



# South West London Healthwatch NHS Long Term Plan Engagement Report



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## 1. Introduction to Our Approach

In Spring 2019, Healthwatch England negotiated funding from NHS England to support engagement about the NHS Long Term Plan. This funding was then offered to the Healthwatch networks.

The South West London Sustainability and Transformation Plan implements the NHS Long Term Plan. In South West London this plan is rightly focussed at a borough level through a series of Health and Care Plans. South West London local Healthwatches have been engaged with the Health and Care Plans from the very beginning.

We agreed that our work would diverge from the Healthwatch England Long Term Plan Survey and associated timeline to enable us to engage with our local partners and community on the locally relevant development of NHS plans. Whilst we took a different approach, our key lines of enquiry within our work across South West London aligned closely with the key priorities of the Healthwatch England survey into the Long Term Plan, namely to collect people's views of:

- How they can be supported to live healthier lives from birth to old age
- What services can do to provide better support
- How the NHS can make it easier for people to take control of their own health and wellbeing.

However, we refined our work to find out what local people think around specific topics relevant plans for our local services. This work was coordinated through a series of meetings involving Healthwatch Croydon, Kingston, Merton, Richmond, Sutton and Wandsworth and the South West London Health & Care Partnership. Our work was split across two distinct activities:

- Supporting the South West London Clinical Conference in April 2019.
- Supporting engagement with the Health and Care Plan discussion documents at a borough level.

More information about our work on the topics of focus for the clinical conference is provided by each local Healthwatch later in this report. The six areas were:

- Crisis Care in Mental Health - Healthwatch Richmond
- End of Life Care - Healthwatch Kingston upon Thames
- Outpatient Care - Healthwatch Sutton
- Diabetes Care - Healthwatch Merton
- Cardiovascular Disease - Healthwatch Wandsworth
- Respiratory Care - Healthwatch Croydon

In line with the borough-based decision making of the Sustainability and Transformation Partnership in South West London, we agreed that the coordination of the work should also be borough-based. As a result, the grant for coordinating this funding was also shared between each South West London local Healthwatch.

This compilation report details our partnership working, findings, conclusions and reflections.

## 2. Our Work - Clinical Conference (South West London)

Below is a summary of the work by each Healthwatch around the topics discussed at the South West London Clinical Conference in April 2019.



### Crisis Care in Mental Health



### Crisis Care in Mental Health - Healthwatch Richmond upon Thames

- Reviewed 550 patient experiences to identify those relating to crisis care
- Analysed 150 patient experiences to answer the 3 questions set by the conference:
- What would prevent crisis?

- o What do people want in a crisis?
- o What do people want after a crisis?
- Visited 2 community groups during the lead up to the conference speaking to around 40 additional patients
- Sought findings from other SWL Healthwatch.
- Presented to the SWL Clinical Conference and participated in discussions around priorities for the HCP.

## Key insights from this work included

### Care in a crisis

People want a well-functioning responsive urgent mental health care system:

- That they can access 24 hours a days 7 days a week
- That can access medical records
- Coordinates care options to ensure that everyone gets the care they need when they need it
- Follows up so that no one falls through gaps between services.
- That's delivered in a comfortable, safe and appropriate environment

### Preventing Mental Health Crises

Rapid access to care and support when approaching a crisis (as above) is essential when a crisis approaches or once it begins.

There are several things that can help prevent mental health crises.

#### *Wider determinants*

Wider determinants include finances, welfare & benefits, driving, employment, housing, meaningful occupations, routine, purpose and leisure.

People say support around wider determinants of health strongly support their recovery and reduce relapse.

Support groups, voluntary sector are key to this and effective at signposting people to further support.

#### *Community Groups*

People told us isolation exacerbates symptoms and delays them seeking support but that they withdraw at the onset of mental health problems.

Groups and networks reduce isolation and encourage people to seek help sooner helping people avoid crisis. They can also be a route to addressing wider determinants of health.

But people see them as underfunded and not open out of hours.

#### *Education*

People who had relapsed several times were clear that more knowledge on how to recognise emotional triggers and spot relapse signs would prevent future crisis

episodes. Training for friends and family on triggers or warning signs would enhance their role in prevention.

### *Primary Care*

Many people told us that a responsive and supportive GP and practice staff had helped them to avoid a crisis.

### **Conclusion**

The system is moving in the right direction with developments such as the environment of Lotus Suite, a step down facility co-located with the Section 136 unit, being able to self refer to care in a crisis, and a Mental Health Assessment Unit located in A&E.

But there is much to do to integrate services to in a way that would create the well functioning urgent mental health care system that patients describe.

*Healthwatch Richmond upon Thames - 'Crisis Care in Mental Health' Conference Presentation follows:*



## Hearing from residents/patients

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## Patient Experience of Crisis Care



We were asked to tell you about crisis care from a patient's perspective

### What we did

- Spoke to 550 patient and carers about their mental health experiences over past 2 years
- Collected 150 experiences relating to a mental health crisis

### How we did this

- Service reviews of 5 major mental health services
- Outreach to community & peer groups, drug & alcohol services, seldom heard/hard to reach communities.
- 100+ people told us about their experiences at a public event
- Checked that our findings are meaningful across SWL

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## Prevention



### Crisis cafés

“One patient highlighted her appreciation for the support she has got through crisis cafes over the last year. However, the nearest ones are still too far away to travel to if her mental state was fragile and therefore their role in crisis care is limited for people living in Richmond.”

“Carers also agreed that recovery cafes might support people who are going through difficult periods but none of the people they knew had used them as they didn’t have the confidence to travel the long distances to use them.”



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## Prevention



### Avoiding Isolation: the role of Community Groups & Social Networks

*“having these people at hand keeps my journey stable”*

### Education

“If there was education available to recognise and manage symptoms I would not have gone into crisis”

### Primary care

*“My GP checks on me every week. It’s very helpful.”*



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## Crisis



*“We need a single point of access for mental health, equivalent to 999 or A&E.”*

*“The crisis line needs to be 24/7. Also the crisis line staff should be able to access your records – otherwise how can they help?”*

*“Services not integrated to work together will play patients off against each other”*

*“I called my care coordinator but she was on holiday and there was no one to cover. I wasn’t seen for 2 weeks and ended up at A&E in crisis.”*

*“They just say ‘do some colouring, have a bath or go to A&E’”*

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## Headlines



**A well-functioning urgent mental health system is**

- 1. Accessible 24 hours a days 7 days a week**
- 2. Delivered in a comfortable environment**
- 3. Able to access medical records**
- 4. Coordinates care options to ensure that everyone gets the care they need when they need it**
- 5. Follows up so that no one falls through gaps between services.**

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## Moving in the right direction



### What's going well?

- Being able to self-refer when in crisis
- Environments like the Lotus Assessment Suite in Springfield Hospital
- Crisis Houses – people who have used them speak highly
- Dedicated safe spaces and faster assessments at A&E (Kingston MHAU)
- Access for people currently open to teams like the Richmond HTT via mobile to a duty officer.



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## Discharge



### Managing discharge

- Gaps between discharge and community service.

***"Shouldn't I have heard by now?"***

- *"Before I was discharged someone told me about support available after I was discharged. Now I can't remember what they said and they're not here to ask!"*

### Wider determinants of health

- People say support around wider determinants of health strongly support recovery and reduce relapse.

***"Many people I used to see are now in work. I don't see them around as much anymore"***

- Support groups, voluntary sector are key to this and effective at signposting people to further support.



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## Take home messages



**Good practice:** Generally good MH & GP service quality. Lots of positive developments.

**Problems:** Gaps between in services, difficulty accessing care, communications

**Patients want:**

1. Access to a well-functioning urgent mental health system open 24/7, access to records, coordinates care across organisations, follows-up to ensure that no one falls through gaps. Appropriate environments.
2. Support with wider determinants:
  - a role for the Voluntary sector?
  - Information following patients
3. Prevention: Crisis cafés where people can reach them. Education.

