



Annual Report

2016



Contents

Project snapshot.....	3
Introduction.....	4
2016 events.....	5
Engagement & partnerships.....	6-8
Patient feedback.....	9
Equalities data.....	10
Looking ahead.....	12

Recommendations and comments

EHC Plans	13-15
Access to health & care for disabled people	16-17
Access to health for young people	18-22
GP services.....	23-24
Digital health.....	25-31
Mental health services	32-35
Men's health.....	36-38
Maternity services.....	39-40
Open doors sex workers project.....	41



Topics

- EHC Plans
- Young People's Access to Health
- St Mungo's Workshop
- Open Doors Focus Group
- GP Services
- Digital Information & Health
- Mental Health
- Homelessness & Health
- Men's Health
- Self-Care
- Maternity Services

11 events



450 Attendees

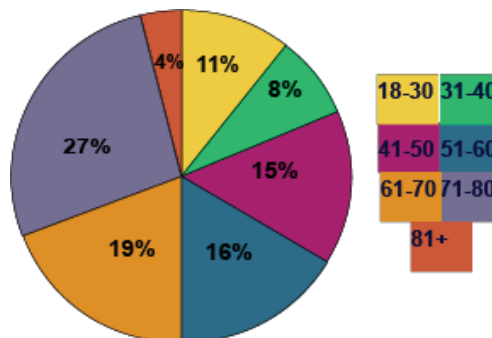
Reach



76%



24%



40% of people have a disability

60% of people from BAMER Groups

36% of people are carers

Better informed about patient involvement



89%

Better informed about health services & how to influence them



88%

Better informed about Self-management



55%



About NHS Community Voice

NHS Community Voice (NHS CV) is a patient led project commissioned by City & Hackney Clinical Commissioning Group (CCG) and delivered by Healthwatch Hackney in partnership with Age UK East London.

The project was commissioned in January 2015 to support the CCG's patient and public engagement work.

The NHS Community Voice Steering Group

NHS CV is supported by a steering Group which meets regularly to discuss health and social care issues affecting Hackney residents. Members are patient representatives from GP based Patient and Participation Groups (PPGs)

The support of the steering group ensures that the project remains patient and resident led.

Members have input into the planning and delivery of meetings including suggesting meeting topics, and chairing meetings.

They also work with the CCG's engagement structures including the Patient User Experience Group (PUEG) and the Public and Patient Involvement committee (PPI)

Recommendations

All NHS CV meetings conclude with a set of recommendations or comments and feedback which are then sent to Commissioners and providers to comment on. Recommendations are sent to attendees and can be found at the end of this report or on the [CCG website](#).

"This year I have enjoyed chairing meetings on EHC Plans and on Men's Health. I also sit on the Public Patient Involvement committee so I can make sure the concerns raised in the general meetings are addressed by the relevant people. These public meetings are a great way of connecting with Hackney residents and patients and bringing their concerns directly to health providers. Intermediate care for people leaving hospital has been a major concern this year."

Tony Harms (Steering Group member)

2016 Meetings and events

Education, Health & Care Plans (with HIP)

The purpose of the meeting was to get parent/ carer views on the EHC process which is a tripartite process between education, health and social care. A key recommendation from this meeting was to simplify the EHC guidelines to better meet the needs of parents.

Access To Health and Social Care For Disabled People (with Disability BackUp)

This was an opportunity for a disability rights group to help shape and deliver an event on the needs of disabled people in health and social care. People raised concerns about the lack of access at health and social care buildings and asked that disabled people be consulted on access issues where buildings are being built or refurbished.

Access to Health for Young People

Young people were a group that we had not reached in 2015 and we did a workshop with Talent Match to understand how young people view health. They demonstrated an interest in various health issues and were keen to engage with the CCG to ensure that young people's voices were being heard at decision making levels.

Workshop with St Mungo's Residents

We partnered with Spice Time Credits who work with St Mungo's residents to look at their access to health services. This aligned with an identified need to engage better with homeless people. A key recommendation here was better signposting to health services for residents who struggle with finding the right service at the right time because of their complex needs.

Open Doors Focus Group Discussion

At the workshop with St Mungo's, we spoke to a resident who was very concerned about the future of Open Doors, a holistic service for sex workers in Hackney. We spoke to 20 sex workers and produced a [report](#) highlighting the continued threat to a comprehensive recognised support service.

GP Services

The steering Group asked to have a meeting on the GP landscape. The meeting highlighted the importance of patients engaging with their local PPGs.

Digital Information & Health Workshop

NHS CV were asked to get the views of patients on a digital offer by the CCG, GP Confederation and the IT Enabler Board. We did a workshop with patients where people were keen to highlight that any provisions should also consider those who are digitally excluded.

Mental Health Services

This meeting coincided with the CQC inspection of community mental health services. NHS CV held a meeting for people to talk about their experiences with the CQC present & their views fed into the inspection.

Homelessness and Health Open Event

We held an open event for homeless people to look at homelessness & health. A key finding from this event was that the majority of people who came to the event had some kind of mental health need.

Men's Health

This meeting was suggested by the steering Group as we had few men attending our meetings. A key recommendation from this meeting was the establishment of a men's health group which would provide peer support for men and a space for them to discuss health issues.

Self-Care Event

We worked with the CCG to hold a self-care event to mark self-care week. We had over 24 organisations holding stalls with information for patients and residents.

Maternity Services

The CCG Maternity Liaison Committee at asked NHS CV to hold a meeting to find out how service users find maternity services.

Community Engagement

NHS CV recognises that it is important for us to work with community and voluntary organisations and groups if we are to reach different sections of Hackney's community. We do this in a number of ways.

Engagement with PPGs

[Patient Participation Groups](#) are local GP based Groups and are a key way for patients to get involved and influence their GP practices.

All upcoming meetings are sent to GP practice managers to be advertised at the practices. We also have volunteers who put up posters across the borough.

In addition we have leaflets at all of our public meetings encouraging people to join their local PPGs.

Engagement with community groups and organisations.

In 2016 we worked with the following organisations:

- Hackney Independent Forum for parents carers of disabled children
- Disability BackUp
- Talent Match
- St Mungo's Hostel
- Spice time Credits
- The OPRG
- Social Action for Health
- Dee Dee Help the Homeless
- Open doors
- City Healthwatch
- Hoxton Health
- Brook Centre (Social Health)
- Young hackney Substance Misuse
- Hackney & City mind
- Huddleston Centre
- Hackney CVS
- Health and Social Care Forum
- Bags of Taste
- Hands Inc
- MacMillan Cancer Support
- Core Arts
- City & Hackney Carers

"It was a great example of how two local 'voice' organisations with common interests can harness energy, reach and resources to make a difference.

As a result of this meeting the authorities revised their EHC plan guidelines to make them clearer and shorter. They also deleted elements in the EHC guidance which were unlawful and misleading for families seeking support for their disabled children."

