

**Healthwatch Southwark's Public Forum:  
"Your Care, Your Services! - Issues to Solutions!"  
Event Report**



**Date:** Wednesday 10 June 2015

**Time:** 3.30pm - 7.30pm

**Venue:** Cambridge House, 1 Addington Square, Camberwell, SE5 0H

## Attendees

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Over 100 people registered to attend this event and we had to close ticket booking and 73 people attended. Attendees ranged from 5 years old to 92 years old with diverse representation. Around 20 people had not been to a Healthwatch public forum event before and 9 registered as new supporters of Healthwatch Southwark as a result of this event. We had 5 young people from Southwark Young Carers and 2 children of attendees, ages spanning from 5 and 12 years old). Attendees included Southwark residents and representatives from voluntary and community organisations.

## Purpose of the forum

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The purpose of this public forum was to inform Southwark residents about:

- 1) Healthwatch Southwark
- 2) Plans to join up health and social care services
- 3) Changes to home care services

It also gave people the opportunity to network, see what the voluntary and community sector has to offer, and receive information about keeping well. **Stalls included:** Age UK Lewisham and Southwark (promoting Safe and Independent Living), Contact a Family (supporting the families of disabled children), Africa Advocacy Foundation (offering a range of sexual health services including: HIV prevention; HIV testing; peer support; and free condom), Southwark's Clinical Commissioning Group (commissioners of health services), Elsie Staples from a faith group providing health checks, NAZ Project (offering sexual health advice and free HIV rapid testing) and more!



## Key issues from discussions....

### Local Care Networks (joining up local health and social care services)

- ✓ People need educating so they use the right services for their needs
- ✓ People prefer to see the same professionals and build relationships with them
- ✓ Communication is key - want to be kept informed and understand what is happening
- ✓ Need to be considered as a 'person' not a 'process'

### Home care services

- ✓ Home care workers are front line and should work in partnership with other health and social care professionals
- ✓ Consistency is important - having the same carer so they get to know the person
- ✓ More needs to be done to raise awareness about what local charities can offer
- ✓ Carers need to be 'culturally sensitive' to the needs of individuals
- ✓ More clarity needed on what the roles are of carers, as this is variable
- ✓ Important to record and track what has been done so all professionals are informed

## Healthwatch Southwark Update

Aarti, Healthwatch Southwark Manager, spoke about Healthwatch - what it is and does:

- The different ways Healthwatch gathers views and experiences from local people
- How Healthwatch monitors quality of services by visiting and speaking to people that use them
- Healthwatch's representation on decision making boards to champion the patient and public voice

To see this presentation, please visit our [website](#).

## Joined up care - from the patient perspective

David Smith, Head of Transformation - Integration at Southwark's Clinical Commissioning Group (the organisation that funds health services) talked about the development of Local Care Networks - which will be joining together health and social care services. The aim is that patients will receive care in the right service at the right time; that care will be tailored to their individual needs and better coordinated.

Graham Collins, Head of Development and Sustainability, at Community Action Southwark (the umbrella organisation for the voluntary and community sector in Southwark) talked about the rich and diverse groups and charities that are available to Southwark residents. He talked about how these could be used to help people keep well (both physically and mentally) without thinking their GP was their only option.

To see this presentation, please visit our [website](#).

### Q&A

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**Q:** Local Care Networks put focus on preventing ill health, but mental health services such as Mental Health Day Centres are being cut to save money which leaves these people vulnerable and without help.

**A:** Local Care Networks will pool together money from both health and social care, and this will prevent specific services being underfunded and cut. It is therefore important for advocates, patients and local networks to be involved giving feedback on services so that, so that right services continue to be provided. I will also get back to you on Mental Health Services. (A more detailed response found here)

**Q:** There is a blame culture - it is never anyone's fault when the system fails you. Patients just want a simple apology. To get a procedure done it involves talking to lots of different people who don't communicate with each other. This is not effective.

**A:** This is the reason Local Care Networks are being formed. There will be a single contact for patients to communicate with, and they will liaise with other professionals/ departments instead of the patient having to.

**Q:** How to we ensure accountability in social care? There are a lot of providers, including charities, providing the same service which doesn't seem the best use of money. Should there not be more joined up care for VCS services.

**A:** The voluntary sector have to get better at working together in partnership, for example joining together and bidding for contracts rather than doing it independently. CAS are bringing VCS into consortium to bid for contract. You're right there are a lot of duplicates but there are also some specialist services.

