Healthwatch Southwark *Building Our Network*

Tuesday 17th December 2013 4pm-6.30pm

Event Report

Purpose: to update Supporters & Stakeholders about the work of Healthwatch Southwark since the launch in June 2013 and gain feedback on the four priorities.

Venue: Southwark Resource Centre, 10 Bradenham Close, SE17 2QB

Attendees: 43 including residents, 3 NHS staff, 1 Public Health, 5 Southwark Council Officers

Choice of discussion topic: at registration attendees were asked which priority they were interested in discussing with others.

Programme:

Healthwatch Southwark Presentation

Alvin Kinch, Healthwatch Southwark Manager:
Presentation

- Purpose of Healthwatch
- Activities since the launch
- Four priorities

HWS and the Latin American Women's Rights Southwark Focus Group Presentation

Sec-Chan Hoong (HWS Development Officer) and Lucila Granada (LAWRS): Presentation

Health and Wellbeing Strategy 2014 engagement Presentation

Tom Sawyer and Adam Boey, Senior Strategy Officers, Southwark Council: Presentation

Table top discussion notes

Following the presentations discussions took place on the four priorities. Each table facilitator was given several statements to read out to the participants. The points of discussion are written below:

Key

A= Agree

D= Disagree

U= Unsure

Priority 1: Access to GP Services

Statements:

	A	D	U
‘It is easy to access information about registering with a local GP’		7	
‘I am able to access my medical notes if needed’	5		2
‘Your feedback as a patient is valued’	1	6	
‘You are clear about the relationship between GP services, the Clinical Commissioning Group, Health and Wellbeing Board and Healthwatch Southwark’		7	
‘More is being done by GP surgeries / by my GP surgery to break down barriers for people to access their series’	3	3	
‘Communication and coordination between GP surgeries and other health and social care services work well’	5	1	

Discussion Points:

Access

- It’s difficult to know what your GP catchment area is.
- Information is not usually sent out in a format for blind/ partially sighted people or with people with disabilities in mind or the elderly
- Lots of local authority websites and GP surgeries are way behind in terms of accessibility.

- On the front page of every person's personnel file - could it not ask 'how do you want to receive your information?' this would immediately flag up to the GP/ receptionist if the person is deaf/ blind etc.
- Could there be an alert that pops up on the GP/ Receptionist computer screen when the person's name is typed in?
- It all comes down to communication, this is really lacking – it's about knowing each person's specific, individual needs and meeting these in all communication
- Registration isn't flexible around people's individual work/ carer commitments
- GP/ small practices are not visible enough which means people automatically go to hospitals instead, there's a lack of awareness
- The information is online but people don't know where to find it
- Could there be a leaflet or welcome pack for when people move into a borough - but from whom – who would produce it? The council?
- Libraries are a good information point – 50% VIP /elderly people do not use the internet
- A carer doesn't have time to do the research for the VIP/ elderly person as they only have 30 min slots to be with them

People have a right to be better informed

- If in one catchment area there are 3 or 4 GP choices you have a right to know what each surgery offers in terms of expertise. For example one could be excellent for diabetes or one for mental health

Patient feedback valued

- Don't feel it is valued because it isn't recorded or surveys aren't listened to or actioned – it seems like opinions are given but then ignored
- Medical records only say what the doctor has written they don't actually describe the symptoms that the patient themselves have given

Receptionist / awareness

- It's all about the receptionist initially – they need disability awareness and diversity training – so do nurses in hospitals. Surely it would not be difficult or expensive to roll out training for all receptionists, whether new or old in post.

Feedback issues / suggestions

- A 10 minute slot with a GP is far too short a slot for patients to be able to give their feedback
- A feedback form is needed in all GP surgeries (and hospitals) and for it to be visible and easily accessible for all groups

- People are scared or reluctant to give feedback quite often as they don't want to be seen/ black marked as trouble makers and because they don't believe action will be taken
- Could there be a telephone survey/ system set up? ''I know you visited your GP on this date – how was your visit etc''?
- Patient participation groups – all GPs should raise awareness of this and have it as a visible option for people to join, very often people don't know this exists

Influencing the NHS

It's not easy to influence no - only option known about is: To write to your local MP

New premises

People aren't asked to be involved in the design of new services; therefore health centres etc. are often built without involvement from groups such as visually impaired. It saves money to involve groups in the beginning.

