Summary of TELCO Consultations with CCG

All information in this document has been gathered from the following house meetings:

1. **St Bart's Church and Community Centre, East Ham – 7th September 2018**

- Key Leader: Paul Regan
- Turnout: 8
- Profile: Mixed group, mainly White British
- Age range:

2. **Shpresa Programme House Meeting – 10th October 2018**

- Key Leader: Flutra Shega
- Turnout: 15
- Profile: Migrant group from Albania
- 30-40% of the group have English as their second language;
- Age range: 21 to 60

3. **Bryant Street Methodist Church & Community Centre – 8th November 2018**

- Key Leader: Elizabeth Osei
- Turnout: 20
- Profile: Pensioners' group, all people in this group have lived or worked in Newham for more than 10 years
- Age range: 40-65+

SUMMARY

Eight broad themes arise from the meetings, which are included under the three questions of discussion: what's working, what's not working and what's missing?

These themes are:

1. Quality of care
2. Responsiveness
3. Patient voice and experience
4. Administration and bureaucracy
5. GP services
6. Referral services
7. Money and affordability
8. Other

With an additional theme of 'NHS and community' for 'What's missing?'

Note that some points may apply to more than one theme.

Text in italics to show examples that participants have given.

WHAT'S WORKING?

- Quality of care:
  - Emergency care for operations
  - The quality of after-surgery care
  - Post-hospital care (Whipps Cross)
  - Follow-up (Westfield) *(e.g. receiving a health visitor and physiotherapy in the last experience of 4-5 operations – Bryant St).*
  - Acorn Midwifery Team – continuity of care from pregnancy to childcare.

- Responsiveness:
  - There is responsiveness in some areas
  - GP usually fits you in for same day, usually with the same one (Westfield)
  - District nursing visits 3 days early in treatment, then reduced to 2 days
  - Response to severe cases
  - Response to CVD and CVD symptoms

- Patient voice and experience:
  - Experience from surgery to after-case (Homerton-Operation)
  - Majority of NHS staff committed and compassionate.
  - Link workers holding Conversation Cafes once a month on various topics on health, diabetes, Alzheimer's, mental health and social needs.

WHAT'S NOT WORKING?

- Quality of care:
  - Maternity services need more resourcing.
  - Dealing with illegal drug use.

- Responsiveness:
  - *Westfield Health Centre may give appointments within 6 weeks; Walk-in Centres are very important (Whipps Cross); 3 out of 15 have used walk-in centres (Bryant St).*
  - Waiting times: there are set waiting times in hospitals (e.g. 3-4 hours), however, even if there are very few patients in the waiting room, this waiting time still applies.
  - Participant reported a long waiting time in casualty (5 hours) but care was quick, blood pressure had dropped by the time they were seen
  - There is a lack of immediate care or regard when a patient is experiencing primary and secondary stages of a disease. This means that a disease may worsen, and responsiveness only occurs when the disease is serious and/or fatal.
  - Providing short term solutions to long term problems (e.g. emphasis on medicine prescription)
  - Not cost-effective, as more money is spent by the CCG/NHS on treatment, which does not align with the principle of prevention being the most important. (residents feel prevention is cheaper)

- *One participant's son went straight to A&E at the incident of a broken arm, waited 3 hours for an x-ray, and received no treatment. Was promised a phone call but received none. After enquiring to the hospital, further (unfulfilled) promise of a phone call was made, and 3 days after arm was broken, patient went back, and treatment was demanded. There was accusation by hospital staff that the patient should not have waited 3 days to go to the hospital.*
- *4 doctors, but only ever see 2 at any one time.*
- Being attended to nurses instead of doctors
- Where translators are provided for patients, these are generally male translators (female participants expressed that they were not comfortable with this, given the health issue that they wanted to discuss)
- Patients often see doctors do their own administration and their computer skills aren't great – they are slow, and this probably wastes time which could be spent with patients. (Is there no way to change this so that doctors have administration support?)
- *Disabled Bay for holder of Blue badge: been waiting for 6 months despite letters to Mayor, local MP and council; health carer sorted out bay situation – council neglecting duty of care*
- *Participant's aunt didn't get right care when she had leg problems; didn't have bandages with them for their visits – patient had to buy for themselves.*

- Patient voice and experience:
  - Lack of relationship between patients, residents and health professionals
  - Experience is different with different GPs – some are better than others, but perhaps experience of being looked after should be the same
  - Patients do not feel heard:
    - Patients have to wait a long time to be referred to a specialist, even if they know what's wrong with them and what they need. Doctor doesn't listen to or value their perspective.
    - *Can't speak to the Practice Manager; Only when you shout do they get the Practice Manager to tell you you're not allowed to come to the GP and that you should do things online*. *You're effectively banned from GP*
    - Information that patient provides sometimes isn't followed, *e.g. allergy to penicillin*
  - Non-English-speaking patients:
    - Appointments are being cancelled due to lack of translators (e.g. at the Royal London)
    - When GPs refer non-English speaking patients for hospital appointments, they don't bother requesting for a translator
    - Sometimes, dialect is different, and things get lost in translation
    - Migrant health concerns are always related to stress. *In one case the 'stress' turned out to be a brain tumour which went undiagnosed for months.*
    - Patients from Eastern European backgrounds say that there is a wide perception in their communities that going to A&E will bypass the GP due to long waiting times for specialist referrals from GP. They also felt that

the alternative for not going to AE isn't working well *e.g . Poly-clinics are in better buildings but not necessarily a better service.*

- Late diagnosis of cancer due in BAME communities due to language problems

- Administration and bureaucracy:
  - Queues on the phone when trying to book an appointment, when caller gets through, there are no free appointments. Receptions provide no further guidance or explanation.
  - You have to tell receptionist what's wrong with you before you book anything
  - Receptionists are unhelpful, rude to patients and have bad telephone manners.
  - Appointment letters are sent too late or to the wrong address.
  - People send letters and are not Patient Participant Groups
  - People left in clinics without transport because of staff failures
  - Hospital transport system sends inappropriate vehicles although forewarned about patient, or late pickup
  - Too many bureaucrats not enough nurses
  - Overall, admin failures lead to unnecessary suffering, waste of staff, and patient time.

