

# Long Term Plan Engagement May 2019

## Introduction

Healthwatch England secured funding to ensure local Healthwatch can support public engagement on the NHS Long Term Plan and contribute to the development of a local plan in the East London Health and Care Partnership.

## Methodology

Healthwatch Newham delivered two focus groups with semi-structured questions, with people with learning disabilities and people with physical and sensory impairments. The engagement was delivered over April and May 2019.

## Key Findings

The following are the key findings and recommendations.

- Patients with learning disabilities or disabilities need to be informed about GP extended appointments. This will help patients explaining their ill-health and understand treatment and save GP time in the long-run.
- GPs should explain medication to patients, including changes, how and when to take it and how and when to use repeat prescriptions. We have consistent feedback that this does not happen, leading to confusion and problems later on.
- Patients responded positively to social prescribing and Newham Self-Care Programme and had ideas about how this can work well for people with learning disabilities and people with disabilities.
- There needs to be improved communications about awareness of cancer symptoms and screening. Some patients are not presenting to GPs with symptoms or do not feel listened to, resulting in late presentation or other health complications. We recognise that nationally, NHS and Public Health staff have experienced challenges with the IT screening systems, we think this emphasises why local information and contacts are vital in informing Newham residents and helping them seek medical help when needed.
- Patients had good feedback on individual GPs and pharmacists which will be shared with these providers and Newham CCG.

## Findings Summary

### Focus Groups Summary of Findings

The focus groups were attended by 21 participants, 12 with learning disability and 9 with physical disability.

Please note that not all participants answered or were involved in all questions. The numbers below reflect the number of participants that contributed to each question/ discussion point.

### **Adequacy of service and support received from health services:**

To start the sessions, we asked a general question about people's overall experience of health services and whether these have met their needs:

Participants with learning disabilities:

- 3 – were happy with the service received
- 2 – found the support inadequate and staff rude
- 2 – like their GP, while 1 found them rude and unhelpful

Physical disabilities participants:

- GPs will allow 1 condition only to be discussed per appointment.
- None of the participants with physical disability were aware they could ask for an extended 20-minute appointment.
- GPs tend to focus on their main condition or disability, even if that is not the issue that they are presenting. 3 participants with visual impairments/blindness said this happens with their GP, which takes up time during the appointment unnecessarily.
- GPs and Pharmacists do not explain when medication or the brand of medication is changed. This is difficult for blind/visually impaired patients, as they cannot see the packaging, and will only realise the change was made after they experienced the side effects.
- Participants agreed that having multiple conditions did not make receiving support easier, in fact in some instances it hinders the process.
- Participants with learning disability found it difficult and uncomfortable to attend tests and scans as they had to undress and did not aware of the process.

### **Awareness of Newham Self-Care Programme**

- No participants had heard of the Self-Care programme.
- 3 – found their pharmacist helpful
- 1 – physical disabilities (visually impaired) participant is unable to do their own diabetes prick test and found the pharmacy charges them to complete it, when this should be free.
- Once explained, participants with physical disabilities thought the self-care programme would be helpful, however, the scheme would need to:
  - Have staff that are available and can enable the patient to make an appointment.
  - Have a private room for the sessions.
  - Provide reassurance about confidentiality.
  - Have a good knowledge of Newham's community and health services.
  - Have staff that have good medical knowledge for people with long-term or complex conditions. Staff would need to know detailed medical information. One example was given of a patient that can't digest certain food but would like to know if they can take liquid vitamins. They would not want to visit a GP for this but are not sure where to go to find out. This is the type of thing a pharmacist could advise on.

### **Social Prescribing**

- Participants with learning disability enjoyed taking part in activities provided by local organisations and groups, such as outings, dance and exercise classes.
- Physical disability participants thought social prescribing is a good thing and could include services such as:

- Diabetes blood-sugar finger prick tests to be provided in community settings as well as pharmacies (for people with disabilities or visual impairments that cannot do it themselves)
- Prove healthy eating recipes that are easy to do for people with visual impairments and disabilities.
- Activities in locations that are easy to get to.
- Personal trainers that are free of charge or at a reduced rate with better support and adaptations for people with disability – participants felt that current gym sessions that are supposed to be for or adapted for people with disabilities are not well run. Staff do not understand the disability and what someone can do or not do; sometimes they are left alone with equipment and the participant feels unsafe or cannot control/stop the equipment (e.g. treadmill) if they are left alone.
- Information should be available in different formats as residents use all different types, such as Braille, Large Print, on CD or online (the latter can be accessed by 'Read Aloud' software).
- Life coaches or wellbeing support.

