

Putting people at the heart of

The Long Term Plan

Informing implementation of the NHS Long Term Plan
across Surrey Heartlands

August 2019

wh  **t**

would you do?

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Background

In January the NHS released their Long Term Plan, a strategy to guide its progression over the next 10 years, using a real terms 3.4% increase in funding from the government. The Long Term Plan sets out areas the NHS will focus on to achieve this, in light of what works well and what needs improvement. These include:

- Helping people to live healthier lives
- Investing more in technology and community services
- Improving the support people need to age well and to have a strong start in life
- Getting better at looking after people with cancer, mental health conditions, lung and heart diseases, dementia, learning disabilities, autism and long-term conditions.

NHS England has asked local NHS areas to set out how they will implement the Long Term Plan.

The independence, networks and expertise of Healthwatch have been called upon by the NHS to influence implementation of these plans. This report supplements the existing Citizen Engagement programme of Surrey Heartlands Health & Care Partnership¹ (Surrey Heartlands).

Purpose

- To explore the views and experiences of people in Surrey on topics relevant to the local implementation of the Long Term Plan set out by the NHS

Objectives

1. To explore people's views on:
 - a. How would you help people live healthier lives?
 - b. What would make health services better?
 - c. How would you make it easier for people to take control of their own health and wellbeing?
 - d. What would you do to make support better for people with long-term conditions?
 - e. Any other topics of interest to the Surrey Heartlands ICS
2. To explore views on these topics specifically with people with, cancer, mental health conditions, lung and heart diseases, dementia, learning disabilities, autism and long-term conditions
3. To explore, in more depth, views of people of particular interest to Surrey Heartlands

What we did

We conducted two surveys, a discussion group and in-depth interviews to find out about Surrey residents views on how this should happen (see Appendix: Our approach), specifically:

1. A general survey for everyone
2. A survey for people with the conditions the NHS wants to focus on improving care for
3. A focus group with young adults (18-25) with Learning Disabilities
4. In-depth interviews with five parents of children with special educational needs.
5. In-depth interviews with two young adults with Epilepsy.

¹ Partnership of health and care organisations working together to improve local services and support people to live healthier lives. (<http://surreyheartlands.uk/get-involved/citizen-engagement-programme>)

Executive summary

What we heard

Local NHS services are working to implement the NHS Long Term Plan. Staff and volunteers at Healthwatch Surrey have collected local people's views and experiences of using the NHS, to help guide this implementation.

What matters most to people in Surrey?

We conducted a general survey for the general public, to find out more about what people want when using the health service (p 5).

Having what you need to live a healthy life:

Participants told us that quicker access to GP appointments was an important issue for them. They also told us they wanted clear information on how to live healthily, by eating well and exercising. We also heard that living in an environment with clean and unpolluted air was important to participants to help them live healthily.

Being able to manage and choose the support you need:

We heard from participants that they want to have an active role when making decisions about their healthcare, for example, their treatment choice and location. People also told us about the importance of having timely, clear and informative communication with NHS staff to help them manage their care.

“... clear, less confusing health and care information.”

The help you need to keep your independence and stay healthy as you get older:

Participants told us they want to be able to stay in their own home for as long as possible as they age. We also heard that they want to have appropriate support and homecare adaptations in healthcare delivery to help them do this. People also emphasised the importance of having travel arrangements to help them travel to and from healthcare services.

How you interact with your local NHS:

We heard from participants that technology can play a highly valuable role in making interactions with the health service more efficient. They told us they want it to be used in a range of ways to increase efficiency, from booking appointments to managing their health records online.

“[having a portal that] you can log in to and check what jabs you have had, if you are due a health check, reminders to book appointments ... making my life easier.”

What matters to people with specific conditions?

The NHS wants to focus on improving care for people with cancer, mental health conditions, lung and heart diseases, dementia, learning disabilities, autism and long-term conditions. We also conducted a survey for people with these conditions to share their experiences of using the health service (p 9). Whilst the sample was modest and not representative of experiences across the NHS in Surrey, some clear themes emerged from the responses.

