healthwatch
Ealing

Engagement Report
Oct - Dec 2020
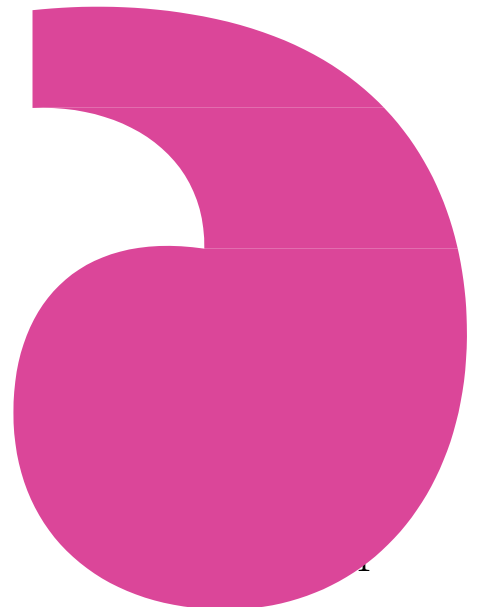
Contents

Abbreviations

GOS&D – Golden Opportunity Skills and Development
CCG – Clinical Commissioning Group
NWP – Northwick Park Hospital
ECN – Ealing Community Network
BME – Black and Minority Ethnic
HWE – Healthwatch Ealing
NWL – North West London
CAPE – Community Activities Projects Ealing
MINT – Mental Health Integrated Network Team

Introduction

Healthwatch Ealing is the independent consumer champion created to gather and represent the views of the public. We play a role at both local and national levels to make sure that experiences of health and social care are considered by the service providers.

Healthwatch Ealing gathers insights from local people about their experiences with local NHS services - including but not limited to hospitals, GPs, dentists, and social care providers. This gives us a chance to find out what is working well, what isn't and what needs to be improved - which can be relayed to the appropriate service, Trust and CCG.

This report covers quarter three, October to December 2020. Healthwatch Ealing, much like other organisations that work with the public in a face-to-face capacity, have had to learn and adapt our scope and methods because of the Coronavirus pandemic. All our face-to-face work has been suspended based on risk assessments, and we have had to move to online/remote working. As such, we have been using much of this time to re-assess and develop new methods of engagement and delivery with the public.

It should be noted that due to the nature of this engagement work, most people tend to express concerns more than they mention examples of good practice. Therefore, for a balanced view of patient views, this report should be read alongside Healthwatch Ealing's Patient Experience reports. This engagement report is also a way to channel concerns into helping to find solutions, finding out what service users would like and where they think improvements need to be made.

Updates

The Q1, Q2 and Q3 Patient Experience Reports can be found online, here.

Engagement activities

Overview

Engagement Event/ Engaged Organisation	Type of Engagement	No. present
Ealing Foodbank	Meeting	~ distributed 250 surveys
Sage	Meeting	~ distributed 150 surveys
Ealing Council	Meeting	4
Acton Town COVID task group	Meeting	30+
Adult and Children's Safeguarding Board	Introductory meeting	2
The Carers Group	Introductory Meeting	1
Public Health Ealing	Meeting	1
West London Mental Health Forum	Forum	
Ealing/ Hounslow CVS	Meeting	2
GOSAD	Introductory meeting and follow-up on BME report	2
Ealing Children and Young People Providers' Forum: Diversity and Inclusion	Forum	20+
Health Watch Ealing - Visiting Angels	Introductory meeting	1
Ealing Mental Health Forum	Forum	20+
GOSAD	Meeting	1
Joint HWE and HWH, HWHF Webinar x2 "Access Services during COVID-19" "Preparing for a COVID-19 Winter"	Webinar	30+ 30+
Healthwatch Ealing x BME community orgs	Focus group	6
Ealing Mental Health Forum	Forum	20+
Kelvin Tame - ECN Vice Chair/ CAPE	Meeting	1
ECN Forum	Forum	20+
Ealing Mental Health Forum	Forum	20+
MINT Workshop	Forum	20+

Challenges

Healthwatch Ealing remained working from home, with suspension of all face-to-face public engagement in Q3 of 2020. Therefore, it is still difficult to reach members of the public. However, we have been able to get back in contact with different services and speak to service users through them as they begin to onboard more clients onto digital spaces. It should be noted this still excludes many who do not have digital access, and Healthwatch Ealing remains available by phone and email throughout as a means of interacting with the public.