### **Cancer Screening**

- Some of the participants with learning disabilities did not at first seem to understand what the term cancer meant. After further explanation, they were aware of cancer and what it involves. It's important that things are explained clearly to help people understand and remember.
- None of the participants recalled being asked by their GP whether they had cervical screening (smear tests), breast cancer, including mammograms and other screenings, except for one participant with learning disabilities.
  - This is most concerning for participants who are blind or visually impaired as they may miss text or letter reminders.
- Participants with learning disabilities seemed to have considerable issues with and concerns around tests in general including blood tests, since they do not seem to be aware of how the tests are conducted and what they involve.
- Participants with learning disabilities said it would help to have someone visit their groups to explain various procedures including cervical screening, bowel cancer test, mammograms etc, what they are, what they involve and what to expect, to make it easier for them to attend.
- Participants with visual impairments stated that they will not be able to see possible signs of cancer such as blood in urine/stools; making it extremely important that they are made aware of other signs and have regular checks.
- Participants with physical disabilities said that the lack of support makes their conditions worsen, increasing costs in the long run. For instance, around how to use self-test kits and being able to pick up on possible signs of cancer

### **Cervical Screening**

- Participants with learning disabilities said it would not help to bring a friend or relative to their cervical screening, because they would not be allowed in during the test and "you will have to do it alone"
- 3 participants with learning disabilities had a smear test and found it uncomfortable.
  - 1 found the nurse helpful,
  - 1 had a very bad experience and they would not go again,
  - 1 said they would go again although she didn't like it, because she understood why it was important.

- 3 said they would not attend an appointment for cervical screening.
- Participants thought it might be helpful to have someone with them, but thought this person would have to wait outside and could not be there in the room or beside them whilst the test was done.

#### Bowel cancer

- None of the participants with learning disabilities were aware of the kit to test for bowel cancer and did not recollect ever having received it.
- When the process was explained, many did not want to talk about it and seemed to find the process uncomfortable and not something they would do.
- 1 physical disabilities participant could not use the bowl cancer home test kit and had to press for a colonoscopy, and felt this delay exacerbated their symptoms and caused ongoing health problems.

#### Mammogram/checking one's own breasts

- No participant could recollect being invited to or attending a mammogram. Some participants were over 50.
- No participant said it had been explained to them how they could check their own breasts.

## Recommendations

#### Learning Disability

- GPs and practice staff to have bite-sized training/guidance to remind them of the challenges and barriers that people with learning disabilities may face and to better support such patients in their healthcare.
- This could be through always arranging double appointments; printing information about conditions in Easy Read for patients to take away.
- Nursing staff or health care assistants to be available to answer questions and provide information about conditions or procedures.
- GP/nurses to explain and remind patients of cancer screening services at annual health checks and other appointments and provide information for patients in Easy Read other languages to take away.
- To explore whether wellbeing and prevention programmes, such as those for diabetes, have staff with awareness or training to support people with learning disabilities, which would help them participate in the group and in the exercises.
- To develop healthy eating and weight sessions for participants with learning disabilities, with guidance from nutritionists and on weight management and exercise programmes.

#### Physical Disability

- GP staff to actively offer extended appointments to patients with disabilities or long-term complex conditions.
- GPs to be reminded to listen to the patient first of all and focus on the main issue they are presenting regardless of their disability.
- GPs should clearly explain any change in medication or the brand of medication. This is vitally important for people with visual impairments.
- GP/nurses to explain and remind patients of cancer screening services and provide information for patients in accessible formats on symptoms and screening.

Healthwatch Newham will share details of the feedback on different GPs with the GP and Newham Clinical Commissioning Group, to help improve the service for patients. Healthwatch

Newham will share the good practice shown by GPs and pharmacists and share the challenges some patients have with particular services.

Healthwatch Newham will liaise with the groups, different cancer charities and NHS staff with the aim to improve trust with NHS services and increase the knowledge and usage of cancer symptoms, screening and services.

## About Healthwatch

Healthwatch Newham is part of a national network led by Healthwatch England, which was established through the Health and Social Care Act in 2012, to give service users of health and social care services a powerful voice both locally and nationally. We are the independent voice for people's views on Newham services, both good and bad. We listen to local people and feedback patient experience and liaise with local commissioners and decision makers, in order to improve services.

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