When first seeking help:

Most participants with cancer told us they were satisfied with their experience of using the NHS when first seeking help. However, many participants with other conditions felt their needs were not met when they first sought help. People with mental health conditions, dementia, Autism and long-term conditions mentioned this in relation to their conditions

Initial assessment and treatment:

We heard from many participants that their wait for assessment and treatment after first seeking help was often slow.

Ongoing support:

We heard from participants who were offered further support after diagnosis and assessment, that this support often either somewhat or did not meet their needs. People fed back a variety of reasons for this; these related to the NHS workforce, communication and continuity between services. However, many people also commented on how supported they felt by staff.

Meeting patient's expectations:

People often told us that in their early care, they didn't mind seeing any healthcare professional who was available immediately. However, in their long-term care, participants more frequently said that they wanted to see the same healthcare professional each time.

The support that patients would like the NHS to provide:

We heard that most participants would like "some support", as opposed to a lot or none, from the NHS to help them manage their condition. People suggested ways they would like this to be done: regular and prompt appointments, having their requests taken into consideration and being supported to live healthy lifestyles.

“Checks on a regular basis to determine how the Parkinson's is progressing. Every few weeks at least.”

In focus: Learning disabilities and special educational needs

The Surrey Health and Wellbeing Strategy identifies people with learning disabilities (LD) and those with special educational needs (SEND) as 'priority population groups'. Senior leaders from the NHS in Surrey told us that they particularly wanted to hear about children and young people with special educational needs and learning disabilities.

We carried out some targeted engagement with these communities (see p 14). Two themes emerged:

- Families told us that having a child with SEND / LD should be less of a battle
- People involved in care delivery need to do more to support transitions from 'childhood' to 'adulthood'

“If you have a SEND child, you think everything is mapped out for you - but it's not”

With this insight, Healthwatch can help to ensure that local people's views and experiences will be considered in the local implementation of the long term plans. This report presents the findings from our work in Surrey and details what action should be taken next.

The general public

What we did with the general public

There were 90 responses to the general survey about what people wanted when using the NHS. The survey had several focus areas:

- Having what you need to live a healthy life
- Being able to manage and choose the support you need
- The help you need to keep your independence and stay healthy as you get older
- How you interact with your local NHS

People from ages ranging under 18 to over 75 took part in the general survey. We heard from people with and without disabilities and long-term health conditions.

Details on survey development and participants can be found in Appendix: Our approach.

What we heard from the general public

Having what you need to live a healthy life

Participants told us that getting **access to help and treatment when wanted** was the most important issue to them in this area. We recurrently heard that **quicker access to GP appointments was an issue** for participants:

“Shorter waiting times to get an appointment with my GP - usually 3 or 4 weeks at present. I was also offered a telephone consultation which was 3 weeks away.” (55-64, female)

“Seeing a doctor on the day I phone for an appointment and not to wait a week!” (55-64, female)

Respondents also said that they wanted **easy access to information** to help them make decisions about their health and care. They told us they valued having **information about healthy living**. We heard from participants about living more healthily in a range of ways.

Emphasis was put on having clear information about healthy eating and being able to easily incorporate exercise into their lives.

“I need more time in the day to fit in exercise” (35-44, female)

“How to eat better food” (55-64, female)

“Engage with other less well known services i.e nutritionists” (35-44 female)

Some also mentioned the importance of **having clean and unpolluted air** in their environments.

“there was more 'healthy' unpolluted air to breathe - maybe bigger open spaces and parks.” (25-34, female)

“good and easy access to open spaces; reducing air pollution from cars; prioritising pedestrians not vehicles (improving pavements rather than prioritising roads; improving the ability to cross roads in [location] town centre etc) so I can maintain an active healthy lifestyle or move around easily when unwell/infirm.” (45-54, female)

“what is important to me is to have an environment that help me have a healthy life, for example open spaces and clean air.” (55-64, female)

Being able to manage and choose the support you need

People told us **they want to have an active role** when managing and choosing their healthcare, and for staff to take their choices into account. Most participants said that it was important or very important:

- For treatment choice to be a joint decision between themselves and staff members
- To be in charge of choosing where and when their treatment was
- To have options to have access to services in other areas if they were not currently available locally

We also heard that **effective communication** with the health service was an important issue for participants; they wanted this to be timely, clear and informative. People fed back that they wanted:

“Ability to discuss medical issues in a way that patients understand.” (65-74, male)

“Clear, less confusing health and care information.” (55-64, male)

The help you need to keep your independence and stay healthy as you get older

People wanted to have support from family, friends and their community as they age. Most participants said it was important or very important for their family and friends to have the knowledge to take care of them as they age. However, one person commented that taking care of elderly relatives was sometimes a burden on family and friends.

