



PEOPLE OVERVIEW & SCRUTINY SUB COMMITTEE (HEALTH SCRUTINY) AGENDA

7.00 pm	Wednesday 20 July 2022	Council Chamber - Town Hall
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Members 2: Quorum 2

COUNCILLORS:

Conservative Group (5)

Ray Best
Joshua Chapman
Jason Frost
Christine Smith
David Taylor

Havering Residents Association Group (4)

Laurance Garrard
Linda Hawthorn
Bryan Vincent
Julie Wilkes

Labour Group (2)

Pat Brown
Frankie Walker

East Havering Residents Group (1)

Darren Wise

For information about the meeting please contact:
Anthony Clements
01708 433065, anthony.clements@onesource.co.uk

AGENDA ITEMS

1 APOLOGIES FOR ABSENCE AND ANNOUNCEMENT OF SUBSTITUTE MEMBERS

(if any – receive).

2 DISCLOSURE OF INTERESTS

Members are invited to disclose any interests in any of the items on the agenda at this point of the meeting. Members may still disclose an interest in an item at any time prior to the consideration of the matter.

3 MINUTES (Pages 1 - 6)

To agree as a correct record and authorise the Chairman to sign the minutes of the meeting of the Health Overview and Scrutiny Sub-Committee held on 17 November 2021 (attached).

4 INTEGRATED CARE SYSTEM (Pages 7 - 34)

Report and presentation attached.

5 HEALTHWATCH HAVERING - ANNUAL REPORT (Pages 35 - 54)

Report attached for discussion with Sub-Committee.

6 HEALTHWATCH HAVERING - EXPERIENCE OF POST-COVID 19 REPORT (Pages 55 - 80)

Report attached for discussion with Sub-Committee.

7 WORK PROGRAMME

The Sub-Committee is invited to consider items for its work programme for the forthcoming year.

Zena Smith
Democratic and Election Services Manager

**MINUTES OF A MEETING OF THE
HEALTH OVERVIEW & SCRUTINY SUB-COMMITTEE
Havering Town Hall
11 November 2021 (7.00 - 8.45 pm)**

Present:

Councillors Nic Dodin, Nisha Patel (Chairman), Ciaran White (Vice-Chair) and David Durant

Councillor Reg Whitney was also present (via Zoom).

Officers present:

Ian Buckmaster, Healthwatch Havering
Steve Rubery, North East London Clinical Commissioning Group (CCG)
John Mealey, Barking, Havering and Redbridge University Hospitals NHS Trust (BHRUT)
Dr Atul Aggarwal, CCG
Melissa Hoskins, CCG
Nick Swift, CCG
Pippa Ward, North East London NHS Foundation Trust (NELFT)
Carol White, NELFT

20 APOLOGIES FOR ABSENCE AND ANNOUNCEMENT OF SUBSTITUTE MEMBERS

Apologies were received from Councillor Philippa Crowder.

21 DECLARATIONS OF INTEREST

There were no disclosures of interest.

22 MINUTES

The minutes of the meeting held on 22 September 2021 were agreed as a correct record.

The Sub-Committee was pleased to note that the Healthwatch report presented at the meeting on Disabled Residents and Covid-19 had won a national award.

23 COMMUNITY PHLEBOTOMY UPDATE

A new model of community phlebotomy had been worked on prior to the pandemic. Three sites in Havering were currently able to offer same day booking for blood tests with the Elm Park clinic offering a one day wait.

Some 97.8% of patients had indicated they were happy with the distance they travelled to the phlebotomy clinic. Work was undertaken closely with BHRUT on sample transport and the sample deterioration rate was currently 4.4%.

Feedback on the new model was currently being considered. There were not specific figures for the time taken to receive blood test results though further details could be provided to a future meeting.

The Sub-Committee noted the update.

24 ST GEORGE'S HOSPITAL REDEVELOPMENT - ENGAGEMENT PLAN

Officers explained that 95% of respondents to the original 2013 consultation had supported the building of a new health centre on the St George's site. This development would help with the aim of people not having to go out of the borough for outpatient services.

In 2019, the Government had awarded £17m capital for the St George's development. An online public exhibition had opened in April 2021 with the proposals being supported by 86% of respondents.

It was agreed that some GP surgeries would close and move onto the St George's site. This was due to some local GPs retiring and the poor accommodation of some existing GP surgeries. It was clarified that a health and wellbeing hub was very different to a polyclinic. The hub would include Council and voluntary services on the same site. For example, all diabetic services could be given on the same site. The workforce could also be employed by different providers across the same site.