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End of Life Care



End of Life Care - Healthwatch Kingston upon Thames

Healthwatch Kingston completed a rapid literature search for existing reports on patient insights on End of Life Care (EoLC). We engaged with a few (time was very limited) key NHS and Social Care Commissioners and Providers of EoLC to scope out what was feasible in the time frame leading up to the SWL Clinical Conference. We discussed the ethical challenges associated with research with people during EoLC and it was agreed Healthwatch Kingston would engage with carers (families and professional providers) that had recently lost a loved one/someone they were caring for.

There was a large event that took place in Croydon that discussed EoLC, just before we did our 'quick' research - 90 people attended including some 'hard to

reach' groups. There was apparently very rich feedback from the event but it was being written up at the time.

We identified two providers that linked us up with professional carers (Crossways Nursing Care Home in Sutton Princess Alice Hospice).

We created a key question that asked 'What was important to carers and their loved ones in the last months of life?' and this then provided a context for:

- Open-ended phone interviews with 7 family carers reflecting on 10 recent deaths (1 spouse, 9 parents)

Interviewees were asked:

- What was most important to them and their loved one in the last months of life

Where EoLC took place:

- 7 deaths in a care home, 1 in a hospice, 2 in hospital

Themes identified:

- Knowing the person and continuity of care
- Choice
- Quality of care
- Uncertainty, and
- A good death

We then created a presentation for the SWL Clinical Conference on 30 April, providing background and local context to this area of care and focused on the last two themes identified.

Our presentation concluded that the ideal death should be peaceful, and we should not die alone. People we know should be with us, and we should have the chance to say goodbye. But this depends on carers and loved ones knowing when the time has come.

*Healthwatch Kingston upon Thames - 'End of Life Care' Conference Presentation follows:*

# End of Life Care

## What was most important to carers and their loved ones in the last months of life?

Dr Liz Meerabeau  
Chair, Healthwatch Kingston upon Thames

30 April 2019



### End of Life Care 1: Background

- The End of Life Care Strategy 2008 led to great improvement in care
- Carers should be formally identified and their needs met (Carers Act 2014)
- EOL care is one of the services Primary Care Networks will need to provide
- A Review of Choice in EOL Care 2015 states: 'the way we care for dying people is a measure of our society' and 'it is vital that we are supported to be ourselves as we near the end of our lives'
- The NHS LTP calls for a 'fundamental shift' in the way the NHS works with patients and individuals



## End of Life Care 2: Our data

- Open-ended phone interviews with 7 family carers reflecting on 10 recent deaths (1 spouse, 9 parents). Interviewees were asked
- What was most important to them and their loved one in the last months of life
- 7 deaths in a care home, 1 in a hospice, 2 in hospital
- Themes identified were knowing the person and continuity of care, choice, quality of care, uncertainty, and a good death
- This presentation focuses on the last two

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## End of Life Care 3: A good death - gentle into that good night

- 'I had thought the last weeks would be serene, but it was busy. And with all the machines you forget to give your wife a cuddle'
- 'I wasn't there to say things while she was still conscious'
- 'A member of staff stayed with her all the time. A very dignified parting'
- 'She wasn't shipped off to a hospital. It was peaceful and she went with dignity'
- 'You felt you did the best for them'
- 'Once she went downhill I knew this is how it's going to end. She's going to slip away slowly'
- 'I got there for those last few hours'

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## End of Life Care 4: Uncertainty

- 'It's difficult to tell how long someone's got. I got there before she died but my sons didn't. I wish the hospice had said to stay overnight- but that's hindsight'
- 'We didn't know what to expect'
- 'In the end it was quick- just five days from a chest infection. Quite a shock, even for the staff'
- 'I wouldn't have known that night was going to be the night she died'
- 'It's difficult to plan when you don't know what to expect, so I didn't complete it (EOL form). It's like nature, it just happens'

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## End of Life Care 5: Conclusion

The ideal death should be peaceful, and we should not die alone. People whom we know should be with us, and we should have the chance to say goodbye. But this depends on carers and loved ones knowing when the time has come.

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Sutton

Outpatient Care



## Outpatient Care - Healthwatch Sutton

You can find Healthwatch Sutton's full report about outpatient services in Sutton at

<http://www.healthwatchesutton.org.uk/outpatient-project>

## A patient's experience of outpatients

Watch a short film about Michael's experience of outpatients (a Sutton resident).

<https://vimeo.com/tinderflint/review/333140614/fa7607bbac> (Password is SW19)

*Healthwatch Sutton - A couple of 'Outpatient Care' Conference Presentation slides follow:*



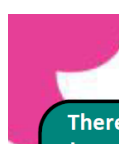
## Outpatients - What matters to you?

We spoke to people attending a wide variety of outpatient clinics at St Helier Hospital. 239 patients completed the survey.

Patients in general were very satisfied with the time spent with the clinician but less happy about appointment systems, waiting times, information given about waiting times and pharmacy delays.

Theme analysis of 122 comments showed the following:

Theme	No. of comments
Positive	47
Delay (waiting to be seen)	29
Directions	7
Parking	6



## Outpatients - Comments

There is not enough capacity at the dermatology dept. I believe I should be seen monthly but I am able to get appointments only after 3 months. I was lucky to get this appointment due to cancellation.

Went to great lengths to explain pros and cons. Fantastic and first class service at St Helier so far

Excellent website. Nurse at eye clinic reception gave me her name when I telephoned and said she would get back to me quickly, which she did in about 20 minutes. Giving me her name was very reassuring.

I have been assessed by several appointments before going for minor operation. The day of operation I was told that Junior Doctor will do while I wanted consultant to do. I was not happy about this as I had several appointments before getting on the waiting list again for minor operation. The junior doctor had got his senior to assess so I think that Dr \*\*\*\*\* wasted my time.

Broken arm, Physio Dept disagree with Fracture clinic as to which exercise to follow.

Was unhappy with pharmacy, had to wait for 45 minutes then was told that my steroid drops had to be ordered. A week later when no one called me back, I phoned - I was told that it was ready. My next appointment was 7 days later while I had to use drops for 14 days prior to appointment.



- **Improved Communication;** People felt a lot of the information they are given is either unclear or confusing, especially when English is not their first language. People are told a lot of things though No-one ever checks to ensure they have actually understood it .
- **Relevant Information;** A lot of information about Diabetes is around, however little information on practical solutions to how people can actually achieve what is being asked of them based on their own life circumstances is available.
- **Peer Support;** A real need to be able to talk with other people living with and coping with the impact of Diabetes on their life using their own experiences to help each other - especially within BME communities.
- **Joined Up and Coordinated Appointments;** People talked about experiences of having multiple of related appointments across many different days for what effectively could have been done in one visit all at the same time or within the same day. Saving both money and time for both patients and the NHS.
- **Greater awareness about Diabetes;** Majority of BME people surveyed reported they only became aware of diabetes once they had been diagnosed and a need is there for improved and greater awareness to support prevention in BME communities.

*Healthwatch Merton - 'Diabetes Care' Conference Presentation slides follow:*





## Insights from our previous activities

In Merton, diabetes has been a key area of focus in the last few years and a lot of activity has already taken place that highlighted key themes:

- Peer and community support has a huge role to play in helping people manage their diabetes.
- A focus on emotional and mental health resilience and support. Diabetes is not just physical illnesses.
- There is plenty of information out there about diabetes - people do not always engage with it or know it exists.
- knowing the causes and risks of diabetes is not enough to change behavior due to lifestyle pressures, working hours and lack of sleep.
- Healthier choices need to become easier choices for people to adopt in their everyday life.