HIP (EHC Plans meeting)

"The Talent Scouts thoroughly enjoyed the health workshop. They were interested to hear about the CCG's plans for young people and the statistics in relation to young people and the health service.

The young people were so inspired that they all volunteered to form a young people's health steering group, as they felt that it was really important that young people voices are heard and acknowledged when making decisions concerning them."

**Deji Adeosun
(Young people's meeting)**

Men's Health



Men's health participants from left to right: Tony Harms, Elon Charles, Laurie Allan, KG Lester, Gary Molloy & Errol McKellar

In 2015 we identified that few men are coming to NHS Community voice meetings and we wanted to do something to encourage more men to attend.

The steering Group members suggested a men's health event which took place in October, the meeting was planned with the NHS CV steering Group and other men from the community.

At the meeting in October 2016 a number of men talked about their own personal experiences of sickle cell and thalassemia, mental health, social isolation, diabetes, prostate cancer and caring for a loved one.

A key recommendation from the meeting was the establishment of a men's health forum for men to share their experiences and support each other.

One of the participants Errol McKellar, a Hackney mechanic who set up MOT Yourself after he was diagnosed with prostate cancer, talked about the importance of communities

and health commissioners and professionals working together more effectively to reach those often deemed 'hard to reach'.

After his diagnosis, Errol found out that his dad and uncle had both died from prostate cancer and found that black men in particular are reluctant to talk about it and are likely to ignore symptoms.

To encourage them to get screened he gives 20% off MOT tests for each man who has a prostate cancer check. Since 2011, 46 men who have walked through the garage have been diagnosed with prostate cancer.

Errol campaigns for better education about prostate cancer for all men but particularly for those with increased risks including black men and those with a family history of the cancer.

"Prostate cancer does not discriminate. It doesn't care about your colour, rich or poor, if you do nothing it will kill you"

Errol McKellar (MOT Yourself)

Engagement with commissioners & providers

NHS Community Voice would like to thank all of the commissioners and service providers who have actively engaged with us through speaking and listening to patient voices at our public meetings.

It is very clear that patients and service users appreciate the opportunity to engage in meaningful dialogue with commissioners and providers at meetings and which plays an important role in making people feel that their voice is being heard.

We have had input from the following Clinical Commissioning Group boards

- Long Term Conditions
- Mental Health
- Children and Young people
- Maternity
- Primary Care Quality

We have also had speakers from the following providers

- Homerton Hospital
- The GP Confederation
- London Borough of Hackney Adult Social Care
- SENDIAGs
- Public Health
- Hackney Ark



Macmillan advisors at the join NHS Community Voice and Clinical commissioning Group 'Self Care Event'

“This will help enormously to inform the direction of travel for the local digital roadmap and make sure we get the priorities and resources right. I was quite taken by the energy and engagement from those there and privileged to have been invited to the event.”

Anita Ghosh (IT Enabler Programme Board) Digital Information meeting.

Patient and resident's feedback

We asked people, what was the best thing about the event?

"The personal stories and experiences given to help you look after yourself."

Men's Health

"The Chair put things into perspective. All the speakers who are brave to address positive and negative questions. All the residents' who came, what a turn out!"

GP Services

"There was a huge range of ideas about using technology in health care."

Digital Information & Health

"The best thing was the information stalls and the interactive elements. Smoothie bike and massage."

Self-Care event

"It was a very interesting meeting with so much information given but there needs to be more meetings like this for parents to hear from professionals about SEN disabilities."

EHC Plans

"All of it, it was very open minded and it gave young people a platform."

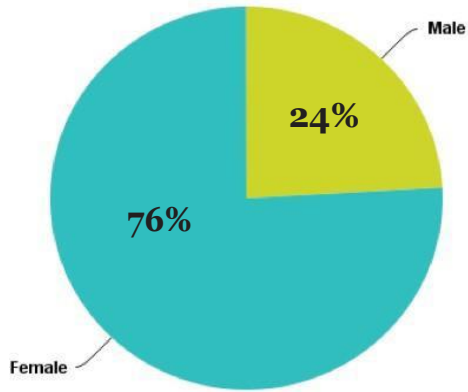
Access to Health for Young People

"Good mix of people expressing issues."