The St George's development had been designed to recognise the many factors leading to ill health and would give the best outcomes to residents.

The Sub-Committee noted the engagement plan and that the full proposals were due to be presented to it at a special meeting of the Sub-Committee on 4 January 2022.

25 BHRUT PERFORMANCE REPORT

The BHRUT Acting Chief Operating Officer explained that there was still some Covid segregation in the Trust's hospitals but that most elective services were now back to being carried out face to face. Whilst there had been a decline in the 4 hour A & E performance, the frailty units (an alternative to A & E) had been very successful.

Referral to treatment timescales had improved but had levelled off recently. The number of patients waiting more than 52 weeks for treatment had increased over the post-Covid period. In excess of 95% of cancer patients received their first appointment within 2 weeks of referral.

Superclinics had been set up to reduce waiting lists in areas such as spinal review, general surgery and orthopaedics and it was hoped these would be repeated. The Trust was heavily focussed on reducing waiting lists and waiting times in A & E. Officers felt this was not being made worse by Covid restrictions and that Covid and Flu cases etc could be successfully managed.

Issues around the vaccine mandate were currently being worked through by the Trust. The Trust was used to dealing with winter pressures and had reduced planned care previously in these instances. It was hoped that such services could continue this year however. Investment had been made in critical care and it was planned to recruit additional staff for this area. Workforce issues were however a challenge nationally.

The Sub-Committee noted the BHRUT performance report.

26 NELFT 0-19 CHILDREN'S SERVICES

A new contract for 0-19 services had been awarded from 1 April 2020. Some work had halted as staff had been redeployed due to the pandemic but all staff had returned to their main roles since September 2021.

All expectant mothers with additional needs had received face to face contact and 95% of new mothers were contacted with 14 days of birth. The service also had a perinatal mental health lead as well as a support group for less acute needs. Weigh-in clinics had restarted and a breast feeding café was available by appointment.

The national child measurement programme had restarted via the school nursing service. Face to face and virtual drop in sessions were available if nurses could not be accommodated in schools. A healthy weight programme was also delivered in partnership with Children's Centres.

A digital platform had been designed with young people including a digital 'red book' for immunisation records. The primary mental health teams had received 80 referrals of children between March and October 2021 and also undertook consultations with teachers concerned about children. There had been a rise in referrals of children and young people with anxiety since schools returned in September 2021.

It was clarified that there was no threshold of needs for a child to be seen by the Primary Mental Health Team. An additional 16 staff would be in post by January 2022 to work with schools. There would not be any threshold for

this service either. Brief interventions such as this could often be more effective than medical treatment.

As regards the impact of Covid restrictions, officers advised that the Government used medical evidence to determine vaccine policy and that Trusts had to follow NHS clinical guidance. A Member raised issues concerning a recent e-mail that referenced the BHRUT Chief Medical Officer. The Chairman stated that she had no concerns about the e-mail.

The Sub-Committee noted the update on NELFT 0-19 Children's Services.

27 HEALTHWATCH HAVERING REPORT - HAVERING AND THE CORONAVIRUS PANDEMIC

A director of Healthwatch Havering explained that the report gave an account of the Coronavirus in Havering until the lifting of restrictions on 19 July. Data in the report was taken from official sources and showed that there had been 960 Covid-related deaths in Havering with 107 in care homes. The last care home death due to Covid in Havering was however on 28 May 2021. The numbers of deaths in Havering was relatively low and reflected the hard work of hospital staff. Care homes had not been affected as badly in Havering as in other parts of the UK. Fifteen Havering care homes had not had any Covid deaths.

The spread of infection had seen London recording the highest figures in January 2021 but this had reduced by April. Incidences had risen in June and again from October 2021. Death rates had begun to fall from March 2021 and death rates in Havering remained low.

Numbers of Covid patients in ITU remained fairly low. It was essential that hospitals retained Covid controls as a Covid outbreak on a ward would mean it not being able to be used for other operations for a period of 10 days. There had been a rise in the number of Covid patients who had recovered following hospital treatment.

Vaccination figures for Havering were similar to the average for England. Around 80% of the eligible population had received a first dose, as had 66% of 18-24 year olds. Figures for the second dose were 94% of over 80 year olds and 56% of 18-24 year olds.