Communication and coordination with other health services

Coordination it's pretty good but there are gaps:

- Paperwork is usually passed on which is good but the patient voice is lacking
- Often no coordination about medication which leads to this not being right or in the right amounts
- It's good the whole system works together but there is often a breakdown in communication with messages getting to the actual patient.

Priority 2: Sexual Health: HIV prevalence and diagnosis

Statements:

	A	D	U
‘Information about sexual health and HIV is feely available for young people and adults including those with English as a Second Language’		3	2
‘It is easy to find case studies on people’s experiences of accessing care services after they are diagnosed with HIV’	2	3	
‘There is a clear referral process & care pathway for patients newly diagnosed with HIV’	4		1
‘There are support networks outside health and social care services for people to be a part of’	5		
‘Family members are considered after a person is diagnosed with HIV and given access to appropriate services’			5

Discussion Points:

Where and how people get information

- For young people and adults, there are a lot of websites that give initial information, some of which are:

AIDSMAP: http://www.aidsmap.com/

NAM: http://www.aidsmap.com/aboutus

AAF: http://www.a-af.org/

NPL: http://www.naz.org.uk/

HIV AWARE: http://www.hivaware.org.uk/be-aware/useful-resources.php?gclid=CIvww8veubsCFWbLtAodmVgAfA

- We shouldn’t only focus on people who have been diagnosed with HIV, there is a lot of work being done around positive prevention which is the first line of information that is being given out now.

- Information around managing the condition is given to individuals on an individual basis

Understanding information

- There is a good system where community outreach and voluntary sector organisations that have created tailored information to meet the needs of the community they work with.
- Community mobilisers (volunteers) who work out in the community play a vital role in providing this information in an accessible, friendly and approachable way. In the way of ‘preventative work’ as well as a ‘support role’
- Accessing testing – there are clinics and spaces for people to access testing at Kings and Guys (Harrison Way?)
- Safer Partnerships – Faith communities working with the GPs and hospitals to provide additional care systems
- Different approach – making sure that information is given in different ways in order to ensure that people understand what the options / process / system is. Recently there have been some Sexual health information leaflets created in a variety of languages which act as a starting point, they are quite informative – the content seems good (produced by NHS London / EMBAC). Clinicians can print them out and give then to the person they are supporting
- Leaflets – are important but need to be complemented by community groups or professionals to make sure patients aware that living well with HIV is very possible and what they are working towards

Case studies

- Some people are encouraged to talk about their conditions with their family and friends – its sensitive
- We use case studies – When we are working with new patients, we have found that using case studies is a good way to communicate people’s experiences with the aim of uplifting them
- It is easier for service users to come forward to share their own experiences – in a safe environment – people are talking about it more
- A lot of work in already being done, instead of reinventing the wheel – you should find what is out there at the moment – talk to the community mobilisers and the HIV patient experience people at Guys and Kings
- It would be good to make partnerships and see if individual interviews could be taken, group settings would be difficult to set up and manage

- There have been national studies which include case studies, we use them in training for GP practices – so they do exist!

- Not sure about more local studies – there would be a need for that

- People are more open to offering their stories, when they have seen that others have done the same. They are inspired and empowered to share what they have been through too.

Referral process & care pathway

- A person will initially have a consultation with their GP, at the Sexual health Clinic or at a community setting at the point of being diagnosed

- Language Skills - some interpreters will be present at the time of diagnosis, to my understanding language line is not normally used to inform a patient that they have HIV. Although interpreters are trained and professional they sometimes do not know the technical terms to translate. Maybe GPs need to use interpreters more.

