“How to help...”
Exploring how mental health services can support emotional wellbeing
June 2018
Executive summary

As the independent champion for users of health and social care services in Surrey, we provide evidence-based insight into the views of local people that use those services.

In February and March 2018 our staff and volunteers enabled 70 people to share their views on a wide range of experiences of mental health services; including of mental health hospitals, of community-based services, as carers and as individuals from 19 to 65+ years of age.

What people told us

• The people providing mental health services are their best asset. If they fall short, or leave, the ‘system’ (however well-intentioned) cannot easily repair loss of trust and wellbeing.

• More problems stem from services being unavailable (or simply not known about) than being ineffective. Patients and carers often want to know the full scope of services and help available, rather than simply being told ‘this is what we’ll do’.

• When people with mental ill-health and their carers are involved in care plans they are substantially more satisfied with services.

• Around half of people accessing services in the last 18 months have not been involved in their care plan.
What should happen now?

1. Commissioners and service providers should review the way they assess the services they provide to ensure that they incorporate feedback reported directly by patients, on the issues that patients told us were important i.e. that they have:
   a. been involved in care planning
   b. been listened to
   c. been understood as an individual person
   d. had calls / messages / texts returned
   e. had consistency of advice
   f. had continuity of staff
   g. had swift access to care professionals (when needed)
   h. had swift access to staff with suitable expertise to offer effective specialist care.

In addition:

2. Commissioners should consider undertaking research to better understand what good information looks like to different people and carers at different stages of emotional wellbeing.

3. Commissioners should investigate the low level of people reporting involvement in care plans (around half) within this report and further explore the reasons why people do not feel involved.

Understanding people’s experience of mental health services

Healthwatch exist to amplify the voices of local people. We put people, and their views, at the centre of decision making in the NHS and social care. Our priorities are influenced by what local people tell us matters to them, and people tell us consistently that mental health issues are important. We want more people to be well supported before they reach a mental health crisis.

A recent survey of an online residents panel by the Surrey Heartlands Health & Care Partnership suggests that around two-thirds of people in Surrey have had a close friend that had a mental health problem, and nearly half of respondents had lived with someone with a mental health problem. The same survey identifies issues that people have in talking about their mental health. Mental health is a prevalent concern in the county which is not readily talked about.

Our investigation, among people with mental ill-health and carers (those providing unpaid care) in Spring 2018, aims to help the general public and decision makers in the NHS to develop a better understanding of the experiences of living with mental ill-health.

This report focuses on the experiences people have of using community-based and inpatient-based mental health services throughout Surrey. In particular, it identifies - in people’s own words - what they found most helpful and important in sustaining good mental wellbeing. It also highlights ways that services could be improved.

What we did (in brief)

The work comprised a series of informal interviews (supported by a questionnaire) at five drop-in centres (e.g. Safe Havens / Mental Health Recovery service sites) conducted by Healthwatch Surrey staff and volunteers. Three drop-in sessions were also conducted at inpatient wards at Farnham Road Hospital in Guildford.

An online survey was also carried out, extending the opportunity for feedback to those unable to attend in person.

Drop-ins and the online survey were advertised via the Healthwatch Surrey e-bulletin, social media, and with support from other voluntary, community and faith sector organisations.

To qualify, people had to have accessed one of the relevant local mental health services in the last 18 months. A total of 70 people shared their experiences, comprising:

- 46 women, 23 Men (1 not stated)
- A range of ages from 19 to 65+
- 47 People with mental health problems, 23 Carers
- 62 with experience of Community Mental Health Services, 21 with experience of Inpatient Services (and some with experience of both)

This is a ‘self-selecting’ approach. We may have heard more from those with stronger opinions; positive or negative. More information on the methodology can be found in Appendix 1.

* These were not necessarily the carers for the people interviewed.
The people most often commented on are Care Co-Ordinators, Occupational Therapists, Psychiatrists and Key Workers. People with mental health problems and carers want:

1. to be listened to
2. to be understood as an individual person
3. calls / messages / texts to be returned
4. consistency of advice
5. continuity of staff
6. swift access to care professionals (when needed)
7. swift access to staff with suitable expertise to offer effective specialist care (when needed).

Information and communication are also key:

1. Information about people’s mental health condition/s
2. Information on the full range and scope of mental health treatments available

What people told us

How helpful was the service you accessed?

