
What we're hearing

About Surrey's priority populations: prepared for Surrey Public Health team

October 2024



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We have had no involvement from Surrey and Borders...I should also have a social worker, but I haven't seen them in a while...

My brother has made lots of safeguarding concerns... but nothing has happened. I am currently homeless, and sofa surfing. I am sleeping in a pub, because the owner has a heart and lets me stay there. I just don't have any support. My brother has also contacted POHWER to see if they could provide an advocate, but they just said I wasn't eligible and that was it."



If you would like a paper copy of this document or require it in an alternative format, please get in touch with us.

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Summary

Over the last 6 months, through local Healthwatch Surrey community engagement and the work of our other Luminus contracts (Giving Carers a Voice, Giving Young Carers a Voice and Combating Drugs Partnership Public Involvement), we have heard from most of Surrey’s Priority Population groups – which include those who are at the greatest risk of health inequalities.

We have found that some of the people within the priority populations intersect with other priority populations. The impact of living with multiple issues is enormous.

For example, a young man, who has experienced domestic abuse, has mental ill-health, and autism. He himself was then arrested for domestic violence.

A mum told us about her son, who is a looked after child, who is possibly neurodivergent and has mental health issues. The impact of misdiagnosis, and everything that he is dealing with is that he is missing out on his education.

The multiple difficulties of not speaking English and being hard of hearing were shared with us in regard to an elderly Polish woman who has had a lengthy stay in hospital. Although her communication issues were known by staff, her daughter had resorted to creating a laminated poster which was stuck behind her mother's bed, to ensure that staff were aware.

In terms of prevention, we have heard that elderly residents are reticent about having flu, covid and RSV vaccinations at the same time, and have made arrangements to have them separately, due to concerns about potential reactions.

Introduction and approach

This report is designed to highlight the themes we have been hearing about and includes quotes from local people to provide context on these themes. Whilst this report accurately reflects what we hear from the individuals we speak to, we are aware that it may not be representative of everyone's views of a particular service. Multiple references to a specific service may be due to where our community engagement has recently taken place.

Any urgent or concerning experiences within this report have been escalated to the appropriate teams. All appropriate information and signposting has already been given.

If you would like more information or examples of what people have shared, please get in touch.

Our priorities

We have listened carefully across our community engagement, Helpdesk, Independent Health Complaints Advocacy, volunteers and Surrey residents to identify and shape our priority areas for 2023–2026.

At the core of all our work, our priorities are:

- Independent, agenda-free listening and feeding back insight
- Information and signposting.

These form the foundation to enable us to focus our work specifically on the following key areas:

- Access to primary care
- Social care
- Mental health
- Involvement of people: the listening landscape
- Amplify voice in the Voluntary Community and Social Enterprise sector
- Assessing the long-term impact of our work.

This report falls within our Involvement of people priority. Within this, we believe that supporting our local system leaders to learn from experiences will help to drive improvements.

The experiences we include within this report have been shared with us during February–September 2024.

People have shared their experiences with us in a number of ways including during community engagement events, through our Helpdesk, Independent Health Complaints Advocacy service, Giving Carers a Voice engagement, Combating Drugs Partnership Public Involvement engagement, our online Feedback Centre and via Healthwatch England.

We have reviewed the experiences in line with Surrey Health and Wellbeing Board's Priority Populations:

- Carers and young carers
- Looked after children and adults with care experience
- Children with additional needs and disabilities
- Adults with learning disabilities and/or autism

- People with long term health conditions, disabilities or sensory impairments
- Older people 80+ and those in care homes
- Black and Minority Ethnic groups
- Gypsy Roma Traveller community
- Young people out of work
- People experiencing domestic abuse
- People with serious mental illness
- People with drug and alcohol problems
- People experiencing homelessness.

Through the Combating Drugs Partnership Public Involvement work, we speak to people with drug and alcohol problems, some of whom are also young people who are out of work and homeless.

Giving Carers a Voice and Giving Young Carers a Voice hear from carers and young carers.

We have not heard relevant themes about adults who have experience of care/being a looked after child or anyone who identified themselves as being from the Gypsy Roma Traveller community.

We ensure that some of our engagement takes place in the key neighbourhood areas which experience the poorest health outcomes in Surrey.

Carers and young carers

Healthwatch Surrey focus our engagement activity to ensure we can meet with people who are most at risk of health inequalities, which often means we speak to many unpaid carers.

The Giving Young Carers a Voice service has been commissioned to run engagement with young carers over the past year, which has provided important insights into the experiences of young people who provide care and support, often to immediate family members. The following experience highlights the challenges that this young carer often faces, caring for 2 generations and the impact that has on her.

