

What we're hearing about Surrey Heath

October 2024



"He needs time to trust, to open up, longer than 8 poxy sessions, with a 6 month wait to get back to the top of the list again, to try again."



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Report overview

This report provides insights into local people's views on, and experiences with, health and social care services in Surrey Heath. It is based on what people have told us at a series of engagement events in the area, as well as enquiries to our <u>Helpdesk</u>, between March 2024 and September 2024

Our report focusses on 5 key areas:

- Experience of Mental Health Services; extended waits for care leading to the need for crisis support, lack of support for carers.
- Experience of General Practice; use of digital applications, equity of access, lack of communication to help people understand their medical conditions, registration confusion, effective referral and diagnosis pathways.
- Experience of secondary care; poor discharge planning, unsatisfactory complaints handling.
- Spotlight on Frimley Park Hospital's Emergency Department
- Spotlight on Secondary Breast Cancer Services

Please note: Any urgent or concerning experiences within this report have been escalated to the appropriate teams. All appropriate information and advice and signposting to complaints processes has already been given.

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



Insight summary

The following table summarises the issues highlighted in this report and the outcomes which we would like to see for patients. Healthwatch Surrey would like to work with Surrey Heath to consider realistic ways in which these can be achieved.

Theme / issue	What would be a better outcome for patients
Mental Health Services	
Extended waits for care leading to	Patients are better informed about waiting and
the need for crisis support	referral times and are given appropriate signposting
	to additional support services whilst they wait.
Support for carers lacking	All carers of mental health patients are identified
	and provided with signposting to additional sources
	of support.
General Practice	
Use of digital applications	Help and support to use all digital applications is
	readily available to all patients and proactively
	promoted.
Equity of access	General practices are sympathetic to individual
	access needs.
Lack of communication to help	All patients are supported as standard once given a
people understand their medical	new diagnosis including signposted to additional
conditions	sources of information.
Registration confusion	Clear information on registration procedures is
	available via all general practices.
Secondary care	
Poor discharge planning	Carers are fully involved in discharge planning when
	someone they care for is discharged. Carers are
	supported to ensure that they can safely support
	the person they care for.
Unsatisfactory complaints handling	All complaints receive a timely response, and the
	complaints process is transparent.
Breast cancer support	



Scans	Patients are better informed regarding the process
	for obtaining scans and results and how to follow up
	is made clear.
No Clinical Nurse Specialist (CNS)	If no CNS exists, patients are informed about who
, , , ,	they can speak to in their place.
Lack of information on secondary	All patients are provided with information on
breast cancer	secondary breast cancer and signposted to further
	sources of support as standard when diagnosed.



What we are hearing

Experience of mental health services

Extended waits for care leading to the need for crisis support

In February 2024 <u>reported</u> that people with mental health needs were telling us that they would like to see more timely support to avoid a mental health crisis. People have continued to talk to us about this.

"My son now has medical PTSD (Post Traumatic Stress Disorder) but can't get over it as Adult Mental Health support is consistently denied. The short-term therapy available will just trigger seizures then stop after 8 sessions. He needs mental health input to deal with the issues left by incorrect treatment, but he needs time to trust, to open up. Longer than 8 poxy sessions, with a 6 month wait to get back to the top of the list again, to try again. They broke him and won't admit to doing it, not helping him to recover."

213163 Surrey resident

Lack of support for carers

Carers have told us that they are having to cope with the emotional strain of demanding appropriate and timely care and living with the consequences when it is not provided.

"I am a carer of a relative with paranoid schizophrenia, anxiety etc and the support has declined so much over the last 30 years, it's so hard."

210680 Surrey resident

They also talk to us about the lack of support they receive as carers "[My daughter] has an eating disorder. I had to give up my job or she wouldn't be here now. Social care for carers just doesn't exist. As a parent, I feel criminalised and blamed for my daughter's mental health problems. It's all about blame. They blame the parents, they blame the parents' mental health, they blame everything on you as a parent. I looked at respite, but I couldn't get it as she isn't accessing social care.



I come to this carer's group as there is nowhere else to go and no-one to listen."

222026 Surrey resident

However, carers have also shared very positive experiences of mental health support, specifically within general practice:

"I'm registered with the GP surgery as a carer for my husband who has mental health issues. They are excellent. Our GP rings up once a month to speak to my husband and then to me, so he gets my perspective as well. My husband will play things down and say he's not so bad, but I am with him 24/7 so I know what he's really like: anxious, not wanting to leave the house, leaving most of the household things to me while he watches TV or sleep."

