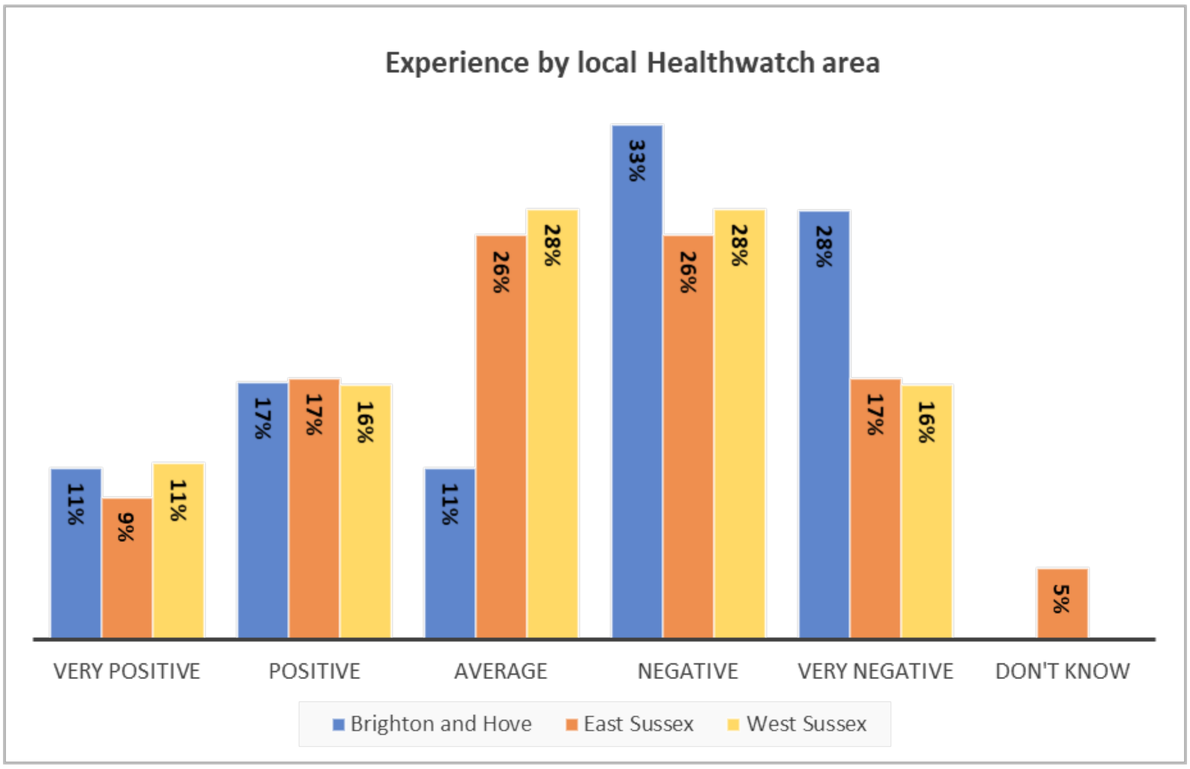
Overall responses indicated that when they first tried to access help, their experiences of whether the support available met their needs were mixed. **47% (76 people)** who responded said that this was not the case, with a further **30% (48 people)** said that their needs were 'somewhat' met.



People who identified as having support for cancer were the most positive in this area, with **58% (14 people)** who identified as having this condition and responding to the question saying the support did meet their needs. Where Mental Health was identified as the condition, respondents indicated the lowest levels of positive support, with **57% (28 people)** saying that their needs were not met.

> "A more holistic approach would have been much better for me - I suffer from diverticulitis and have had to manage it myself. This has had an impact on my mental health"

Respondents were mixed in their views of their overall experience of getting help for their condition, with **46% (74 people)** expressing negative answers and a further **25% (41 people)** saying that their overall experience was 'average'. Again, people's experiences of cancer support were the highest, with **67% (16 people)** who responded saying their experiences were positive. Shown below is a breakdown by local Healthwatch responses.