Young Carers

"I'm [under 12] and we have always had to look after my mum, she's poorly and so is my gran who lives with us. I think my mum has ADHD, I don't really know, and my gran has bad legs. Soon my sister and her [young child] are coming to live with us too. There'll be so many people in our house then. I have to help with lots of things, sometimes when I get home from school, I forget to do my homework, and I worry I'll get into trouble so I don't sleep. I'll speak to my teacher about it, she's very nice. My friends don't know I'm a young carer and I don't want them to know, especially as there are so many people who live at my house, they may find that strange."

214336, Female under 12, May 2024

For more experiences of carers and young carers please see our Luminus reports:

[Giving-Carers-a-Voice-Q1-Insight-Report-July-2024.pdf \(luminus-cic.uk\)](#)

[Giving-Young-Carers-a-Voice-Insight-Report-July-2024.pdf \(luminus-cic.uk\)](#)

Looked after children /children with additional needs

A mum whose son was in foster care, told us about his education and health issues. Her son does not attend school due to illness: possible misdiagnosed as chronic fatigue syndrome, now possibly neurodiverse with trauma. The mum has concerns for his mental health and wellbeing, due to unresolved trauma. The son has a social worker, but they feel they have had very little support.

"I have a son who is now 14 years old who has a 2 year history of non-attendance from school due to illness. In the past they believed that this is because he has chronic fatigue syndrome (CFS), however they now believe that he is possibly neurodiverse and has trauma. My son also had

chronic ear problems, and it is an ENT [ear, nose and throat] blood test that has flagged the possible enzyme deficiency.

Investigations have shown that he may have been misdiagnosed with CFS and have now said that it is possible trauma/neurodiversity. I was told that I would need to go through the right to choose pathway for neurodiversity, which I did last week. They also think he has unresolved trauma, I am really concerned about his mental health and wellbeing, he sleeps for most of the day and stays up during the night, he is really isolated, I am the only person he interacts with regularly and our relationship is now fractured because of the stress of everything going on. He has a history of being in foster care and was flagged as a looked after child in February this year.

Because he is a looked after child he does have a social worker, who has seen him 3 times, but we have not had any help. He promises help but we never see anything change and I have very little confidence in things improving as we move forward”.

217085 Helpdesk, Reigate and Banstead, July 2024

In the course of our engagement work (particularly for our Combating Drugs Partnership Public Involvement work) we meet many people who interact with and support looked after children, however, we don't necessarily engage with the children themselves.

Adults with learning disabilities and/or autism

For our involvement of people priority in 2024 we conducted a project looking at neurodivergent people's experiences of outpatients in Surrey hospitals.

[Neurodivergent-peoples-experiences-of-outpatients-in-Surrey-hospitals-August-2024.pdf \(healthwatchesurrey.co.uk\)](https://healthwatchesurrey.co.uk/Neurodivergent-peoples-experiences-of-outpatients-in-Surrey-hospitals-August-2024.pdf)

A person living in supported living told us that they were forced to move to a different town because their previous residence was closed down. They shared with us the impact this had on them in terms of social isolation.

“I live in supported living, and I want to move but my social worker is not facilitating this. They keep on saying ‘What’s changed now’ and not helping me. I don’t like my social worker, she doesn’t listen to me at all.

I want to move because I have had enough of where I am now. I don’t like the way the staff treat me; they aren’t nice to me and they just let themselves in to my property without knocking. I am also quite lonely and would like to move closer to friends that I could see. I have also been recently bereaved, so my mental health is not great.

I didn’t have a choice in moving to Leatherhead. The supported living that I was living in in Woking closed down and they moved me to Leatherhead, away from all my friends.”

218177 Helpdesk, Female 25–49, Mole Valley, July 2024

People experiencing domestic abuse /adults with learning disabilities and or autism

Below we have highlighted 2 experiences of people who have experienced domestic abuse, one from their son, (who had also experienced domestic abuse from their father) and another experience where a wife has experienced domestic abuse from her husband.

The son also has autism and mental health issues. This experience highlights the intertwining of priority populations, but also the difficulties when a person doesn’t meet the thresholds to receive support.

The Healthwatch Surrey Helpdesk remit is to provide reliable and trustworthy information and signposting about local health and social care services. However, people often contact us because they feel turned away from other services and bounced around the system without any clear guidance. This example demonstrates the breadth of services involved in this family and yet there are a number of needs seemingly not met.