## Recent key insight documents:

### Community Conversations in East Merton - 2016

<https://www.mertonccg.nhs.uk/News-Publications/Publishing/images/Pages/Publications/Wilson%20Update%20HWB-%20community%20conversations.pdf>

### Merton 'Diabetes Truth' programme - engagement in 2018

<https://democracy.merton.gov.uk/documents/s22963/Item%205%20Appendix%201.pdf>

### Tackling Diabetes in Merton - Learning from a whole system approach

[https://www2.merton.gov.uk/APHR\\_2019\\_Diabetes\\_In\\_Merton\\_FINAL\\_WEB.pdf](https://www2.merton.gov.uk/APHR_2019_Diabetes_In_Merton_FINAL_WEB.pdf)



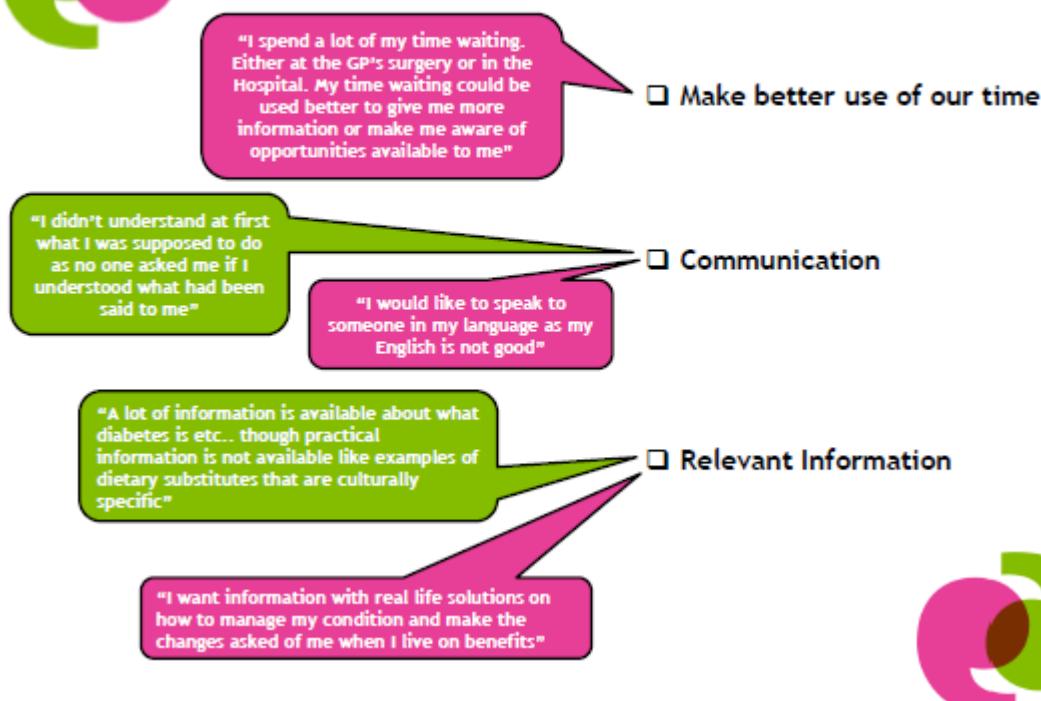


## Who we spoke to and how we did it

- We spoke with community groups (many of which are BME groups) at a number of sessions and events being held locally who have Type 2.
- We created a survey which was promoted via our local community groups network.
- Talked 1to1 with people living with the condition

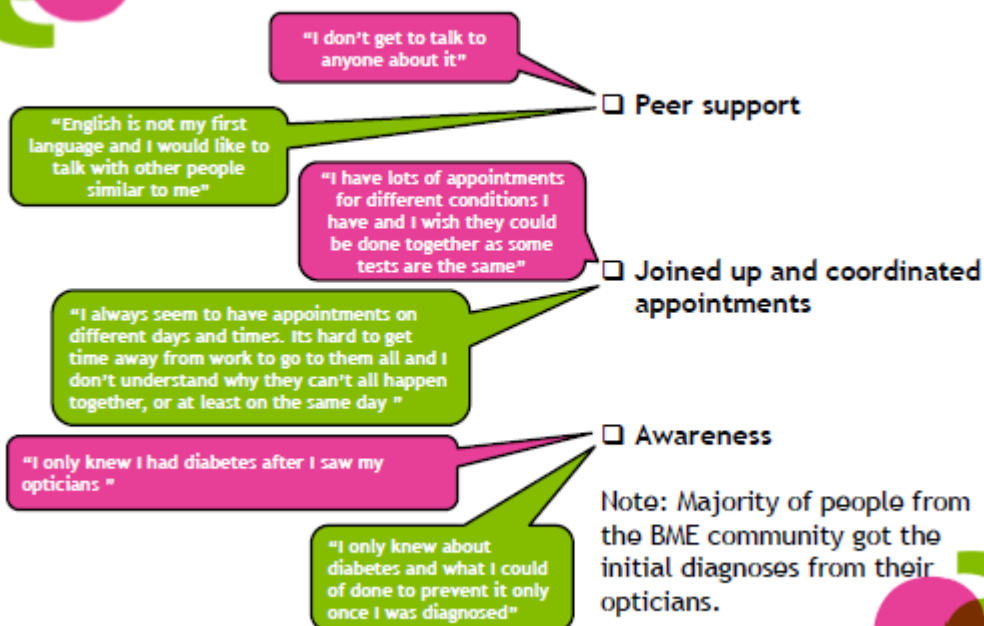


## What matters most to people?





## What matters most to people?



There was also a short film.



Cardiovascular Care



Cardiovascular Disease - Healthwatch Wandsworth

Our topic

Healthwatch Wandsworth researched patient experience of Cardiovascular Disease, specifically focusing on the following groups:

- **Stroke Prevention** - target group was patients with atrial fibrillation (a medical term for a condition that includes symptoms such as irregular heart rhythm and can those who can be at risk for a stroke, those on anticoagulant medicine (which thins the blood to prevent it from clotting - e.g. Warfarin).

- **Heart failure** - target group was patients who are not managing well/well managed, and who struggle to lead an 'ordinary life.'



## What did we do?

### Background research

We did a short search for existing patient insights on the topic of Cardiovascular Disease. Only one existing Healthwatch story was found and shared from HW Richmond. We also looked at other sources of patient experiences and found 10 stories from the British Heart Foundation, Heart Rhythm Alliance, Patient Research Exchange, The Guardian and the Daily Mirror.

### Background research findings:

The **top themes** throughout the patient stories were as follows:

+ It takes time to get the medication dosage and combination right, to manage my health condition.

**'I feel I am on a medical treadmill with tests, drugs, consultation.'**

+ Patients need to make lifestyle changes to manage their condition (diet, fitness, socialising and avoid stress).

**'Knowing when to listen to my body and rest is essential and avoiding stress as much as possible is also critical at keeping AF [Atrial Fibrillation] quiet.'**

+ Patients want to keep fit, but require guidance and possibly supervision on what exercise is safe and what their limits are.

**'I am frightened to exercise, I don't do any exercise, I worry that exercise is going to set my heart off again.'**

+ Patients are increasingly dependent on family and friends for practical support.

## What did local patients tell us?

We then went to speak to local people about the topic. We created a survey asking patients ‘What matters most to you’ when managing your condition and living your life as and we also asked how services and clinicians can help them to achieve what matters most to them.

We promoted the survey on line and 5 people relevant to the patient group responded (A few more completed the survey but we could not use their stories for this project but they can be used by Healthwatch Wandsworth in other work).

We also interviewed 3 patients with Heart Failure at St Helier Hospital and 24 patients at St George’s Hospital.

### The findings

Feedback included both positive and negative experiences but these themes represent what matters the most.

They described the **effect on work, money, family and relationships and more** and said that the following matters most to them to help them live well.

+ Clear guidance on how to self-manage their health condition and an understanding on what one’s limitations are (pacing and coping mechanisms and how to live life at a pace that is manageable.

‘The nurse’ explanations regarding fluctuations or changes in my condition makes me reassured’.

+ Improvements in communication between hospitals and patients to prevent unwanted stress (reducing administration errors and cancelled appointments).

‘Awaiting for fibrillation to be done - misplaced paperwork. I need to keep chasing and causes unnecessary stress, worry and I get anxious.’

+ Reducing the burden of managing their own health.

+ Better referrals from GP practices and additional GP support.

+ Getting the right medication to manage condition.

+ Participating in group exercise and rehab.

Some patients had tried to keep active. Overall patients want their health and fitness levels to improve (but were unsure what was safe) and more information would be helpful, others found the cardiac group rehabilitation classes very useful however ‘there needs to be something out there that people could go to after’ subsidised exercise classes, could be related to physio or general health.