The most important issue in this area to participants was to be able to **stay in their own homes for as long as possible as they age**. Many comments were made about how people want to achieve this, focussing on care in the home:

“Rapid access to home adaptations when I need them.” (25-34, male)

“Support and care provided at own home” (35-44, female)

“Free care in the home if necessary.” (45-54, female)

and the importance of **travel arrangements** when living at home as an older person:

“Better public transport” (35-44, female)

“Recently I have had knee op and could not drive - it if had not been for friends and family I would have been really stuck even to get to local village which is 1.5 miles away and cost me £15.00 each way. Again that is okay for me but not for many others.” (65-74, female)

“Convenient, affordable and available ways to travel are really important” (75+, female)

How you interact with your local NHS

The role of **technology to enable efficient interactions** with the health service was highly valued by people. Almost all participants told us it was important or very important to:

- Talk to a doctor or health professional wherever they are
- Access services from a phone or computer
- Be able to make appointments online
- Make the best use of technology when communicating

When asked what changes would allow patients to better interact with health services, comments were also made about using technology to help manage and streamline services:

“A personal government portal that you can log in to and check what jobs you have had, if you are due a health check, reminders to book appointments for seasonal allergies ie. hay fever etc. Making my life easier to check what I have had/what I need and then maybe a connection to my local GP to book an appointment.” (25-34, male)

“Share information between organisations or have one universal system that stores all my info. And that everyone can access” (35-44, female)

People also told us that they want to feel confident in the secure management of their data. Almost all participants said that this either important or very important to them.

A number of barriers to interactions were mentioned:

“There needs to be much more accessible health care for home and bed-bound people.” (under 18, female)

“Access is a huge issue in rural areas, with 1 bus a day to the village and hours in between accessing the GP or hospital is almost impossible, work is needed with the local council to provide better transport facilities.” (25-34, female)

“As medical practices appear to be merging, it has to be taken into account whether I am able to travel there.” (75+, female)

People with specific conditions

What we did with people with specific conditions

Forty-eight Surrey residents participated in the conditions-focused survey, telling us about their experiences of using the health service. The focus areas were:

- When first seeking help
- Initial assessment and treatment
- Ongoing support
- Meeting patient's expectations
- The support that patients would like the NHS to provide

We heard from respondents with all of the conditions the survey targeted. Most commonly, people had long-term conditions, followed by mental health conditions. Many participants also considered themselves to have a disability. People with ages ranging from under 18 to over 75 participated.

Details on survey development and participants can be found in Appendix: Our approach.

What we heard from people with specific conditions

First seeking help

Most participants with cancer were satisfied with their experience when first seeking help. Most said their needs were met and that their experience of seeking help was positive.

“Breast cancer diagnosed via a mammogram. Support was consequently quick and good.” (45-54, female)

“I was really pleased with the help I got and was in hospital within weeks.” (65-74, female)

“With my cancer, to be honest, the care was so superb I doubt it could be bettered. I am in the process of finding out if my cancer has returned and I have been seen to so quickly. My care is better than anything private care could give.” (55-64, female)

However, **among respondents with other conditions, half told us they felt their needs were not met when they first sought help.** Many participants described a lack of support from staff or services. Whilst there was a general consensus from participants about this, **those with mental health conditions, dementia, Autism and long-term conditions such as Parkinson's specifically mentioned this** in relation to their conditions.

