
What we're hearing about East Surrey Place

September 2024



"My husband needed a GP appointment recently; I went to the messaging service online and it had all changed. It's now via the NHS App and it's only between 8 and 10am. We are both quite tech savvy but there are so many changes to the way things are done, and you can only find out about them by learning for yourself. Communication is key and it would be good to send out a text every now and again to explain/refresh what the booking processes are. Tell patients what we should be doing as otherwise we don't know."



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Report overview

This report provides insights into local people’s views on, and experiences with, health and social care services across East Surrey. It is based on what people have told us at a series of engagement events in the area, as well as enquiries to our [Helpdesk](#), between March and July 2024.

Our report focusses on:

- Experiences of General Practice
- Spotlight on East Surrey Hospital
- Experiences of Adult Social Care
- Experiences of CAMHS and mental health
- In the East Surrey community

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.

Summary and recommendations

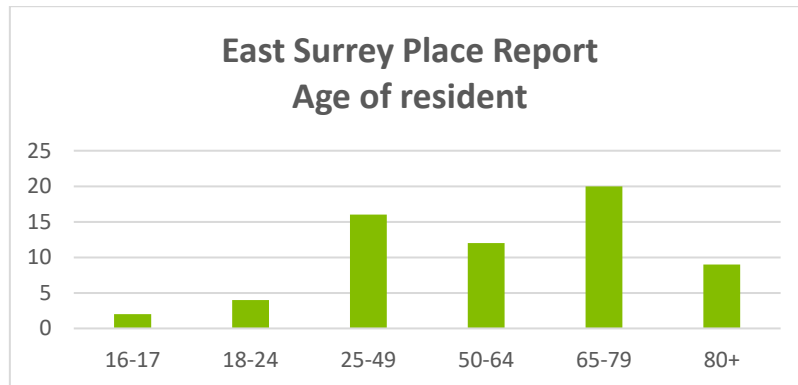
The following table shows evidence and recommendations for the themes highlighted in this report.

Theme	Evidence	Recommendations
Experiences of General Practice: Poor communication about process resulting in barriers to care	People being unsure about the process. Page 6.	<p>We recommend that local providers of care consider the following:</p> <p>Clear information is given:</p> <ol style="list-style-type: none"> 1. To patients by all members of staff (including clinicians) about process to book, cancel appointments and to order medication. 2. About any action a patient must take to follow up on their care (when told a GP will follow up)

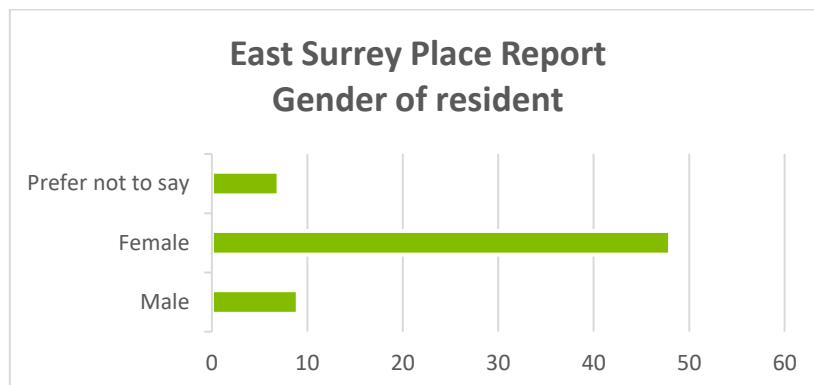
Experiences of General Practice: Ordering new or repeat prescriptions	People unable to find out if the prescription request has been accepted or rejected. Pages 8 and 11.	3. GP practices given support to develop a 'how to' guide clarifying the process for repeat prescriptions in their surgery. To include clear information when a prescription has been approved and action when rejected
East Surrey Hospital: Poor environment in some ward areas	Case study 1: Mixed experiences in cardiology. Pages 15.	4. Review trip hazards and ensure risk assessments carried out 5. Ensure that bedding is fit for purpose
East Surrey Hospital: Staff attitude and communication	Case Study 1 and 2: Staff attitude and clinicians not listening. Pages 15 and 17.	6. Clinicians given support to understand the importance of listening to patients and relatives/carers
Experiences of community services and communication with carers	Case Study 3: Carers experience of support for parents. Page 23	7. Review the pathway for the provision of incontinence pads
Experiences of Adult Social Care	Carers of people understanding the process for receiving care and requesting a review. Pages 24 to 26.	8. ASC given support to develop a 'how to' guide which clarifies the process for obtaining social care. To include clear information about the review process.
N/A	N/A	9. Sharing any other actions related to the experiences presented within this report.