“I have a son, who is 21 and has autism with persistent demand avoidance (PDA). Recently there was an incident, where he had a meltdown, and I had to call the police. He was charged with domestic violence and was arrested and placed in a bail hostel. While he was there, his brother had to call an ambulance for him because he was suicidal. So, we removed him and sent him somewhere he was safe. We have been told by 2 different psychiatric nurses that my son needs to be referred to the learning disabilities social care team. However, they have said he is not eligible because he does not have a low enough IQ, they also don't understand PDA.

He does have a social worker, but our experience with them has been awful. The whole reason the meltdown happened was because we needed to get some respite, I called the social care team countless times to try and get some respite. However, we were told we fall in to a “grey area”, because he is not considered to have mental health issues but is also not considered to have a learning disability. This was why they could not give him respite.

The social worker was also supposed to refer me for domestic violence services, but she hasn't sent the referral. The social worker has also told us that he's not bulimic, because he doesn't stick his fingers down his throat to vomit, even though he makes himself vomit every time he goes over his calories for the day. He has lost over a stone in the past 7 weeks he has been away from me. He also has Hypermobility Ehlers Danlos, so finds it easy to make himself vomit on command. I have also raised concerns about his

wellbeing, because he had not bathed in 10 days, but they didn't seem to care.

His current social worker has never met him, and is going off another social worker's reports, who only met him twice. He does have a care package, but he won't engage in services, because of the PDA. So, they keep on threatening to take away the care package all together. The social worker has also told us that they don't work with the police, meaning that everything is separate and not at all put together. He has trauma as well as the other diagnoses, because of the domestic abuse he experienced from his dad and the bullying he experienced at school. He was under the domestic violence team, before being sent to CAMHS.

We have also been told to request an urgent mental health assessment; however, this was turned down. We have tried to book a GP appointment to get him referred as his mental health has declined, but they couldn't give us an appointment until next week. From the last assessment he had, they gave us a plan. We have done everything on that plan, I have gone to safe havens, I have asked for the urgent mental health assessment, I have written to the learning disability team. You guys are my last resort.

He needs to come home, but because he has been prosecuted and I am considered the victim, he's not allowed to come home. However, I am still able to take him to the GP and he is still able to contact me. I get 30-40 calls a day from my son, because he isn't coping. I have had to pay for a clinical psychologist to help us as well, but I am not made of money".

219029 Helpdesk, M 18-24, July 2024

Black and minority ethnic groups and domestic abuse

This lady's experience highlights the difficulties when a person experiencing abuse feels they have nowhere to turn (in this case all her family are in India).

"My son is 2. He is my only child. I had him in Royal Surrey County Hospital and was well supported in hospital. My mother came over from Mumbai two months before and left when he was 3 months old. But my wellbeing since the birth has been bad. My husband is abusive verbally and I am worried about my son. He is picking up on some of the words my husband uses.

My health visitor spoke to my husband about his behaviour, but she made things worse. She gave me a number for a domestic abuse helpline, and I called them. I would like to know if there is a record of my call for the future. I want to leave my husband, but I don't want to involve the authorities as I am worried my son will be taken away. I also have nowhere to go and no money. All my family are in Mumbai.

A big worry is the rising cost of living. I am not working, and my husband is paying for everything. He is very resentful about this. I have offered to go back to work but he doesn't want to pay for childcare. Our marriage was fine before the birth of the baby".

214121, Female, 25-49, Asian Indian, Waverley, May 2024

People with serious mental illness

Below we hear from a lady who contacted the Surrey crisis mental health team. Her experience was not in line with what is promised on the Surrey and Borders website (as detailed in the box below):

[Get help in a mental health crisis : Surrey and Borders Partnership NHS Foundation Trust \(sabp.nhs.uk\)](https://www.sabp.nhs.uk)

- Listen to you and help you work through immediate problems
- Work with you, using your crisis plan, to find ways to move forward or suggest ways of coping
- Give you information about other services that may be helpful to you or the person you care for

We can also advise you about the wide range of local and national help available including:

- Relevant mental health services
- Statutory and third-sector organisations e.g. helplines, support groups and networks, advocacy services
- Information on specific conditions such as stress, anxiety, depression, psychosis and obsessive-compulsive disorders
- If necessary we can help you to speak to another qualified practitioner.

“I was suicidal & very depressed due to a change of antidepressants, PTSD [post-traumatic stress disorder] & daily grappling of 10 health conditions. I rang my Surrey Crisis Mental Health Team in tears – a lady answered & just wanted to know if I was going to kill myself, I said no, as I have a 10-year-old daughter; she said see your GP & hung up...I rang Samaritans, no answer. That was a very long & hard night”.

210814 Healthwatch England, Female 50–64 East Surrey, February 2024,

People experiencing homelessness

We heard from an ex-prisoner who has ADHD [attention deficit hyperactivity disorder] and suspected autism, who lived in supported living when first released from prison, but this became untenable. They have had little support from their social worker, probation officer and are not eligible for advocacy support.