‘I’m a very active person, so exercise is very important to me - but that’s immediately restricted after surgery, and it takes a while to build back up. What surprised me was that there was no physiotherapy contact to let me know the do’s and don’ts of what I can do physically after surgery. This would have been a useful

thing for me. The only advice I got from the surgeon was to breathe deeply for as much as possible.'

+ 'One to one' dietary advice would be helpful - patients told us that they have had to make dietary changes and want to eat healthy, however, they are not always sure where to start.

+ Maintaining good mental health - make it easier to access mental health services to manage emotional health (current waiting times are too long).

Here are a few further quotes from people we spoke to:



What happened next?



*Sarah Cook, Healthwatch Wandsworth Manager, centre right, providing the patient perspective from our research at the clinical conference.*

The findings were reported in a presentation at a clinical conference on 30<sup>th</sup> April 2019. We presented the views of the people we spoke to a room of clinicians and health and social care decision makers who were then tasked with discussing how improvements can be made to how services work across South West London. Our presentation was immediately before the discussion with the intention to make sure the conversations focused on ‘**what matters most**’ to patients.

We await a final report from the conference about future plans relating to the discussion, but the below diagram was produced to describe the ideas generated.



## Respiratory Care



## Respiratory Care - Healthwatch Croydon

### Clinical

Once offered respiratory services we undertook 41 surveys at six outreach events over three days in early April. These were: 18 in Croydon community (5 Purley, 3 Thornton Heath; 5 New Addington; 5 South Norwood); 15 at St George's Hospital outpatients; 8 at St Helier Hospital outpatients).

27 White British; 3 White Irish; 3 European; 4 Indian Asian; 4 Black British/ African/Caribbean/Mixed. 18 had a disability; 23 did not. 39 Service users; 2 relatives.

We asked four questions as agreed with NHS South West London, here are the results:

## Living with your condition

24 responses coded as positive; 10 neutral, 7 negative

### Positives:

The condition is now very easy. I can't do a lot of what I want to do. But getting an appointment is very easy. Waiting to have an operation for a lung transplant. The care is very, very good. They are very helpful, and very supportive. (St Georges)

What matters the most is being able to breathe. They are good here - able to get better. When I see the consultant, she is good, she is on the ball. (St Georges)

The most important is my health and wellbeing, to be active, if I am not active it attacks the rest of me. Just being able to get with life. Generally without having to take a lot of medications. (St Georges)

Worst is limitations of doing what I want. I accept it, have to stay relaxed. Being able to access the service is important, for example car parking needs to be adequate. (Croydon South Norwood)

The whole thing has been advantageous to me. Medicines delivered quickly to GP. Sudden flare up, get quick referral to CUH rehab, not having to go via GP. Last year Nov 2017- March 2018. I hardly did anything. Got enrolled here, don't like the walking but did achieve 26 minutes without stopping - major achievement. Do 30 minutes a day. Down to community support. Had 10 lessons. They fitted me in today. I started at another group. (Croydon New Addington).

### Negatives

Diagnosis - scar on lung - one or both. Information given unclear since a year ago. Seen by GP for past 3-4 yrs? COPD? Asthma? Unclear, no reassurance, would like definite information of own health condition. (St Georges)

Dad has sudden pain on left and right of chest, so it cause a mini attack. This is a first proper referral. Most important thing is getting to the route cause. It has taken quite a while to get referral from the GP to secondary care respiratory clinic. Would be better if the doctor to make a quicker decision, especially if resident is at a certain age. (St Georges)

Continuity of treatment- this does not work well. It's very important that you see the same doctor, with a condition like this and his wife had many operation (Croydon Purley)

Saw respiratory <team> in November. Just fitted in now - long time to wait for an appointment. Perhaps an admin error? I had to persist. Need support needs to be prompt. (Croydon South Norwood)

## Care and treatment - positives

24 responses coded as positive, 9 negative, 9 neutral

Want to know health condition and plan for the future. Do not wish to be on medication long term. On medication. Good relationship with Drs and physio. Felt listened to. (St Georges)

Mainly want problem solved when found. No medication given. The staff are very good at explaining and demonstrating things. (St Georges)

Everything. I want to improve, walk further, be active. I want to be how I was before my accident. I am expected to make a full recovery. To be able appointments quickly. (Croydon South Norwood)

Medical staff helps with care and treatment - breathing. Techniques to get better quality of life. That the treatment I get works. (Croydon New Addington)

I was incapacitated so long. Had a damn good year this year 50% improvement. No doubt its this service. (Croydon New Addington).

If I felt something was urgent, I could speak to someone about it. All clinicians I have met here are very through. Particularly when you consider what they deal with. (St Helier)

## Negatives

1. Seeing the same person every time I have an appointment - crucial. 2. Not Being discharged in order to meet NHS targets. 3. Having the conditions and treatment explained clearly. (St Georges)

Just to be mobile really, to be able to pick my son up without being completely breathless. Just general care. Just need a lot more support. Probably need a nebuliser now. Financially as well struggling - can't work like this. Like to be able to work because I had to be off-sick. (St Georges)

Getting an appointment from the GP/hospital. GP> common problem, getting an appointment takes 2/3 weeks if resident is lucky might have to result in a telephone appointment. Hospital> sometimes on time, sometimes cancelled. Appointment was cancelled 3 times, then was told if I do not attend the appointment, they will discharge. (St Georges)

Being seen on time: Never seen on time. Prompt appointments. They get sent every 6 month. Have waited up to 2 hours before. (St Helier)

## Needs from clinicians

Responses graded 4 low, 17 medium, 10 high.

### Low needs



Improve my health. Seen three-monthly by nurse and consultant. Most of the time the same consultant.

Sympathy and competence which I what I am receiving. (St Georges)

As much information as possible - other services met expectations.

Staying alive! All of your needs are fulfilled.

(St Helier)

Been well looked after by everybody and can't think of anything that would make a difference.

Doing a great job, especially offering rehab really helps. Don't need inhaler anymore. Now I am doing OK. (Croydon Purley)

Just advice as to what type of exercise I should be doing. (Croydon South Norwood)

## High needs

GP service reasonably quick. Consistent GP service - one GP mainly. However in hospital - seen by different doctors. Physio = one man.

Reassurance and clear/definite diagnosis and treatment. More information about conditions.

Need a straight answer!

Find out if there is a way I can manage my condition. Is a better or new way

Just want a final conclusion, to what can be done, with my respiratory condition? (St Georges)

Nothing, I'm very happy with my clinicians. They explain everything with details and as long as they are friendly and happy to treat patients I am happy too.

(Croydon South Norwood)

GP service - very good. However not seen the same Dr for appointment. six monthly check on medication. Good information. Easy to access appointment same in person and online. (Croydon Purley)

Timeliness, attention, support and rapport. Good relationship with all staff important. Advice and information freely given, I know where an who to go to. Learned to manage my condition. Support staff are trained a lot better now. Amazed me. (St Helier)

## Needs from others -

Responses graded 18 low, 19 medium, 3 high

## Lower needs

One the whole not problems. Appts - do get changed. Receptionist- polite. Central appt booking - good.

Don't think anything else is required. If I could not get around, may need help, but it is not required. (St Georges)

At the moment, no, just understand the issue. People who has respiratory conditions can't do the same stuff as the average person.

Have family to support me, but I try and be as independent as possible.

(Croydon New Addington)

The admin side of appointments. Kept on time, which they are. The is one that was changed up to now has been five <times>. (St Helier)

The need to publicise the service to others may find out about it.

I pay for care. I am lucky I can do that. People who can't pay get help? (Croydon South Norwood)

## Higher needs

Support, psychological support to be around and to talk and engage with people.

Resources. Prevention. The fact that they have a special place at Croydon University Hospital without GPs referring is rather good. Special place for people with COPD and respiratory. Paying attention to it. By running these groups, they must be saving money as opposed to rushing people into hospital. Taught us so well how to cope with our illness.

Emergency - excellent experience. However getting more and more difficult at being seen quickly. Long waiting time to see a doctor, following assessment by a nurse. (3-4 years experience).