Demographics:

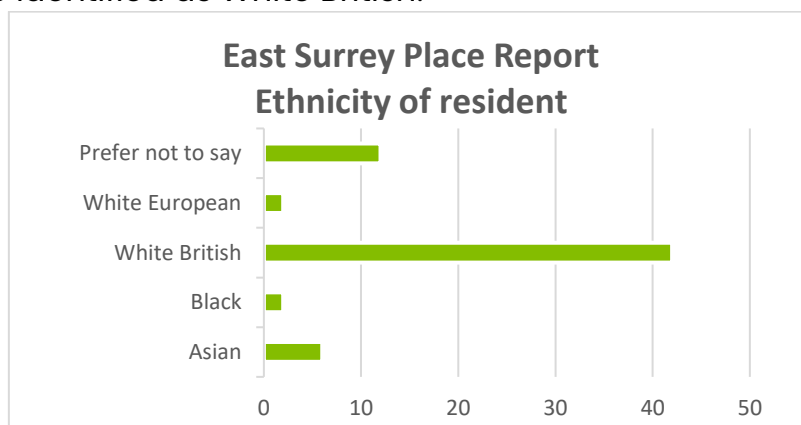
64 people gave their consent to share their experiences in this report. We heard from people of all age groups; the majority were from the 65 to 79 group.



Most people we spoke to identified themselves as female. A few people preferred not to share their gender.



Most people identified as White British.



What we're hearing about:

Spotlight on General practice

Virtually every person we spoke to has needed to contact their local GP practice at one time or another, resulting in GP practices being one of the 2 most talked about topics in East Surrey. In general, we have heard about how easy or hard the processes around accessing a GP practice have been for patients.

We visited Lingfield surgery in July 2024 to hear from their patients, we also gathered experiences from people in our other engagement events across East Surrey. Experiences are about several GP surgeries, and we have consistently heard the same themes:

Contacting GP practices, digitally and by phone.

We have heard from people who have found contacting their GP Practice simple and efficient:

"When I phone for an appointment, they get back to me same day, always really helpful, triage always call the same day, GP has helped me with referrals and tests."

210923 Banstead and Reigate resident

"Very happy with my surgery, easy to access, I call on the phone or walk in and get a face-to-face appointment or telephone call."

210921 Banstead and Reigate resident

However, we have also heard from some people who feel that practices have gone 'completely online'. People have told us about using/not wanting to use the NHS App. Our Engagement Officers have been explaining the NHS App and signposting to tech support at local libraries or Tech Angels (provided by Surrey Coalition of Disabled People).

"There's no problem getting a GP appointment when you really need one. However, they have just changed their system to needing to complete a form, so not sure how that's going to go. Not sure I want to do it online and some

people can't. I do need to make an appointment, but it's putting me off, it sounds daunting."

241921, July, East Surrey resident

"I tried to use online forms before, but with real difficulty. They don't work at night. The NHS App is hopeless, and the surgery said not to use the App as it doesn't work properly with them. I would like to be able to make appointments for 2 or 4 days' time. You can only get appointments 2-3 weeks in advance, or same day."

219257 Tandridge resident

"I do have problems with the phone system. The call back system doesn't work – it will keep cutting you off, so you have to keep ringing back."

219258 Tandridge resident

"We don't go to the GP very often but my husband needed an appointment recently, I went to the messaging service online and it had all changed. It's now via the NHS App and it's only between 8 and 10am. We are both quite tech savvy but there are so many changes to the way things are done, and you can only find out about them by learning for yourself. It would be good to send out a text every now and again to explain/refresh what the booking processes are. Tell patients what we should be doing as otherwise we don't know."

211009 Tandridge resident

Frustrations around processes

We heard frustrations expressed by patients around overly complex processes, and the need to chase results. Some examples of what we've heard are:

"I would say we are not unhappy with the health centre; the care is excellent but the barrier for all patients is the first step of getting 'in' to be seen or to speak to someone. I had some tests recently at East Surrey Hospital and I needed to be followed up with by the GP to be referred for a scan. They wrote a letter to my named GP at the surgery but I'm not

sure anything would have happened if I hadn't prompted it. When the hospital say GP follow up, they need to say 'you' need to follow up with your GP rather than putting the onus on the GP and you waiting for them to proactively contact you. The onus is on the patient at every step now, but I don't think people realise."

211009 Tandridge resident

Communication from reception staff

We were also contacted through our Helpdesk to support someone who saw poor communication from front line reception staff as a barrier to care:

"A few weeks ago, I had a potentially cancerous mole removed from my head. A pharmacist today said he did not like the look of it. Accordingly, I attended my GP practice to seek an appointment. This was refused by the receptionist. She stated that I had to use the new online system. But this only has about 5 categories of illness and mine was not one of them. So, I could not get an appointment online. This system has unquestionably been introduced to prevent older people and people who are not good with technology from getting an appointment. Unfortunately, it is almost impossible to get through to the surgery on the telephone."

219259 Tandridge resident

Confusion over prescriptions

People have told us that managing medications is being made more difficult by repeat prescription delays and confusion about the process.