62 people had an experience of Community Mental Health Services and 21 had experience of Inpatient Services in the last 18 months. Some had experience of both.

There were a wide range of views on how helpful these services were. Most satisfied are those having accessed only the Community Mental Health Recovery Services (CMHRS) and those least satisfied had used the CMHRS and inpatient units.

Carers often tend to be more critical than do first-hand users, with many giving harrowing accounts of people they love being given (in their view) less-than-adequate support. ‘Safety’ is a recurrent theme.

What was most helpful about the service?

People were either harsh critics or loyal advocates of their care and most impassioned when talking about the people involved in their care.

The carer’s viewpoint is never considered. [Carers] can see what happens closely on a day-to-day basis but have no input or voice. After my daughter’s first suicide attempt we wrote a letter and never received a reply from CMHRS. We are left isolated and stressed. Due to my carer role I am now using IAPT [Increasing Access to Psychological Therapies] and have been prescribed medication for stress.

(Female, 55-64, Carer, 2*)

With the services could perhaps be better advertised. It’s easy to find online so not a problem for me - but elderly people may struggle.

(Female, 25-34, User R, 10)

The psychiatrist was fantastic. Dr. Jeremy Mudunkotuwe. A very caring, compassionate human being who clearly cares about his patients’ wellbeing. I was treated with dignity and respect at all times.

(Female, 45-54, User R, 9)

My Care Co-Ordinator / OT is incredible. She’s the first person who’s ever ‘got’ me and she stops my problems from escalating - so I haven’t had to use inpatient services.

(25-34, User R, 8)

I had a very kind, understanding, supportive therapist. I felt listened to, and they worked with me to pinpoint exactly how Cognitive behavioural therapy (CBT) could help. I learned strategies to deal with and minimise my anxiety and panic attacks.

(Female, 25-34, User R, 10)

The Mental Health Midwife at St. Peter’s Hospital (Chertsey) was extremely helpful in pregnancy and post-natally, and helped avoid serious mental illness.

(Female, 25-34, User R, 7)

Being able to text my Care Co-Ordinator if I needed to.

(Female, 18-24, User R, 5)

* see note: verbatim comments (p16)
Key finding: Involvement in care plans

Those involved in their care plans are substantially more satisfied with the services they receive. Care plans appear to have the twin virtue of strengthening trust and empathy among all those involved and hopefully in developing coping mechanisms / resilience for people with mental health problems and carers in the longer-term.

During my last stay I had a really in-depth clinical assessment and they wrote a report from it with their findings, and I was really involved in that. They asked me about my life and spent time getting to know me, what I’m like, and the stresses and thoughts that I have. They used that to help find treatment and really followed through with getting it all sorted. The whole assessment was done in a really friendly and approachable way and it took the right amount of time. It felt like they were actually listening and paying interest to me and what was going on, and like they wanted to work out how to help.

(Prior admissions to Langley Green Hospital Crawley, ACU [Abraham Cowley Unit, St Peters Hospital Chertsey] and contact with Portland Place [Epsom CMHRS])

However, around half of those who had accessed mental health services in the last 18 months reported they had not been involved in their care plan.

This finding is supported by the Care Quality Commission’s most recent survey on Community Mental Health services, where ‘involvement in care’ was cited as a key area for improvement nationally and wherein respondents from Surrey were less satisfied than other areas of the country with involvement in care planning.

There is no care plan in place at all that I have seen and they hide so much. We’ve only just found out about a couple of things recently which have been recorded for a long long time; you ask them questions about things and they hide behind confidentiality.

(Mother [Carer] and Daughter with experience of the Eating Disorders Service)

Can more involvement in Care Plans optimise value?

Surrey Heartlands Health and Care Partnership (www.surreyheartlands.uk) have an objective “to measure what matters to people focused on optimising value” in mental health services3 . These findings suggest there is, potentially an important role in measuring and monitoring the success or otherwise of practitioners’ efforts to involve people in care plans. This should be an important consideration for all Sustainability and Transformation Plans.

Around half of people were not involved in their care plan

What could be improved?

Virtually everyone had strong opinions, even those satisfied with their own experiences. Also notable was how specific the suggestions were.