People who identified as having a Learning Disability described their experiences as 'average' at best and where Autism was given, most people felt negatively towards their experiences. It should be noted that the number of respondents for both condition types was low – under 10 for both categories.

> "Autism in girls and women is under diagnosed and missed. There needs to be greater awareness amongst NHS professionals and more psychologists and psychiatrists available to diagnose and provide support"

People were asked to tell local Healthwatch if they had more than one diagnosed condition and whether they felt that this impacted on their experiences of seeking support for more than one condition at a time. **52% (85 people)** indicated that they did not have any other condition than the one disclosed at the time of completion.

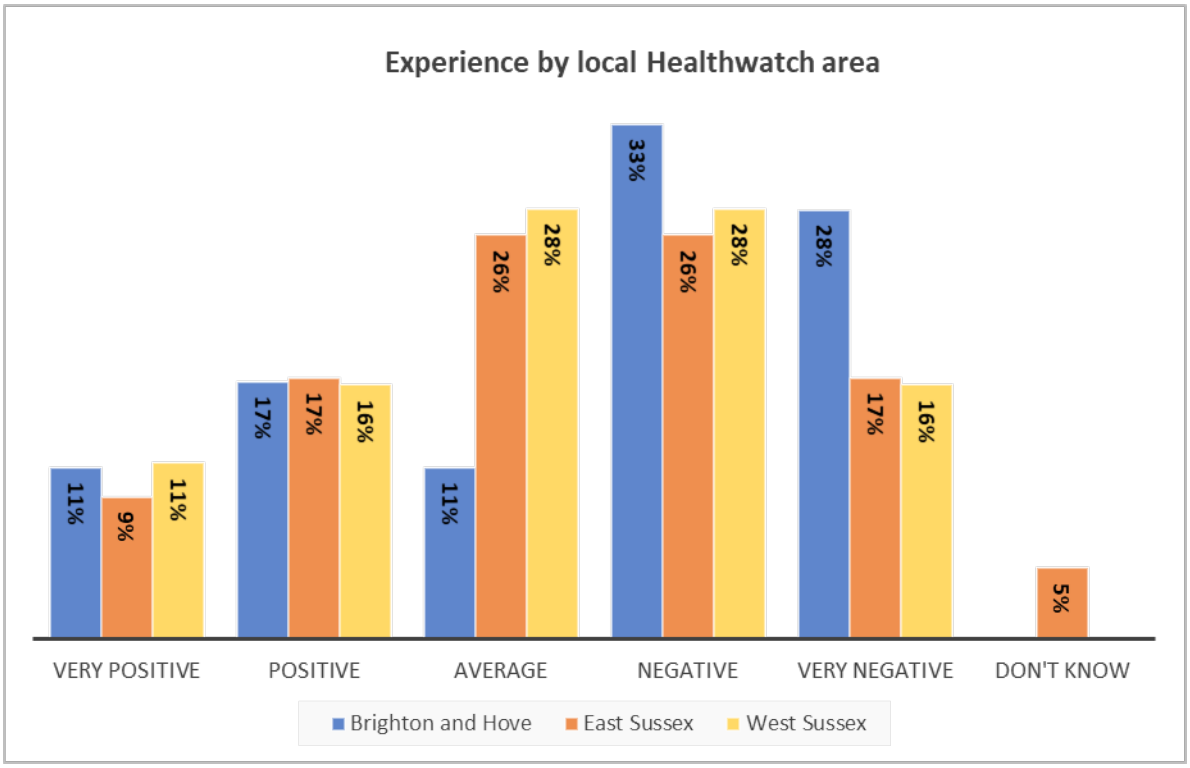
Of the people who said that they did have another condition **55% (42 people)** responded that having more than one condition made their experience of seeking support harder. **27% (21 people)** said it made no difference.