Successes

Building on the success of our first webinar over the summer, Healthwatch Ealing has teamed up with our sister Healthwatch in Hounslow and Hammersmith & Fulham to provide a series of webinars. These will be ongoing for the foreseeable future. The two we have had jointly so far have been well received and attended, both by attendees and respective CCGs.

The two webinars were:
- "Preparing for a COVID Winter" with 67 sign ups and approximately 30+ attendees on the day
- "Accessing Services during COVID-19" with 70 sign ups and approximately 30+ attendees on the day

Due to the COVID-19 vaccine announcements we decided to use the second webinar to run a poll during the event to find out more about people's attitudes towards the vaccine and discuss it. This is now being used as the foundation for a COVID-19 vaccine related report which will be released in the coming months once all the data is collected.

As these webinars have been successful, and have been found useful by participants, they will likely be continued as one of the services we provide during the pandemic and then reassessed for need once face-to-face services reopen. The next one will be at the beginning of 2021. We have now added a page on our website where video presentations and other information from the webinars can be found if people were unable to attend.

We have continued to grow out Twitter by 43 more followers during this quarter and are putting out more regular content. We have also adapted our newsletter so most of the information is in the body of the email rather than expecting people to click through to our website and download the PDF versions only.

Feedback

Feedback about vaccines and COVID-19 can be found in appendix. This section will cover feedback from our focus group with local BME-led organisations who participated in a local BME report. We conducted this focus group to discuss how we could work with them and start priority setting for Healthwatch Ealing's own health inequalities research in the future.

Range of services

The organisations have been supporting older people with isolation and loneliness as they have had to shield, physical exercise, food distribution, social justice projects, and information and advice.

One of the main things each of these organisations ended up doing was advocating for the people and communities they worked with. This was in a multitude of ways, either supporting them with appointments, following up with health and social care complaints or noticing when people needed support in this, or intervening in matters relating to Ealing council. Even though this is not the main role of these organisations, it was something they felt they had to do as they understood their communities needed support and were not always able to represent or stand up for themselves.

Service users

Many of the service users (SUs) are in some way vulnerable, either with socioeconomic or health-related difficulties. The organisations spoke of SUs who have mental health issues which are especially strained during COVID-19 with both loneliness and the increased economic pressures. Therefore, they try to help and reassure them where possible.

Generally, there has been an increase in stress and emotional traumas during COVID-19 for SUs of these organisations due to increased vulnerability.

Telephone appointments

It was noted that older people needed support in phone consultations as they found retaining and understanding information difficult. This was not specifically about language barriers, though this can also be an issue, but just being able to retain all the information. Organisations were unsure if there was appointment related support for older people but, felt it should be taken into consideration especially when many people need additional support to understand what is being said / recommended by doctors.

Another issue with telephone appointments related to that of local authorities and being able to access disability benefits. It was noted that during in-person appointments the tribunal can see the individual in person and can noticeably inspect the level of disability – this has been taken away over telephone appointments making it harder to convince tribunals resulting in people being turned down. This was also brought up as an issue in an array of health assessments. From Healthwatch Ealing's point of view this is a problem as less-visible disabilities would not be assessed by "sight", so should be investigated.

Digital exclusion

The issue of digital exclusion was brought up. For some SUs the issue of lack of accessibility to online services was an issue – not having laptops or adequate internet access. There was also the need to make sure people knew how to use programmes such as Zoom as most services were now online. It was noted that it takes a lot of time

to onboard SUs to these platforms. It was also noted that for dyslexic people trying to do everything online was quite difficult and people preferred direct communication and support via telephone. Additionally, there were issues around language and literacy levels deterring access, and simply preferences.

Some of these organisations were trying to stay in touch with their SUs through phone calls and physical newsletters to remind them they could access support, and someone was thinking of them.

Disability & Mental Health

Some disabled SUs said they were finding it difficult to get support to do shopping or fulfil other basic needs during the pandemic. IT was also noted that the representatives felt that emotional trauma should be considered a disability, and this was particularly true those who had other compounding disabilities.

It was also noted that people with increasing mental health issues were not getting the support they felt they needed, and many people are undiagnosed with mental health illnesses but have seen them regress during the pandemic. Representatives spoke about spending hours on the phone to Ealing Council to get support for their SUs due to the lockdowns.