There had been a number of consequences of the pandemic in Havering including the lockdowns, increased working from home and problems accessing GPs and dentists. Digital exclusion was an increasing problem and other issues included an inability to visit care homes and hospitals as well as an increase in mental health problems.

The Healthwatch Havering director felt the report showed that people were not prepared for the pandemic and that preparation would need to be better for any future pandemic.

It was suggested that Healthwatch Havering should send their report to all Councillors.

The Sub-Committee noted the report.

Chairman

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PEOPLE OVERVIEW AND SCRUTINY SUB-COMMITTEE, 20 JULY 2022

Subject Heading:

North East London Integrated Care System

Report Author and contact details:

Anthony Clements, Principal Democratic Services Officer, London Borough of Havering

Policy context:

NHS officers will give details of some new NHS arrangements covering Havering and North East London.

Financial summary:

No impact of presenting information itself.

SUMMARY

NHS officers will present to Members information on the new Integrated Care System and associated local NHS structures.

RECOMMENDATIONS

That the Sub-Committee scrutinises the information presented and considers what, if any, actions it wishes to take in response.

REPORT DETAIL

An important recent change to local health services has been the replacement of the local Clinical Commissioning Group with an Integrated Care Board (NHS North East London). This is part of the establishment of a wider Integrated Care System covering both Havering and the wider North East London area.

NHS Officers will give details (attached) of this important change to NHS arrangements and Members may wish to consider the implications of these changes on the scrutiny work programme.

IMPLICATIONS AND RISKS

Financial implications and risks: None of this covering report.

Legal implications and risks: None of this covering report.

Human Resources implications and risks: None of this covering report.

Equalities implications and risks: None of this covering report.

Environmental and Climate Change implications and risks: None of this covering report.

BACKGROUND PAPERS

None.

ICS & ICB Update

Havering Elected Members



Introduction

Luke Burton, Director Place Based Partnerships

Ground Rules – Stop me if something isn't clear or I use acronyms I have not explained

- What are the big changes in the NHS
- What is an ICS
- What are the place partnerships
- What are PCNs /Neighbourhoods
- What is being asked of the administration
- What are the key opportunities, challenges and risks

How does the NHS in England work and how is it changing?

<https://youtu.be/blapgFKXv0I>



And what will these changes mean for you and me?



The establishment of NHS North East London

- In April 2022 the Health and Care Act achieved Royal Assent. As a result on 1 July CCGs were disestablished and replaced by Integrated Care Boards (ICB). Our ICB is known as NHS North East London (NHS NEL).
- NHS NEL is led by Marie Gabriel CBE, Chair and Zina Etheridge Chief Executive as well as a newly appointed board and team of senior executives.
- We have moved from the governing body of the CCG, made up of primary care leaders and lay members, to an integrated Board that retains an important role for primary care but includes a broader range of other members from our Trusts, local authorities and the voluntary, community and social enterprise sector.
- We have an agreed constitution which can be accessed online:
<https://www.england.nhs.uk/wp-content/uploads/2022/06/8-nhs-north-east-london-icb-constitution-010722.pdf>

NHS North East London Integrated Care Board members

2x NHS Trust partner members

2x primary care partner members

1x VCSE*
partner
member
(TBC)



Marie Gabriel
Chair



Zina Etheridge
NHS NEL CEO



Shane DeGaris
Barts/BHRUT
Group CEO



Paul Calaminus
ELFT CEO



Dr Jagan John
GP



Dr Mark Rickets
GP

3x non-executive members



Henry Black
Chief Finance &
Performance Officer



Diane Jones
Chief Nursing
Officer



Paul Gilluley
Chief Medical
Officer



Rajiv Jaitly
Audit



Imelda Redmond
Quality



Diane Herbert
Remuneration & workforce

2x local
authority
partner
members
(TBC)

*VCSE refers to the voluntary, community and social enterprise sector

NHS North East London executive leadership team



Zina Etheridge
Chief Executive Officer



Paul Gilluley
Chief Medical Officer



Diane Jones
Chief Nursing Officer



Henry Black
Chief Finance and
Performance Officer



Charlotte Pomery
Chief Participation and
Place Officer



Francesca Okosi
Chief People and
Culture Officer



Johanna Moss
Chief Strategy and
Transformation
Officer

North East London Health and Care Partnership (NEL HCP)