People identifying with a mental health condition experienced further difficulty if having more than one condition with **63% (15 people)** said they found it harder to access the right support. Others who indicated a long-term condition also said that they found it harder, with **58% (15 people)** responding their experiences were not so good.

The provision of ongoing care and support

People were asked to tell us about their experiences having initially accessed support and an assessment, and after this including how quickly they received a diagnosis and treatment and whether ongoing support met their expectations.

Overall **53% (84 people)** said that their waiting time between initial assessment and diagnosis was 'Very Slow' or 'Slow'. More positively **24% (38 people)** saying that their waiting time was 'Ok' and **19% (29 people)** said they received a diagnosis in a 'fast' timeframe. Shown below is a breakdown by local Healthwatch responses. Brighton and Hove showed the highest levels of dissatisfaction with the timeframe.

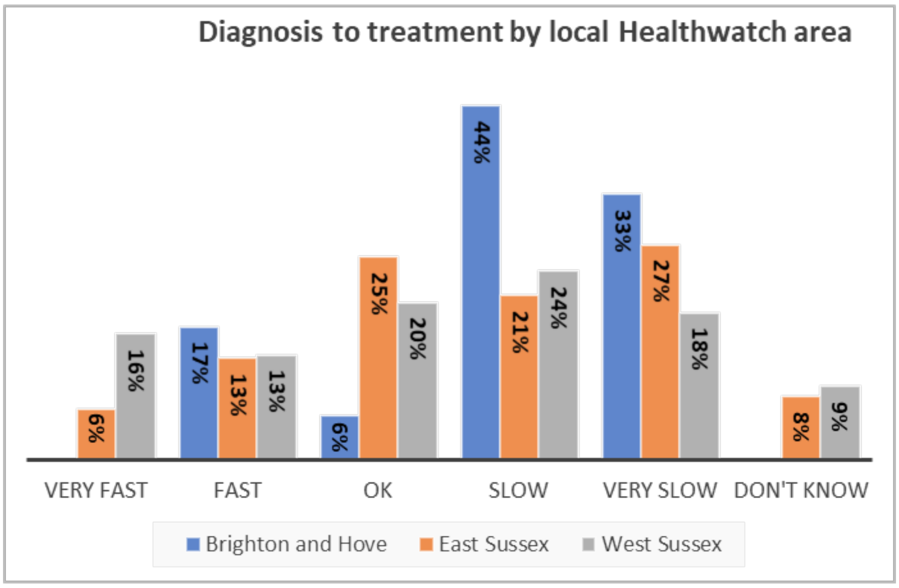


Those who identified as having Cancer were the most satisfied with the speed between initial assessment and diagnosis, with **67% (16 people)** feeling it was fast or better.

Having received an assessment and diagnosis for their specific condition local Healthwatch were keen to find out how long it took to receive treatment or support for their condition.

Overall **43% (69 people)** said the time it took to receive treatment from diagnosis, ranged from 'Ok' to 'Very Fast', with most of these respondents saying it was ok. Again, when responding about a specific condition, people diagnosed with cancer responded the most positively, with **84% (20 people)** answering positively about the time it took to receive support.

The graph overleaf shows the answers by local Healthwatch area.



After diagnosis or assessment overall people were split about being offered further support, with **54% (84 people)** being offered access to further help or care. People were also asked if they were referred to a specialist for their treatment, with **72% (115 people)** saying that they were referred. People who identified with a mental health condition gave the lowest rates of response for referral, with **34% (16 people)** not being referred.

Responses again were mixed with regards to the perceived speed of referral, where people had identified as needing to see a specialist. **55% (62 people)** who responded to this said their referral time was 'Ok' or better.

> "I will have had sciatica for 2 years next month. I waited 18 months before being seen by an orthopaedic consultant at my local MSK centre. I am still waiting to be seen at the neurology unit. I have repeatedly reported pain issues to no avail"

While reviewing the concept of timeliness of referral or assessment, it should be considered that a timeframe and a person's expectations are subject to an individual's conceptions of what a quick service look like.