"As arranged with my GP, I received a text asking for a response to stopping one medication. My reply was unable to be delivered. I had to use the NHS App, choose 'request an appointment' to type my reply. I needed clear instruction on how to respond to a GP text and a system that works. I was very unhappy that I had to spend time sorting it out."

218473 Tandridge resident

Registering as a patient

The person below experienced difficulties trying to register with a different GP practice. We signposted to the practice website to the feedback form and complaints process and support as well as Surrey and Borders Partnership Trust Mental Health Crisis line and Samaritans as he mentioned depression.

[Independent Health Complaints Advocacy - LUMINUS \(luminus-cic.uk\)](https://www.independenthealthcomplaintsadvocacy.org.uk/)

“I have a massive concern which has obstructed me to go to any GP in the UK. I registered with a GP in 2022 in Redhill which put me as deceased or dead person in my medical history. I talked to them several times, but they are not being helpful, rather pushing me away and giving a lot of excuses. Meanwhile, due to that deceased medical history, none of the new GPs are admitting or registering me. I am really in depression with current situation as I am not able to have any treatment.”

215536 Redhill resident

Accessibility and consideration of special requirements

We heard about the difficulties in this person getting a COVID-19 vaccination for her sister who is housebound.

“My sister is 88 and housebound. She has dementia and is waiting for a cataract operation. I'm her live in carer. She needs a Covid vaccine but needs someone to come to the house to give it to her. I've phoned the GP practice, but they've said they don't deal with Covid vaccines. I was advised that if she isn't on the official 'housebound' list with them then her vaccine won't have been triggered.”

215665 Tandridge resident

Praise for GP practices

We were pleased to hear positive experiences during our visit to Lingfield about the Lingfield GP Surgery. These related to prompt referrals and examples of good quality care.

"I had a good experience at my appointment today. It was bang on time. The appointment was easy to make by phone, on the same day."

219257 Tandridge resident

"I had an appointment this morning which was pre-booked following the removal of a suspicious mole. I have one more appointment booked. I use the online form to make appointments. The staff here are all great."

219258 Tandridge resident

"I have a problem with my eyes. I'm blind in one and susceptible to eye infections in the other. I was able to get an appointment with my GP and get antibiotic drops. Satisfied with care and accessibility of appointment."

218927 Tandridge resident

"The surgery here is so good. I can't say enough good things about it. I'd give them 10/10. If you need an appointment, come in the morning and they'll get you one if they can. I came in once for an appointment about earache and went out with blood pressure taken, diagnosis and treatment. They are very thorough. The pharmacy at Boots is also excellent. Between the two they will sort you out. They liaise well together. This morning, I picked the wrong box for medication for prescription renewal and I have run out. The GP is liaising with the chemist to get me new medication for tomorrow."

219259 Tandridge resident

"GP service. Excellent. Always seen when required within a few days. Very holistic care and I know the GPs do care about their patients. I couldn't recommend them highly enough. The practice lead doctor is second to none. A shining star."

212925 East Surrey resident

This person has a learning difficulty. They described how the manager of the home he lives in contacts the GP practice on their behalf with the result being easy access to the GP. They felt listened to and well supported.

“I live in a supported house and the home manager phones the surgery on my behalf. I am unable to do online and have difficulty speaking on the phone.”

218928 Tandridge resident

Spotlight on Pharmacy: the value of pharmacy

In recent months several pharmacies in Surrey have closed. In East Surrey we did not hear of any experiences relating to pharmacies closing but we did hear about a provider change to the Lingfield Pharmacy; experiences were mostly positive.

“I use Boots in Lingfield. They used to be bad, but something changed about 6 months ago, and they are now good.”

219258 Tandridge resident

“The pharmacy at Boots is excellent. Between them and Lingfield Surgery they will sort you out. They liaise well together.”

219259 Tandridge resident

“Boots is the only pharmacy in Lingfield and there is always a long queue. I know they do their best. I’ve not been affected by shortages.”

219259 Tandridge resident

“My GP surgery [name given] has merged. It’s a terrible service leaving my wife, who has Alzheimer’s, without medication. The patient app we’re supposed to use is useless. I can order my wife’s medication but there is no way of finding out if the request has been accepted or rejected. When I call them about it, they say they’ve never received my request. I asked the chemist, and they’ve put in a request and the practice have never completed the request either. These include sleeping tablets for my wife- she needs them

otherwise we're both up all night and I'm her carer. The practice knows she has Alzheimer's, but I don't think they recognise that I'm her carer. I've never been offered any carer's support. Her needs must be prioritised above mine."

212924 Tandridge resident

We signposted this person to the NHS complaints process and IHCA support as well as Action for Carers for support.

In April 2024 Healthwatch England released their report "[Pharmacy: what people want](#)" exploring the current state of pharmacy services and offering recommendations for healthcare leaders and the wider sector. The report is based on a national poll as well as interviews undertaken by local Healthwatch, including Healthwatch Surrey.

