



Living with a respiratory condition in South West London: What matters most to patients?




South West London
**Health & Care
Partnership**

**South West London NHS
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Who we spoke to

- 41 people: 18 in Croydon community (5 Purley, 3 Thornton Heath; 5 New Addington; 5 South Norwood); 15 at St Georges 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.
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Living with your condition - positives

24 responses coded as positive; 10 neutral, 7 negative

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).

Living with your condition - negatives

24 responses coded as positive; 10 neutral, 7 negative

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)

Care and treatment - negatives


24 responses coded as positive, 9 negative, 9 neutral.

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- low needs

Responses graded 4 low, 17 medium, 10 high.

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)

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


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)



Needs from clinicians- higher needs

Responses graded 4 low, 17 medium, 10 high.

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- low needs

Responses graded 18 low, 19 medium, 3 high.

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)

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)

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)

Needs from others - higher needs

Responses graded 18 low, 19 medium, 3 high.


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)



Needs from others - higher needs

Responses graded 18 low, 19 medium, 3 high.

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)



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.
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Conclusions

- **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.
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Film



Discussions