“I was in supported accommodation when I was first released from prison. However, things kept escalating, so they removed me. I was placed in a supported accommodation setting, supplied by the charity Renewed

Hope. I was told that there would be staff there to help and monitor the home, because it is a dry house. However, there was no staff, so there are drugs and alcohol there. There was an incident where I needed to climb into the back window to stop someone else from committing suicide with a knife. After that I had a mental health break down. An ambulance was called, but the ambulance couldn't do anything for me until the police came. No one told me this, so when the police arrived, I panicked and ran away. They went all round Redhill trying to find me, when they eventually did, they took me to East Surrey Hospital to their A&E. When I was in A&E a doctor from the mental health team came to speak to me and told me that it would be a while before I was seen, so I left. I have not had any follow up at all.

We have had no involvement from Surrey and Borders, I should be monitored because of my ADHD medications, but I am not. I should also have a social worker, but I haven't seen them in a while. My social worker was present when I was having a meltdown. But the social worker then walked away and hasn't been in contact since.

My brother has made lots of safeguarding concerns, as have other agencies, but nothing has happened. I am currently homeless, and sofa surfing. I am sleeping in a pub, because the owner has a heart and lets me stay there. I just don't have any support.

My brother has also contacted POHWER to see if they could provide an advocate, but they just said I wasn't eligible and that was it".

219681 Helpdesk, male 25-49, Reigate & Banstead, August 2024

People with long term health conditions, disabilities or sensory impairments

In terms of sensory impairments, we heard from a lady whose mother is deaf in one ear, and does not speak English, she was an inpatient at Frimley Park Hospital and had been on the ward for 5 weeks.

The daughter made a sign to highlight her mother's communication needs, because, although it was in her mother's notes, she felt that the staff needed to be reminded.

"Mum gets frightened easily and I noticed that often doctors or staff will just approach her bed and start asking her questions that she does not understand, even though it is known she cannot speak English and is deaf in one ear. I made a laminated sign to put over her bed that says that she could only speak Polish and is hard of hearing and also asked that people please smile when you're talking to me so that she was less frightened. I don't think that staff always appreciate that by smiling they put the patient at ease rather than a serious face that worries them. I think it would be a better service if all patients could have these notices above their bed that point out some key facts about the patient as a standard".

216944, Female, white European, 25-49, Surrey Heath, June 2024

Older people 80+ and those in care homes

As part of our social care priority, we have visited several community cafes (some run in council-led community centres), and specifically targeted groups for the elderly.

We have also engaged with older people, including those living in care homes as part of our social care project:

[Who can help me plan for my future as an older person? - June 2024 - Healthwatch Surrey](#)

The people we spoke to told us about themes which we hear about frequently, such as issues with GP access, digital exclusion and communications.

A new concern has emerged regarding having 3 vaccinations at once.

Our colleagues at Luminus have recently done some research commissioned by Surrey Heartlands looking at barriers to COVID-19 vaccination.

The main barriers were about fear of side effects and the impact on health for people with pre-existing conditions.

“I have been invited by the surgery to get the COVID-19 booster, RSV and the flu jab. They want me to have them all at once, but I don't want to in case I have a reaction. They won't let me book them separately, so I think I will need to go to the pharmacy for it, so I can spread them out”.

222229 Female 80+, Surrey Heath, September 2024

Thank you

We would like to thank everyone who gave their time and shared their experiences with us.

We would also like to thank our volunteers who supported us during our engagement sessions and to the all the organisations who welcomed us.

About Healthwatch Surrey

Healthwatch Surrey champions the voice of local people to shape, improve and get the best from NHS, health and social care services. As an independent statutory body, we have the power to make sure decision makers listen to the experiences of local people.

We passionately believe that listening and responding to local people's experiences is vital to create health and social care services that meet the needs of people in Surrey. We seek out people's experiences of health and care services, particularly from people whose voices are seldom heard, who might be at risk of health inequalities and whose needs are not met by current services. We share our findings publicly and with service providers and commissioners to influence and challenge current provision and future plans.

We also provide reliable and trustworthy information and signposting about local health and social care services to help people get the support they need.

Contact us

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We are proud to be commended in the National Healthwatch Impact Awards, recognising our work helping to improve local NHS and social care. You can view [our video](#) highlighting how feedback has enabled us to make positive changes to health and social care services.



We are committed to the quality of our information. Every three years we perform an audit so that we can be certain of this.

Luminus

The Healthwatch Surrey service is run by Luminus Insight CIC, known as Luminus.

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