In addition to contributing to this national report, we have also been working with communities in Guildford and Waverley and Thames Ditton) to explore how people have been affected by recent closures and what people want from their local pharmacy provision. We will be using this insight to inform our position as part of the Pharmaceutical Needs Assessment steering group in the coming months.

[Pharmacy closures: Impact on Surrey residents - What we're hearing about pharmacy provision \(summary\) - Healthwatch Surrey](#)

Findings at a glance:

- Residents **value the service and clinical expertise** which their local pharmacy can provide – this supports the [Healthwatch England report](#) which found that pharmacies are often the most visible and accessible part of the health system.
 - 64% of people would consider going to their pharmacy instead of their GP practice for minor illnesses or health advice.
- The impact of the closure of one pharmacy on the alternative provision in the area is a huge concern for local residents – if alternatives don't meet their needs in terms of capacity, space or opening hours **the value of the service is hugely reduced.**

- **Travel distance from home** is the most important core indicator for people when visiting a pharmacy, but this is more complex than a crude mileage value – **people need to be able to walk or have reliable / accessible / affordable public transport options.**
 - The ease of getting to a pharmacy impacts how often 71% of people go.
- Good customer service is also considered to be critically important, but people’s **confidence in this is eroded if a pharmacy is seen to not have sufficient capacity.**

Spotlight on East Surrey Hospital

We also heard a lot of feedback about hospitals, with most experiences related to East Surrey Hospital. We heard mixed experiences of Accident and Emergency and inpatient care. Communication to patients, clinical care and staff attitude remain the top themes and we heard experiences of communication from the hospital from the perspective of carers.

Praise for quality of care

We heard experiences of good care at East Surrey Hospital. We heard how 1 person was fast tracked under the faster diagnosis standard and how communication was good. We also heard a positive example of good stroke care.

“I was fast tracked on a 2-week period for blood in urine with no other symptoms. Referred by GP, phone call the same afternoon with an appointment 9 days later for a cystoscopy. I received a phone call 3 days later with an appointment for a CT scan with dye. This was on day 13 after referral. Results were given to me over the phone by cystoscopy doctor 4 days later. I was very impressed.”

211784 Redhill resident

“I had a stroke and heart attack in last year and went to East Surrey Hospital which was a good experience. Then I went to Queen Elizabeth Rehab centre, and it was decided I could not go home to my sheltered accommodation in Reigate. I went to a residential home where I am very happy.”

218926 Tandridge resident

Experiences of Accident and Emergency at East Surrey Hospital

Accident and Emergency was the hospital department that people told us about the most. We heard about the breadth of care this vital service offers patients, often under intense pressure. We heard praise for the care received. However, we also heard that communication and clinical decisions during busy times could be improved, illustrated below:

“I did have to wait at A&E a few weeks ago for 4 hours but in that time I had blood tests, scans. And the parking there is so much better than it used to be.”

219254 Tandridge resident

“I was told me to take my husband to the hospital as his nose would not stop bleeding. Accident and Emergency was packed, no seats, screaming patient and no info about how long we would have to wait.”

211078 East Surrey resident

“My son sustained an injury whilst playing football. After 10 days it was not improving so I took my son to the GP who advised me to take him to Accident and Emergency. I was given information regarding what tests/treatment would need to be carried out, in the opinion of the GP. We were sent home from hospital with painkillers and advised there was no fracture... his condition deteriorated resulting in a temperature and more pain in his leg, so I took him back to Accident and Emergency later the same day and the doctors found his Sepsis makers were raised. I feel that if Accident and Emergency had taken on board what the GP had advised, my son’s condition would not have got worse, and he would not have needed antibiotics for an extended period and resulting in an abscess needing to be drained under a general anaesthetic causing great and unnecessary anxiety.”

212670 Reigate and Banstead resident - Independent Health Complaints Advocacy

Inpatient care at East Surrey Hospital

We heard mixed experiences of inpatient care. We heard that staff were friendly, and people referred to how stretched the services are.

“The staff were friendly and attentive, making sure she [relative] is comfortable and well informed about the procedure. The experience for knee surgery was efficient, professional and caring and highly recommended.”

211309 Reigate and Banstead resident

We heard that some people had negative experiences.

“My mum was in East Surrey in December 2023 for 6 weeks. During that time, we had to repeatedly ask for information, repeatedly prove that we held Power of Attorney for her. She had her hearing aid locked away, (which we were told was lost) and when we got a replacement that got locked away too (which is how we discovered the first missing one). She was left in dirty clothes, crying in pain, and discharged to [a care home] with 3 sacral pressure sores, 1 pressure sore in her ear, bruising and oral thrush. None of this we knew about until she arrived there and were shown the photos. She died in February 2024.”