NEL HCP - the Integrated Care System

- The North East London Integrated Care System is known as North East London Health and Care Partnership and is chaired by Marie Gabriel and with Zina Etheridge, ICB CEO, the system convenor.
- NEL HCP is a formal alliance of partners with a role in improving the health and wellbeing of our residents. Together we set the overall strategy that will guide our collective work and hold the wider health and care system to account for how services are delivered in a more joined up way.
- As of 1 July the governance of the NEL HCP will be via the Integrated Care Partnership, a core statutory component of the system. In north east London partners have agreed that we will establish an inclusive ICP, with wide membership across our partnership. It was agreed that a smaller 'steering committee' would be established to plan and coordinate the business of the ICP. The proposed membership of the ICP 'steering committee' includes the ICB Chair, two elected members –inner and outer, two NHS trust chairs –acute and mental/health, the ICB chief executive, a VCSE collaborator, a Healthwatch group nominee and a primary care collaborative leader

North East London Health and Care Partnership purpose, priorities and principles

Our purpose:

“We will work with and for all the people of North East London to create meaningful improvements in health, wellbeing and equity.”

We will design and operate the NEL ICS in a way that:

- improves quality and outcomes
- secures greater equity
- creates value
- deepens collaboration

NEL's flagship priorities

- Children and young people – *to make NEL the best place to grow up*
- Mental health – *to improve the mental health and well being of the people of NEL*
- Employment and workforce – *to create meaningful work opportunities for people in NEL*
- Long-term conditions – *to support everyone living with a long-term condition in NEL to live a longer, healthier life*

Formation of Integrated Care Systems (ICS)

Building on strong NEL partnership foundations to form our ICS

ICS are a **new form of partnership between organisations** that support the health and wellbeing of local communities

Partners include the **NHS and local councils alongside voluntary, community and social enterprise sector organisations**

The ICS will be established from 1st July (although major changes will be phased)

The ICS is how we describe all partners across the system working together for the benefit of the north east London population

Integrated Care Systems

Integrated care systems (ICSs)

Key planning and partnership bodies from July 2022

NHS England

Performance manages and supports the NHS bodies working with and through the ICS

Care Quality Commission

Independently reviews and rates the ICS

Statutory ICS

Integrated care board (ICB)

Membership: independent chair; non-executive directors; members selected from nominations made by NHS trusts/foundation trusts, local authorities and general practice

Role: allocates NHS budget and commissions services; produces five-year system plan for health services

Integrated care partnership (ICP)

Membership: representatives from local authorities, ICB, Healthwatch and other partners

Role: planning to meet wider health, public health and social care needs; develops and leads integrated care strategy but does not commission services

Cross-body membership, influence and alignment



Partnership and delivery structures

Geographical footprint

System

Usually covers a population of 1-2 million

Provider collaboratives

NHS trusts (including acute, specialist and mental health) and as appropriate voluntary, community and social enterprise (VCSE) organisations and the independent sector; can also operate at place level

Place

Usually covers a population of 250-500,000

Health and wellbeing boards

ICS, Healthwatch, local authorities, and wider membership as appropriate; can also operate at system level

Place-based partnerships

Can include ICB members, local authorities, VCSE organisations, NHS trusts (including acute, mental health and community services), Healthwatch and primary care