> "I had to wait some months for a consultant appointment but i believe this has improved in the last few years"

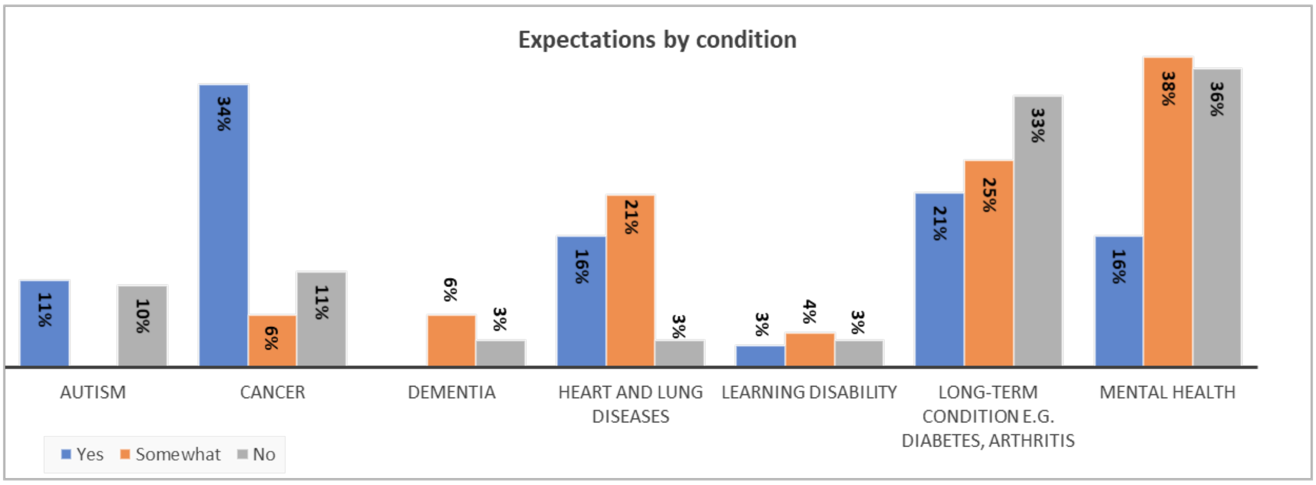
If needed, local Healthwatch asked people if they found it easy to access any ongoing support after their assessment or diagnosis. **39% (55 people)** said they were happy or felt 'ok' about getting access. A further **10% (15 people)** who responded said this did not apply to them individually.

People diagnosed with cancer were happiest with their ability to access further support, while those diagnosed with either a mental health condition or long-term condition responded less positively overall.

Local Healthwatch also asked about a person's perceptions of getting support for their condition in a known timeline and having consistent communications with all the services that they encountered. **52% (79 people)** responded ‘yes’ or ‘somewhat’ to this question. Consistently, people with cancer were the most positive, while those diagnosed with a long-term condition were less positive.

> “They addressed the medical symptoms only, they did not address any life style changes I could make to improve my future outcomes”

When asked about how the support met a person’s expectations, people were mostly positive, with **59% (86 people)** saying that their expectations were met or somewhat met. People treated for mental health and long-term conditions showed the highest levels of satisfaction for their expectations being met.



Travel to and from Support

Most respondents identifying as having a specific condition relied on their own car or getting a lift from another person to get to their appointments. People who identified as having a mental health condition showed the most varied response, with public transport also featuring prominently.

Overwhelmingly, people would be prepared to travel to receive a diagnosis for up to two hours, with a time of 30 minutes to 1 hour being the most prevalent response – this was consistent across the condition types.

A similar trend was also identified for a person to be able to receive specialist treatment or support.

Expectations at different stages of care

People were asked what was most important to them at different stages of their care and the what they felt was the right level of care provided by the NHS to help them stay healthy.

When first seeking help

Being able to see any medically appropriate health professional who was free was the most popular answer for people when looking for help at the very first stages of their journey. This was reflected as the most popular choice across all the identified conditions.

Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
27% (40 people)	**59%** (86 people)	**14%** (20 people)

When you first received a diagnosis and explanation of treatment and support options

During the stage of first diagnosis and treatment explanation people also said it was most important to them to see any medically appropriate health professional, however the responses to seeing the health professional you may normally have – but you may have to wait – were closer than in the previous stage. This too was reflected as a trend across the identified conditions.

Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
37% (53 people)	**52%** (69 people)	**11%** (16 people)

During your initial treatment or support

Like the previous stage, people were happy to see any medically appropriate professional for quicker treatment, however this was closely followed by those happy to wait for a regular professional if they had to wait.

Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
40% (57 people)	**49%** (69 people)	**11%** (15 people)

During your long-term support

In contrast to the previous stages, overall people felt it was more important to them to have a continuity of contact with a health professional, should they need long term support, while having access to an appropriate professional who was free was less so.

Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
58% (83 people)	**33%** (48 people)	**9%** (13 people)

Supporting you to have more control over your own care

Finally, people were asked to express how much support they felt the NHS should give them to stay healthy or manage the condition they have. Over half of respondents, felt that the NHS should offer ‘some’ support, with other respondents feeling that the NHS should offer ‘a lot’ of support. This was reflected consistently across the conditions identified.

A lot of support	Some support	I don’t need support	Don’t know
25% (40 people)	**56%** (89 people)	**11%** (18 people)	**8%** (12 people)

Intentionally Blank

What could the NHS do to help you stay health and manage the conditions you have?

Access to appropriate exercise and healthy eating programmes featured in the comments left and respondents identified this as potentially an important way to help them manage their condition. Also, some mentioned regular health checks as being a positive way of managing conditions.

Information and communication also featured as themes from respondents, with the availability of accurate and appropriate information leading to cost-effective treatments being more readily available. Respondents also commented on the need to be listened to as a patient, as in some cases they felt that they understood their own condition better than a professional had done.

> "Communication, Communication, Communication - right support, right time, right place, right person and venue. I am an individual and need to be treated as such"

Some specific mentions were made about improving access to mental health support services and the use of medication to manage mental health conditions sometimes not being in the best interest of the patient.

> "If I could change one thing about the way the NHS is run, it would be to join up the understanding between physical and mental health. GP's seem blind to how physical mental health must be treated together, as they each compensate in sympathy. The laziness of psychiatrist prescribing of drugs, rather than doing the work of addressing psychological issues, offer the most offensive example of this ignorance"

Some references were made about seeing the patient 'as a whole' and helping support them to manage their immediate condition but provide a more holistic support service if appropriate.

Engaging people in health service delivery

Focus Group feedback

Summary of Findings for people living with poor or enduring mental health conditions in West Sussex:

What matters most to these people?

- Having **safe areas** in the community to help people to stay well and connected. These are safe because they provide non-judgmental relationships and an atmosphere of support and light-heartedness.
- Trusting that **access to services** (including General Practice), with trained/empathic professionals is available promptly when needed.
- Having **information** about support services at your finger-tips.
- Support to understand and **manage medication** is vital for long-term wellness.
- Getting a **diagnosis** for some was, they felt, something that could help them to move forward with their lives (but was missing).

What works well?

- Being able to self-refer to Time to Talk and having this provided free to people is particularly important in low-income areas such as Bognor.

Having community places that provide safe spaces, where others can help and support you to stay positive or help you when you can't do this. Key is such spaces don't make you feel judged or stigmatised for your mental health.

What could be better?

Workplaces need to acknowledge mental health and provide support. Royal Mail was given as an example where there is support, as they now have *Mental Health Peer Supporters*.