(Croydon New Addington)

GP: To have a consistent doctor as always seen by different ones. GPs seemed not to be aware of my prescriptions. Different GPs would prescribe different things. Took a long time to be referred to hospital.

If I never had a carer, I would have to be brought here, so that could have been an issue. Need ready access to the antibiotics from GP, but that can be difficult. The GP needs to get on board when clinician says. I need an energy pack and medication Why does it take five days? I could be dead if treatment's slow.

Might be better if there is someone who speaks the language, Regular checks, better for communication so you can openly talk.

I like to try and do things for myself. I can ask for help. Getting the right information helped me to get financial help. No-one tell you about it. A family member told me. (St Georges)

On this occasion, services have worked well together. Living with several conditions. Have family support has made a difference (St Helier)

## Conclusions

- **Referral:** Patients would welcome a swifter process.
- **Diagnosis:** Patient want swift decision to reduce uncertainty - information on why it may take some time would help.
- **Information:** Needs to be not just on the condition, but about the whole pathway they are taking - look at patient journey.
- **Medication:** For many, finding other ways of maintaining their health, other than medication, is preferred.
- **Self-management:** Patients welcome opportunities to look after their own health - the community training is particularly welcomed.
- **Continuity of care:** Whether GP or clinician, seeing the same person every time is important, or at least the records being there, by which the patient does not need to repeat the same information.
- **Other support:** Supporting families/carers to help, financial advice and transport/ good parking facilities to enable access.

These were presented and discussed at the Clinical Conference



Gordon Kay, Healthwatch Croydon Manager presenting the data.



Working with Emily Symington, Croydon GP (left) and South West London colleague turning feedback and insight into planning.

View the whole presentation at <https://www.healthwatchcroydon.co.uk/wp-content/uploads/2019/05/SWL-Clinical-Conference-Respiratory-Services-Healthwatch-Croydon-April-2019-revised-shorter.pdf>

### 3. Our Work - Health & Care Plan Engagement (Locally)

Across SWL Local Healthwatch engaged their local communities in relation to the Health & Care Plan Discussion Documents that are developing in each borough. These are plans developed by a range of health and care services to tackle enduring local health issues that they feel they may be able to tackle through collaboration. Each borough in SWL has differing health challenges and so each borough has its own Health & Care Plan.

#### Healthwatch Richmond upon Thames

##### What we did

We had worked closely with the Communications & Engagement Group (Richmond and Kingston hold joint meetings) to plan our work. Unfortunately timescales were shorter than expected due to later than planned publication of the Discussion Document.

This was originally publication was due “in March” with Engagement “until June” giving 2-3 months for engagement. It was published on May 1<sup>st</sup> and the deadline for feedback was 31<sup>st</sup> May leaving 1 month for engagement.

**Activities:**

- We had fed into the development of the engagement and communications plan for the HCP
- A presentation on the HCP was given to our Board on 11<sup>th</sup> April (12 people)
- The Discussion Document was presented to our volunteers meeting on 2<sup>nd</sup> May (20 people)
- The relevant sections of the Discussion Document were presented to our Youth Out Loud! (YOL!) Group on 20<sup>th</sup> May (6 people - low numbers due to exams but a very productive discussion!) (YOL! - Healthwatch Kingston run this group of young people from Kingston and Richmond in partnership with Healthwatch Richmond).
- End of life care presentation to HWR Committee (23<sup>rd</sup> May) 10 people
- We sent extensive communications promoting the HCP Discussion Document and related consultation including:
  - Inclusion in a 2000 newsletters distributed in May
  - Inclusion in social media and bulletins
  - Survey responses were collected by our Council so outcomes not yet known.

**What we found**

We expressed disappointment to our CCG over the engagement period covering only 21 working days, as this placed significant limitations on the amount of communication and engagement that was possible.

From the limited engagement that was possible within this timeframe we identified we were able to make the following comments on the Health & Care Plan.

**Start Well**

Young people were generally supportive of the Start Well priorities but questioned the focus on prevention and under 5s, the lack of attention within the plan to young people with current mental health needs and the lack of clear priorities relating to risky behaviours. In relation to the under 5s, young people questioned whether children of this age would be able to understand and benefit from mental health support, and whether there might be unintended consequences from stigma and labelling children at such a young age.

*“People wondered why, given that the public health data they had just seen and their own experience showed a need for mental health care for teens, support was being prioritised for under 5s and not for people currently experiencing mental health needs.”*

Young people had lived experience of long waits to access mental health care and being unable to access this care until needs were severe, this strongly aligns with our wider work in this area. Young people were surprised by the data on the level of risky behaviour in Richmond but recognised that alcohol, drugs and tobacco were widely available to children through schools. They did not feel that the HCP

priorities addressed the need identified through public health data or their own experiences.

There was also a sense from young people that practice didn't match priorities, for example services that would have supported the priorities being cut and healthy food not being an attractive option in schools.

Our own observations are that greater clarity would be welcome in the report around:

1. the reasons for the focus on under 5s in the HCP
2. what the neurodevelopment offer is
3. the age ranges covered by Start Well
4. how the actions will address the needs of young people with mental health conditions
5. how the actions will address the significant levels of risky behaviour

### **Live Well**

We felt that the actions under Live Well were not as well developed as those under Start Well and the work on long term conditions requires unpacking in future versions. It is notable that neurological conditions were not included in previous commissioning policies such as outcomes based commissioning, and this plan provides an opportunity to address that deficit.

### **Age Well**

The Age Well priorities appeared to be the least developed area of the discussion document, particularly in relation to end of life care where actions are simply the implementation of the end of life care and dementia strategies. Further descriptions of what this entails would be welcome in future documents.

### **Wider comments**

The HCP Discussion Documents were relatively limited in explaining how actions would be delivered and how actions would address priorities. Ensuring that these details are clearly laid out in the Delivery Plan that follows will be critical to enabling a clear understanding of the HCP and for its implementation.

The HCP also sits within the context of significant changes to the governance arrangements around decisions and Accountability such as the integration of the separate CCG's into single South West London CCG, the Integrated Care System and Primary Care Networks. These will directly impact on the HCP and the wider Sustainability and Transformation Partnership.

We asked for clarity and assurance over how governance arrangements and how a consistent approach to patient and public engagement would enable the delivery of the HCP.

## Healthwatch Kingston upon Thames

### What we did

We had worked closely with the Communications & Engagement Group (Kingston and Richmond hold joint meetings) to plan our work. Unfortunately timescales were shorter than expected due to later than planned publication of the Discussion Document.

### Activities:

- We had fed into the development of the engagement and communications plan for the HCP
- A presentation on the HCP was given to Healthwatch Open Meeting on 17<sup>th</sup> June (15 people)
- The relevant sections of the Discussion Document were presented to our Youth Out Loud! (YOL!) Group on 20<sup>th</sup> May (6 people - low numbers due to exams but a very productive discussion!) (YOL! - Healthwatch Kingston run this group of young people from Kingston and Richmond in partnership with Healthwatch Richmond).
- We sent communications promoting the HCP Discussion Document and related consultation

Survey responses were collected by our Council who are now reviewing further feedback so final outcomes not yet known.

### What we found

We asked young people at YOL! some questions about the Kingston Health & Care Plan. This is what we asked and here's some of the raw data of what they said that has been fed back to our local Health & Care Plan Leads:

**Do you agree with the actions being proposed to improve the health and care of local people over the next two years?**

- Focusing on more attainable outcomes will be more achievable and have knock on effects
- Good. Linking other issues (drug use) to mental Health
- Unsure about why under 5s support for mental health. How will they understand?
- Think 5 is too young
- One young person living with OCD and anxiety would not have understood when she was five
- Focusing on young age could teach respect for others, but wouldn't understand themselves. This is more for the parents (support)
- How do you tell the difference between regular small child behaviour and mental health condition like OCD?
- Fears around labelling and being misdiagnosed at a young age
- Understand the positives for getting early help
- One person's friend has been waiting three years for a therapist
- Someone's friend not properly diagnosed until year 5 (9/10 years old) which meant missed out on a lot of learning support
- If there is a focus on supporting people with learning disabilities to be independent why are groups that enable this having their funding cut?