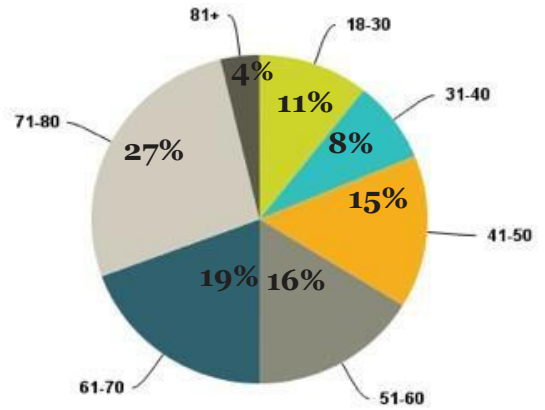
Access to Health for Disabled People

Equalities Data

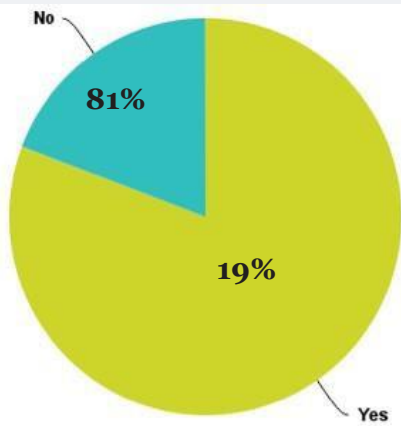
Gender



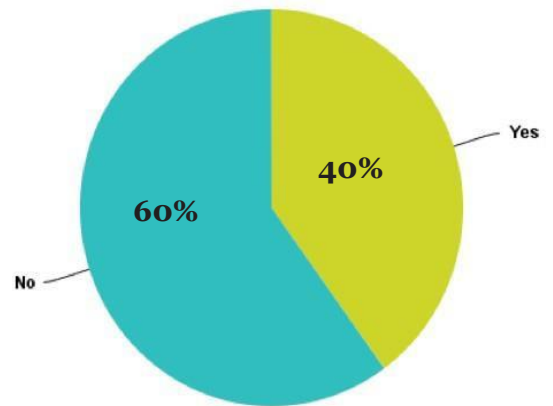
Age



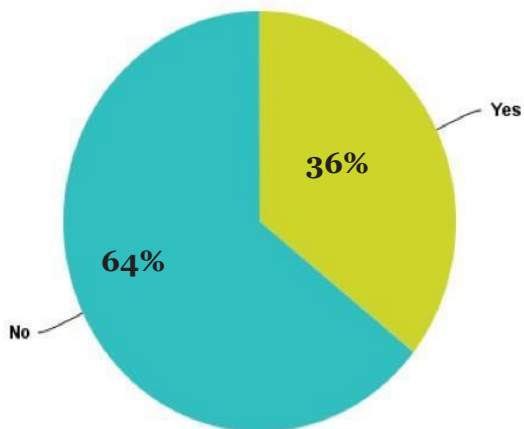
English as a first language



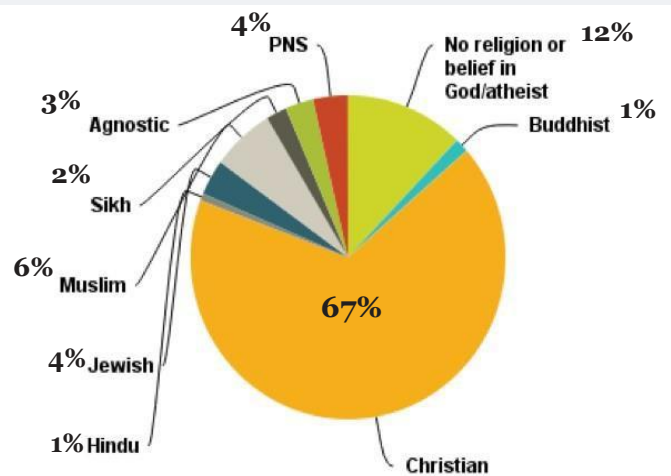
Disability



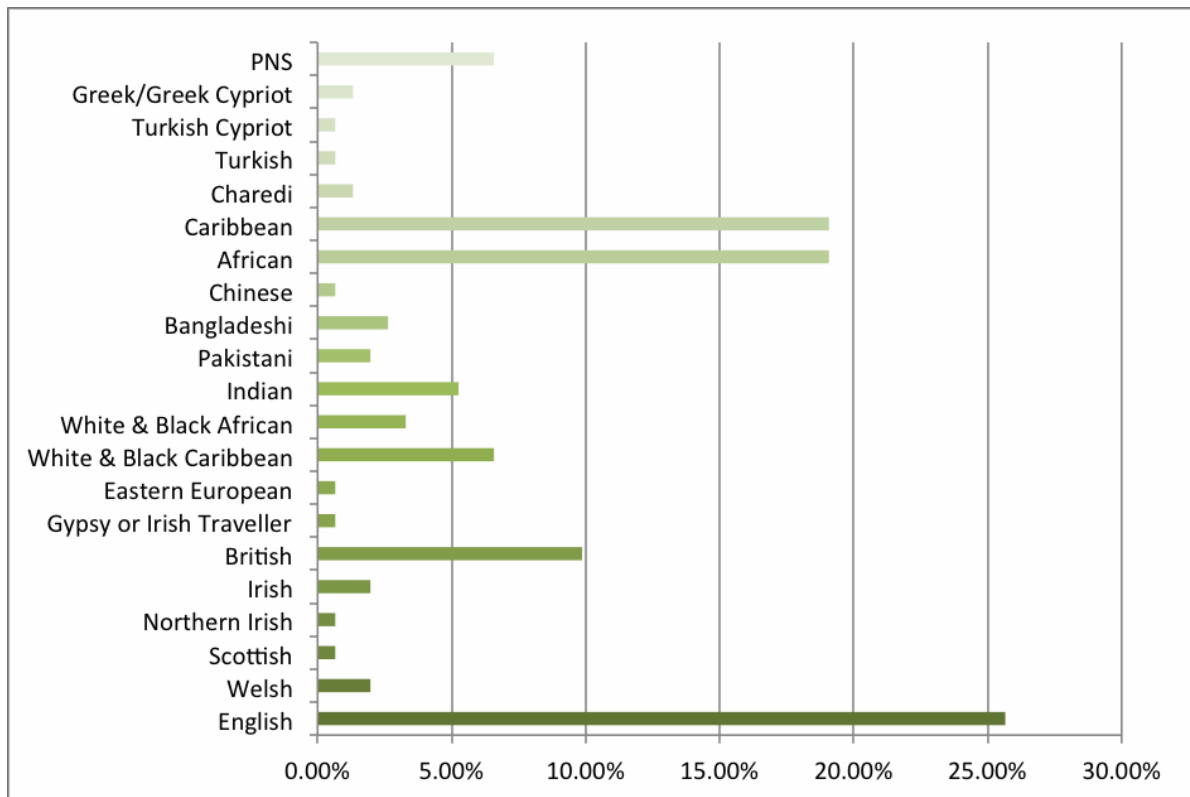
Caring responsibility



Religion



Ethnicity



Looking ahead

NHS community Voice is becoming a key forum for Hackney patients and residents to discuss health and social care services in Hackney.

The feedback we receive tells us that people feel better informed about health services and public involvement after coming to the meetings and people like the range of information and signposting that they get.

For this reason NHS Community Voice is becoming a key vehicle for mass engagement on health and care and we want to build on this in 2017/18.

In addition we want to do more focus group discussions to build on the work we did in 2016 with homeless residents at St Mungo's and sex workers. What worked really well in both of these sessions is the depth of information we were able to get which is not always possible with mass meetings.

People are increasingly asking for more self-management and we hope to work with the CCG to see how we can support people with this.

For 2017 our aims are to:

- Widen the pool of patient representatives from different community groups
- Increase the number of small focus group/workshop events
- Increase the number of men attending meetings
- Increase the number of non-English speaking people attending the meetings
- Reach out to more groups such as people with mental health needs, people with long term conditions, young people and LGBTQ+
- Look at the wider determinants of health such as housing, unemployment and poverty
- Strengthen relationship with Adult Social Care

Get involved

**If you would like to get involved with NHS Community Voice or to find out about our meetings and events please contact
Sulekha Hassan: sulekha@healthwatchhackney.co.uk: 020 7923 8367**



2016 Recommendations and comments

Education, Health and Care Plans for Disabled Children

Recommendations	Recommendations/comments for	Related comments
<p>Eligibility criteria The 'eligibility criteria for EHC Plans' should be referred to as local guidelines for EHC plans</p>	Hackney Learning Trust	The term 'eligibility criteria' is wholly inappropriate as it implies that these are statutory guidelines which they are and appear intimidating to parents, carers and other professionals.
Eligibility criteria should be simplified and clear and made available in both easy read and other languages for those parents and carers whose first language is not English	Hackney Learning Trust	The eligibility criteria as a 30 page document is not accessible to large groups of parents and carers.
Emotional welfare and behavioural needs should be properly considered even if a child's educational attainment is high.	Hackney Learning Trust	
The eligibility criteria should mention the SEN code of practice and should do so explicitly	Hackney Learning Trust	
There should be a clear and defined process for parent's views to be appropriately translated onto EHC plans	Hackney Learning Trust	At the moment the process is patchy and the parent voice is only heard as a result of interventions by the Independent Supporters who are encouraging parents to submit their views in writing.
<p>Training for SENCOs SENCOs and schools are struggling to write EHC plans; they need intensive training to write the plan in a way that ensures children get the best possible support they can.</p>	Hackney Learning Trust	One parent had a SENCO tell her that they did not know how to write the plan after her child was refused an assessment