- There is a lot of planning to find the right interpreters, especially if the person is from an ethnic minority background. There is an issue that the interpreter could be from their own community – patient confidentiality at risk. Community mobilisers speak different languages and could be of use at this stage as they are trusted and understand

- Word of mouth is helpful, as it signposts people to where they need to go

- From the GP, you would expect a referral to Guys or Kings where you would see a health advisor – South London HIV partnership

- You would then expect to see a HIV specialist to talk about treatment care – a timeline of 2 weeks is set for this appointment from the time you are referred to the hospital

- They will then be your contact and will signpost and refer you to additional services such as psychological therapies and community groups. Communication with the GP is maintained through this process.

- Patients sometimes prefer to access services outside of the borough they live in as they are concerned people they know will find out.

- This should not affect the quality of care they receive and actually it is a normal practice with many long term health conditions for patients to travel to a service they choose to use

- Important to give 1:1 support – there are opportunities for this, just need to find them and ensure its quality

Priority 3: Access to Mental Health Services

Statements:

	A	D	U
‘My GP take my emotional health seriously’ Comment: Depends on individual GP		2	6
‘If I need help that my GP cannot provide, I find it easy to aces these services i.e. counselling and support groups independently’		6	2
‘GPs practices and community Mental Health teams work well with the Voluntary and Community Sector’ Comments: Depend on individuals – varies greatly People weren’t sure entirely what statement means.			8
‘Services users understand the term ‘Mental Wellbeing’		8	
‘I have a say in Mental Health service design/redesign’ Comment: Difference between having a say and being involved in the decisions.	3	4	1
‘People from diverse background who have English as a Second Language are GPs aware of mental health services available to them in the borough’		8	
‘There is enough counselling for people suffering long term health conditions and Older People’ Comment: Both formal therapy and GP-based counselling		7	1
‘Patients are made aware of how to manage their condition with medication and understand the potential side effects’ Comment: The one that agreed referred to children	1	7	

Discussion Points:

Access to therapy / triage

- While access to CBT / counselling is improving, this is not suitable for everyone and access to specialist psychological therapies is getting worse. Feeling that CBT / counselling being pushed as it's a cheaper option than specialist psych support that many people actually require. More people entering system and CBT is used as sticking plaster but doesn't get to root of problem. Expansion of access to therapy was promising but actually it means lower-level therapies are used for people with more serious problems. Others thought that CBT has an important part to play and investing more in it may be cheaper in the long-term by dealing with low level MH before it escalates.
- It can be more damaging to have e.g. 6 sessions of CBT when individual's needs are greater or for something different.
- Waiting times can be long.
- Triage system seems to be faulty as misses those with real needs for long-term support - described as a lottery.
- Is there a greater role for peer support, as an interim for those on waiting list for psych services? Does exist in borough and some voluntary organisations run schemes but not well used as not enough peer workers trained to do it. There needs to be initial investment to train up peer supporters.

Accessibility

- Interpreters for ESL not available – patients/their family member translators often don't understand terminology, purpose of CBT or why they're attending appointments.
- For MH, even a 10 min double appointment often not enough, should be 20 mins especially if there's a language barrier.
- *Medication options and side effects*
- One of main issues is that GPs not MH trained so there are unwanted side effects of medication because GPs don't have enough knowledge about this.
- It would help if more communication between GPs and Community MH teams about how people are getting on with medication. Even consultants don't understand full effects of some anti-psychotics as individual results can be so variable. There needs to be a strong relationship between the GP or prescribing consultant so the GP can feed back and change medication if it's not working for patient, e.g. manage side effects and avoid long-term harm. But individuals and some GPs won't challenge consultants because of power dynamic.
- People need more information about different medicines, likelihood of side effects, what to expect, what counts as a good result, their options re asking

to change medication. Role for pharmacist here. Pharmacists often go onto MH wards to answer questions about medications and hold info sessions. Similar would be helpful in a GP surgery.

Attitudes of GPs

- Role of PPGs to change culture at GP surgeries to take MH more seriously. Encouraging signs that they are doing so at some surgeries, perhaps sign that stigma of MH reducing in wider society? Attitudes vary, though many GP surgeries do have a positive approach – perhaps based on fact that many GPs themselves will have personal/family experience of MH problems after all.
- Works best where there is a long-term relationship between GP and person built over years and consistency in contact.
- Improvements needed over awareness of how MH as cultural dimension (e.g. stigmatised in certain communities so reluctant to talk about it) and medication training.