“No support for Parkinson's. Nurses overloaded and consultant wait extensive!” (75+, I'd prefer not to say)

“I was diagnosed with [bipolar disorder] about 5 years ago and last year I got a referral to the community mental health team who upon seeing me, didn't think I was sick

enough to have support. There needs to be easier access to support, drop-ins as well as specialist care teams who actually know about BPD and can help.” (25-34, female)

“When I was initially diagnosed, I was not told for several months what the condition was nor how to live with a long term disability. I was given no support nor help lines to contact, another patient filled me in with contact details” (65-74, female)

Of the participants in our survey who had a co-existing illness, around half said this made getting help for another condition harder.

Initial assessment and treatment

Well over half of our participants told us their wait for an assessment after first seeking help was either “slow” or “very slow”. This was across a range of conditions.

“I waited 10 months before starting therapy and had a 6 weeks wait before seeing the eating disorder team, even though them, my GP and care team were aware I was getting worse” (18-24, female)

“I have had good back-up from the local surgery doctors, but it's the hospital appointments that seem to take forever.” (65-74, male)

“They just wanted me to turn-up when convenient to them. No or little customer focus. Many appointments had to be rearranged.” (65-74, male)

However, nearly all respondents with cancer described the wait to get an assessment as either “fast” or “very fast”.

A majority of respondents said the wait for treatment (after an assessment) as either “slow” or “very slow”. This could be linked to a need to wait before seeing a specialist, which 32 of our 48 participants were referred to. Most people told us this wait was either “slow” or “very slow”. Several participants commented that they switched to private care to see a specialist more quickly. These findings were for a range of conditions.

Ongoing support

More than half of participants told us they were offered further support after diagnosis and assessment. However, most people told us that the support offered either didn't - or only 'somewhat' - met their expectations. Our findings suggest reasons for these responses.

People with mental health conditions, long-term conditions such as Parkinson's and autism commented on what they felt was a lack of understanding or support about their condition from staff:

“I wanted help and access to DBT [sic]. But couldn't be referred. Needs to be more specialists who understand mental health conditions such as [bipolar disorder] as well as offering the right support.” (25-34, female)

“More time and people trained in Parkinson's” (75+, I'd prefer not to say)

“Women with autism is unusual, rarely considered and misdiagnosed as other conditions.” (55-64, female)

People and families living with dementia told us about a similar experience:

“There is not enough help for dementia patients and their families, families are trying to juggle work, children and their own healthcare, as well as their parents with dementia, believe me, it is demanding and takes its toll on your own health” (55-64, female)

“All NHS staff should be trained to be Dementia Friends. One size does not fit all, receptionists at GP surgeries and hospitals definitely need training.” (Did not specify)

“Treat dementia as a terminal illness and a long term disability that is complex and multiple needs” (45-54, female)

However there were also participants who commented on how supported they felt by healthcare staff when describing what worked well about the service:

“I have specialist nurses whom I can contact and now have a great team to call upon” (65-74, female)

“Initial breast cancer nurse support at surgery stage was very good.” (45-54, female)

“Communication with the counselling service on the phone, they were very friendly.” (25-34, female)

Respondents also told us about other problems in ongoing support:

- Workforce-related - staff overloaded with patients, inconsistent care between consultants, needing more financial investment in frontline staff
- Communication - less efficient methods used such as post, needing to chase up staff
- Options - not being informed of all available
- Continuity - services and support from staff were disjointed.

Continuity between services and staff appeared to be a particular issue:

“I was referred to several different departments none of which spoke to the others and all tried to treat my complex condition as individual conditions instead of seeing me as a complete person.” (45-54, female)

“Need a more joined up approach across all clinical needs, therapies and support groups.” (45-54, female)

“I had to explain situation repetitively though my son's situation hasn't changed (it won't change too much in a short period of time), and I have to explain to different department for the exactly same thing.” (35-44, female)

Meeting patients' expectations

We asked participants what was most important for them at 4 stages in their care and support:

- When first seeking help
- When you received a diagnosis and explanation of treatment or support options
- During your initial treatment or support
- During your long term support

When first seeking help most participants preferred to see any health professional who was available immediately or agreed that they didn't mind who they saw. One-third of the participants said they would prefer to see their usual health professional. In their long-term support, more people said it was more important to see the same staff member each time.