<p>Health co-ordinators should be clearly briefed to ask parents about any CAHMS and SEN provisions.</p>	<p>CCG Children's Board</p>	<p>Hackney Learning Trust and health services (like the Hackney Ark) need to work together to capture the mental health needs of children. A high proportion of children with SEN and disabilities also have mental health needs, there seems to be a blind spot if a child is seen and diagnosed within mental health services like the East London Foundation Trust.</p>
<p>Support for SENCOs and holding schools to account There should be some financial incentives for SENCOs to stay on for a minimum of stated years.</p>	<p>Hackney Learning Trust</p>	<ul style="list-style-type: none"> • SENCOs are seen by many parents as the 'front door' to the system and if access to information and support here is lacking, the process can be incredibly hard for parents. Parents have reported problems with contacting SENCOs at schools as a result of high turnover of SENCO staff. • This high turnover of staff is problematic for children as relationships between the child and the SENCO are not able to develop with EHC plans being written by SENCOs who have had very little contact with the child. Consistency is really important here
<p>There should be some form of sanctions against the schools if they break the rules and refuse to take children especially in cases where both the parents and the learning trust are in agreement that this is the right setting for the child. Training for school governors to keep on top of SEN provisions within schools to improve practice in schools.</p>	<p>Hackney Learning Trust</p>	<p>There are no enforcement measures against schools who are acting illegally by not taking children with SEN.</p>

EHCs: The Charedi Perspective: Interlink Foundation comments

1. £6k intervention:

The new guidance requires schools to provide evidence that the child/young person requires interventions above £6k. As independent faith schools, Charedi schools do not receive delegated funds. This creates a challenging situation for the schools.

2. Educational Psychology Service:

The guidance expects schools to work with a range of agencies to support pupils at SEN Support, including HLT's Specialist Support Teams and the Educational Psychology Service. Accessing support from the EPS is a particular challenge since this is a traded service and Charedi schools do not receive delegated SEN funding. As a result, when submitting a request for a child to receive a statutory assessment, parents need to pay for a private EP evaluation. This costs in the range of £700-£1000. If HLT has agreed to assess a child, they will then send in their own EP to do another assessment; this does not seem like the best use of resources.

3. Support at transition stage:

There is inadequate support for YP transitioning from their school settings onwards. Also, there is no natural pathway for YP once they have finished school.

Access to health and Social Care for Disabled People

Recommendations	Recommendations/comments for	Related comments/comments
	<p>LBH/CCG/ELFT/Homerton hospital/St Leonard's services and all health and social care services</p>	<p>Access to toilets in health and social care buildings</p> <ul style="list-style-type: none"> • Access to public toilets for disabled people is a fundamental human right • The toilets in the Hackney service center are inaccessible for disabled people even though it is a new building which should have complied with disability access law. • The new toilets at Hackney Town Hall are also inaccessible. • The toilets at Homerton Hospital and St Leonard's are also inaccessible for disabled people. • Access to the Homerton ramp is unsafe.
	<p>GP Confederation</p>	<p>Access to GP clinics , some GPs are inaccessible for a number of reasons including:</p> <ul style="list-style-type: none"> • Door bells being too high for wheel chair users, lack of appropriate ramping and uneven paving • Group asked that NHS CV and DBU send an audit report by DBU member on GP access to relevant commissioners and providers. • People questioned why all GP practices do not have automatic door access during opening hours as the doorbell system is inaccessible particularly for people with visual impairments.

<p>Homerton hospital should remove two seats to ensure that wheelchair users can wait comfortably in the clinics</p>	<p>Homerton Hospital</p>	<p>There is only one clinic at the Homerton Hospital with space for wheelchairs in the waiting area. Wheel chair users feel unwelcomed as they cannot fit their wheelchair in between the large number of seats</p>
	<p>Choose and book</p>	<p>Problems with ‘choose and book’</p> <ul style="list-style-type: none"> • One password for life deemed impractical. • For carers and advocates it is difficult to negotiate the system on behalf of someone who uses choose and book including dementia patients who require support to use the system. • Lack of choice for patients who do not want to be referred to the Homerton due to previous negative experiences
<p>Patient engagement and representation</p> <ul style="list-style-type: none"> • There needs to be a process which allows patients and service users to directly engage with landlords of buildings like St Leonard’s and providers to ensure that buildings are complying with legislation around disabled access. • Both health and social care providers need to ensure that they are engaging with disabled people at all levels. 	<p>CCG PPI/LBH Engagement</p>	<p>DBU you are currently not funded to be able to engage with services, the direct payments group no longer meets and both of these are important vehicles for disabled people to be able to engage with and influence the commissioning and provision of services.</p>

Access to health for Young People

Recommendations	Recommendations/comments for	comments
<p>Engagement and representation</p> <ul style="list-style-type: none"> • A number of Talent scouts asked to know more about the work of the CCG and expressed interest in being observers on the children and young people's board or PPI with the long term view of having a young person's representative on the board. • There should be a consideration to pay for young people's time when they are consulted on health and social care issues 	<p>CCG PPI /Public Health</p>	<ul style="list-style-type: none"> • There was a perception that there was a lack of visible opportunities for young people to engage with health and public Health services. • Young people were keen to highlight that they are willing to engage and be engaged on health and wellbeing issues. • Young people's opinions and views need to be seen to be valued by statutory organisations. • They felt there should be holistic approaches to the issue of health and wellbeing as socio economic factors including unemployment, housing and poverty.
	<p>Primary Care Quality Board</p>	<p>Primary Care experiences</p> <ul style="list-style-type: none"> • Young people felt put off to go to the GP, because of long waits to get regular and emergency appointments • Feeling rushed when speaking to the doctor about their health issues • Not trusting GPs because of a past experience including one young person who was wrongly diagnosed with TB, when he had to call an ambulance he was in fact told that he had pneumonia. • Difficulty in getting referred, one young person said she has been

		<p>trying to get a referral for 4 years and felt as though doctors were preventing referrals.</p> <ul style="list-style-type: none"> • One young person reported a 3 month wait and ended up going to Poland for treatment.
	Public Health	<p>Sexual health services</p> <ul style="list-style-type: none"> • CHYPS service at Clapton goes up to 19 and one young person mentioned that some of the young people he knows who could not access CHYPS in Lower Clapton because of their age were unable to access services at the Homerton sexual health clinic because of area code wars. • Most of the young people agreed that whilst the issue of post code conflicts was declining, it was still affecting how young people access many services not just health.
	CCG Children's Board/Public Health	<p>Self-management</p> <ul style="list-style-type: none"> • There was a degree of self-management with a few of the young people saying they would only go the GP if they felt it was a real problem which needed medical attention. • 6 of the 14 young people said they went for regular health check-ups.