- The hours services are available do not match when people need them.
- Doctors need to deal with the causes and not just symptoms. More training is needed to enable general practice to support people in non-medicated ways.
- Have more preventative/earlier intervention support. The lack of psychiatrists within the community has meant people are only getting support if they are likely to be hospitalised or harm others. People in both areas have been told this, which has created mistrust and a loss of faith in mental health services.
- Labelling everyone as having the same traits, when they live with a specific mental health condition, is unhelpful. Reducing the need for form filling, especially benefits forms and mental health questionnaires, is important – people find this stressful.
- Access to information about services. People at the focus groups were not aware of Pathfinder or West Sussex Connect to Support. People felt this was not so much about creating a single front door but ensuring the right people within the community know the information.

Summary of Findings for people living with poor or enduring mental health conditions in East Sussex:

In East Sussex, Healthwatch co delivered three focus group activities alongside People in Partnership. People in Partnership (East Sussex) support individuals with mental health challenges, their families and carers to have the opportunity to shape the experience and quality of mental health support and provision in the area.

Mental Health focus was chosen because it is a frequently identified local priority (within East Sussex) and more recently by the Sustainability and Transformation Partnership (STP) activity which is running concurrently with local Healthwatch. Also, East Sussex has a significantly higher suicide rate than the England average, which has been the case for a few years.

The focus groups were held in different locations, Hastings, Eastbourne and Hailsham. A total of 18 individuals attended and looked at the same specific conditions, mental health pathway as part of the 'What would you do' discussions.

Each group looked at different aspects of the pathways to accessing mental health treatment and support including:

- via GP's (primary care)
- using Emergency Departments (A&E) and other out of hours mental services
- Waiting times to treatment
- Treatment and support options
- Young people accessing CAMHs; and
- Lack of access to good quality Post-traumatic Stress Disorder (PTSD) support

One group spoke specifically around issues for young men / adult males accessing mental health support and the need to make services easier for men to access.

Key themes across all discussions include:

- NHS staff do the best they can with the resources they have, there are good examples out there to learn from.
- Little or no communication whilst waiting for treatment
- Voluntary and Community Sector groups picking up services Statutory sector no longer provide; and
- Support at primary care level – Health in Mind (HiM) through to crisis support; big, unfilled gap in between

> "Some patients too ill for HiM but not severe enough for Assessment & Treatment Service (ATS)"

Varying experiences using the GP pathway:

People told us that:

> "some GP's are very knowledgeable, empathetic and supportive, others not so"

Of those better experiences, several described their experience as *'excellent'* another went on to say,

> *"GP in my practice is amazing"*

However, all added;

> *"when you can get passed the receptionist"*

Accessing support through Emergency Departments

This again generated mixed responses, one example included an individual at Beachy Head, was 'talked down', transferred by ambulance to A&E, once in A &E specialist staff shortages resulted in the individual being discharged in the early hours of the morning with no treatment or intervention.

When asked about the good examples, some spoke about Crisis Lounges in hospital A & E department appearing to work well, Idea expressed included, could they work well only in hospital or also in the community? e.g. Staying well service in Hastings is like 'Crisis Lounge'.

Accessing interim support out of hours using the mental health line also received mixed, mainly negative responses, including:

> *"not always available"*
>
> *"only have 20 mins to talk"*
>
> *"left on hold for approx. 15 minutes with unhelpful auto recorded messages, adding to low mood and rising anxiety levels; and not always answered between 23.00 and 01.00 hours"*

Waiting times to treatment

One individual provided an example detailing what is not currently working well:

> *"From Beachy Head to consultation [with psychiatrist], 7 months wait with nothing in between"*

The current pathway is: Beachy Head Chaplaincy > Police > Street Triage > referral to see specialist. The individual believes that the Chaplaincy service reassure the individual in good faith that they will receive support promptly and are not aware just how long people wait for consultation with a specialist.

They added:

> “NHS has a duty / responsibility to provide timely support. It is not for the Voluntary and Community Sector (VCS) to plug gaps in the service by providing such essential support. VCS seem better at keeping their service users updated than statutory services i.e. with statutory services there is a big silence between contacts/while waiting”

Therefore, the patient wonders ‘why the long wait?’ /Have I been lost/dropped off the list?’ / ‘what are my options?’