- GP services:
  - Poor access to GPs, by the time an appointment can be given, patient is better *(e.g. waiting time of three weeks)*
  - Can't book appointment to see a GP on the same day
  - Fear of GP closures
  - Waiting times
  - Patients cannot discuss more than one problem to their GP in a single appointment, despite there still being time – patients forced to choose most urgent problem. This is problematic as patients may be not aware of which issue is more important.
  - GPs not correctly identifying health problems or writing off symptoms that end up being harmful *(e.g. case of a patient who had breathing problems which were shunned by GP and told to use private healthcare. Private health consultant told patient that an operation was needed)*
  - Relationships between GPs and pharmaceutical companies leading to unnecessary overprescribing
  - Inconsistency in follow-up appointments – different GP each time

- Referral services:
  - Need for better access to advice, information and guidance.
  - Finding the appropriate information to deal with physical and mental issues and where to go.
  - *Have to start referral again after 2 years of receiving letters to follow-up.*

- Having to go through the NHS referral system in order to receive a service that you know you need – experiences in other countries suggest that patients can go to the relevant department straight away if they are aware of a health problem (can increase efficiency)

- Money and affordability:
  - Cuts to community services: who decides and on what evidence are services cut?
  - Money being wasted on computers etc, and not on health care e.g. more beds
  - Expensive eye-care for elderly
  - Some participants feel no choice but to go private, to receive better care, but at a financial expense that isn't suitable for them.
  - Dentists & opticians should be brought back inside the NHS as its not affordable…expensive eye-care for elderly
  - Some migrant and refugee communities require counselling due to trauma but costly due to need for translator and therapy in your own language

- Other:
  - Prevention - information on healthy lifestyle; how to control certain illnesses such as diabetes which is possible (Are CCG just sending out leaflets or can they send health professionals to share information in the community on a monthly basis?)
  - General health information in a language people understand.
  - People don't feel like they know the Locums
  - Collaborative working between NHS, LBN and 3rd sector voluntary and community organisations. (see attached documents)
  - CRUK statistics better for BAME communities
  - No health care in the Night Shelter – volunteers don't know how to help guests with health issues in the shelter, compounded by language problems (NewWay); Homelessness in Shopping Mall

WHAT'S MISSING?

- Quality of care:
  - Cultural awareness training
  - Cultural respect
  - Changing rooms for newborn babies - other countries known to have these. At the moment, babies must be changed in the hospital bed, and there is concern by participants over hygiene

- Responsiveness:
  - Information:
    - *Not being told how long it will take to be referred to a specialist appointment.*
    - Lack of information on local eye specialists

        - Changes to health services not explained
        - Not being fully informed about impacts of operations *e.g. on knee and hips*
        - Lack of information on how long it takes to get an appointment for different problems

    - Follow up from hospital when patient leaves, after receiving an operation or surgery *(e.g one participant's son was promised a follow up visit after he left hospital, and nobody came)*

- Patient voice and experience:
    - No counselling or counselling referrals for migrant and refugee communities due to "lack of translators". Cases from North London prove otherwise i.e. translators *are* available.
    - People not knowing their rights when using the NHS. Expectations not known. Patients often feel powerless in the relationship with their GPs

- GP services:
    - Some people experience lack of access to weekend and out of hours GPs: need greater access to these services, or stronger symmetry of information so that people know what services are available to them

- Referral services:
    - Being recommended alternatives, if a person is unwell but not unwell enough to receive a GP appointment

- Other:
    - Reflective practice within the NHS
    - Supply of wheelchair repair/maintenance services. Privatisation not working.
    - Parents do not know their responsibilities for maintaining their child's health, that health professionals may like them to know e.g. compared to Foster Carers who are required by law to do an annual check-up for their foster children – should all parents be doing the same?

- NHS and community
    - Wellbeing provision and preventive work in mental health:
        - Mental health services in schools, starting from primary school
        - Inclusion of parents
        - Awareness training for teachers in mental health and drug use.
        - Funding and other support for 3rd sector community organisations who can bridge the gap in NHS services. *For example, mental and emotional support for parents as provided by culturally sensitive community projects such as NCT's Parents in MND. Women, in particular, who are in need can be identified earlier, as many will not attend secondary care services due to stigma.*
        - Community centres to tackle loneliness in elders, to lessen the 'worried well' attending GPs.
    - Lack of community health advocates to promote certain health issues (e.g TB), especially for more isolated communities (e.g. refugees)

- Social prescriptions, where GP's refer their patients to specific groups for support and the group would receive money...according to a participant, this was meant to happen but they are unsure if it ever took off
- Signposting information from NHS services to community services
- Tackling loneliness:
    - Taking action on loneliness: people who are lonely tend to make GP appointments and GP's shouldn't just send them away and glance over it – they should have some involvement in referring people to specific places and groups that can help them. This way, we can ensure that they don't keep coming back for appointments, and that an increasing social problem is being solved.
    - Residents suggest a Free Phone for people who are lonely as they feel this could help cut costs
- Training for Health Champions as in Redbridge and North London – a number of good initiatives seem to have disappeared