	<p>CCG mental health board</p>	<p>Mental Health</p> <ul style="list-style-type: none"> • There was a perception that mental health was over medicated in the black and ethnic minority community • They felt there was a tendency to treat low level mental health episodes clinically rather than offering social and community support that could easily help to prevent mental illness • They felt that there were a lot of young people on the cusp of mental health illnesses who need support to build resilience, and not enough was being invested in prevention. • They also thought there is little investment in finding out what the causes of bad behavior which is readily labelled as mental health is in schools and colleges particularly amongst young BAMER people. • The young people also commented on the fact that mental health in general is still a stigma and people with mental health are treated as a problem that needs fixing by health professionals, particularly GPs.
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	<p>IT Enabler Board/CCG/GP Confederation</p>	<p>Digital information</p> <ul style="list-style-type: none"> • Many of the young people felt that face to face interaction with a GP is important especially where responsibility and accountability for patient welfare is concerned. • One young person said that whilst she would not opt for online GP consultations for herself, she would use it for her child, and argues that many young anxious first time parents may find it useful as it could reduce the tendency for them to visit A&E. • Another young person said they'd be happy to consult a GP online in the case of repeat prescriptions or getting blood results. • All of the young people said that the internet including NHS Choices was their main source for health information but felt that the information wasn't marketed towards them.
	<p>IT Enabler Board/GP Confederation</p>	<p>Online Medical Records</p> <ul style="list-style-type: none"> • There were strong objections to having patient data online; the key issue here was how secure and confidential the data would be. • Nearly all of the young people expressed the view that they would be worried about their patient data potentially being open to abuse, especially if they had mental health issues or were diagnosed as HIV positive. • Where they did think that it could be helpful is being able to know their

		blood type, view blood results and any hereditary diseases. The view was expressed that this would give young people more insight into their overall health and wellbeing as at the moment GPs are inputting information about them and they are unable to access
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We asked the young people what they would do if they were the children and young people’s commissioner, they said:

- Teaching young people in schools and colleges about health and wellbeing and general life skills including spending habits to prevent debt which could cause anxiety and depression.
- More health and sports based activities in the college setting.
- Better engagement and consultation models which would mean young people are the heart of any decisions about service provision for young people.
- Fund therapeutic arts and sports which would appeal to young people
- Young people’s walk in health centre (with a number of different clinical and community provisions)
- Make community spaces like gyms more young people friendly including lower gym membership and making healthy eating more accessible (affordable health eating)

GP Services

Comments For CCG Primary Care Quality Board and GP Confederation

When asked by the Chair, only one or two of the 80+ older people present said they knew anything about NHS England (and what it does). 6 older people knew what the CCG is, and what it does. Only one or two people had heard of the "Devolution Pilot" in Hackney. There was also ignorance about new service developments: for example, few people were aware they could access a "Duty Doctor" and many others were not aware of the existence of Patient Participation Groups. The speakers endeavored to fill at least some of these voids, and were listened to attentively.

At question time, which drew vigorous and often critical, participation, some of the following points were raised.

- People repeatedly stressed the need for **better information** across the board in relation to health and social care.
- Several members raised personal issues with actual service delivery whilst others cited difficulties **with getting GP appointments**, and very long **waiting times**.
- Questioners specifically asked **how/where to make complaints about individual GPs** and if they can complain to the GP Confed or NHS England if they have exhausted their individual GP Practice's complaints process.
- There was a question about how patients can challenge what they deem to be inaccurate information on their GP health records.
- It was evident that patients considered Primary care **monitoring** was vital to achieve the desired standards, but were unclear as to how this was being done, who was responsible for it and how to connect with the process.
- It was further noted that many problems for service users issued from the **fragmentation of services**, which was felt to be far greater now than in the past when the PCTs were in being. There was a general call for a return to **'joined up'** provision.
- Regarding **NHS England's (NHSE) policy of managing an over-supply of pharmacists by cutting funding to pharmacies leading to an estimated reduction of 3,000 nationally** which appears to conflict with the policy of "pharmacy first" designed to reduce the pressure on GPs, a Hackney resident reported already being adversely affected by the closure of his neighbourhood's only pharmacy.
- NHS England (NHSE) was asked about why Hackney was given so little time to put together the STP plan
- NHSE were also asked about funding for PPGs (the NHS representative said she will feed this back, NB: this was the same answer given by the same officer at a previous health in Hackney scrutiny committee meeting.
- In addition, attendees said that in some case people are being asked to *join* their PPGs which could be off putting, there needs to be a standardised process across GPs on how people can get involved.
- Other questioners highlighted the need to address perceived gaps in provision for Women's health and unpaid carers.
- In addressing service gaps, and aligning relevant providers, the importance of influencing **housing policy** was stressed, particularly with regard to **providing social housing locally for key workers**.

Much of the discussion was given over to debating the underlying 'politics' of healthcare with many members commenting heatedly on aspects of the manifest crisis in the NHS.

There was strong encouragement from the platform to members to engage with local service issues by joining their GP Practice Participation Groups as a first step in making their views known. This would help to build the professional-patient partnerships necessary for shaping future services to their requirements. The fervent request to fill in feedback forms from the meeting produced a gratifying response!

Open workshop on health and digital information

1. City and Hackney Directories (iCare and CityHealth)

Recommendations	Recommendations/comments for	comments
More and better use of images and visual cues in the directories	iCare/CityHealth App/GP Confederation/CCG	<ul style="list-style-type: none"> Text is typically fine and suitable for most, but many residents mentioned that images would help them navigate the sites better

Comments for information only (for iCare, City Health, GP Confederation & CCG)

Overview of people's thoughts on iCare, City Health and other online directories

- All seemed very interested in "all things digital" even if they were not frequent digital users themselves;
- Three residents, including one who was not a digital user themselves, showed considerable concern about security and safety of personal data as soon as websites were mentioned. iCare/CityHealth
- None of the residents had previously heard of iCare or CityHealth. Many were curious for a more general discussion around "what is a directory" and "what a directory is for."
- Regarding other online directories: Google, Duck Duck Go. Many do not use themselves but in conjunction with family members. One resident noted how that although her grand-daughter does the internet for her, she didn't like being a burden and wanted to learn to do it herself but doesn't quite know where to start.
- There was a consistent theme throughout the two workshop sessions regarding limiting search and lists to the individual's immediate vicinity. Many talked about how "there are no activities in my area" (in general) and felt this was more to do with the services and activities not being listed in pamphlets and directories rather than an actual lack of activities.
- Make more use of images and visual cues. Text was typically fine and suitable for most, but many residents mentioned that images would help them navigate the sites better.