The support patients would like from the NHS to manage their condition

The majority of respondents said they wanted “some support”, and one in three wanted “a lot of support” from the NHS. A small number of people said they didn't need any support. People came up with generalised ways in which the NHS could support them to live healthily and manage their condition. These related to interacting with staff:

- Having regular and prompt appointments
- Ensuring patients requests are listened to
- Supporting people to live healthily through advice and a holistic approach to care.

“Checks on a regular basis to determine how the Parkinsons is progressing. Every few weeks at least.” (75+, I'd prefer not to say)

“Act promptly with help and listen and respect my wishes.” (45-54, female)

“Good teaching about eating well, weight control, exercise and being able to get enough sleep. I think if basic needs are met well then you often don't develop serious long term medical problems.” (75+, female)

“Look holistically and be person centred. Stop separating physical and mental health as they are intrinsically linked.” (35-44, female)

Focus on: Children & young people with SEND / LD

What we did with children & young people with SEND / LD

Learning disabilities and autism were two of the conditions with the least respondents to the surveys. We also know that the Surrey Health & Wellbeing Strategy prioritises these ‘population groups’. Our system partners identified an interest in hearing more from these communities.

We conducted some additional engagement to further explore their perspective. The engagement activities included a discussion group with young adults (18-25) with learning disabilities, in-depth interviews with five parents of children with SEND and in-depth interviews with two young adults with Epilepsy.

Details on survey development and participants can be found in Appendix: Our approach.

What we heard from people with SEND / LD

We heard two key messages during these conversations:

- Families told us that having a child with SEND / LD 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.”

The 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 over 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, 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 are a valued source of support - practical and emotional - and likewise some of the physical support groups such as those which meet at Disability Challengers in Guildford.

Approaching adulthood

We heard how transitions from ‘childhood’ to ‘adulthood’ can be particularly difficult. This is certainly true for parents, but also - to varying degrees - for young adults themselves.

“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.”

Those we spoke to with Epilepsy told us how their anxiety takes root very quickly and often dangerously. Parents, carers and professionals have a difficult line to tread between involving young adults in decisions and not prompting harmful physical or emotional reactions.

Further insight into children & young people with SEND / LD

Our day-to-day work with people across the county provides another important source of insight into - and lends emphasis to - the challenging situations that young people with SEND / LD and their families can find themselves in.

“[person with LD] started an apprenticeship in engineering but did not pass the final assessment. He is now at home all day playing computer games and gets frustrated and angry and is becoming violent. The GP says there is nothing more she can do to help.”

“when a child is diagnosed... [information] packs should be given to parents and carers about support groups, the different stages... transition to secondary school...”

“When my son turned 18, he was effectively off CAMHS books and we were told we had to go back to the GP, the GP will not prescribe unless he is seen by a [mental health] professional... it took months...”

“you are able to talk to doctors and professionals on [the child’s] behalf. As soon as they turn 18 that all changes, even if the doctor has a letter signed by them giving permission for you to talk to the doctor... it is still difficult.”

Next steps

Healthwatch Surrey will:

- Use the findings to champion the views of people at the Health & Wellbeing Board and at other meetings where it's staff and volunteers are involved in discussions about service transformation
- Share the findings with its Citizens Ambassadors, who provide an independent perspective on health & social care transformation within the Surrey Heartlands NHS
- Further explore the views and experiences of people with Learning Disabilities in 2019

Response from Surrey Heartlands Health & Care Partnership:

Surrey Heartlands welcomes the report by Healthwatch Surrey which provides helpful insight on the views and experiences of local people on a range of health and care services, with more detailed feedback from parents and families of children with learning disabilities and special educational needs, both of which are key priorities in the recently published Health and Wellbeing Strategy for Surrey.

Listening and acting on feedback from local people is extremely important to us and across Surrey Heartlands we have established a robust citizen engagement programme which builds on our wider engagement work with stakeholders, patient participation groups and other members of the local community. This programme includes detailed engagement work with local citizens on a range of areas, using robust co-design and other research methodologies to ensure we hear and act on the views of local people. This targeted engagement by Healthwatch Surrey will be a valuable addition to this wider work and will be used by programme teams as further insight as we come to implement the NHS Longterm Plan.