215309 Frimley Green resident

Experience of general practice Use of digital applications

People have shared their experience of using the NHS App, as well as other digital applications such as E-consult, My Frimley Health, Patient Access and The Skin Doctor. Some people find this technology easy to use and helpful whilst others would prefer to speak to a person. There is a feeling that help and support to understand and use these forms of digital communication is lacking.

"My feedback on E-consult - it is confusing to start with, I thought it was the same as Patient Access, which I am registered for. The first time I completed it my daughter talked me through the whole process, and it took about an hour. I think I am quite IT savvy, but the length of the consultation forms, plus the detail you need to put in can be time consuming, confusing and seems repetitive. I get very frustrated and stressed when using it sometimes, which makes me angry or anxious."

211964, Surrey resident



"Once I completed one [an e-consultation] and the message I got was to contact my GP as I needed to talk to them, which I did, only to be told by the receptionist that there were no appointments that day so to redo the E-consult and to change the wording so it did not appear as urgent. She offered no help on how to do this. I ended up ringing the surgery at 8am the next morning and did get an urgent appointment; the GP gave me antibiotics for a sinus infection. What would help is some guidance on what to include in the E-consult."

211964, Surrey resident

"I use Patient Access to get my repeat prescriptions. I did not like the NHS App, I tried it but it seemed to keep bombing me out, so I deleted it."

212052, Surrey resident

There were frustrations that the different applications didn't "talk to each other" so individual ones are used for different purposes and information isn't shared or held centrally.

"A nurse rang me 2 hours later and booked an appointment for me that day. Following that she referred me to the community dermatologist. I received a message from the Sussex Community Dermatology Service. I had to download their App (My Skin Doctor) which was not easy to use, but I guess if used often would become more instinctive. I had to submit photos, medical records and prescription details. To do this I went into my NHS app and did screenshots so I could upload these, rather than type it all out. I could not understand why this information is not shared as it would be a lot easier and less stressful."

211964 Surrey resident

Equity of access

In January 2024, we <u>reported</u> on the usability and accessibility of GP practice websites in response to guidance produced by NHS England in their Delivery Plan for Recovering Access to Primary. The report identified



the importance of flexibility in approach meaning that - though those who are able to use digital means should be encouraged to do so - nobody should be at an advantage or disadvantage based solely on how they contact their practice. Our findings suggested that there is still some way to go to realise this vision of equity of access and, for this reason, a multichannel or agnostic approach ensures a level playing field. People have told us that they continue to experience difficulties in accessing appointments.

"I am waiting to book in my flu jab. I tried to call, but the phonelines are always engaged or I am number 46 in the queue. I recently had an infection that required long term treatment. So, I had some tests done to make sure that it hasn't affected my liver and kidneys. Because of this I need to book an appointment with the same doctor I spoke to initially, but I can't get through on the phone. I don't want to go digital though, I want to speak to someone.

222228, Surrey resident

"[My GP practice] will only let you book on their website. It's open from 8-3pm, which is longer than it was. They will book an appointment for you if you call but it means hanging on the line. I went for my 9am face to face appointment this week and when I got there, the receptionist told me that I hadn't got an appointment. I showed them the text confirming the appointment, but she said that it hadn't been written down and the doctor was too busy to see me now. So, I had to go home. I then got a text asking me for feedback on the appointment that I never had. You couldn't make this up, could you?"

215306, Surrey resident

This issue is compounded when people want to see a named doctor for continuity.

"I would like to be able to see the same doctor. I find it difficult to trust someone new. It's also such a palaver getting an appointment face to face. I had a telephone appointment which I waited 2 weeks for and when I had it, I



was told that I'd need a face to face but couldn't have this for 2 weeks. So, I waited and then had it. I asked to discuss another issue and was told that I couldn't. I would have to make another appointment for 2 weeks' time. So now we're 6 weeks down the line. Why couldn't they just have dealt with everything in one appointment. I have mobility issues and so getting to the surgery isn't easy."

215308, Surrey resident

People also told us that the lack of flexibility around appointment booking processes and timings made it difficult for them.

"I'm a school teacher and it's really hard to ring as I work 8am – 6pm. Even if I do have time, I don't want to ring during work hours as others will be able to hear. However, I have been able to get an appointment when I've needed it, but have had to hang on for 40 minutes, which is not possible for everyone and not if you're ill. My neighbours have elderly parents, and they gave up trying to get an appointment and then he was in hospital with sepsis."

218175 Ash Vale resident

However, when access was seen to be purely channel agnostic, it led to a positive experience.