213860 Reigate and Banstead resident

Case study 1: Mixed experiences in cardiology

Some people had a mixed experience during the same inpatient episode.

“I recently suffered a heart attack and was taken to East Surrey Hospital. I was taken immediately to the cardiac emergency room and the staff there were wonderful. Later, as I was recovering in a side ward the consultant came to see me and said I was still in Atrial Fibrillation but doing well and it wasn't long before I was taken to Holmwood Ward. The nurses there were very hard working, but everything was obviously at full stretch. The sheets were torn, the loos only worked intermittently, the air conditioning didn't really work at all.

Very early the next day a junior cardiac doctor came and said I should have 'a pacemaker' and they could do it later that day, if I agreed. I said I would like to consult with my family first so he said he would come back by lunchtime for my decision. I struggled out to find an area where I could get phone reception. My daughter came and said she had also asked other members of the family, and we all thought, 'yes, let's go for it'. So, then she and I waited and waited and waited, but nobody came for a decision, and by nightfall we thought it would be better to at least wait until I wasn't so stressed and also had some more information on what having a pacemaker would mean.

I wasn't seen by any doctor, and by evening the next day my general condition was so bad that the nurse phoned my heart and blood oxygen levels through to the cardiac department and I was hastily moved to a different ward. Here, there was more air and space and indeed it seemed more like a private ward. Though I had the distinct impression I wasn't welcome, I've no idea why. I was feeling very tired and miserable, I had a migraine overnight and asked for an ice pack and some aspirin but was told a doctor would have to ok it. When my daughter arrived, I told her I just wanted to go home. A ward doctor came and asked if I wouldn't like to wait and discuss it with a cardiologist, but my daughter and I said we had waited 12 hours for a cardiologist, and none had appeared so we were not confident that waiting would do anything useful.

Lunches arrived, but they wouldn't let me have mine as I was 'going'. Two hours later my daughter put her foot down and said we were not going to wait any longer for the discharge papers - this brought a panic-struck junior doctor from cardiology to say he needed time to prepare the report, but my daughter said to email it to us, and we left.

Once home I slept for 12 hours and later agreed with my family that if I had another heart attack, I didn't want an

ambulance called, I would live or die in the comfort of my own home.”

213982 East Surrey resident

Case Study 2: Staff attitude and clinicians not listening to me

“Inpatient care has been appalling for both me and my husband. They ignored clinical signs of sepsis, and we were very lucky to get away with our lives on separate occasions. Surgeons extraordinarily rude on both occasions when we were admitted. They were arrogant and not caring and would not listen when we voiced concerns regarding rising blood levels which indicated internal infections (I am an Allied health professional advanced practitioner, but the surgeons did not take any notice of me - in fact, one called me a pseudo medic and what did I know?). If I had not asked for a different surgeon after being in hospital for 4 days and in extreme pain I would have died. This is not an exaggeration - the second surgeon told me this.

Accident and Emergency – unfortunately I have been there several times. The experience has been mixed. The nursing staff are excellent and do their best in the extremely difficult circumstances. The care by various medical professionals again has been varied from ignoring symptoms leading to sepsis but excellent when I had sepsis second time. Staff in Accident and Emergency are overstretched, there are not enough beds in the hospital to admit people who need intravenous antibiotics. Mistakes are going to be made. The only point of salvation is the ambulatory emergency clinic where patients can be sent and admitted on a day-by-day basis. The treatment in there was excellent and extremely good from both medical and staff. The nurses do their best and show empathy. Some medical practitioners are arrogant, some are empathetic.”

212925 Tandridge resident

Waiting Lists at East Surrey Hospital

We heard about long waiting lists and people said that not knowing when they will be informed about an appointment can cause anxiety.

[Waiting for hospital care - Healthwatch Surrey](#)

“Hospital waiting lists are also important. It’s more about knowing how long you need to wait, what’s acceptable before you should contact them to check. And, about what you need to do whilst you are waiting. My son has an enlarged spleen and is waiting for an appointment at East Surrey Hospital. But how do we know that whilst we are waiting his spleen isn’t enlarging more, there weren’t any signs, it was discovered during a kidney check. What if we leave it too long?”

241921 East Surrey resident

Understanding of neurodiversity

“I’ve got 3 children all under 5. My middle child has Sotos Syndrome. He is non-verbal and has learning disabilities. He had a seizure, so we were blue lighted to East Surrey Hospital. He had meningitis. When we got to the hospital and I told them about him, I could hear the medics googling his syndrome. No doctor has ever heard of Sotos syndrome. I feel very on my own with everything.”

217121 Out of Surrey resident who uses East Surrey services

Estates/environment

The Healthwatch Surrey Helpdesk heard an experience about the ward environment at East Surrey Hospital:

“I was taking my mum to visit my dad in hospital. She is his carer. The corridor to Smallfield ward is like a building site and she tripped on the bad flooring, broke her hip and needed to have emergency surgery. It’s not just the danger to my mum, it is a danger to others. They’ve put down some brown tape and that’s it. It’s like a building site and has been for at least the 5 weeks that my dad has been in there.”