Neighbourhood

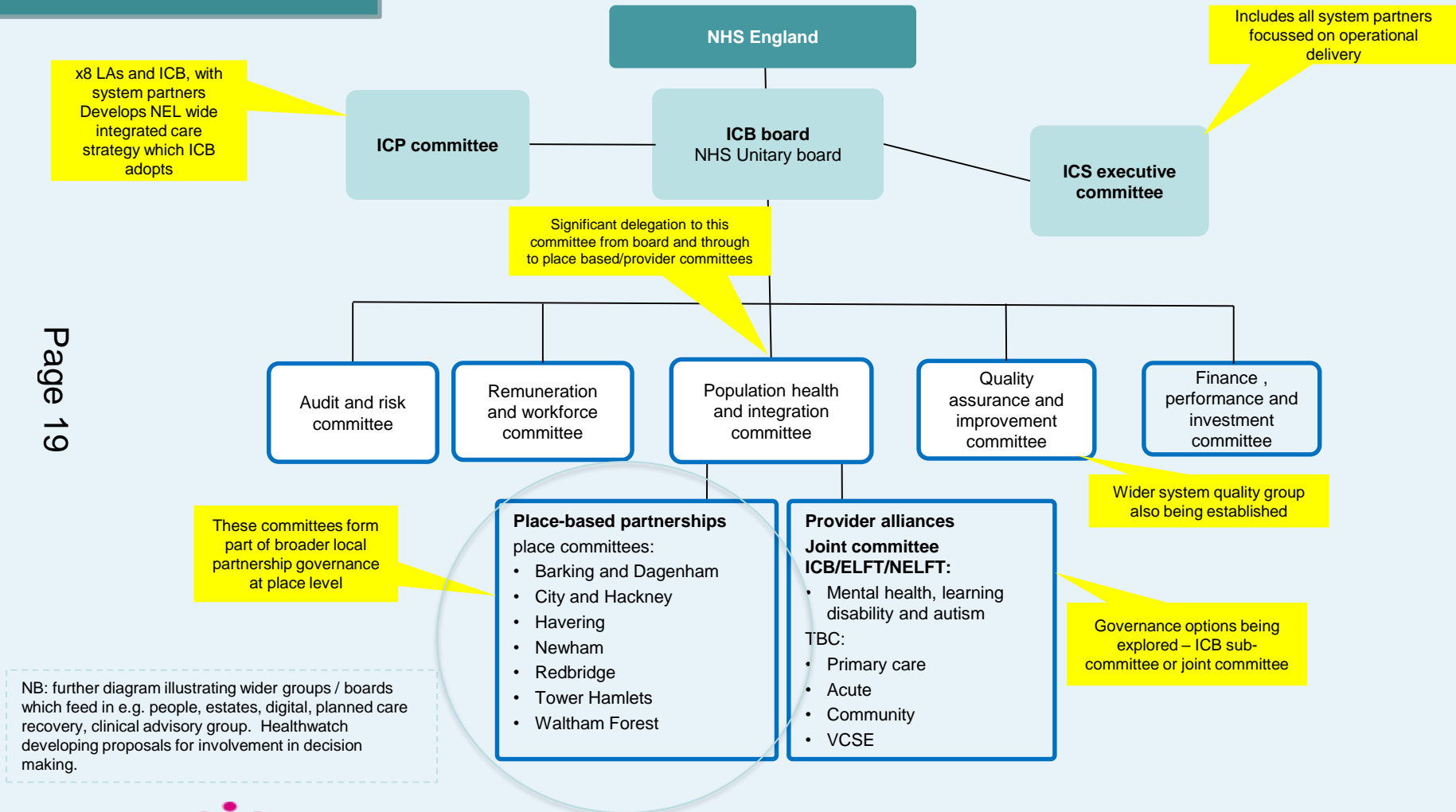
Usually covers a population of 30-50,000

Primary care networks

General practice, community pharmacy, dentistry, opticians

ICS/ICB formal governance 1

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Formation of NHS North East London ICS

NEL CCG will no longer exist and a new statutory organisation – an **Integrated Care Board (ICB)** – will be established, which we will call **NHS North East London** - take on the NHS commissioning functions of CCGs

And **Integrated Care Partnership** will be created as a formal alliance of partners with a role in improving the health and wellbeing of our residents. Create a joint plan for improving health for our community and how services will be delivered in a more joined up way

Place-based partnerships are collaborative arrangements involving the organisations responsible for arranging and delivering health and care services in a locality or community. PBP's will be a **formal sub-committee** to the ICB

For NEL Place-based partnerships are based **across a Borough boundary**, which is why Place-based and Borough Partnership is both used

Havering Place Based (Borough) Partnership



Key Functions of a Place Based Partnership

Understanding and working with communities

- Developing an in depth knowledge of local needs
- Connecting with communities

Joining up and coordinating services around people's needs

- Jointly planning and coordinating services
- Driving service transformation

Addressing social and economic factors that influence health and well being

- Collectively focusing on wider determinants of health
- Mobilising local communities and building community leadership

Supporting quality and sustainability of local services

- Making best use of financial resources
- Supporting local workforce development
- Driving improvement through local oversight of quality and performance

These functions are where there is greatest potential to add value over and above the contributions of individual organisations or entire systems.



Joining up and coordinating services

Example:

High Intensity Users (frequent fliers)

Residents in our community who bounce around and have many touch points with our services.