Very lengthy discussions around the ability to search for listings that are:

- Accessible** i.e. detailed descriptions of whether the site / activity listed is truly accessible, **how many steps**, is there a hoist available, does a booking need to be made in advance for someone with access needs. Quite clear from this discussion that the words "wheelchair accessible" is insufficient information for some people to be able to make a decision on whether they can attend the facility or not. "I decide on whether I can attend a service or not based on how many steps there are. Some people are happy with two or

three steps, and on some days I can handle this, but usually I need one step or less" (referring to stairs)

- **Transport options.** Simply stating the address doesn't seem sufficient, many residents need more information about exactly what transport options are available, how far from the bus stop or train/tube station etc.
- Nearly all residents wanted the directories to remain available even if there was an all-encompassing app (some even wanted additional, separate apps for CityHealth and iCare). However common comment was "these should all be joined up";
- Two or three residents asked about why there are so many directories

What would help people use digital services?

- Leaflets and pamphlets available in libraries and GP offices. Ability for people to generate their own printed out leaflets from listings on the sites; to give to people they know who don't use the internet.
- Many would like training in how to engage with digital services (in general) but particularly with digital health related.
- Interest expressed in participating in smaller, more regular workshops that are "show and tell" / learning based.
- Many liked the idea of meeting up with panel members in smaller groups of 2-4 residents.
- One resident raised the very salient point about learning how to use these digital offerings within their own lifestyle context i.e. at home with the people who also use it.
- A "learning to use digital health" booklet or course would be good - many thought having this and a "navigator" at the GP practice that could answer questions would be the best place. Skeptical of libraries doing this was "mine has already shut down". A few residents agreed with my suggestion that perhaps their pharmacy could also be a focal point for learning about digital health offers (but somewhat skeptical - GP is favoured).

2. Demand management in Primary Care and Access to Health Records

Recommendations	Recommendations/comments for	comments
	<p>IT Enabler Programme Boar/, GP Confederation/CCG</p>	<p>Patient questions</p> <ul style="list-style-type: none"> • What type of patient data is being shared and how many people are able to see patient records? • Can parents access children's records and how does this work in terms of children who may want privacy regarding contraception for example? • The main problems are communication between the GP & Hospital and people

		<p>wanted to know if the EMISS system will help with this.</p> <ul style="list-style-type: none"> • How does it work in the case of carers who are caring for family members with dementia? • People were worried about patient data falling into the wrong hands and wanted reassurances that their data is being share within secure systems and are not shared for research purposes. • Is there a patient access app?
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3. Digital technologies, self-management, prevention and patient activation

Comments for information only	Comments for Public Health/CCG Long Term Conditions Board
<p>This group discussed the potential of digital technologies in supporting people with maintaining healthy lifestyles and with illness prevention, as well as acting as a tool for self-management and patient activation. Discussion was framed around three key questions:</p> <ol style="list-style-type: none"> 1. Have you come across any websites, apps or other healthcare related technology that you have found useful? / Benefits of digital technologies <ul style="list-style-type: none"> • Apps that enable blood pressure and blood glucose recording (although it was acknowledged that this may in fact increase work load for GPs if system would require someone to monitor and respond to people’s data) • Motivational text reminders, motivational health apps. Health apps often only manage to engage people for the first few months, so would need to keep user interested and motivated. • Apps on prescription - GP would recommend a specific app for patient to use. Progress reviewed after few months. • BBC website, Alzheimer’s Society website • Mindfulness App – Headspace • Air quality app for people with Asthma and COPD (this received multiple positive comments) • Apps for healthy recipes • Online support groups focused on specific topics • Online webinars – people can log in from multiple locations to listen to a professional talk about a specific health 	

<p>issue followed by an opportunity to ask questions</p> <ul style="list-style-type: none"> • Use of Skype - explore potential for group consultations? 	
<p>2. What are your views and experiences of IT and health?</p> <ul style="list-style-type: none"> • Multiple comments about self-diagnosis and being able to take control of your own health • Enables increased emphasis on self-management and prevention • Keeps your brain active • Not sure how to use a smartphone / don't want to use a smartphone / mobile screen too small to see properly • Worried about further health implications that technologies might have i.e. radiation from mobile phone • Cost of internet access can be a barrier • NHS Choose &Book not always working well • Worried about insurance companies having access to personal data via apps • Technology can potentially make people less active and socially isolated and could make some people symptom check unnecessarily and worry about their health. • Quality of information varies and is not always monitored. It would be useful to have a library of quality checked websites and apps that are officially endorsed by the NHS/Public Health/GPs. Too much information can also be an issue. Better to have clear summaries. • Training and information to be made available to people about how to make online bookings, use apps, renew prescriptions online <p>3. Are there any areas you think we should be investigating?</p> <p>See Q1 above re benefits</p> <p>Summary of key points</p> <ul style="list-style-type: none"> • Digital technologies can be beneficial when used in conjunction with, and as part of other support and services (i.e. apps on prescription, peer support online etc.) • Include patient and service user views when developing any tools, apps or directories, and to ensure that information and training is available. • Important to have a quality monitoring process in place for any websites, apps or tools endorsed by the NHS or Public Health 	<p>Public Health/CCG Long Term Conditions Board</p>

4. Access and support for patients		
Recommendation	Recommendations/comments for	Comments
<p>Access to information for vulnerable people Any digital offer should actively consider those who are digitally excluded.</p>	<p>CCG/GP Confederation/LBH/Public Health</p>	<p>'What about non-internet users? People who have cognitive impairments or mental health needs? They may get overwhelmed by having to use digital technology to access health. How will they be catered for? Will they be left behind?'</p>
<p>Need for more and better advocacy in digital health future including 'digital champions' at hospitals.</p>		<p>'Vulnerable patients, people with learning disabilities, brain injury, mental health needs, older people and some visually and hearing impaired people will need advocates and funded peer support to help them navigate the news system. There should be vulnerable patients champions in practice, hospitals and clinics to help them.'</p>
Patient Comments		Comments for information only
<ul style="list-style-type: none"> • 'GP's and hospitals need to get basics right first. They want to use digital technology but at the moment they won't even communicate with visually impaired or hearing impaired patients via email or text when requested' – visually impaired patient. • 'What about non-internet users. People who have cognitive impairments or mental health needs? They may get overwhelmed by having to use digital technology to access health. How will they be catered for? Will they be left behind?' • 'People may need to use library computers to book medical appointments. That is inappropriate as it not private. How can you go to the library to make an appointment if you are ill?' • People without the knowledge of how to use the technology and people with illnesses that prevent them using technology, like stroke patients and people with failing sight, will lose out. • 'You can't answer a text from a doctor with a text.' • 'Digitally advantaged people who can text will use the online appointments system easily. So will appointments get booked up quicker? Surely that will make it much 		<p>Primary Care Board, Homerton hospital, GP Confederation</p>

harder for less digitally able patients to get an appointment. How do we prevent that from happening? What are the safeguards?’

- ‘I always ‘ask nicely’ for help first and it is always good to emphasise the positive but then you have to be really firm if they are not responsive. There is an important role for advocacy here, for those who can’t assert their rights under the Accessible Information Standard.’

Online medical records

- ‘I have no confidence in the security of my medical records if they are available online.’
- ‘Apps are much better solution than computers.’
- ‘I used the patient access to medical records recently. It was a horrible user interface.’