Several themes emerge, centred around:

- the information provided, and
- the shortage or availability of resources
- GPs’ understanding of mental health problems and their willingness or ability to refer
- access to key people when needed (in particular during periods of crisis)
- a stronger sense that professional care givers want to listen, to advise and to help

Also clear are some of the ‘damned-if-do-damned-if-don’t’ challenges facing mental health providers. For example, in one case it was felt the GP should have escalated the matter more quickly, and in another the escalation was seen to hinder, as it ultimately involved the police.

People are also often seeking simplicity from a complex system. High quality care co-ordinators, who can simplify things, are valued more highly than almost anything else. However, that reliance on one person brings distress when staff leave or are unavailable.

We also heard criticisms about the ‘mental health crisis line’, a service to support those in mental distress.

I was made to feel guilty for reaching breaking point. My day-to-day safety had to be managed by friends who would not leave me at home alone day and night until my next meeting. I was left to manage alone by the mental health services for all but 1 hour a week. That led to several suicide attempts. The crisis line did nothing to build rapport or trust and offered absolutely no support. Had the operator communicated sensitively, an enormous cost would have been saved by two police forces not having to be involved.

(Female, 45-54, User, 3)

The community team and crisis line have been no help whatsoever; lack of consistency in what’s offered.

(Female, 35-44, Carer R+I, 1)

I think in principle a regular appointment with a care co-ordinator would be helpful if the appointments actually did more than just offer a place to talk. I am lucky that I can talk with my friends. What I need from a care co-ordinator is skilled mental health planned care.

(Female, 45-54, User, 3)

GPs are the gate-keeper to services, but people come up against dead ends, GPs can’t do a lot because accessibility is so limited... It’s different information depending on which GP practice. They need designated mental health GPs who know about it and the support. If GPs don’t know, then where do you go?!

It could have been easier to access CMHRS in the first place when I was very unwell. I feel that GPs often lack understanding of mental health issues and should have escalated my case. I should not have been referred after being passed around and eventually being an A&E problem.

(25-34, User R, 8)

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2 Community Mental Health Survey (December 2017), Care Quality Commission (http://www.cqc.org.uk/publications/surveys/community-mental-health-survey-2017)

3 Mental Health Mandate, Surrey Heartlands Health and Care Partnership (http://surreyheartlands.uk/our-priorities/clinical-pathways-old/mental-health/)
Co-ordination of mental and physical care needs is a key issue for some... 

...and more broadly the issue of integration across organisations and between health services themselves:

They need to improve their communication, that’s the least they can do. When she transferred over from CAMHS I had to write a four page letter explaining everything that had already happened and what the problems were because they just didn’t hand anything over properly - it took four months to get an appointment with adult services! (Mother [Carer] and Daughter with previous use of Child and Adolescent Mental Health Services [CAMHS] in Reigate and Banstead, and of the Eating Disorders Service)

My transition from the Child and Adolescent Mental Health Services [CAMHS] to Community Mental Health Recovery Services [CMHRS] was awful and I ended up going three months with no support because no one communicated with each other. (Female, 18-24; User R, 5)

Young people’s specific needs are not being met. SABP (Surrey and Borders Partnership NHS Foundation Trust) recently said they wouldn’t send young people out of area but they don’t phone. They are busy, but you’re waiting on that phone call and having negative thoughts and doubting yourself. It confirms all the negativity and doubts in your head. (Prior admissions to Langley Green Hospital Crawley, ACU [Abraham Cowley Unit, St Peters Hospital Cherstey] and contact with Portland Place [Epsom CMHRS])

Having a 1-1 at PICU in Epsom was helpful – more staff means more helpful... Psychiatrist and care coordinator went the extra mile ... to guide me to get to a positive outcome, and helped me with housing. (Current user of CMHRS and inpatient at Berkley House Godalming, Epsom PICU [Psychiatric Intensive Care Unit], Safe Haven)

Having a plan in place that feels as though it will help; having people who have the time to offer real support, who are compassionate and consistent. (Female, 35-44; Carer R+I, 9)

A key worker or a buddy who understands me and my carer role. Isolation can have a detrimental effect (Male, 45-54; User R, 4)

Richmond Fellowship, Community Connections and Safe Haven are the most important support networks for me. Safe Haven is very useful to people who find their homes unsafe. I feel Gatton Place does the minimum. (Current User of CMHRS Gatton Place [Surrey & Borders Partnership NHS Foundation Trust])

What’s most important to you to ‘stay well’?