The representatives noted that other services promote what they do, but when they call to ask for help for SUs they find those services do not have the capacity. They noted that the whole community sector was clearly struggling to appropriately support SUs.

Organisations in Ealing find they must support many SUs with quite a range of traumatic experiences even if it is not their main work. Many SUs are refugees who come from abroad i.e., Syria, but found there was not a service that could adequately cater to their needs.

These representatives have been trying to take part in local initiatives around mental health and have found there are not very diverse or representative of the borough. Overall, there seemed to be quite a lot of complicated mental health needs in the borough, and these organisations felt more work was needed to support people and move beyond a 'one size fits all' approach, and that they had been let down during the pandemic.

Joint working

All the organisations acknowledged they were in a difficult position and to really support SUs they would need the support of the greater community and all organisations to work together. The issues faced by their SUs are multi-pronged and therefore need a joined-up approach. Their first step was to build relationships with other organisations, so they knew where to signpost their SUs. They felt "co-production" could not be talked about if these initiatives were not aiming to be diverse and representative of the borough. They believe people need to be properly involved in designing services, from the very beginning, rather than being labelled "hard-to-reach".

In Healthwatch Ealing's point of view, there needs to be collaborative working with statutory services, and we know these organisations are struggling to receive appropriate action at the local authority level.

For these organisations, there are also issues around budgets and capacity building. They have been asking for support long before the pandemic and have not been able to access very much. They found it contradictory that BME-led services were being praised for the work they have been doing during the pandemic, but do not receive, in their opinion, adequate financial support to carry out this work. They found some organisations were receiving COVID related funding whilst others were not and were unsure how this was being allocated. These organisations want to grow and provide more support to their communities but find they cannot afford to do simple things like hire out more spaces.

Other

- GPs have asked for money to release medical reports, which individuals could not afford, and organisations have had to advocate on their behalf.
- Volunteers have had to use their personal phone or laptop to support SUs during the pandemic and found they are unable to receive support for work equipment.

Follow-up activities and next steps

As a result of the report by Public Health England regarding the impact of COVID-19 on Black and Minoritised Ethnic (BME) communities, Healthwatch Ealing is currently pursuing a best course of action regarding our own research on health inequities in the borough. Having spoken to these BME-led organisations in Ealing, we aim to establish a research project in a specific area of health inequities where we feel we can bring useful recommendations and hopefully, tangible impacts for the community. Next quarter we will begin planning for this project with implementation in April 2021.

We will continue to deliver a series of webinars for the public, to provide them with information and signposting of health and social care services, and community and voluntary sector organisations. We will continue working with neighbouring Healthwatch's in Hounslow and Hammersmith & Fulham to deliver this work for the tri-borough area. Now that we have information around the COVID-19 vaccine, and as this becomes a more salient issues, we will continue to collect this data during webinars and put together a full research report on our findings by the end of March 2021.

This report will be published on our website, sent to relevant partners, and presented at relevant CCG, Local Authority and Service Provider committees and meetings.

APPENDIX

**A – Exploration of attitudes to the COVID-19 vaccine**

Healthwatch's Ealing, Hounslow, and Hammersmith and Fulham held a webinar on 11 December 2020, briefly discussing, and polling, attendees' views of the COVID-19 vaccine and whether they would be willing to receive it. A total of 38 attendees participated, including a mixture of members of the public and professionals from the community and voluntary sector. A summary of results and perceptions are covered in this report. Healthwatch has also provided an analysis of the types of information the public may need or find useful based on the discussion and responses of the public health representatives. Ultimately, we found that there are wide-ranging knowledge gaps that could be countered with an effective public health campaign or information programme, and professionals should be cognisant of their audience.

**Poll results**

The polling questions were:

1. Would you consider taking the Covid-19 vaccine?

Out of a total of 38 attendees, 22 people (58%) said they would receive the vaccine, however 16% (n=6) said they would not, and 26% (n=10) were not sure if they would take it yet.
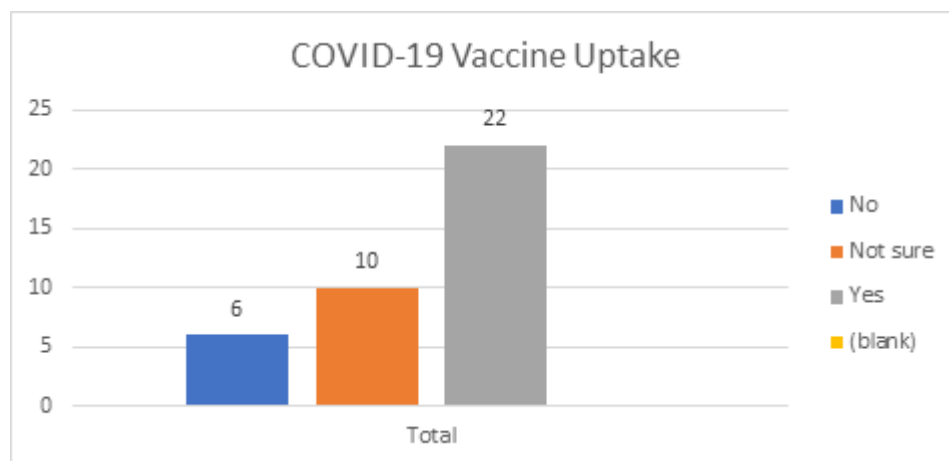
2. Have you downloaded the Covid-19 app? (not the NHS Test and Trace app)

With respect to the COVID-19 app, 37% (n=14) people said they had downloaded it, and 58% (n=22) said they had not.

NHS Test and Trace App downloads
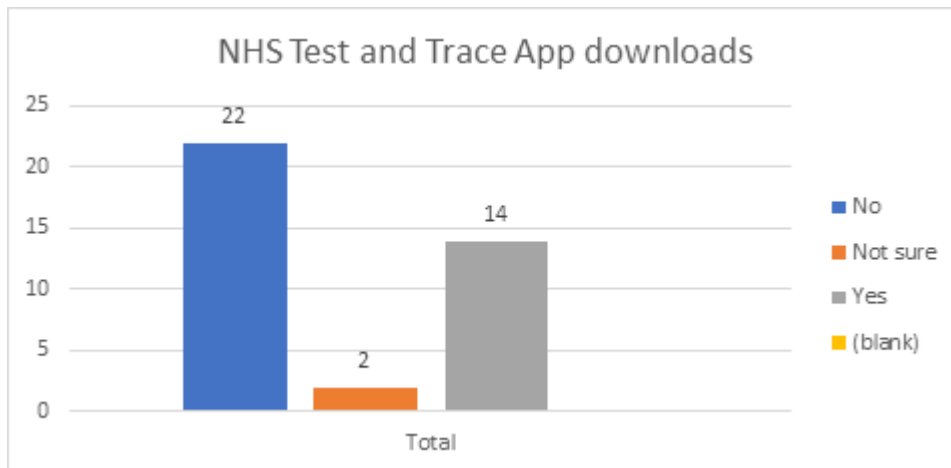
Discussion feedback

Concerns

- **News regarding adverse reactions**: Concern caused by news-media coverage of individuals who had a severe reaction to the vaccine. The follow-ups on who these individuals were and why they had a reaction does not seem to be as amplified as the news of the initial adverse reaction itself.   Some spoke anecdotally of knowing people who would not take the vaccine because of this news. However, others felt they were not concerned about the adverse reactions of a very few people.
- **Trial participants:** It was noted that trial participants were not likely to be representative of the most vulnerable populations that the vaccine is being rolled out to first i.e., over 60s and those with long-term conditions. Therefore, there was some concern that the effect of the vaccine on these groups was not well known. Additionally, some were concerned that people with allergies were not included in the trials initially or thought of.
- **Trial time-period:** The trial period was perceived to be too short for the COVID-19 vaccine, especially when compared to how long other vaccine trials might take - *"trials take years not months"*.
- **Monitoring:** Assumption that continued monitoring of effectiveness/reactions and the risk of side-effects, as well as perhaps not having a properly representative trial sample, equated to the roll-out making *"guinea pigs"* of the public.
- **Immune system:** It was felt there should be more information about the immune system, how to keep it strong, and the effects it might have on the ability to recover from COVID-19. Discussed a general lack of education and awareness around this topic, and noted that when people are isolated their mental health suffers and as a result so does their immune system.

Questions

- *"Is there anything else that will come out from the roll out itself (information about the vaccine, regarding adverse reactions or that it may not be as effective as promoted) that will make people hesitant to take it?"*
- *"Could the COVID vaccine bring back normality?"*
- *"If coronavirus mutates is it back to square one?"*
- *"I would like to know how the NHS is addressing people's additional concerns that have been raised by the reactions which happened on the first day which was unlucky I think. But how are you dealing with trying to lessen the concerns and not saying 'well saying it's been tested*

and there's lots of scientists' we've heard all that. Is there any real active information or effort coming out?"