Accountability and safeguards for vulnerable/communication impaired patients

- ‘There needs to be better GP accountability around the process of accessing services and appointments including implementing the Accessible Information Standard.’
- ‘Vulnerable people need to know that there are face to face services available. They also need to know they have a RIGHT to face to face appointments too.’
- ‘We need more “know your rights” groups.’
- ‘What about monitoring and enforcement? They may tell us that vulnerable patients won’t lose out but how will we really know their needs are being met? This group find it harder to complain and assert their rights. There has to be really good monitoring.’
- Access to healthcare for people who struggle to speak and understand English
- ‘What about people without English as a first language? How are they going to cope? Any technology has to include access to good quality translation especially when it comes to medical and health issues. It has to be accurate.’
- ‘Advocates (including advocates who interpret, should use plain English and be good quality.’

Miscellaneous comments

- ‘People would feel more comfortable with greater use of technology in healthcare if

Primary Care Board, Homerton hospital, GP Confederation

they knew they speak to a doctor or GP when they needed to.'

- 'Good accessibility saves money with less missed appointments.'
- 'Some people when they finally bother to engage with digital technology find they always have to up-grade because it becomes obsolete too quickly.'
- 'Accessibility is still a work in progress.'
- 'How young do we start introducing self-management to young people?'

Suggestions

- 'GP practices should actively use phone calls to contact vulnerable patients.'
- 'There should be alerts for patients who have issues with communication.'
- Doctors will have to proactively phone patients with communication difficulties and offer them a bespoke service.'
- 'We need more widespread use of text reminders.'
- 'There is a role for telecare in advocacy.'
- 'There should be people in surgeries available to simplify the apps on people's mobile phones. That would make it easier for patients. Customised phones and apps would make it easier for non-techie people to use mobile health technology.'
- 'There should be an opportunity to 'opt out'. It is often easier to visit the GP.'
- 'What about the young teaching the old about technology?'
- 'Studies at universities, FE colleges and on apprenticeships could be deployed to support people to use the technology.'
- 'When people are waiting for test results, please can doctors call non-mobile'
- 'Silver Surfers and other older people's groups can help older people use IT and encourage them to use technology.'
- 'Invest in good technology, especially social services.'
- 'Could you incentive non-emergency patients to use digital contact to by giving them priority appointments?'
- 'There is a role for advocates in helping to make sure vulnerable patients have a red 'flag' and a role for paid carers to help with this too.'
- 'Middle-aged and older people need encouragement and good quality teaching to get over their difficulties with new technology.'

Mental Health Service Meeting

Recommendations	Recommendations/comments for	Comments
<p>Service user representation and involvement</p> <p>There should be service user representation on the mental health programme board and PPI to ensure proper service user involvement</p>	<p>CCG mental health Programme Board/PPI</p>	<p>What is the CCG doing in terms of service user representation on the mental health board?</p> <p>There is still a lot of stigma in certain communities like the Asian community about mental health and we have to ensure that service user groups are as diverse as possible and reflect the borough's diversity.</p>
<p>Information and publicity about services</p> <p>The local authority and the CCG should create a map of where the different mental health services are in the borough.</p>	<p>CCG mental health board/LBH</p>	<p>People often feel lost in the system and the different pathways</p>
<p>Better publicity about the autism diagnostic service for adults as well as better information for GPs and other health professionals to support appropriate referrals</p>	<p>CCG mental health board</p>	<p>There is a lack of publicity about the autism diagnostic service; no one in the audience seemed to know anything about it. Better publicity about the service is needed.</p>
<p>Patients should be informed about mental health advocates on the wards.</p>	<p>Homerton Hospital</p>	
<p>Better joint up working between CMHT and support workers</p>	<p>CMHT & Support workers/CCG mental health programme board</p>	<ul style="list-style-type: none"> • Assisted living support workers experiences: people are discharged by the locality teams after they have missed an appointment and the supported living workers are left to pick up the pieces. There seems to be little consideration for the fact that these are people with mental health conditions, some of whom self-neglect. She also said that Community mental health

		<p>teams (CMHT) are not engaging with those working with people with mental health issues including informing them about the discharge of clients which makes their work more difficult. Often, clients also have to be evicted because there is no crisis intervention.</p> <ul style="list-style-type: none"> • Another support worker said it was difficult to engage with Donald Winnicott Centre as they could not get someone to talk to them on the phone. The support worker also said there was a poor response from Anita House in response to a safe guarding issue.
	<p>CAHMS/CCG mental health Board</p>	<p>CAHMS Services (for information only)</p> <ul style="list-style-type: none"> • One young person said she felt that some CAHMS practitioners just didn't understand her needs as a young person and didn't feel listened to. Once she turned 18 she was essentially told that there was nothing they could do for her, she was concerned about the transitory process for young people once they turn 18 and are deemed adults. • One person who works with young people has said that young people who use CAHM services don't feel that much better even though they have used the service for more than a year. • She said that whilst CAHMS was good at diagnosing what the issues are, it lacks in the intensive support and interventions that young people may need.

<p>Complaints and monitoring Healthwatch Hackney to quality review Crisis Line</p>	<p>HWH/CCG Mental Health Board</p>	<ul style="list-style-type: none"> • There was frustration at the complaints system at ELFT PALS, more than one person had complained to them but there was no follow up. The same was said of Homerton PALS. • There was a feeling in the room that the entire complaints process was designed to discourage complaints. • There was a formal request for Healthwatch Hackney to do an enter and view into CMHT service (Anita House, Donald Winnicott Centre)
	<p>CCG Mental health team board/Primary Care Quality</p>	<p>Primary Care experience (for information only)</p> <ul style="list-style-type: none"> • People said that GP mental health awareness varies from practice to practice and that there are 'big' disparities in the way they deal with mental health patients. • One service user said she was convinced that more people are falling through the net given her experience with her former GP practice that had not checked on her for over 4 years despite knowing about her mental health needs. When she presented herself and asked for help, she felt dismissed and no longer felt able to talk to her GP about her health. • There were reported delays in referral times from the GP to mental health services. One person said they waited 4 months for a referral to get counselling and are still waiting. One other person said that by the time you

		<p>are referred to see someone you feel worse.</p>
		<p>Prevention</p> <ul style="list-style-type: none"> • More than one person found it difficult to get support after relapse, particularly where they had a long term mental health condition. • One person said they would like to see some type of follow up prevention plan for patients who are discharged so they don't relapse. • The 6 week plans don't work for people with complex mental health conditions that need a longer service. • Short course therapies (IAPTs) were reported to be difficult to access. • One service user recounted their experience at the Donald Winnicott Centre where they said they felt intimidated by staff who it seemed "were answerable to nobody." He also said he received no help from social workers and instead relied on support from Mind and family mosaic, he said he had fallen through the gaps so many times and that it was important for people with mental health issues to receive timely and appropriate support. They added that if you have a bad CMHT you have little choice but to rely on your church and the third sector or face feeling utterly hopeless.