"I use a mix of online/phone for making appointments. I've used the NHS App as well. The systems here at [the surgery] are easy to navigate. Sometimes I even just pop in, they will always make an appointment for you however you want to make it."

222683 Lightwater resident

"I have no problems in getting appointments with [my surgery]. I don't use E-consult and find the easiest thing is to call into the surgery or ring them. I don't have a smart phone, and my mobile phone does not have a very good signal where I live. This means that I use my husband's phone to deal with the surgery and any other medical people."

212923, Camberley resident



Lack of communication to help people understand their medical conditions

People reported finding a lack of information to explain their condition and treatment plan, compounded, in part, by short appointment times which didn't allow for enough discussion to aid understanding.

"Last autumn I suffered from swollen feet and had some blood tests and was told I had diabetes. At the time I was given two leaflets and said I would be referred to the Diabetes Course...I just wanted to sit down with someone who would be able to explain it all to me, what it means and what I should do. Since the diagnosis I was contacted by the surgery and told to attend an appointment with the nurse for a blood test to check my blood sugar levels. I went with a lot of questions that I wanted to ask her, but she had assumed that I was there to have my asthma check up (as she is the nurse that deals with this) which wasted some of the appointment. She was running late, and you only get 10 minutes with a nurse for these types of appointments and while she tried to answer some of my questions it was very rushed. She did try to explain it by writing down what my blood test results meant and what they should be, however I found this really confusing when I read it back. It would be good if I could book a longer nurse appointment for those times that I want to discuss in more detail what I should be doing for my different medical conditions."

212922, Camberley resident

"I made the appointment for today here last week. My wife has Dementia, and I look after her. My son comes in on a Saturday to help. The GP diagnosed her two years ago and left us to it. My wife is incontinent and needs pads, but I don't get them through the GP, I use homemade ones. I want to keep things as is though. I have pride and want to look after her. I don't want her taken away. We were given a Dementia booklet, but I can't read it – the print is too small."

222685, Lightwater resident



Registration confusion

People reported confusion around GP registration and boundary limitations.

"I moved and looked into GP surgeries. I really don't want to go to [my nearest practice]; the reviews online are awful and local gossip in the village is rife with issues. I've contacted [the next closest which is in Surrey Heath] and they say they are full; this is where I really want to go. [Another] says I am out of the boundary; I'm only 1/2 mile from [there] and [a 4th practice] say no. So, I'm trapped."

221997, Chobham resident

"The boundaries have subsequently changed. If patients move home to the Chobham/West End area they are now asked to leave Lightwater. Most of their new registration requests are now from the Camberley surgeries, from patients who are struggling to get appointments more locally to them."

222680, Lightwater resident

Effective referral and diagnosis pathways

People spoke to us about efficient referral and diagnosis pathways which led to fast follow up treatment and patients feeling that there were being actively listened to.

"Recently had to have major surgery. I was referred to a consultant urgently by my GP and within 24 hours I had had half an hour telephone appointment with them. Then was referred for a full colonoscopy which showed that I had severely infected haemorrhoids I needed surgery to rectify these."

222680 Lightwater resident

"I have been in a lot of pain with my thumb. I was triaged by a nurse at the surgery and referred for physio. Whilst having the course of physio treatment, I mentioned to her that I was having problems with my shoulder which was quite painful.



She was concerned because it was both shoulders, not just one, so didn't seem to think that it would be a pulled muscle. She referred me for a number of blood tests and, as a result, polymyalgia was diagnosed. I have been on a course of high dose steroids since October and I'm slowly decreasing these with the help of the practice nurse and my GP. I get regular checks for my blood and I'm really thankful to the physio who listened to what was happening to me and for the treatment."

212923 Camberley resident

Experience of secondary care

Poor discharge planning

People told us that they felt there was a lack of consideration in discharge planning for the people they care for.

"My husband has had 9 inpatient stays since January 2024, so 9 discharges. His stays vary from a week to over two weeks... Every time my husband was discharged no one ever spoke to me and asked me how I was going to cope. They came up to him when I wasn't there and said, "Do you want to go home?" and, of course, he said, "Yes", and they said, "Have you got anyone at home?" and he said, "My wife". He does say to them that I can't do a lot, but they ignore it and say, "Oh, I'm sure you'll manage", or words to that effect."

222514, Surrey resident

This case was referred to the System Quality Group for Frimley Hospital in October 2024 under the theme of carer support during hospital stays.