Services in Havering working in this way:

A and E – those with multiple attendances (Drug, Alcohol, Mental Health, Loneliness, Frailty)

Housing services – drug and alcohol support services

Social care – working with providers around discharge

Police – criminal justice drug and alcohol triage in custody

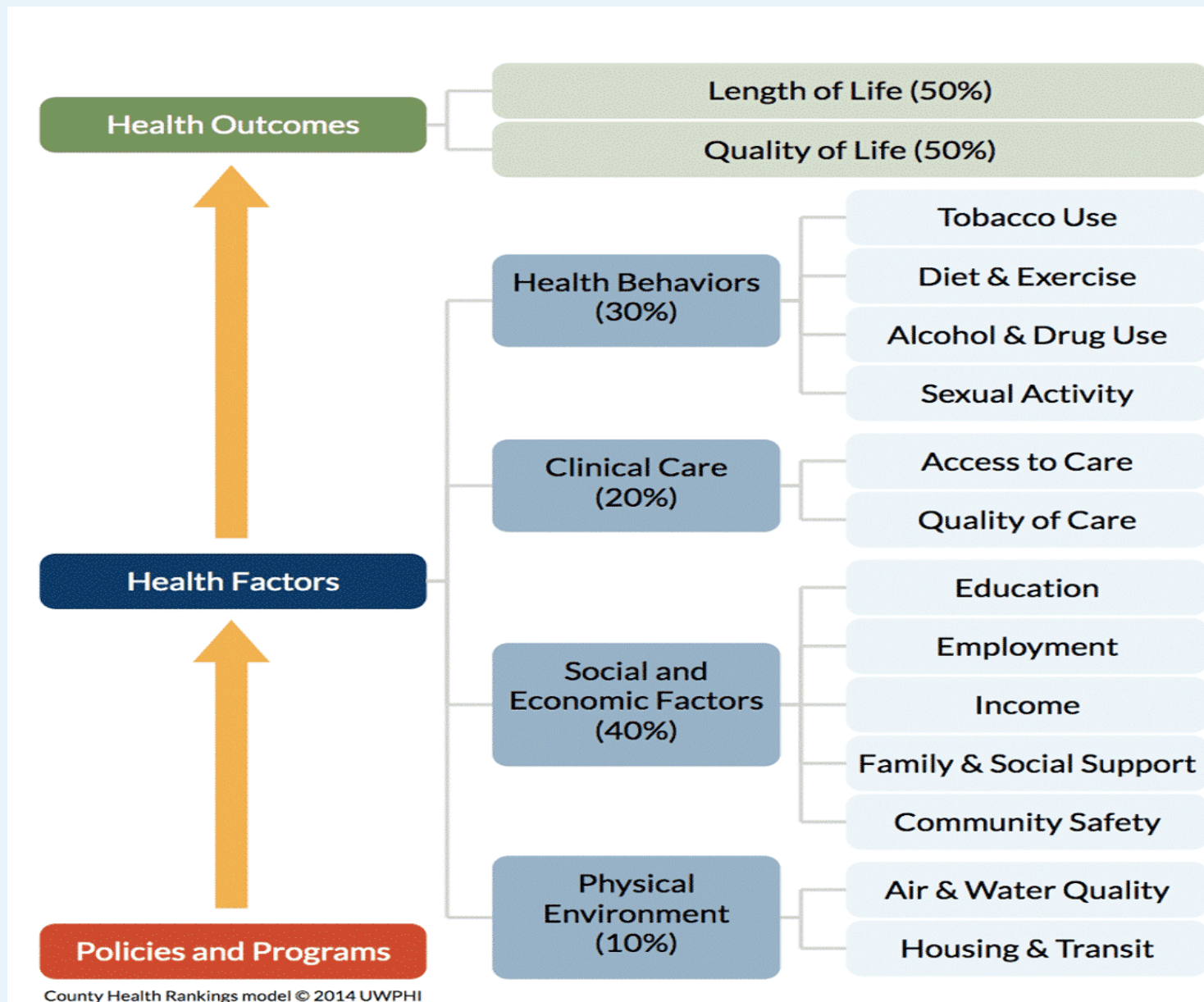
Primary care – MDTs targeting those with multiple long term conditions

Whilst there are some links, work is happening in isolation

Wider Determinants of Health

If we get the best clinical care possible e.g. 100% efficiency. We will still only be affecting 20% of someone's life