**Q:** Black and minority ethnic (BME) communities are overrepresented in hospitals and prisons. There is no mention of tackling BME inequalities in these planned changes. You also don't mention 'open peer support dialogue'.

**A:** Commissioners of health services (clinical commissioning group) and commissioners of social care (council) are now working in partnership. Public Health are also involved, and their role is to look at Southwark's population and what the needs are of specific communities. This helps commissioners address inequalities when planning design and delivery of services. We are also working on doing outreach and working with different groups, we recognise it is a challenge. (Outside of the meeting, a response from the CCG was provided in relation to the query around 'open peer support dialogue' and tackling BME inequalities).

**Q:** Joining up services has been discussed for around 20 years. This time, how will you ensure plans will come into fruition?

**A:** The process of contacting different people has started; different parts of the system are talking already. All services are looking at working towards common outcomes. Process of having uniform information record has started. Hospitals and GPs will have access to health records. Patients too will be able to see records. If a patient is interested in reading personal health notes, then GP is legally obliged to make the notes available to patients.

## Group discussions

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### What are the issues?

**Information:** There is a lack of information so difficult to keep track of changes in how the system works. People felt that it 'goes on endlessly' and that the experience is 'appalling' as a consequence. How are you supposed to know if your issue is 'minor' or 'major'? 'Education' needed to let people use the right services (e.g. leaflets). More clarity needed when using services - sometimes you don't know who to contact or whether to wait for them to contact you.

**Choice:** Customers should have a right to information about their health issues and treatment. Rather than just being 'prescribed treatment', patients want to make 'informed choices'. This would be useful for patients in managing long term conditions.

**Consistency:** People value seeing the same professionals and feel this is when they receive the best service. One person said they had seen four or five different consultants over a couple of years, and asked 'where is the commitment?' For one issue you often have to access different departments - experiences are variable at different stages. At some it is excellent, but the next it can be chaotic and you feel let down.

**Communication:** Clear and consistent communication is key. One person said ‘Doctors get medical training, but no training on how to talk to people’ and another said ‘they need to say who they are, who sent them, and what they are there for’.

**Whole person:** You want to be seen as a person, not just feel part of a process. There needs to be a shift in culture to change this attitude. This will help improve the patient experience.

**Mental health support:** Concerns were raised about people with mental health problems. They felt there are lots of hoops to jump through to get support. It was felt you are listened to and given support when something happens (e.g. someone gets hurt). They need to receive these services now and continuously.

**GP appointments:** GP appointments are hard to get even when people phone in first thing in the morning leaving people with a feeling that they are being ‘fobbed off’. People have to wait for two weeks sometimes. This prompts some people to then use A&E.

**Service user involvement in reviewing service:** Reviews do not consider the opinion of service users in a meaningful manner. GP practices need to involve service users in finding out what is working and what is not. Patient Participation Groups (PPG) not very effective and go around in circles.

**Accountability:** Considering the historic difference between health and social care providers, **how can we be sure that they will work together to provide a seamless service.** With the involvement of different organisations including charity organisations, all working to a common outcome, some issues will be around different styles and capacities. Some organisations are more efficient than others and this will have an impact on the quality of care. **Who will take responsibility if things go wrong?** Who will get the blame? **What happens when organisations disintegrate,** considering the current funding climate? Linking disparate aspects of care - social/physical/mental - how will this happen? People want honesty -if there are problems then front up to them.

**Confidentiality:** There were concerns around confidentiality and consent. Who will have **access to patient data** and **what happens to user details?** It should be made clear as to who the data is being shared with.

## What are the solutions?

Suggestions that were made included:

- GPs act as the first point of call
- More advocates needed - to act as a coordinator between different professionals.
- Ensure professionals are adequately trained to be caring and compassionate
- Ensure carers are given adequate support

- Improve access - hard to get through to GP at 8am as line busy
- Take pressure of GPs e.g. online appointments rather than face-to-face
- Routine procedures could be made available elsewhere so easier to access
- More health visitors to see sick people at home
- Educating service users about self-management.
- Making it easier to access information especially if English isn't the first language.
- An advocate for those who are in distress who may need help in raising issues/complaining.
- My Healthy Locker- allowing people to have control over their health information.
- Being inclusive, factor in support e.g. personal budget, for vulnerable, isolated, homeless or hard to reach so that they are not excluded.
- Redressing past mistakes, to do something for those who have been 'let down' a long time ago.
- Pharmacy First step in the right direction.