- *"If trials are in phase 4, and are being rolled out, does this mean we are all going to be guinea pigs and part of a continued trial?"*
- *"What is the timescale to receive vaccine for younger people in care homes?"* Most news focused on older people in care homes.
- *"The World Health Organization laid claim to eradicating polio but because some parents declined to be vaccinated, its back, so should it [COVID-19 vaccine] be made mandatory?*
- *"Is there not a gov sponsored vitamin-d supplement due to start soon for the vulnerable?"*

Positive feedback

- Having read a wide variety of information, one person felt they trusted the vaccine and were willing to receive it. It should be noted this was an older individual from a middle-class White British background and a professional in the third sector.
- *"I am keen to have the vaccine and I think it would give people more motivation if they were given vaccine certificates".*
- *"I know people who will be happy to take it but not in the 1st phase.*" People want to know how others may react before taking the vaccine themselves, this seems to be built on the lack of clarity around the evidence, news media, and knowing there have been some adverse reactions. People may want the vaccine but are wary in these initial stages.

Case studies

CASE 1: Elderly person has son with severe learning difficulties in care home with co-morbidities. They wanted information of when younger people in care homes would receive the vaccine as news and information has predominantly focused on older people in care homes. Has concerns that people who came forward to be part of the trials would not have had learning difficulties or other co-morbidities and would not have been in the age group of over 60s as trial participants tend to be younger. Concerns regarding the vaccine and about giving permission on behalf of her son who is unable to give his own consent.

CASE 2: An older couple in their 80s are due to receive the COVID-19 vaccine at their homes, as part of the first rounds of the vaccination programme.   They did not express any concerns about receiving the vaccine.

CASE 3: An older person (70s) living in a bubble with their partner (60s) and parent (90s) is aware they are all in a high-risk category. Therefore, they would like to receive the vaccine – *"I would just go for it but that's just me!"*. They note balancing the risk of catching COVID-19 and ending up in hospital with a long-term condition or dying, versus feeling more relaxed having had the vaccine with a small chance of adverse reaction. Additionally, pointed out that there is a risk involved in taking any drugs as they all potentially have some side-effects. It should be noted this individual was from a middle-class White British background.

CASE 4: One person who had coronavirus in 2020 and has had some other health problems was hesitant to take the vaccine.   They said they still suffered from effects of long-COVID after being very ill.

Recommendations

Informing the public

- More information about:
  o How vaccine trials work, and the size of trials prior to public roll-out
  o The vaccines reviewing process, different regulatory bodies, and standards needed to be met prior to public roll-out
  o How vaccination works, how much of the population needs to be vaccinated, and how it effects transmission rates and mortality rates in separate ways (individual-level changes vs population level)
  o Understanding on how science changes constantly, and how different strains work
  o Where the research for this vaccine comes from, and how long the knowledge has existed
  o The breakdown of trial participants, and effects / efficacy on people who are not young and healthy
  o How to support the immune system
- Honesty about what "normal" may look like going forward, and what restrictions may continue to be needed.
- It seems some people already know the basic information about testing etc but want to know what type of actual engagement the NHS is doing with communities. These are likely to be professionals in the third sector.
- The NHS has put out updates and information around Vitamin D more recently, and this information should be shared with the public in an appropriate manner that does not frame it as a solution, but a way to build a stronger immune system which may support recovery.

Engagement with public

- Public health professionals should engage the concerns and anxieties people have without judgement, instead of being dismissive or assuming prior knowledge, or that the public trusts institutions to the same degree as themselves.
- Public health professionals discuss vaccine trials with assumed prior knowledge such as knowing what different trial phases are. All language and information should be simple and easily understandable by lay publics with assumed non-prior knowledge.

Based on a review of a few presentations and some feedback we received from webinar attendees.

Next steps

All three Healthwatch's recognise that public health professionals and statutory bodies are constricted by national policy and strategies but would press for as much local adaptation through learnings as possible. We will continue discussions about COVID-19 vaccine through forums, such as our monthly webinars with local people. Insights will be fed back to local CCGs and public health teams to assist in vaccine rollout with the view to improve uptake and engagement with the public to address concerns. The next webinar takes place on 12 February 2020.

Appendix

Breakdown of attendees.