In reading the report, there are many areas that resonate with other pieces of engagement and research we have undertaken and this adds to the mix of views and experiences already shared with us (for example, through the work we've done around the Health and Wellbeing Strategy, engagement on our transformation work for children and young people's mental health services) and which we will continue to explore.

This helps to underline key themes that we know are important to local people and which we can take forward in our future planning and work programmes.

This includes:

- **Improving access to GP appointments** - we have already increased the number of GP appointments available through extended GP access - around 50,000 additional appointments at evenings and weekends between August 2018 and end of March 2019. Other initiatives such as online appointments are also increasing the number available, (for example the LIVI app in North West Surrey which has offered over 14,000 skype-style appointments since last October). New Primary Care Networks - groups of GP practices working together across local populations of between 30,000 and 60,000 - will also help create opportunities to further develop care provided by family doctors, for example through offering a wider range of services locally such as mental health support and different therapy services locally.

- **The importance of prevention and having more information about how to live healthier lives** - this is a key priority and theme within the Long-Term Plan and locally is reflected in one of the three key priorities of our recently published Health and Wellbeing Strategy (Helping people in Surrey to lead healthy lives). The work within the implementation plan for this priority is a major focus for Surrey Heartlands and builds on the work taken forward to date through our Prevention workstream. It is encouraging to see this picked out within the main themes of this report, and provides useful insight to build on as the detail of the plans for each of the seven focus areas is developed.

- **Digital and technology** - we have just published our digital strategy which has been informed by some early engagement work with local citizens; we know that using technology to make services more efficient is something that people want to see more of, and we are already starting to use applications such as Skype as an alternative for some routine appointments. Our strategy will explore these areas in more detail, including record sharing and allowing patients access to their health records through an online portal. We are also working on developing the 'e-redbook' to provide a digital record of a child's health record which will help ensure professionals have easy access to immunisation records. All the feedback shared here helps to reinforce these priorities as the right ones.

Children with special educational needs and/or learning disabilities

We particularly welcome the more detailed feedback on services for children with special educational needs and/or learning disabilities. Alongside the priorities in the Health and Wellbeing Strategy, this group is also highlighted as one of the five key population groups that need to be supported to improve health and wellbeing outcomes and on providing opportunities for this cohort to achieve their potential.

Through our transformation programmes we have already done some comprehensive engagement around transforming children and young people's mental health services which has informed a new strategy for Surrey. We recognise that there are areas that will need more collaborative work to deliver the transformation required, and are working in partnership with Surrey County Council's Special Educational Needs (SEND) team and children's mental health services to deliver the changes. The following areas have recently been taken to the Surrey Children's Transformation Programme for inclusion in the next phase of development: Access; Crisis; Early Help; the BEN pathway (behaviour, emotional and neurodevelopmental); and vulnerable groups.

Surrey services for Learning Disabilities (all ages) and Autism: we are working collaboratively across the system, with Surrey County Council as a key partner, to develop an all-age pathway to support young people moving from children's to adult services as we recognise this is a key area that needs addressing. To deliver this programme, we have created an integrated health and social care commissioning role to work on the service development; work is also underway across all transition points to deliver joined up pathways that will support young people into adulthood and older adults into later years. Transition services are also reviewing all young people aged 14 with the Special Educational Needs team, to understand the needs of young people and to help bridge the period from 14-25.

In addition, we are undertaking some early research to plan a new programme of cocreation focused on transforming services for families of children aged 0-5 with

special educational needs and disabilities; this is about empowering the system to support families and aligns with the early help and prevention approach suggested in the Long-Term Plan.

Moving forward

The recently published Health and Wellbeing Strategy - signed up to by all public sector partners across Surrey - sets the local priorities for improving health and wellbeing across the population and includes targets for the next 10 years which are currently being finalised for final approval at the December Health & Wellbeing Board meeting. As highlighted above, to avoid any groups of the population being left behind, Surrey will focus on tackling these priorities across the entire population, as well as within specific target groups of people which are often overlooked or most at risk.

Following the recent production of the strategy, we are now starting to set out our implementation plans in more detail against each of the priorities which are: leading healthy lives; having good mental health and emotional wellbeing; and fulfilling potential. These plans will seek to build on action being taken through existing work programmes (such as the work we are doing to transform support for children and young people with mental health issues) whereas others will be newer areas of work (such as building stronger partnerships between housing and health) needing more time to develop.