Mental health conditions do not ‘end’ in the same way that many physical ailments do. ‘Recovery’ is sporadic, prolonged, fragile, unpredictable - and prone to setbacks beyond the immediate control of people with mental ill-health, carers or professionals.

Even in the absence of the conditions themselves, the fear of their return weighs heavily.

And so the prospect of patients’ care regimes being altered or withdrawn is stressful and felt perhaps most keenly by carers.

Service users and carers alike cling to the people and treatment regimes they know and trust e.g. care co-ordinators, community psychiatric nurse, key workers, psychiatrists and regular one-to-one sessions. Continuity, regularity of contact and swift access to help are again emphasised.

Notably, few people cite medications or drugs as playing a part in their mental health care and virtually nobody names any such drugs by name. While they are often a crucial part of the mix, they are rarely ‘front and centre’ in people’s comments.

Now I see my Care Co-Ordinator regularly and I feel really lucky. They’ve phoned when they say they’ll phone and they see me when I need to be seen. I hate when you’re expecting a phone call but they don’t phone. They are busy, but you’re waiting on that phone call and having negative thoughts and doubting yourself. It confirms all the negativity and doubts in your head. (Past user of IAPT, 1-2)

I’m making myself do more things now - I see friends and social groups. I have the support of my family and I keep active. Physical health is important - I look after my weight now so my diabetes is under control. I can speak to the nurse at Safe Haven if I need to and can speak to my sisters, they’re there for me. I tell people how I feel. And I’ve set myself a goal to go swimming. (Past user of Farnham Road Hospital [Inpatient] and Guildford and Waverley CMHRS)

More care should be taken of patients’ physical wellbeing, which seems to be completely overlooked. (Male, 35-44; Carer R+I, 3)

Bridgewell House (Woking) signposted to Corner House for anxiety and depression. She is diabetic, and comfort eats. Has a 3-6 monthly medication review. We attend Corner House three times a week and have been for years. We enjoy the walking group and having a cooked meal. (Carer of current CMHRS service user)

The problem with my hearing is a contributing factor to my mental health and I get very frustrated with my communication team. You cannot have a communication team which does not acknowledge hearing / visual disabilities. (Past User of CMHRS Gatton Place)
Many patients and carers also feel nervous that inadequate ongoing care will jeopardise any progress services and facilities which could be at people’s disposal if they were better known about.

The final ‘summing up’ comments from the interviews included observations about the wide range of full needs have not been met. This view is more evident still among carers and inpatients.

I’m crying out for help but I’m not getting it. I tried art therapy as I thought it would be helpful, expressing myself in different ways, but the therapist didn’t want to go into any detail when I wanted help... and I need a medication review...Mind Matters have said they will write and try and get a referral. I’m starting to believe I am broken and always will be.

(User of various services for PTSD [from Military Service])

I’m not sure as not entirely sure what all my needs are but am concerned what will happen when the final of my eight sessions of psychotherapy ends.

(Female, 55-64, User R, 8)

“One size fits nobody” courses have their place as an introduction, but a year on there is still no one-to-one therapy being offered.

(Female, 55-64, Carer R, 6)

It was all very ‘medical’ and did not address vital social needs in any practical way. It seemed much more focused on getting through one crisis, until the next one occurs; rather than helping people to build full, healthy, sustainable lifestyles.

(Male, 35-44, Carer R+I, 3)

I was diagnosed as an adult but could’ve got diagnosed much earlier and would’ve gotten the support I need. The system is not designed for borderline care.

(Past user of CBT , with Asperger’s Syndrome, Autism Spectrum Disorder (ASD), Dyspraxia and Depression)

Carers view point is never considered. [Carers] can see what happens closely on a day-to-day basis but have no input or voice. After my daughters first suicide attempt we wrote a letter with our concerns about her problems and never received a written or verbal reply from anyone at CMHRS. We are left isolated and stressed... due to my care responsibilities... I am now using iAPt and been prescribed medication for stress by my GP

(Female, 55-64, Carer R, 2)

Have all your needs been considered?

6 in 10 respondents in our investigation say their full needs have not been met. This view is more evident still among carers and inpatients.