211713 Reigate and Banstead resident

Complaints

In January 2023 we produced a report which looked at the Independent Health Complaints Advocacy service ([Maximising the learning from complaints - Healthwatch Surrey](#)). We shared our findings to suggest best practice relating to complaints, including recommendations and suggested opportunities for further learning. Our recommendations were:

- We recognise that most providers do provide information about their complaints procedures on their websites but suggest ways this could be improved
- We recommend that where Advocacy services are provided, they are more prominent
- That during the complaints process, providers should communicate directly and on a regular basis with the person making the complaints

We continue to hear from people who do not feel that the communication during the complaints process is adequate. A number of people have complained about their experience to the hospital and not received a response. We also heard from people who were unhappy with their care and wanted to complain. They were signposted to the provider PALs and complaints service.

The person giving the following experience was unhappy about the pain management and pressure care for her mother-in-law during an admission to Accident and Emergency. She was assisted to draft a complaint email by the advocacy service, which was sent off to provider, and is awaiting a response.

“My mother-in-law was admitted to East Surrey Hospital via Accident and Emergency having had a spinal haematoma. She was in significant pain which was not managed well in the Accident and Emergency department and when she went for MRI's – she was in too much pain to lie down so they had to abandon it twice. We notified the staff nurse that she had been on a hard dining room chair for over 12 hours and being on a hard A&E trolley was risking her getting pressure ulcers. She did not receive any pressure area care for over 14

hours. We made a formal complaint in November and are still waiting for the trust to give us a date for a final response [April 2024]. My mother-in-law was independent and mobile until the day of her admission so had no pressure ulcers prior to admission to the trust. We made verbal complaints to the trust due to their lack of effective pain management – these were never recorded or effectively actioned.”

219259 Tandridge resident

“I have been suffering excruciating pain since 2018. On a cocktail of very strong painkillers, I can’t work, and this is now affecting my mental health and financial situation. My GP has been very good, written several referral letters. I have seen my consultant but feel that I am just being fobbed off and given medication and not getting to the root of the problem, and in the meantime, I have been suffering greatly. I have also been at Accident and Emergency multiple times for pain relief. I complained to East Surrey Hospital PALS and said the response was “too bad, there are big waiting lists, you will just have to wait”. I don’t know where to turn next.”

218182 Reigate and Banstead resident

We advised this person to speak to their GP about medication, to request the GP to expedite the referral to the appropriate pathway and they were signposted to the hospital complaints process.

Spotlight on CAMHS and Mental Health

In addition to our Healthwatch Surrey contract, which exists to champion public and service user involvement in the design and commissioning of local services, Luminus also holds the contracts for Giving Carers a Voice, Combating Drugs Partnership Public Involvement, and Independent Health Complaints Advocacy. This work builds our reach and expertise in understanding what people need and want from services, analysing and reporting this back in a constructive and actionable way to commissioners, thereby enabling people to have their voices heard.

[About Us - LUMINUS \(luminus-cic.uk\)](https://www.luminus-cic.uk)

As part of this extended work, we heard from parents how they have struggled to get mental health support and autism/ADHD diagnosis for their children.

“My 17-year-old son is constantly having a mental health crisis. I am on probation and really stressed with life. He is about to move under Adult Mental Health, it feels like no one will help. I can't cope with him. I am struggling. I wanted to go into a refuge, but they wouldn't take me and my son, just me. He is slitting his wrists. We were in Accident and Emergency this weekend. Last week he did 'spice'. It's all a cry for help as his mental health is not being looked after. It's easy for him to get drugs, he orders them like it's Deliveroo.”

**214176 Redhill resident – Combating Drugs Partnership
Public Involvement**

“Both my children [14] have ASD/ADHD. It's taken my daughter from the age of 8 to now [she's now 13] to get the ASD and ADHD diagnosis. She was referred to Mindworks after her paediatrician flagged her. She had had a cognitive assessment and was diagnosed with ASD, but the ADHD diagnosis was needed. We thought that we were on a waiting list and were waiting to hear what was happening, but no one had contacted us. Then at 13 she was again referred by a paediatrician to CAMHS for an ADHD diagnosis. We had to fill out more forms and then we waited for nearly a year to be told whether we would be placed on the waiting list. This is now nearly 3 years later. We have now gone privately to get the ADHD diagnosis. We are also paying privately for medication for my daughter. If we are referred back to Mindworks for this, there will be another long wait and my daughter can't wait. It's been 3 years since we were referred for a social care assessment, even though we have an Educational Health and Care Plan.”