Men's health		
Recommendation	Recommendations/comments for	Comments
<p>There should be a commitment to a men's Group in the borough</p>	<p>City and Hackney CCG (CCG)</p>	<ul style="list-style-type: none"> • Men need to be more visible and express themselves in forums like this; this should include faith communities and other communities within Hackney. • A lot of the things that were discussed at the meeting including some of the effects of particular conditions, self-management and the information shared at the meeting could be done in spaces where man are able to share their experiences and provide support for each other.
<p>Prostate Cancer awareness Information for men needs to be available in places where men are most likely to frequent, community cafes, garages, barbers etc. Men are unlikely to go out of their way to go to health settings to get information so information has to be more accessible.</p>	<p>Public Health</p>	<ul style="list-style-type: none"> • This was best illustrated by Erol Mckeller who gives men 20% off their MOT at his Hoxton garage if they go for a prostate cancer check. Supporting initiatives where members of the community are community health champions is important. • This type of engagement is really helpful in challenging taboos, in the case of the Black community prostate cancer is seen as a big taboo and men are reluctant to come forward to get tested and treated even when they have symptoms • Women also need to be a part of the conversation because they can offer support and advice to the men in their lives. • Community champions are able to

		also talk to men about some of the sexual health effects of prostate cancer so men have a better understanding of what they can expect when diagnosed
The importance of exercise, healthy eating and mindfulness to help people manage their conditions needs to be communicated effectively to service users.	CCG Mental Health Board	<ul style="list-style-type: none"> Men find it difficult to express their feelings as they are scared of feeling vulnerable. But not sharing their fears and anxieties results in a pressure cooker effect and men need the right support structures to be able to understand that there is strength in vulnerability and it is ok to talk.
Diabetes <ul style="list-style-type: none"> Possible side effects such as mood changes, depression and possible sexual health effects should be communicated to men when they are diagnosed so they can get help earlier. 	CCG Long term conditions board	<ul style="list-style-type: none"> Diabetes affects your mood and it is not unknown for people with diabetes to suffer depression It also important that men understand the sexual health effects of diabetes, which they are reluctant to talk about.
Patient comments for information only		

Men as Carers

- Male carers need emotional support and counselling to be able to cope with their responsibilities as carers.
- Male carers are often overlooked as it is often deemed that caring is traditionally done by men but this is changing and services need to reflect that in their support provision.
- Again, the importance of exercise and taking of yourself as a carer was emphasised.

Social isolation

- There should be much better information for men on the importance of pre planning and ensuring that you have built up a network of people before agreeing to surgery, particularly for older men who may not have family networks. This should be done as early as possible so that people avoid becoming socially isolated because they are unable to leave their house and have no visitors except for health staff.
- There needs to be a better way for people to find out about the wealth of community resources that are open to people, there is so much that is provided within the community but the information doesn't filter through to people.

Maternity services

Recommendations	Recommendations/comments for	Comments
Support is needed for new mum's to have a better idea of what to expect in early motherhood	Homerton Hospital maternity services	<p>Current narratives around motherhood give women the impression that everything will be great, or conversations are centred on the actual birth experience and not post birth. These could take place during ant-natal sessions and could help with:</p> <ul style="list-style-type: none"> • Women making better informed choices about when to return to work • how to seek help and what to say if they feel they need support, sometimes women know they need support but don't know what to say • Mitigate against the fear of telling professionals they have a problem for fear of having their children taken away-this is a real barrier against women seeking support.
Ante natal classes for women in the community especially during out of office to enable working women to attend.	CCG Maternity Board	
Support for women around miscarriage which is still not widely discussed.	CCG Maternity Board	
	CCG Mental Health Board/ Maternity Board	<p>Mental health support</p> <ul style="list-style-type: none"> • There are gaps in support for women who just find it difficult to cope or feel isolated and do not qualify for mental health support. • Proper follow up needed for women who are referred to low level support to see if they need

		<p>extra support</p> <ul style="list-style-type: none"> • Mental health support for women during pregnancy and early motherhood should be on an equal footing as support with nutrition and physical health, breastfeeding support etc. It should be a public health issues. • Information and education for family members, GPs, receptionists, and other health staff on the symptoms of postpartum psychosis, ante natal and post-natal depression.
<p>Monitoring and evaluation of mental health services</p> <p>CCG to monitor providers on following up self-referrals to mental health services</p>	<p>CCG mental health programme board/CCG Primary care quality</p>	<p>Self-referrals: It can be really frustrating when people self-refer and services don't get back to them.</p>

Open Doors (sex workers project) Full report [here](#)

Recommendations	Recommendations/comments for
Hackney Council's public health team should return to its previous format of including Sex workers in the City and Hackney Joint Strategic Needs Assessment (JSNA). It should update the current version of the JSNA to include a specific section on the current health and care needs of sex workers in City and Hackney, and amend the Mental Health and Substance Misuse chapter accordingly.	Public Health
Public Health should make a genuine effort to understand the integrated health and social care delivery model and its actual costs and continue to commission and fully fund this excellent service to ensure some of Hackney's most vulnerable and marginalised residents are appropriately supported and enabled to live safer lives, and where possible move into healthier work and life styles.	Public Health
Hackney Council's public health department should carry out an equality impact assessment (EIA) to assess the impact of any proposed or planned changes to the service and this EIA should include a consultation with Open Doors service users.	Public Health
The Hackney Council should terminate support for police use of dispersal orders and Community Protection Orders against sex workers. Evidence shows that criminalisation adds to the health burden of these already excluded residents	LBH
The council should end the local requirement for vulnerable sex workers' personal information to be with shared with the SUOM panel before police and other agencies can refer sex workers to specialist services like Open Doors. We believe this gate-keeping puts sex workers at high risk, creating barriers that will prevent sex workers from reporting crimes and/or engaging with services.	LBH
The long-term health and wellbeing of street sex workers depends on their access to stable emergency accommodation at the point of crisis. Hackney Council should enforce the service level agreement between Open Doors and the homeless unit to restore agreed protocols. This would ensure that street sex workers are treated as highly vulnerable residents and ensure their timely access to emergency accommodation.	LBH
Hackney Council should ensure that all staff likely to work with sex workers are trained to deal sensitively with this vulnerable group	LBH

Please note

- There are both recommendations and comments in these documents. These come under the **recommendations** box and may be elaborated on in the **'comments'** box.
- Where there is a recommendation, it should state which commissioning board or provider the recommendation is for.
- There is some information in this document which is advisory only where we think that commissioners or providers could benefit from being informed of general patient's experiences. These come under **'comments'** without recommendations being attached to them.
- In some cases, there are also suggestions made by patients that we think may help commissioners and providers when they are making commissioning decisions or are providing services and care.

If you would like more information about the recommendations and comments or would like to speak to someone about this document, please contact Sulekha Hassan: sulekha@healthwatchhackney.co.uk: 020 7923 8367