In essence, people repeat their concerns of inadequate ongoing care. Many respondents feel disorientated, unsafe, excluded and let-down.

It was all very ‘medical’ and did not address vital social needs in any practical way. It seemed much more focused on getting through one crisis, until the next one occurs; rather than helping people to build full, healthy, sustainable lifestyles.

(Male, 35-44, Carer R+I, 3)

Had a psych evaluation and was taken to St Peter’s [Hospital, Chertsey] by the police in November. I was sectioned in January and stayed for 4 weeks. The wards are a bit brutal. My care co-ordinator was withdrawn in July. I was assessed to not need one as I was attending Corner House and Safe Haven. (Current user of Guildford CMHRS, past inpatient at Farnham Road Hospital)

Carers view point is never considered. [Carers] can see what happens closely on a day-to-day basis but have no input or voice. After my daughters first suicide attempt we wrote a letter with our concerns about her problems and never received a written or verbal reply from anyone at CMHRS. We are left isolated and stressed... due to my care responsibilities... I am now using iAPt and been prescribed medication for stress by my GP

(Female, 55-64, Carer R, 2)

What else would you like to tell us?

The final ‘summing up’ comments from the interviews included observations about the wide range of services and facilities which could be at people’s disposal if they were better known about.

Many patients and carers also feel nervous that inadequate on-going care will jeopardise any progress made earlier.

Tell patients and carers about the many community and voluntary sector groups that are out there and available.

(Male, 35-44, Carer R+I, 3)
Summary

The gap between users’ expectations of mental health services and what is actually delivered is extremely wide.

The comments also shout loud and clear about the hurdles that people with mental ill-health and their carers face - even once referred to specialist teams.

In short:

1. When people with mental ill-health and their carers are involved in care plans they are substantially more satisfied with services, though around half of people accessing services in the last 18 months have not felt involved in their care plan.
2. Carers can feel excluded from interactions between those they care for and the various ‘professional’ organisations involved - and this compounds carers’ (often extreme) distress.
3. More problems stem from services being unavailable (or simply not known about) than being ineffective. Patients and carers often want to know the full scope of services and help available, rather than simply being told ‘this is what we’ll do’.
4. There is often a lack of integration between mental health care services and those focussed on serious physical impairments. e.g. conditions such as hearing loss have a direct impact on people’s state of mind, but the treatment employed is likely to focus predominantly on the physical aspects.

5. The people providing mental health services are their best asset. If they fall short, or leave, the ‘system’ (however well-intentioned) cannot easily repair loss of trust & wellbeing. These are some of the things that service users want from the people involved in providing their services:
   - to be listened to
   - to be understood as an individual person
   - calls / messages / texts to be returned
   - consistency of advice
   - continuity of staff
   - swift access to care professionals (when needed)
   - swift access to staff with suitable expertise to offer effective specialist care (when needed).

Finally, we heard the views of two staff members who work at the drop-in centres:

We are not mental health trained but we hear the same kind of stories again and again - and it’s up to us to do what we can. It’s frustrating. People don’t know who they’re supposed to talk to, they mistrust services, and even if they do meet the threshold there are only a few places which offer proper support. People feel alone and not listened to, there is a time limit and no one takes notice. We listen to people and we do what we can - walks, monthly check in centre, activities...

We don’t get told who people can go to: we have to find out where to signpost people ourselves. People come here in significant distress, and we have concerns about where people can go next. They don’t necessarily trust the NHS, so you can signpost as much as you like... People are falling through the gaps at [Community Mental Health Service]

What should happen now?

1. Commissioners and service providers should review what patient reported experience measures are regularly monitored and ensure alignment with the NICE Quality Statement on mental health services*.
2. Commissioners and service providers should review the way they assess the services they provide to ensure that they incorporate feedback reported directly by patients, on the issues that patients told us were important i.e. that they have:
   - been involved in care planning
   - been listened to
   - been understood as an individual person
   - had calls / messages / texts returned
   - had consistency of advice
   - had continuity of staff
   - had swift access to care professionals (when needed)
   - had swift access to staff with suitable expertise to offer effective specialist care (when needed).

3. Service providers should make an explicit commitment in strategies and work plans to improve the extent to which people and carers feel involved in care planning.
4. Service providers should promote the key findings of this report with front-line staff and, in particular, the finding that “Those involved in their care plans are substantially more satisfied with the services”.