Treatment and support

Mostly people waited up to 12 weeks – could be longer with some noting:

- Don’t receive any updates on where you in the ‘queue’ or how much longer you will have to wait
- If you try and make contact to find out, often the local number you are given just ‘rings out’ and then cuts off after 21 rings…
- No opportunity to leave voicemail, makes people very frustrated…

Young people’s views of accessing CAMHs services

Those young adults attending the session described their experiences of accessing CAMHs services mostly as poor. They listed the following factors:

- Not being listened to…
- Not medicated when need to be (in their view)
- Better consistency of care packages needed; and
- Better communication between clinicians and young people.

> ‘still away to go in young people’s services – referring into services still a challenge’

The lack of access to support and understanding around PTSD was raised. People said greater awareness of the issue especially around complex PTSD is needed amongst NHS staff as complex PTSD occurs over a much longer period. Several individuals felt more training amongst staff is required to be able to support people appropriately and sensitively.

People also had the opportunity to contribute to the activity other than attending focus groups, one individual shared their views via email:

> “I do feel very much on my own at the moment with all this and feel that my wishes are being disregarded which is making me feel so very low and anxious. I've lived with my illness for 23 years and therefore know what it is I am seeking and this is just not happening. The feeling have is that I am being 'punished' for having a mental health illness rather than a physical

> illness and that too many threats have been waved around which is definitely not conducive to a trusting and respectful therapeutic relationship. Ultimately I am of sound mind and wish for my thoughts and feelings to be respected even if it is against medical advice...”

They went on to say:

> “... I really want to get back my confidence and strength after being crushed and pained from my treatment from this team which has never been helpful and in fact the most damaging thing I face here since my move to Eastbourne last year. I really really hope you can help me. I am rational and have capacity to make clear and thought out decisions taking into the potential risks involved but know how they have treated me has been unsupportive and really really unhelpful. It has made things worse and I want to get my life back on track which I would like support to help me talk with them so they really listen to me and my decision respected as someone who has capacity over my treatment”

What people expect during their treatment journey

Consistent themes include:

- People's experiences accessing cancer services gave overwhelmingly positive responses
- People's awareness of diet and exercise in leading a healthy life and the need to for individuals to take more responsibility of their own health
- People spoke about a 'more holistic approach' working to care and good examples were given highlighting the need and desire for more personalised care going forward; and
- People sharing views on mental health support received most of the negative responses

What people expect during service change and transformation

Themes around current views on the NHS included:

- Availability and timeliness of appointments
- Being able to see any medically appropriate health professional, whilst recognising the need for continuity of care
- More joined up understanding between physical and mental health; and
- Communication, Communication, Communication with patients, staff and organisations

Next steps

Statement from STP/ how we will use the insight gathered to inform local work

The STP Executive have expressed their thanks and appreciation to Healthwatch for the work undertaken to gather the insight within this report. The feedback will be reported to the STP Executive and the STP Clinical and Professional Cabinet in July and will inform the development of the system health and care strategy that is due to be published in the autumn. The report will sit alongside the findings of the engagement work that has been carried out by the NHS across the STP and will act as one of the evidence sources for the actions, recommendations and plans that result from the local strategy.

To ensure there is a clear link between the insight in this report and the development of the strategy, Healthwatch will continue to be involved in the STP Strategy Steering Group and will be asked to provide comment in the final recommendations of the strategy before publication.

In addition to informing the strategy, the feedback in this report will feed into existing work across the STP to ensure 'business as usual' better reflects the needs of our local populations. To achieve this, the report will be shared with all system partners and considered within the development of local strategies and the planning process for 2020-21.