Within all of these however, the focus will be on where we can work together to improve outcomes for people as a partnership rather than trying to capture everything that is happening in these areas of work. Engaging local people in these plans, and co-designing how we deliver services in the future will be an explicit part of our ongoing planning and development work throughout the life of the strategy.

We are also finalising the detailed plan on how we will implement the specific requirements of the NHS Long-term Plan across Surrey Heartlands, which will cover the next five years. The plan will be submitted to NHS England in November when we will also publish it on our website. Ongoing engagement with local people has played an important part in developing these plans and the feedback provided in this report by Healthwatch is an important additional contribution. Citizen engagement, which we are building into our key work programmes, will continue to be a major theme moving forward and will help us track progress against our priorities.

Dr Claire Fuller

Senior Responsible Officer, Surrey Heartlands Integrated Care System

July 2019

Appendix: Our approach

Survey development:

The survey was developed by Healthwatch England's intelligence, policy and communications teams and tested in-house. The priorities in the Long Term Plan influenced the shaping of the questions. Closed questions were developed to gather focused information with open questions to provide qualitative feedback if participants wish to explain further. The surveys were then delivered to local Healthwatch in a variety of formats for differing needs.

Survey promotion:

We promoted both surveys through a range of channels to increase their reach to Surrey residents. Surveys were advertised on the Healthwatch Surrey website, through our e-bulletin, engagement events and by emailing members of voluntary, community and faith sector groups. They were also posted on social media platforms Facebook, Twitter and Instagram several times. Surrey news sites Get Surrey, County Border News also gave coverage to our surveys. We also shared our surveys with Citizens Advice and several charities so they could share them with their members. Surrey County Council also included the survey in their April monthly newsletter.

Survey participants:

Demographics of general survey participants

We had 90 responses to our general survey. We heard from people from a range of ages; most commonly they were aged between 55-64 (n=31). Seventy-five were female, 13 were male and 2 did not specify. Participants were most commonly White British (n=81), heterosexual (n=78) and either Christian (n=47) or held no religion (n=30). Some participants had a disability (n=22) and many had one or more long-term health conditions (n=42). Eighty-six people responded on their own behalf, 3 on someone else's and one did not specify.

Demographics of condition-specific survey participants

We had 48 responses to our conditions survey. Our participants were a range of ages; most commonly they were aged between 45-54 (n=11) and 65-74 (n=11). Thirty-four were female, 10 were male and 4 did not specify. Participants were mostly White British (n=38), heterosexual (n=38) and either Christian (n=20) or held no religion (n=15). Twenty-one people said they had a disability. Twenty-seven people completed the survey based on their own experience, 18 about someone else's and 3 did not specify.

| Condition | Frequency | Percentage |
|-------------------------|-----------|------------|
| Cancer | 5 | 10 |
| Heart and lung diseases | 2 | 4 |
| Mental health | 13 | 27 |
| Dementia | 5 | 10 |
| Learning disability | 2 | 4 |
| Autism | 2 | 4 |
| Long-term condition | 17 | 35 |
| Not specified | 2 | 4 |
| Total | 48 | 100 |

Analysis of survey results:

Survey results were collated into databases and were then analysed in Excel. Descriptive statistics of respondents for each survey were compiled. Answers to each question in both surveys were analysed by determining the frequency of each response. Written feedback was analysed by searching for shared themes and by comparing responses from different participants.

Learning disabilities focus group and interviews:

One discussion group with SEND / LD young adults, held at the YMCA in Reigate on the afternoon of 23rd May, 2019. Twelve participants attended (following their attendance at a previous regular session there) and we were assisted by three YMCA Youth Workers. After the group, we also conducted two short informal interviews with the Youth Workers to complement the group's views. Two in-depth interviews were then conducted with young adults at Young Epilepsy Lingfield on 6th June, 2019.

In-depth interviews with parents of children with SEND:

Five individual depth interviews with parents of SEND / LD children. One was conducted face-to-face and the other four conducted over the phone.

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- Andrea Collings from Family Voice Surrey

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