Furthermore three recommendations for further research are made:

5. Commissioners should investigate the low level of people reporting involvement in care plans (around half) within this report and further explore the reasons why people do not feel involved.
6. Commissioners should consider undertaking research to better understand what good information looks like to different people and carers at different stages of emotional wellbeing.
7. Commissioners should consider undertaking research to better understand the current experience of crisis lines.

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4 National Institute for Health & Care Excellence (2011) Service user experience in adult mental health services. Quality standard [Q814]
Thank you

First and foremost, we would like to thank all those who took part and shared their experience with Healthwatch Surrey. Your time, openness and courage has informed future improvements to services.

Thanks also to the staff at Surrey & Borders Partnership NHS Foundation Trust for accommodating visits to their services in order to speak to current patients.

Members of the Surrey and North East Hampshire Independent Mental Health Network also played an important role in encouraging people to share their experience and by commenting on a draft of the report.

Finally, Healthwatch Surrey would like to thank the volunteers who took part in the visits and interviewing whose support ensured many more voices were able to influence this report.

Note: Verbatim comments

Attribution of Verbatim Comments

The verbatim comments are anonymised, in accordance with respondents' wishes or expectations.

We have, however, added some information to each one to give some context to what is said.

These attributions have been done in two ways based on the information collected:

Drop-in Respondents' comments include a general record of each respondent’s history of mental health care interactions (eg ‘Current user of Guildford CMHRS, past inpatient at Farnham Road Hospital’).

Online Survey Respondents' comments have been attributed by:

1. Gender (Male, Female)
2. Age Group (18-24, 35-44, 45-54, 55-64, 65+)
3. Relationship with Mental Health Services (User, Carer)
4. Recovery service and/or Inpatient service (R, I)
5. Overall rating of service’s helpfulness (score out of 10)

The Healthwatch Network

The Healthwatch network exists to help ensure that people’s needs are at the heart of health and social care. We listen to what people think is good about services and what people feel could be improved. Local Healthwatch produce reports and recommendations based on the feedback gathered from local people about health and social care services. These are directed at commissioners and providers of care services, and people responsible for managing scrutiny of local services. Local Healthwatch also provide information and advice about accessing health and social care services.
Appendix 1: Methodology & approach

Participants
Between the end of February 2018 and the end of March 2018 we collected feedback from working aged adults who access or have accessed, community and/or inpatient mental health services in the past 18-months. We also spoke to carers. In total, 70 people shared their experience (Male = 23, Female = 46, Other = 1). Of the people we spoke to 47 had accessed services themselves and 23 cared for someone who had accessed services. 62 of the experiences gathered related to community mental health services and 21 to inpatient services, with some experiences relating to both.

Recruitment
Drop-ins and the online survey were advertised via the Healthwatch Surrey e-bulletin, social media, and with support from other voluntary, community and faith sector organisations.

The aims of the project were explained to all participants prior to collecting their experiences and participants gave informed consent for their feedback to be used anonymously. All participants were offered the opportunity to be included in a prize draw for the chance to win one of five £20 vouchers.

Drop-ins
Five drop-in sessions lasting two hours each were scheduled across Surrey and were located at the sites of existing mental health services (for example Safe Havens and Community Mental Health Recovery service sites) to maximise accessibility. Local people with experience of adult mental health services were invited to drop-in and share their experience us. A survey was completed by each person attending in addition to the use of prompts to gather more qualitative detail.

Further drop-in sessions were arranged at three inpatient wards at Farnham Road Hospital, each lasting two hours and utilising the same survey questions as used in the methods above.

Online survey
Drop-ins were used in combination with an online survey (the same as was used during drop-in sessions). The survey consisted of some open-ended questions as well as a section for demographic information. The online survey was used in order to extend the opportunity for feedback to people unable to attend the drop-ins. In addition, local people were invited to contact the Healthwatch Surrey helpdesk to arrange a conversation by telephone if preferred.
Healthwatch Surrey is an independent local champion that gives the people of Surrey a voice to improve, shape and get the best from health and social care services.

**About Healthwatch Surrey**

Healthwatch Surrey is an independent local champion that gives the people of Surrey a voice to improve, shape and get the best from health and social care services.

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