- It was noted and agreed by all young people that schools do not offer healthy lunch options
- The healthy options are often very unappealing or in some cases (vegan diet) didn't exist so student ate an apple for lunch
- Sometimes the healthy options are not as healthy i.e. creamy pasta rather than fresh food
- Healthy food is more expensive inside and outside of school. One young person overheard a conversation where someone went to McDonalds 'because it was cheaper' (not supporting poorer families to eat well)
- Unhealthy food more convenient even when making a healthy meal having a packet of crisps while you cook.
- Schools have lessons on balanced diets but nothing changes.
- More could be done to put people off unhealthy diets. More scare tactics (similar to risks of smoking)
- Money is a huge issue. Especially when you are 13 years old with pocket money (eat cheaper and have more money for other things)
- Trying the healthy food schools talk about is good to encourage you to eat healthy. But suggested its cooked by someone else
- Two young people had different experiences. One enjoyed the healthy food they cooked the other was put off because they didn't make it right
- Step competitions (fitbits) are a great way to get people moving.

Is there anything missing in our plans that you would expect to see there? If so, what?

People wondered why, given that the public health data they had just seen and their own experience showed a need for MH care for teens why support was being prioritised for under 5s and not for people currently experiencing mental health needs.

Have you any other comments about the Health and Care Plan discussion document?

- Massive concerns about council decisions not linking in to this. Rose Theatre losing their funding. Meant a lot to the community as well as families going to shows
- Rose theatre was a distraction from being bored
- Similarly why are youth groups for disabled children having funding cuts when its on the objectives (opportunities to flourish and be independent)
- Street parking permits increased from £90 - £400 a year. Do the funds link? (why being asked for more and getting less?)
- School nurse is not always available. The school don't announce when she is there but only when she is not
- Surprised by stats around high percentage of 15 year olds drinking in London
- The young people have noticed some of the risky behaviours in school and other students smoking pot. Must be a security risk (how are so many young people getting drugs so easily)
- Lots of pressure on children to be cool and fit in (rather than make healthy life choices)
- One young person commented that mental health is seen as 'trendy' and people claim to have OCD or depression. Which is insulting to those with



formal diagnosis. They believe this is due to a lack of understanding of how hard it can be.

## Healthwatch Wandsworth

### What we did:

- + We worked closely with SWL and Wandsworth and Merton CCG on the design of the local engagement event for the Health and Care Plan in November 2018.
- + Having insight into the emerging topics we have been able to speak to people at our event in December 2018 so that they could give us their feedback.
- + We also incorporated the draft topics and asked people for their comments in a survey we ran between December 2018 and April 2019 in which 150 people took part.
- + We held another event in May 2018 at which we presented the draft Health and Care Plan and ran a workshop allowing people to provide feedback.

We combined the above insights and other general feedback we have had from local people to provide a formal response on what local people have said about the plans. Broadly the plans incorporate most of the themes people had said were important but we were able to offer a few further comments shedding more light on their point of view. Our key recommendation was that developing and final plans should demonstrate outcomes and quality measures that reflect what local had said was important.

### What we found:

Below are summaries of what people have told us are important for the plan to address according to the draft plan. Some of the areas they highlighted areas are mentioned in the draft plan, but the comments perhaps highlight some alternative aspects to consider.

### Start well

- + School and parental support were mentioned most frequently as well as the role of schools, particularly in helping children gain knowledge and make informed healthy choices. The plan acknowledges this and commits to working with schools and parents.
- + Support to learn positive strategies and what people can do to maintain wellbeing and good mental health, e.g. diet planning and mental health coping strategies, either from professionals including dieticians and social workers, or from community and peer-led groups.
- + Make sure people feel they are in a safe environment and have someone to ask for help or available support networks.
- + A number of people felt there was a need for more youth clubs.
- + Support to be given to enable social gatherings, community building, activities, events and groups - services could help with financing and resourcing. Some felt children and young people should be involved in the wider group and community rather than doing healthy activities in isolation.

- + People told us that affordability is very important for participation in exercise and recreational activities. College students particularly highlighted this and said that some facilities available to adults should also be extended to be available to them. Tackling affordability is not specifically mentioned in the plan.
- + Increase access to nutritious food and reducing accessibility of junk food as well as giving children and young people a sense of 'involvement' in activities like cooking. It is important that healthy food is affordable and easy. The plan mentions family-based weight management interventions and supporting children and young people through healthy places. Can the plan reference more about what 'healthy places' are?
- + Some people highlighted the need to reduce pressure from exams, technology and social media.
- + Some comments suggested that there needs to be increased access to mental health support and implied that access is currently not easy or quick enough. Ease of access and waiting times are not directly mentioned in the draft plan.

### **Live Well**

We asked people about physical and mental health being considered at the same time by services and about health and social care services working together. Below is a summary of what they suggested, which are broadly in line with the health and care plan but may provide further specifics for focus of project plans and measures of success.

- + Easy and quick access to services was highlighted as important by many - access needs to be clear, especially given the transient population in Wandsworth.
- + More community and peer led drops-ins and multi-disciplinary teams.
- + Advocate and buddy systems based in the community.
- + Mental health and drug and alcohol services working together.
- + Easy access to people with expertise to help, advise and provide information, including prevention and self-management to keep well.

Feedback relating to diabetes specifically suggested the following, which broadly align with the health and care plan, although awareness raising (that is sensitive to different cultures, languages and characteristics) and easy access to the services was mentioned by the people we spoke to as important to build into the programme.

- + More access to information, support from dieticians and physical activity were mentioned by most who provided feedback.
- + Tailoring information and support for different cultures and language users was highlighted as important.
- + Community-based support groups, buddies and peer support (some already attended a community group that helped provide this support and felt it was very useful).

### **Age Well**

We asked people about the draft health and care topics about dementia, isolation and about health and social care services working better together. Most of the feedback related to community building and increased access to services. Most of

the actions in the health and care plan relate to specific health services and interventions and suggest the voluntary sector will bring community-based support alongside services. However, specific community capacity and resource building isn't outlined in detail, although there is a brief mention of building capacity and connections on page 35.

- + Intergenerational projects with schools and young people.
- + Support networks, buddy systems and community activities and information about support available - support for financing and resourcing community activities.
- + Advice and proactive access to services (rather than reactive).
- + More services and support for dementia, including lifestyle services that can help as well as cognitive rehabilitation.
- + Access to transport was mentioned as important.
- + People need to feel safe in the community and have someone to ask for help.

### **Wider comments**

There were several themes people identified as impacting across the themes in the plan as a whole:

- + Administration processes within services need improving to prevent delays and errors
- + Less silo working and more joint working across the system, for example mental health and diabetes champions could also be addressing issues of isolation. This might in some way be addressed by Make Every Contact Count but perhaps plans are needed to ensure those working on one aspect of the plan can be involved in others, particularly because these have been selected as priority topics to tackle.
- + Ensuring the right incentives (perhaps for services and for the individuals concerned).
- + Developing affordable physical and recreational activities in the community, community building and community led strategies.
- + A focus on schools to provide information and awareness and for parents and the rest of the community to focus on prevention.
- + Developing support networks and mental health support, particularly including parents, families, friends, healthcare professionals, carers and personal coaches.
- + Youth clubs, mentoring and peer coaching were also felt to be useful to help support children and young people's mental and physical health.
- + Transport is a crucial enabler in helping people access services and stay well.
- + Sustainability of interventions should be considered from the person's perspective. Further funding for support of affordable activities will be needed if people are to continue to stay well after initial support has been provided.
- + Clear and easy to find information that leads to fast access to support and knowledgeable support in the community or from health and care professionals that is specific to the needs such as dieticians and physiotherapists.

Some people highlighted to us that the distinction between start, live and age well compartmentalised issues that cut across the generations such as diet and exercise and mental health. People experience age-related issues at varying ages (we found this when speaking to young people about mental health transitions from children to adults' services for example). It also perhaps makes it more difficult to recognise the interconnections between the generations' issues, for example how dementia does affect carers, families and friends who could all be impacted by and play a part in ensuring the wellbeing of the person they know. This is to some extent addressed in the intergenerational projects mentioned but perhaps the cross-connections could be easier to manage without the hard lines drawn between the categories.