218472 Redhill resident – Giving Carers a Voice

“I have 3 sons, and my youngest son is autistic. My son [19] is so stressed and freaked out. He doesn't engage much. Surrey Choices have been great. My son spoke to the GP

about his mental health as he's now over 18. He is now on some meds but I'm not sure if his anxiousness is anxiety or autism or both or a combination. The GP has been great with him and he is happy to talk to her about his mental health. I was relieved once he got diagnosed as at least now I can explain his behaviour. He has dyspraxia also. I had a carers assessment about four months ago as the transition team recommended it to me."

217775 Tandridge resident - Giving Carers a Voice

Carers support

Communication to families and carers is key to a safe and effective treatment and hospital discharge for patients. Poor communication can hinder discharge and prevent appropriate follow up care for patients.

In our [2021 report of carers experiences of discharge](#) we found:

- Carers are at a serious disadvantage. They are often unaware of assessment processes, how decisions are made and who has responsibility for what actions. They cannot contribute to the discharge and cannot quality check the discharge.
- These weaknesses can result in actual patient harm.

East Surrey Hospital responded to the report recommendations:

Proactively identify unpaid carers:

- Carer Awareness training is provided by Surrey County Council, Action for Carers Surrey and West Sussex Carers Support. Referrals to the carer support associations have increased over the last 3 years.
- The carers information page on Cerner updated to include additional questions, a text box for recording carers contact details, recording the issue of a carers passport and referral to the carer support services.
- Carers tab on the electronic notes system, rolled out to the whole trust and regular reports are run to identify if there are any wards that are not fully utilising the carers tab.

Review hospital / carer communications:

- Funding was received by NHS England and was successful launching the carers passport and increasing awareness. Referral

numbers increased and work is continued by the patient experience team to continue to build on this.

Provide professional handover to carer:

- To improve handover to carers we have added carer specific questions to the discharge checklist. Including that carers have been notified and are aware and agree to the plans for discharge. This went live in 2023, and the carer steering group will consider how to review the use of these discharge questions.

Spotlight on Community Health services

We heard about a person's experience with community nurses. This person was advised that the service is provided by First Community Health and Care and was given their details for complaints.

"He [relative] has 2 leg injuries and has been having visits by the district nurses. He had a call to go to the hospice to see his wife, so he got a cab to go and see her. Because of this he was told he is now mobile and therefore can go to the practice for his treatment. He mentioned he was unhappy with the way he was spoken to by the district nurses and that it was rude."

211708 Reigate and Banstead resident

Case Study 3: Carers experience of support for parents

We heard about difficulties when caring for elderly parents. They live on the Surrey border and use East Surrey services. They were signposted to West Sussex carers support, to contact local authority to arrange carer assessment for their sister and to contact their GP practice re: the continence team.

"I'm a carer for my mum [87] and my dad [90]. Mum came out of hospital [East Surrey] in March and was sent home and there was nothing else they can do. She is terminally ill so her care is fully paid for. Both mum and dad are still at home. Dad has dementia and we are paying £1300 a week for all his care. It's so expensive but my sister and I don't

want him to go into a care home. Mum and dad have some savings and my sister, and I are contributing too.

Both mum and dad are incontinent. Dad's getting through about 7 pads a day and they cost a lot of money. We've been waiting to hear from the continence team for over 6 months now but nothing. My sister took early retirement but now she is just looking after mum and dad. She's there every day for a couple of hours to give the carers their break. She's stressed out and exhausted with it all and needs a break. They've recently changed dad's meds as he was anxious and not sleeping. And that in turn was keeping mum awake, His new meds have made him like a zombie and now he is totally incontinent. I'm going to speak to the GP about changing his meds. I visit them every other day, but my sister is there every day. They get attendance allowance, and I think my sister is claiming carers allowance."

**216101 Out of Surrey resident who uses East Surrey services
- Giving Carers a Voice**

"My husband has MS [multiple sclerosis] so I'm a carer for him [in addition to my son with autism and dyspraxia]. My husband was diagnosed about 8 years ago and struggles to get up the stairs. The MS nurse came round 3 weeks ago and suggested getting a lift on the outside of our house as we don't want to move. The occupational therapist [OT] came after that too and even arranged someone to come and talk to us about that who said it would be possible. The OT is lovely and helpful. My husband is doing drug trials at The Royal London Hospital. He should have gone today but his transport didn't pick him up. He's gone downhill a lot lately. He does see his physio a lot too. "

217775 Tandridge Resident - Giving Carers a Voice

Spotlight on Adult Social Care

We heard through the Healthwatch Surrey Helpdesk from a gentleman who had previously spoken to POHWER, Independent Health Complaints Advocacy, Action for Carers Surrey, Age UK Surrey and Citizen's Advice. He

described how he is frustrated with Adult Social Care.