The 80% happens outside traditional clinical settings



Formation of Havering (Borough) Place Based Partnership

- Clinical and **Care Leadership model** being implemented
- **Governance model agreed** and accountable officer being agreed
- **Membership** and ToR for Sub-Committee **of the ICB agreed (subject to partnership sign off tomorrow)** and established
- Partnership **budget and delegated functions** to be **confirmed**
- **Projects** initiated in priority areas of **mental health, social inclusion and Health Inequalities**
- **Community engagement** model in development
- Mapping of current **Havering wide programmes** from all partners
- Joint **Insights and Population Health Management Data** - in development
- **Delivery structure** to designed – keen for joint teams where possible



Emerging Priority areas

- **Children and Young People** – Mental Health, Healthy weight, 1st 1000 days
- **Workforce** – recruitment and retention into target roles e.g. Allied Health Professionals (e.g. OTs, Physios)
- **Older People** – Frailty, hubs, end of life, social care provision, keeping people at home
- **Long Term Conditions** – managed in a more coordinated person centred way
- **Community connections** – Local Area Coordination, social prescribing
- **High Intensity Users** – for all of our services not just A and E

All underpinned by using Population Health and working with those who face the biggest health inequalities



Primary Care Networks / Localities

Reminder – primary care networks – *usually* population 30-50k, but can be 90-100k

4 networks in Havering – GP's decided how they would form into networks.

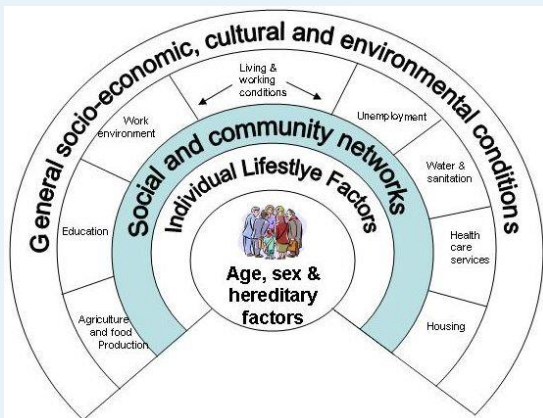
- North – 13 practices – total patient population 80k
- Havering Crest – 8 practices – population 41k
- Marshalls – 3 practices – population 44.5k
- South – 14 practices – population 96k

Local area
coordination

ASC and NELFT community health services – had been arranged into localities coalescing around PCN predecessor arrangements

NELFT and ASC to plan on reorganising our service delivery to be more aligned to the PCN boundaries, although Marshall and Havering Crest will be treated as one.

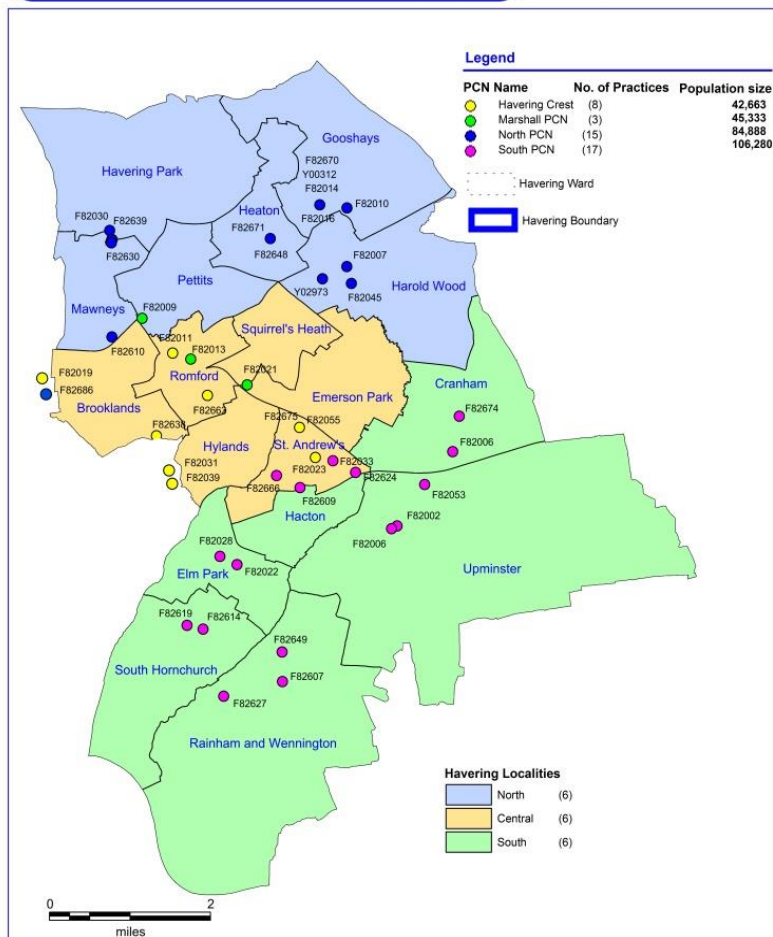
Borough Partnership offers opportunities to work at "Place" and "Neighbourhood" level differently – not just NHS and adult social care, but also across council and partnership functions – CSC/education, public health, housing, regeneration, leisure activities.