Finally, the plan articulates a strategic level of information and we hope that, when projects are planned in detail to tackle the issues discussed, the input from local people will inform how things are done, the outcomes expected and measures of success. We hope that further engagement, involvement and transparency will come as projects are shaped and implemented. As this happens we would hope to see a commitment to including some of the following in the action and project plans:

- + Accessibility (including transport)
- + Any adjustments or additional considerations that may be needed ensure that groups from protected characteristics and those who are at risk of health inequalities and additional barriers to access.
- + Considering and planning for information provision and communication about services and how this can be easy and quick to access in a single place and proactively reaches out into community groups.
- + Although there is recognition of the important role of carers and supporting them in dementia cases in particular, there could be more in plans for all projects to look at how carers can be involved in the design and delivery of projects as well as how they can be considered an integrally important part of the service's delivery and success.

We hope to contribute and support public and patient involvement as project plans emerge.

## Healthwatch Sutton

Healthwatch Sutton representatives have been involved from the early stages in the development of the Sutton Health and Care plan.

Some of our reports are already being used to influence parts of the plan.

For example our report showing the findings of a survey carried out by over 5000 secondary school students is being used a part of the intelligence to develop the 'Start well' part of the plan. The full report can be found here

<http://www.healthwatchesutton.org.uk/children-and-young-peoples-mental-health>

In addition our Perinatal report looking at the experience of people who are pregnant or who have had a baby in the last 2 years (and their partners) is also

feeding in to the plan. The full report will be published soon here <http://www.healthwatchsutton.org.uk/perinatal-health-and-wellbeing>

We are still working with the Sutton CCG, Sutton Council and other organisations to define any further engagement that is needed to help influence other areas of the plan.

**healthwatch**  
Merton



Healthwatch Merton has supported Merton CCG, Merton Council and the voluntary sector with developing a Local Health and Care Plan together that seeks to make services better connected and more joined up.

Healthwatch Merton supported and helped design an accelerated design event in November 2018 on the Health and Care plan making it as accessible as possible for a range of stakeholders and knowledge bases. It brought together local people, frontline staff and key stakeholders (including local councillors and voluntary and community groups) to help agree priority areas that we all could focus on.

More than 130 people attended the day - this included around 50 local people. A strong representation from the local Voluntary and Community groups in Merton attended, which included; Healthwatch Merton, Merton Voluntary Service Council, Inner Strength Network, Mitcham Town Community Trust, Mental Health Forum, London in Your Language, South Mitcham Community Centre, Merton Seniors, LGBT forum, Friends of St Helier, BAME Voice, Ethnic Minority Centre, Wimbledon Guild, Polish Family Association, Carers Support Merton and MENCAP.

In addition, Healthwatch Merton has shared with our database via our E-bulletin to over 2'500 local people the Merton Health and Care plan draft for people to have further opportunity to comment on its development.

Healthwatch Merton are still working with both Wandsworth and Merton CCG, Merton Council and other organisations to agree, define and support any further engagement that is needed to help launch the plan effectively and bring it alive for local people to get behind.

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## Healthwatch Croydon

In Croydon the health and social care system is working differently to the other boroughs in South West London. They are considering how the organisations can function using a 'Integrated Care Network' (ICN) model to work together on health issues, whereas in other boroughs the organisations work independently but look to collaborate on a partnership basis. Healthwatch Croydon therefore focuses its engagement with the public on the ICN model itself. Healthwatch Croydon also spoke to people about the local Health and Care Plan topics separately. For the results of this work, read on.

### What we did



In early May, Healthwatch Croydon, in association with NHS Croydon Clinical Commissioning Group, ran two successive two-hour public events in Thornton Heath to gain insight into how the new ICN+ model of services would be received by local residents.

There were four aspects that were explored:

- Views on the new model of care
- How can providers engage better through ICNs?
- How can new models of co-production be created?
- How can health providers be locally accountable?



## What we found

Here is what we heard:

### Understanding the model

- **Confusion over the Integrated Care Network/ Primary Care Network model:** It is seen by the public as too difficult to understand and with much terminology. It is difficult to see the individual resident's place in this. It is seen as unclear where the GPs have a role.
- **The focus of the model is still too much from the NHS perspective:** It needs to emphasise the community more and the wider partners where health and social care impact such as Department of Work and Pensions and schools.

### Widening access

- **Link workers have a role to play in understanding communities:** They can have a crucial role in bringing together different parts of the community.
- **Accessing younger and working populations:** Model looks good for those who are currently older or ill, but the younger and working populations are not really represented.
- **Funding opportunities:** Many community groups where community life happens, or could be developed, need funding. This could be an incentive to work with providers in developing the ICN+ model.

## Communications

- **Don't underestimate the personal:** While it is sensible to digitize some services and reduce unnecessary GP appointments, many people value personal contact whether for information or advice.
- **More effective communication is needed on why people do not need to see a GP:** The GP is still seen as the reliable and trusted part of the health service. Communication needs to increase the confidence of residents that other providers can meet their needs so well.
- **Clearer, simpler explanation of pathways is required:** particularly where they do not involve a GP.
- **Little information on how long it is going to take to get to this new model:** This may create expectations on how quickly this can be delivered.

## Building community ownership and representation

- **New and creative ways need to be considered to engage and build a sense of community:** This needs to be done physically as well as digitally and needs to reflect diversity of approaches and languages, encouraging ethnic group representatives to support these initiatives.
- **The process of influencing and representation is seen as confusing by residents and there is the issue of balancing these:** There is a need to explain this in simple terms using models understood beyond health and care. This includes level of formality, whether the role is paid, how much experience representatives need to be effective and whether training and mentoring could be given to widen access.
- **There is an interest in developing a community engagement model that leads to ownership and then leadership in neighbourhoods:** This should explore ways of empowering people at each stage to be involved, take ownership and responsibility for leadership roles in each locality.



These are our recommendations which are relevant to provider and commissioner:

### Understanding the model

#### **ICN/PCN model needs to be presented from the patient perspective:**

Healthwatch Croydon can provide a neutral role and advise on simplifying the language and setting this out from the patient perspective.

- Look to build strong relationships and learn from organisations beyond health and social care services such as schools and relevant government departments.

#### **Widening access**

- Enhance the link workers role to be the facilitators of real community engagement, co-production and representation, or create new roles in terms of community development.
- Focus activity on engaging those of working age and younger populations by going where they are and not expecting them to come to providers.
- Create or maintain funding streams to build community assets and raise profile of new ICN/PCN networks.

#### **Communications**

- Create opportunities for personal face to face contact to occur.
- Expectations need to be managed concerning rollout and timescale, with communication of clear timetables and regular updates to build confidence.

#### **Building community ownership and representation**

- Community mapping to build networks across different groups and relevant materials to get out to hard to reach groups.
- Apply principles that worked with Department of Work and Pensions 'Yes We Can' event and SLAM membership schemes to build a community engagement and empowerment structure.
- Look beyond current approaches to ask the public for their ideas around some simple questions.
- Consider a community engagement model that leads to ownership and then leadership in neighbourhoods.

#### **Response**

One Croydon have been supportive of the recommendations and we presented at Croydon's Health and Wellbeing Board on 19 June where the insights and

recommendations were accepted by the board with a commitment that this insight would be used to plan the next stages, which Healthwatch Croydon will be a partner in the process.

#### Croydon Health and Care Plan response

**healthwatch**  
Croydon

## Let's discuss Croydon's Health and Care Plan

**Wednesday 12 June 15.00-17.00**

Carer's Support Centre, 24 George Street, Croydon CR0 1PB

Croydon's new draft Health and Care Plan discussion document has been published and needs your feedback by 17 June. [Read it here](#) and [give your responses via the survey here](#) (organised by the NHS Croydon Clinical Commissioning Group).

To time with this discussion, Healthwatch Croydon are organising an event to discuss the proposals further and **give independent feedback to the commissioners**. So, come along, give your views and make your voice count!