"My mother is currently in [hospital] a fall. She lives in her own home but did have carers going in before she had her fall. I'm dreading her coming home. I don't have a good relationship with her, but I'll be expected to do things for her. The carers that she had before weren't very good and that's why I had to do things as well... I was also helping my neighbour up to a couple of weeks ago. He has since died



and he had a terrible time. He lives on his own. His daughter lives abroad and did come and stay with him briefly but then went home. He was discharged from Frimley and had carers come in. He couldn't sleep in his bed, so was on the sofa downstairs. No Occupational Therapist came to see if the house was suitable for him to come back to alone.

222096, Waverley resident

The carer of this Waverley resident was signposted to the PALS at Frimley Park Hospital.

"My Dad is 91, has dementia. He was admitted urgently to [hospital] for 3 days on an insulin drip, to return him to 'normal' levels. My Mum was just sent home with him and the tablets, with no guidance on the relationship between the medication and his diabetes. In addition, he returned home from hospital with Covid, although the paramedic from [the GP practice, who was called out, did not diagnose this. His symptoms screamed Covid to me, so I bought a test kit and, yes, they both had it. I realise that all the medical resources are under such pressure that things get missed, but to send home a 91 year old man with dementia and a previous history of a hospital admission for his diabetes, with steroids that were, seemingly, extremely likely to cause a rapid decline in his health, with no guidance, seems remiss. " 221999, Chobham resident accessing services within **Surrey Heath**

Unsatisfactory complaints handling

We also heard that people don't think their complaints are being handled satisfactorily, echoing the findings of our November 2023 report, 'What we're hearing about Frimley Park Hospital'. In March 2024, we produced a report about hospital feedback mechanisms which identified that people didn't fully understand the role of PALS and how to access this service.

"I didn't complain to PALS. I did probably 3 or 4 years ago, and I got the ward manager telling me off. I haven't had any



reply regarding request of discharge policy. It was someone else who was told that was what was needed."

222514, Surrey resident

"At hospital the nursing care was superb. The discharge procedure was terrible. The PALS service is useless; I wrote to them and all they said was that they had passed my concerns on. I didn't get a proper response."

221995, Cranleigh resident

Spotlight on Frimley Park Hospital's Emergency Department

Urgent Care Centre

In our August <u>Insight Bulletin</u> we featured a spotlight on urgent and emergency care services which sought to identify the drivers and barriers for people to attend the Aldershot Urgent Care Centre (UCC) and Frimley Park Hospital's Emergency Department. Our research since then identified:

- There was a lack of awareness of UCC which was expected at the time as this service was being piloted.
- Most people had been referred to UCC by their GP rather than directed by A&E.
- Most people said they wouldn't have considered A&E for this episode of their care

Since then, the pilot phase for the UCC has ended and the decision taken to locate it on the Frimley Park Hospital site as part of the Urgent Treatment Centre (UTC).

Emergency Department

The following case study adds to the findings presented in the August bulletin with the following issues:

- Long wait times before being seen by a doctor
- Unsuitable waiting conditions for person's specific needs
- Being discharged early without a full diagnosis



 Carers feeling like the person's condition is not being treated with the care and urgency it requires

These issues are highlighted through the following case study:

"On April 22nd, 2024, an ambulance was called after my elderly mother woke up with chronic diarrhoea, vomiting, a high temperature and very bad shaking. On the advice of the paramedic, she was taken to Frimley Park hospital. After having some preliminary tests, she was placed in a trolley bed in the corridor and waited several hours until she was taken for an X-ray. After this she was placed back in the corridor. She asked for something to eat but was not given anything. Although she was given a hydration drip, she waited around 4 hours in total until there was an examination room free and she then saw a doctor. The doctor's diagnosis was that my mother had a viral infection which would, after time, go away. She was told to wait for paperwork and then she could go. After 30 minutes we still had not received any paperwork and when we inquired, we were told that it would be sent via email. She was released the same day from hospital with no paperwork. The next day she received a call from a hospital doctor informing her that she needs to return to the hospital. No urgency was expressed at that time. My mother returned to the hospital at 4pm and eventually saw a doctor who informed her that she had a 'bug in the blood' and an Infection in the lungs and needed to be admitted. She spent some time in 2 different waiting rooms. At the 2nd one she was given an infusion. At 11pm, due to a shortage of beds, she was given an examination room with a hard, high couch. The was uncomfortable and very difficult for her to get on and off. During the time from arriving at the hospital to being assigned to an examination cubicle (4-11pm) she had to use the public toilet in the A&E waiting area which was very difficult given her mobility, nausea and chronic diarrhoea. She managed one successful trip to the toilets but on the second trip she could not make it back to the cubicle, feeling giddy and was sick in the corridor. Luckily a male staff



member saw her, stopped her from falling and helped her back to the exam room. Almost immediately she was taken to a private room that was free, that had an adjoining toilet. As she still had diarrhoea she had to go to the toilet frequently. One trip to the toilet she lost her balance, slipped and banged her head."