### Home care services: now and in the future

Andy Loxton, Commissioning Manager at Southwark Council talked about how home care services will be transformed. This will involve going out to issue new contracts for all forms of home care (for adults and children). The Council want to involve local people in shaping this plan.

To see this presentation, please visit our [website](#).

### Q&A

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**Q:** If you want to make a complaint about a home care service, but you aren't a relative, will you be listened to?

**A:** You would have to get consent from the person you were complaining on behalf of.

**Q:** Where can we find the Ethical Charter of Care? *This is set out in the report to the October 2014 Council Cabinet and summarised below.*

**A:** The published version is only available as part of a Cabinet document. A shorter version has been put together, which the Council will share with Healthwatch.

**Q:** A lady spoke of the importance of patient choice and communicating with carers/family when decisions are being made around End of Life Care, reflecting on her own experience which was very poor

**A:** The importance of patient choice and also clear communication and involvement of carers and family is key. It can get messy with different providers such as Hospices and

other services. But the joined up care through the Local Care Networks between local authority and the NHS should improve this. This conversation was continued privately.

**Q: Is residential and nursing care the same as home care?**

**A:** Home care relates to people living in their own home and receiving personal care. It enables people who want to live at home, to do so with the help and support they need. Whereas Residential care, the care and treatment is the same, except that individuals are not in their own home and there is staff at the residential home all the time.

**S: A negative experience was relayed about home care services for her husband. She said that if she was not there, it would have been very bad**

## Group discussions

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There were two groups that discussed home care services. The discussion focussed on what is important to the person and their family when receiving home care, what doesn't work so well, and how home care staff could work better with NHS teams.

## Experiences of home care

The group had an average experience of home care services either as users directly, the carers of people who use home care and even some who are home care workers in their professional life. Groups commented that it often isn't thorough or flexible enough, whilst acknowledging that **'there is only so much a carer can do'**. Someone said they had an **'excellent service'** because the daughter (carer) had ensured this was the case. There was a general view that there was mixed experience of home care and that issues were particularly difficult when the regular carers were off on leave sick etc.

Some felt that the range of what home carers can offer varies too much, with some simple tasks not being covered e.g. putting in eye drops, lift things, give medication etc. Crossover between home care and medical care unclear - a grey area.

## What is most important when receiving care at home?

**Consistency:** Better to have the same people delivering care, rather than different people each day. Carers should be well informed about the person they are caring for - know their history, their likes and dislikes. They should have the time to get to know the person - this is difficult if no consistency.

**Good quality carers:** Carers need to have dignity and respect for the people they care for, and they need to be compassionate and sensitive. They should treat that person how they would want to be treated.



**Timing:** Carers should come when is convenient for the person and should have sufficient time to do the job well and not be rushed. They need to be reliable.

**Communication:** Important to use clear language and providing explanations to ‘jargon’ terms.

**Documentation:** It should be clearly recorded who did what and when so knowledge is shared between carers and other professionals.

**Person-centred:** Carers need to ‘culturally adapt’ and be sensitive to the individual needs of the people that they care for. They also need to have the ability to ‘observe’ the people that they care for - both physically and mentally, and feel confident to escalate and report issues when appropriate.

### Relationship between NHS professionals and home care services

The group felt that home care workers should not be isolated from the rest of the health and social care world - they are a front line service and should be included in discussions and kept informed. If possible, home carers should be involved in conversations when someone is discharged from hospital so that there is clear handover, what the person’s medication and needs are following a spell in hospital.

Conversations also arose about attitudes towards home carers - that they lack status and respect in the field. A culture shift is needed to ensure this changes.

### Role of the voluntary and community sector in home care

The group were not fully aware of what local groups and charities could offer them in relation to home care and the registration requirements with the Care Quality Commission to provide personal care. Reference was made to befriending, but people felt volunteer-led home care was limited.

Suggestions were made about the best way for them to hear about what local groups and charities could offer: flyers in GP surgeries and libraries, and through word of mouth.