Methodology

The Healthwatch England surveys were available in a variety of formats, to enable as wide a range of participants as possible to be able to give their views. The surveys were designed nationally, by Healthwatch England and disseminated to all local Healthwatch in a variety of formats including:

- Online via the Healthwatch England Website
- Paper based versions – including easy read

All surveys were completed anonymously, and consent sought as per GDPR guidelines and all data is held by Healthwatch England. Local information was filtered by the relevant STP area by Healthwatch England and made available for analysis locally, to give the statistics in this report.

Local Healthwatch were free to promote the surveys and engagement activities within their localities as part of their normal feedback gathering mechanisms.

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- All survey respondents
- All focus group participants
- All Healthwatch staff and the volunteers who spoke to the public
- All the local event organisers and participants who we were able to engage with
- Local CCGs and their staff
- Local authorities and their staff
- The Sussex and Surrey STP
- Healthwatch England
- All other partners who helped us deliver our activity

Contact Details

For any further information about this report, please contact us using one of the following methods:

Call: 0333 101 4007
Email: Enquiries@healthwatcheastsussex.co.uk

Appendix 1

East Surrey activity

Engagement activities included a discussion group with young adults (18-25) with Learning Disabilities and in-depth interviews with five parents of children with SEND. We heard two key messages during these conversations:

having a child with SEND / Learning Disabilities should be less of a battle
people involved in care delivery need to do more to support transitions from ‘childhood’ to ‘adulthood’.

Examples of effective support

We heard how there are many people ‘working wonders’ to ensure that young lives are as fulfilling as possible.

“The next step is The Grange. It’s just lovely and very impressive. They have cooking facilities and a shop there where she can work so that’s a long-term objective.”

“The Grange take them in and make them useful in life - they make them live. They don’t just stick them in front of the telly - they make them work and study. It’s the same with Orpheus. If you want to see a college doing something right, go and see them. They work really hard and have to put on a lot of performances. And it’s full of people with different abilities all working together. It prepares them for going into a work environment.”

“The only true respite I’ve had in the past few years is St John’s in Leatherhead who go on holiday weeks. They’re marvellous. The kids absolutely love it. They go to the theatre, the seaside, play games. But she’s 19 now so we’re not getting that anymore.”

Parents we spoke to were adept at networking via social media and we heard how mainstream schools undertake much of the day-to-day support of those with moderate needs.

Engaged in a battle

Parents often spoke in terms of ‘fights’ and ‘battles’. One said “you just get worn down by it”, and another that “you have to pick your battles”.

When discussing health and social care services, improvements and specific services were often identified, but just as often was the sheer logistical challenge of supporting a young person with SEND / LD to get to school, college or work, on time, day-after-day.

One recurring theme was that schools sometimes chop-and-change their willingness to accept / keep a young person who has special needs. In some cases, even specialist facilities struggle.

‘If you have a SEND child, you think everything is mapped out for you - but it’s not’

Parents want better co-ordination between the various SEND professionals. Often, they cite very specific examples such as a meeting between case worker and parent, or the need for a school to complete a child’s ‘Communication Book’ daily and not just when something specific happens.

Many of the parents of children with SEND / LD parents, who may be able offer a wealth of experience and advice to others, told us that they were simply exhausted. Inevitably their day-to-day energies focus on their own child/ren. But online forums and networks of such parents are a valued source of support – practical and emotional – and likewise some of the physical support groups such as those which meet at 'Challengers' in Guildford.

Approaching adulthood

We heard how transitions from 'childhood' to 'adulthood' can be particularly difficult.

"There's got to be a smoother transition than falling off the shelf at 18 years old. Access to medical facilities as a child were very good – I can't complain. I think they did a tremendous job – it's just this transition period."

"The problem is that she needs an annual check from the doctor which is right to do so but now she's 18 it means she must go and answer the questions which she can't. Fortunately, I have a brilliant GP who understands us. If she has to run through all the same information again and again she gets bored and begins to play up."

"Unfortunately, we lost the local paediatrician from Epsom who knew us and was great, but now we're into Adult Services which is quite frightening for her – having to go into an adult area rather than a child's area. She's still a child mentally."