Information and stigma

- Info should be provided about GP appointments before people attend so make best use of time, e.g. explaining process of MH services, what options they have and what the different types of treatment involve.
- Role for ALL organisations to reduce stigma among the population – VCOs, press, social media. Education for children and teachers would be very helpful (we do sex education after all). Stigma can be particularly difficult for minority groups as it can be taboo in some communities, can be seen as just another barrier to integration and something that makes them vulnerable to discrimination (so they don’t want to label themselves). Lack of awareness re what doctor will do – will they be locked up, put on drugs? BAME Mental Health patients are more likely to be sectioned than others so this may be a fear.

Priority 4 Social Care, those outside the Fair Access to Care (FACs) eligibility criteria

Statements:

	A	D	U
‘Social care service changes are easy to follow’		11	
‘It is easy to find and choose a good quality provider outside council services that meets my needs best’		11	
‘I know what is available to me if I need social care service support’		11	
‘People are able to share what is working well and what is not working well in accessing social care services in Southwark’	3	11	
‘People outside of the Fair Access to Care criteria are supported to access services to maintain independence’	3	11	
‘Those with substantial and critical care needs get the support they require’ Comment: It depends			11
‘Staff assessing individuals under the FACs (Fair Access to Care) criteria fully understand the persons care needs’ Comment: it depends			11
‘Those who do not have capacity to consent will always receive person centred care’ Comment: Not all			11

Discussion Points:

Patients with substantial and critical needs

- Some receive the support they require
- Transition – there is no support from the period when you leave hospital and find your feet – no care, no signposting
- You have to know the system
- We need more info from hospitals when you leave. You need to know your rights
- Personal Budgets – You are given a budget and told that you can do all these different activities with your budget but you need to know that you can go back to them and re-evaluate your personal budget and change the service that you choose to spend your money on
- Information about services needs to be available to people at point of access from GPs
- You may not have heard any information yourself about the health issue in the past. Your family support network or carer may have had no information about the health issue in the past either. This needs to be provided by GP. And we need information in more accessible formats
- Social Care needs to be integrated with health services. We need a “Pathway to good health” and to spread the word about this
- We need to understand what support is out there
- We need to know where to go for different types of care
- Not everyone has a personal budget yet. The Council sells the system as an amazing way to choose and control your own care, but in practice sometimes third parties manage your personal budget and this can cause problems. We have a situation where some people are being dictated to about what to do with their personal budget
- It takes time for any project to flourish – usually between 1 and 2 years. The reality is that it’s too hard to get a support plan together in a month
- For blind people or people with sight loss – adaptations and equipment can make a real difference, but if you don’t have that equipment or money to buy adaptations additional care and support is needed
- Information about services available is constantly changing – services are closing and opening up. We expect Social Services to be able to provide everything. We need to know how to access services.
- You generally need to do a lot of personal research to find out about care and health issues – online and methodically and some people just don’t have those kinds of skills or anyone who can do that for them

Observations / ideas

- Assessment Process – needs preventative aspect
- Information – to understand what is available (including adaptations and equipment)
- Assessment Process – people are vulnerable
- Discharge – need additional support and signposting
- Transition – difficulty moving from child to adult services and moving from school into training and employment – transition can be difficult

What could Healthwatch do about these issues?

Information:

- HW could give details to discharge section of hospitals about support services locally
- VCS services need to network really hard and meet as many people as possible to advertise their services and get the details out there
- Being blind is a specific disability but the council has a list of registered blind people and even if those people were sent information once per year about new and existing services available to them and any other useful information in an accessible format that would be really helpful for them
- GPs are key in this – they need to be more interactive with their patients. They are a key source of information. People don't always ask when they don't understand
- Services need to work together better and should talk to each other more
- N.B. This is what SLAM is trying to do – should we be duplicating?