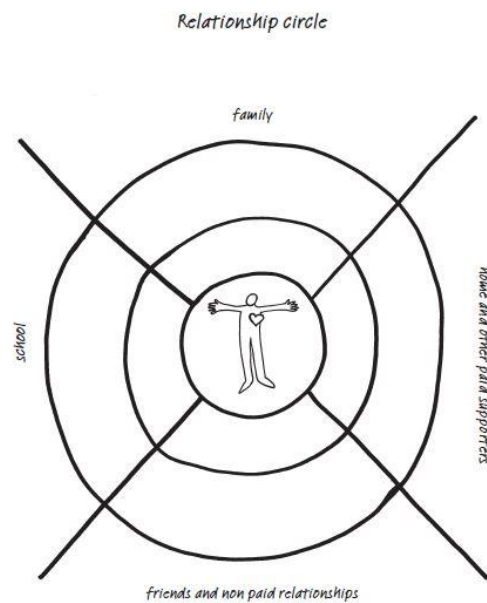
Some members of the group were involved in local groups: Patient Participation Groups, Healthwatch, Pensioners Forum, tenants and residents associations. When asked what their experiences have been of these groups/organisations, comments were positive - they felt they were passionate people, who took the time, and it was ‘**pleasure to be with them**’. When asked if they had an impact on their life, they said it was ‘**positive**’ and they had been informed of local services through these groups.

## Relationship circle of young people

5 young people aged 8-12 came from Southwark Young Carers who provide practical and emotional support to young people who have a caring role within their family. We planned a separate creative and interactive activity for the young people to participate in which would connect with discussions around joined up care and the Local Care Networks.

What is important to a person will always include who is important to a person. We wanted to learn and record the important people in a young carers life by having conversations and using the below 'Relationship Circle'

We were able to find out who they talk to, how they get advice and support, and what qualities they think are important for someone supporting young carers.



## Group discussions

### School

We had a conversation about the people at school that are there for them and they would include in their 'relationship circle'. We had a number of comments saying that they 'didn't like' professionals at school but agreed that they would be there for them if they needed any help. What follows are some of the verbal and written comments made during this conversation and some images.

- "Mrs Phips helps me calm down when I'm angry"*
- "Music therapy in school"*
- "Speech and language therapy"*
- "Child and Adolescent Mental Health Service (CAMHS) at school"*
- "Social Worker at school"*
- "School council to say what we want in the school"*
- "After schools sports club"*
- "Mentors"*



*"Inclusion team"*

*"Homework club"*

*"Favourite teacher: My teacher deserves a favourite teacher award because she's honest and there for me"*

## Family

This area of discussion was a sensitive one and was supported by the two support workers from Southwark Young Carers (SYC) to get the following responses. Some young people preferred to draw rather than talk or write down their responses to this section.



*"Family is really important"*

*"SYC is like family"*

*"Aunty gives me help with my problem and is always there for me"*

*"Mum: Because she loved me and took care of me for 12years"*

*"Brother! Even though annoying still my best friend"*

## Paid Supporters

We had a conversation about people in our lives that are paid to help us to keep healthy and well. We asked the young people to think about who those people were and why they chose to mention that person in this section.

*"There is the woman at Kings College hospital that helps me, her name is Tracy"*

*"There is a woman at school I can talk to if I get angry in class"*

*"Everyone at Southwark Young Carers is there for us"*

*"I know I can talk to Ben if I need help with anything"*

*"I love that we finish at 8pm at SYC, it's something different to do"*

*"Ben: (young carers) because when I have a problem I go to him"*

*"Young Carers – Make Friends: In\*\*\*\*\* Support, Build relationships, College support, young carers support in schools, school support, trips, respite, work experience, friends"*



## Friends and non-paid relationships

We had a conversation about other people in our lives that are not paid to support us. There was a lot of conversation about friends they had made at Southwark Young Carers but found it difficult to think about who was in their lives that were not friends or relatives and unpaid.

*"Pierre: We've been friends since reception and been friends since"*

*"My diary"*

*"Books"*

*"My best friend"*



## Issues

- There are many professional available to help young carers, it is hard to know where there support starts, ends and who then picks up that support
- Funding constraints can limit the activities offered at Southwark Young Carers
- Sometimes the professionals supporting young carers are not appropriately trained
- *"My life is very stressful"*
- *"Other children don't understand what we go through"*
- *"We don't have time to play like other children, we need to be at home to help"*

## Solutions

- Appropriate training for staff in schools, hospitals, community services to understand the complexities of issues faced by young carers and support them in their role accordingly
- Awareness raising work with children and young people to understand some of the issues faced by young carers
- What qualities do professionals need to have when helping young carers
  - "If someone listens to you"*
  - "If someone makes eye contact"*
  - "They shouldn't say 'What?!' if they don't get what you are saying"*
  - "They need to be able to keep a secret"*
  - "When they try their best to help"*
  - "Someone that makes time to hear what the problem is"*



Thank you all who attended this event!

If you have any questions or would like to find out more about Healthwatch Southwark, contact the team!

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