Book now via link below or call 0300 012 1235 if not online:  
<https://discuss-croydon-health-care-plan.eventbrite.co.uk>

Refreshments will be served

In addition to the work agreed under the grant, One Croydon announced a public discussion over the Croydon Health and Care Plan between 24 May and 17 June. Healthwatch Croydon decided to run an independent meeting to support feedback from residents while encouraging them to still fill in the One Croydon survey, which they could do confidentially. On Wednesday 12 June, Healthwatch Croydon organised a public meeting to provide feedback on the recently published Health and Care Plan discussion paper. Reflecting the themes of the survey accompanying the discussion paper, Healthwatch Croydon created an open forum to discuss:

- What people understood about the plan?
- Do people agree with it?
- What was missing from the plan?

The event had 24 attendees. The object was not to explain the plan, indeed there was a link to it and the survey in the invite with the request that people came along and asked questions afterwards. Responses were recorded verbatim and then analysed. The following comes from a professional independent transcript that was taken at the event.

**Understanding about the plan**

It was clear that it was linked to the NHS Long Term Plan. Some of the aspects of the case for change were there, but more detail on sources and assumptions behind these would have been relevant.

**Do people agree with it?**

There was general agreement with what was in it. No one suggested aspects should be taken out or were not relevant, however there were wide range of responses who felt much was missing.

**What was missing?****Measures of what success looks like and how there will be accountability**

- A lot on aspirations but a lack of objective targets and measures of success. Question and concerns on accountability

**Case for change background information**

- No clear reference to the wider issues not affecting demand and supply, ie GPs retiring and nurse shortage and how perception of Croydon might affect this.
- No reference to non-health issues that impact health such as environment, education, social deprivation.

**Lack of communication strategy**

- Individual perspective needed - How will this affect individuals? What will be the process of change? There is a need to present the stages and show the journey of progress so that expectations can be managed. For example, how long will it take for this to be deliver and what will change first.
- A need for better signposting and information in one place - how about a Croydon health Google?

**Lack of engagement strategy**

- Lack of full engagement strategy - different methods to access different groups.
- In terms of delivering the community and voluntary sector approach, there is a need for organisations to work together and also access funding more easily irrespective of size, rather than a bias to larger, well-staffed/ funded organisations.

**Lack of clarity about some of the initiatives presented**

- Lack of clarity about what hubs will provide.
- Lack of clarity between the following roles and their remits and how they work together: Care navigator; Personal Independence Coordinator; Link worker
- No reference to how the health and social care provider will work closer with those other areas that relate to health such as education

**Fit with current initiatives taking place**

- Unclear where other initiatives fit in to this such as Mental Health hubs and Live Well.
- No preventative strategy presented - this is focusing on the already ill.
- No reference to other key strategies being defined which would impact or contribute to this such as: autism strategy both for adults and children linked with education and social care as well as health; carers' strategy again across health and social care.

#### **Suggestions to include in revised plan**

- Objective clear measures of success and how these are accountable to residents.
- SWOT analysis of health and social care services in Croydon to show more clearly and concisely the case for change.
- A communications strategy that focuses on individual perspectives and their expectations, showing the journey and timetable as well as destination.
- An engagement strategy to really work in communities, using Integrated Care Networks and Primary Care Networks and funding opportunities.
- A clearer explanation of some of the new initiatives and roles and how they work together in a way a lay-person will understand it.
- A clear explanation of how current initiatives outside this plan that are already underway or proposed relate to proposed actions that are within this plan.

#### **Response**

These insights were included in a paper on feedback presented at the NHS Croydon Clinical Commissioning Group meeting on 2 July 2019, where many of the points were responded to. It was also revealed at that meeting that there were only 30 responses to the survey meaning Healthwatch Croydon's contribution gave significant additional insight. Healthwatch Croydon is actively working with all partners to ensure the revisions to the plan are reflected going forward into implementation, particularly around communication, involvement, co-production and accountability.

## 4. A Summary of Overall Findings:

The following are a few comments we have been able to draw out across all of the work discussed above. However, our ability to draw these comments together are limited by the differences between the topics each Healthwatch discussed at the clinical conference, our local borough contexts and differing Health & Care Plans.

### Clinical conference topics:

A few similarities across the our findings on the different clinical topics discussed were are follows:

- + Information - knowing own limitations and how to maintain normal healthy life
- + People don't want to go to hospital and would prefer support in the community or closer to home
- + Uncertainty of how a condition or situation will develop was really important for patients to understand and develop coping strategies
- + Mental health support is important in most physical health contexts and needs to be easy to access
- + Better information and efficiency of administration is needed to reduce stress and complicated health care journeys

Healthwatch comments on participation in the work:

We felt that the patients experience was presented at the same level as the clinical presentations and were timed and designed to directly influence discussions on future plans for services. This was a succinct and immediate process and impact was achieved through partnership working across SWL HW and the SWL STP.

We await action plans to be made available in September to understand what patients have been able to influence.

### Health and Care Plan Discussion document engagement

The Health and Care Plans for each borough are quite different, so it is difficult to draw conclusions or comment generally on the plans themselves. However, below are some common themes our residents across South West London talked about:

- + The importance of communicating effectively with carers and the role that they play.

- + Communities could better support each other to stay well if the infrastructure and resources are in place. Everyone wanted an easy place to find information and resources for their health.
- + Improved and closer working between health and care organisations and Education.
- + It is important to local people to get appointments when they need them and that they don't fall through the gaps between services (referrals, mental health support and GP appointments).
- + How can the aspirations of the plan be aligned with austerity and challenging budgetary situations.
- + It is important that 'what matters to local people' informs the intended outcomes and measures of success for services or projects in the plan so that services are achieving what is important e.g. help is available closer to home or in the community.
- + People were concerned about the process and progress of the plans and accountability for the different areas of delivery. They wanted to be sure there was clarity in how things are progressing, how it is affecting individuals and if it is achieving what is most important to people.
- + There was an interest in opportunities for co-production in the more specific plans. So far the report has been high level and strategic and the local residents involved in discussions were from the general, yet diverse, population but not necessarily the people directly affected by the topics in the plans. This is in contrast to the work on the clinical conference where we spoke to specific patient groups targeted in the Long Term Plan.

Healthwatch comments on participation in the work:

- + Issues around discussion document not being either publicly available or not widely available.
- + Not all HW areas had a specific piece of work allocated but did have our own ways of making sure the public were informed. For examples, Healthwatch Kingston and Richmond were able to hold a workshop at 'youth out loud'.

## Final reflections on the process of the work described in this report

The extremely short timescales and difficulties getting clarity on what was required early on in the process because we were doing something different in Southwest London compared to the other Healthwatches in England. The gaps between partners involved and clarity of what was needed were filled by a flexibility in our approach, working with our partners and Healthwatch England. However, there was a significant on our teams and our workload and priorities as a result of the tight timelines the NHS worked to. Timelines also prevented us from accessing additional resources available but we were able to benefit from additional resources provided by SWL NHS who listened to and worked to support our resource challenges. Due to this we think there was a benefit to being able to deliver something this locally relevant with some additional funds rather than

undertaking work with an agenda that competed with local priorities. Better coordination, clearer messages about expectations and time for us to decide what is important locally would have allowed us more time to reach even more local people.

Progress reports and updates were not possible within the national framework due to the tailored nature of our local work. Whilst it was acknowledged that our progress did not fit in to the national framework numerous requests were made for us to submit reports in formats that were not relevant to our agreed approach.

As small organisations with very limited resources we ideally need more preparation time and implementation time and the resources should be linked to the timescales involved. The success of this type of generic request will depend on how effective the local outreach our research data is already in place. For example as a minimum, we usually need one month to decide on feasibility and scope, two months planning, one month implementation and one month for 'all' reporting. Time and resource does vary between healthwatch so we need be flexible accordingly.

Working together and ensuring local people have a voice in SWL commissioning of health and care services is an ongoing process. As local NHS structures evolve over the coming years we hope to remain in continuous dialogue with our local NHS and local authorities about how local people can be involved and we always welcome further resources to help us achieve this.



Thank everyone that contributed to this

SOUTH WEST LONDON HEALTHWATCH - NHS LONG TERM PLAN REPORT 2019