“When we choose a new agency, they change the goal posts. We have a weekly schedule for carers to come in for my mum. Adult social care (ASC) is saying the new agency must mirror the schedule. We didn't want that schedule. ASC never said that we can request a formal review. They won't tell us the correct process for getting a new agency or for getting a new schedule. Reigate and Banstead Locality team is our main contact, and we've told by one person [name given] they can help with a list of agencies to choose from, however another person [name given] says there isn't a list.

We had a terrible problem with the carers, and we reported [agency name given] to the CQC [Care Quality Commission]. The carers walked out and left mum on the landing in her nightie. Carer didn't put on clean sheets for 2 nights. Mum was sleeping on a dirty incontinence sheet. I live at home with my parents. I fed back all the issues to CQC. We take one step forward and the ASC put all these barriers in place they are contradicting themselves [with different advice from named people].

The schedule changed last week. They are happy with the revised schedule. ASC didn't listen. The also didn't tell us that we have the right to request a formal review under the 2014 Care Act. We only found out about it two weeks ago. Why did ASC say that the new care agency had to mirror the schedule that the previous agency had? Why can't we have a fresh start, with a schedule that fits my mum's needs. We have put up with doing it their way [ASC] for 2 years, why can't we have what we want now?”

214818 Reigate and Banstead resident

This experience was shared with the customer service team at Adult Social Care.

Case Study 4: Support for a looked after child

"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, however they now believe that he is possibly neurodiverse and has trauma.

I was told that I would need to go through the right to choose pathway for neurodiversity, which I did last week. 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.

My son sleeps all day, so although he is linked in with the YMCA, he can't access anything. He is on melatonin and has been for the past 2 years. I raised a complaint with PALS and had a letter sent to me in January saying they will send their response soon, but we have had nothing since.

217085 Reigate and Banstead resident

The above experience was shared with the Healthwatch Surrey Helpdesk who signposted support agencies and how to make a complaint.

Spotlight on the East Surrey community

Our community engagements are an opportunity to listen to people in person and offer information and signposting to residents. Visits to community settings such as local libraries and community cafes, along with visits to local community services, empower people who may not have had their voices heard to have their say. Whilst most of the feedback has been added to the general themes across East Surrey, we have also selected specific groups to share insight about.

A few people talked about the support given by the Redhill Muslim groups at Longmead Community Centre.

"I really enjoy coming to the women's group here, it is time for me. I enjoy the crafts and meeting others. I find out so many things by coming along and I can give back some of my own skills. I look after my husband but also have severe arthritis and fibromyalgia and listening to this conversation today, it makes me realise that I am an unpaid carer for my husband. I help him with day to day tasks and also all his medical needs and now my husband wouldn't be able to cope without me."

212325 Reigate and Banstead resident – Giving Carers a Voice

Another person described the support given to her by the Rainbow Group in Horley.

"I've got 3 children all under 5. My middle child has Sotos Syndrome. There is nothing out there for parents like us. I came to this group [Rainbow Group, Horley] and I found my people. At this group, I can be myself, the kids can be themselves. I'm not judged, and I can speak to other people who are going through similarly difficult situations with their kids. Since the diagnosis, no one has ever explained anything to us about Sotos Syndrome and what it is and what it entails. I feel alone and abandoned with a child with significant needs."

217121 Out of Surrey resident who uses East Surrey services – Giving Carers a Voice

One person told us how she values The Lost Sheep Autistic Support group.

"My son [13] is autistic and was diagnosed aged 3. The early diagnosis I think was really helpful. It's hard to know what is autism and what is just teenage boy. I come to this group as it's really useful to just chat to other parents and share our experiences. If I am having a bad day, I go online to a Facebook autism support group and I can chat to people on there which I find really helpful."

217774 Tandridge resident – Giving Carers a Voice

“My daughter is waiting for an ADHD diagnosis. I attend the YMCA groups as every time I attend, I come away feeling that that I have learnt something. The lady who runs the group really knows who to invite along who she knows would be useful to us all. My time as a parent carer is limited, so I don't want to waste what time I have going to groups that don't offer me something. I need things that will actually help me. One person [name given] is also so welcoming and she really knows her stuff and is so knowledgeable about things. She has lived experience and so knows the system. I know I can ask her anything and if she doesn't know she'll find someone who does. She really is fantastic. I am registered with Action for Carers but their groups tend to be further away for me.”

218472 Redhill resident – Giving Carers a Voice

Following a stroke and a period of rehabilitation this person was unable to return to her supported living.

“I am very happy in Charters Court. The activities carers take residents out to the Lingfield Church cafe, and they also do baking, games, outings.”

218926 Tandridge resident

“I am registered with Action for Carers. They are fantastic. I did their moving and handling course last week which was great. I'm also registered with my GP as a carer [for son and husband]. When I need more support, I go online to a Facebook group called “the other side of MS”. It's an absolute lifesaver, an absolute lifeline.”

217775 Tandridge resident – Giving Carers a Voice

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.



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.

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