215562, Surrey resident

Spotlight on breast cancer services

In October 2024 we were invited to attend the Secondary Breast Cancer Care Support Group run by Breast Cancer Now. We talked to nine ladies about their experiences and identified four key areas of frustration:

- Scans
- Attitude of Oncologist
- No Clinical Nurse Specialist (CNS) at Frimley Park Hospital (FPH) for over a year
- · Lack of information shared about secondary breast cancer

Scans

Scans were either not being requested and/or people were waiting 4 – 6 weeks for the results. This had a detrimental impact when the results are needed for a 6-month review with the oncologist. There was frustration that this is not an automatic process and on several occasions the individual had to request this themselves:

"You need to have a scan before seeing your consultant. If I didn't chase it, my consultant would be asking me why I didn't. When I was first diagnosed, the breast cancer nurse was great – she did all the chasing for me. It's all admin and sometimes you just don't feel like it."

"It used to be that you couldn't book a scan appointment until three weeks before your appointment to see your consultant which is not enough time to get the results; it's easier now I'm on "three months" but is harder if you're on "six months"."



"At the consultant oncologist appointment, we should get the results of the scan, and this is often not available for the appointment. When I'm told I need a scan in 6 months this has to be requested I month before. This does not happen automatically [by the oncology team] and I need to chase."

Attitude of oncologist

The group wanted to talk about their experiences with their oncologists, which weren't always positive.

"No empathy, no bedside manner. The other doctors will hold your hand."

"The consultant is cold - still my consultant. Makes me feel as though I have no hope. I was not well enough to complain. There was no positive spin on my diagnosis

"... just treats the symptoms, not the person."

We did hear some positive stories, however.

"The doctor will say, "you've got secondary breast cancer, but you also scored 8/10 on... I don't know what that means, but they also put a positive spin on things. They have been known to phone me just to see how I am doing."

No Clinical Nurse Specialist (CNS) at Frimley Park Hospital (FPH) for over a year

We heard that there is only one Clinical Nurse Specialist (CNS) for Breast Cancer and there was frustration that that there was no CNS for secondary breast cancer.

"They don't even have a complete list of secondary cancer patients. Primary to secondary should just be an extension but it isn't. It's like black and white. They rarely do surgery on you when you're secondary. There are at least three CNS in primary but only one in secondary; I'm not sure why. We've



got a spread of people who have been living with secondary in this room from 9 years to 18 years."

They talked about the importance of the CNS:

"It needs a Breast Cancer CNS to sit with the patient when they get a poor prognosis."

"When the consultant left, there was no one for me to talk to."

Lack of information is shared about Secondary Breast Cancer

We heard that information about secondary breast cancer was not forthcoming, and people were not given information about where they could get support.

"When there was a CNS, I was given an envelope, and it was an invite to join this support group. Then the group was 29 people but now there are no new people. They need to pick up sending the letter again [but who would do it?]."

One participant told us that they had missed a number of MRI scans because they had not been included in an NHS England Secondary Breast Cancer list and felt their outcome would have changed if there were yearly MRI scans.

"For me, it's not knowing what to look out for. I was 39 when I was first diagnosed but thought I had a trapped nerve for a year, but it was cancer in my hip. NHS England say we should all have regular MRIs. I was told, "Sorry, but you've been missed off the list since 2003". That's 20 years. There are 1,400 people who have been missed off."

The participants felt that better communication was needed between hospitals, within hospital teams and with patients, and that telephone consultations caused increased anxiety.



"I had a telephone consultation which was set at 11.40 but I received the call at 15.15. Why couldn't someone have told me there was a delay?"

"My stress level is raised and when the call says, 'No Caller ID' I don't know who is calling."

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 on these visits/during our engagement sessions and to all those who welcomed us on our community visits.



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

Website: www.healthwatchsurrey.co.uk

Phone: 0303 303 0023

Text/SMS: 07592 787533

Email: enquiries@healthwatchsurrey.co.uk

Address: Freepost RSYX-ETRE-CXBY, Healthwatch Surrey, Astolat, Coniers

Way, Burpham, Guildford, Surrey, GU4 7HL.

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IM <u>Healthwatch Surrey</u>





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 <u>our video</u> 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.



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

Registered office: GF21, Astolat, Coniers Way, Burpham, Surrey, GU4 7HL.