Community
Hubs

Government wants Integrated Care Systems to have a real focus on population health management – with the NHS to have a much bigger role, including possible investment, in reducing inequalities and seeing health through the lens of the wider determinants of health.

Havering GP Practices by Primary Care Network



Data Sources:
BHR CCG's, May 2019

Produced by Public Health Intelligence

What is being asked of you, the administration

To Note:

The formation of the ICS on 1st July 2020

The **functions** delegated to the ICB be NHS only

Reps from **local authorities** will be on the ICB

2-representatives for NEL will be nominated from local government – 2 places on the ICBP covering all 8 local authorities. EG one councillor / leader representing all 8 LA's

To consider:

- How decision making at **Place** will work – e.g. think about committees in common over time
- Between July and April 2023 (and beyond), what **council functions** (if any) may be delegated into the Placed-Based Sub-Committee – and any changes to the **council's constitution** that may be needed.



A huge opportunity for the NHS, Local Authorities, Voluntary Sector and the Community, to work together to improve the lives of our citizens.

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However we face many challenges and there are risks with working in this way...

Population Growth

At an overall projected growth of 10% by 2041 (from 2021), Havering actually has one of the lowest expected population growths in NEL. However, within this, there is a significant expected increase in those aged 80+ (45%) – health and care services for this population group in particular are significant compared to other age groups, and partners will need to prepare and plan for this over the coming decades. There is also an expected 24% increase expected in those aged 70-79.

Access to Housing

- Increasing number of homeless people, and increasing need to support Refugees placing further pressure on housing stock
- Housing shortage: need to build more market and affordable housing
- High number of people in 'interim' housing
- Need to improve the quality of housing services
- Significant link between housing and health

Workforce

- Some historical underfunding in community health services, and primary care.
- This is reflected in high patient to GP / Nurse ratios in the community, and lower numbers of district nurses in the community.
- Significant number of GPs at, or beyond retirement age
- As a borough we have a high number of vacancies across all front line roles

Urgent and Emergency Care

Havering are an outlier for non-elective admissions for older people, and local people have to wait longer for access to non-elective care than in other areas.

Life Expectancy

Those aged 65+ in Havering have a worse life expectancy than those in our neighbouring Redbridge; an average male and female of age 65+ in Redbridge can expect to live 19.2 and 22.0 more years whereas Havering 18.2 and 21.2.

Planned care waiting times

Following the pandemic, there has been a significant increase in the backlog / waiting times for planned care services.

Key challenges and issues

Known Barriers to access

- Awareness of services
- Trust in services / cultural acceptability
- Language barriers
- Services that are not flexible to meet local need
- Accessible pathways into services
- Capacity of some services, particularly following the pandemic
- Poor access to preventative and early interventions – particularly for underserved and underrepresented communities
- Increasingly diverse population with multiple social challenges which influence need and access
- Significant expected increase in demand for non-elective services at Queens Hospital – Havering Residents are the largest proportionate users of this hospital

Physical space to deliver Integrated Care

Primary Care estate is often constrained, with no ability to expand, particularly where this is within converted housing. Space to deliver integrated care, particularly with the ARRs roles within primary care, is needed, to support the delivery of integrated care, closer to home.

Access to BI/ Data to inform our work

It is essential that the Havering PbP has access to timely and joined up BI and data to inform their work, including more up to date acute data, and the ability to join up primary care data with community data, to create a whole view of the needs of local people. Access to timely / joined up data is currently an issue within the system.

Sharing of PID data between operational leads

Simple process to share PID information between front line staff, and track patients is needed to support seamless delivery of care and more integrated working. Currently this is a barrier to the delivery of seamless care. Many operating systems are not interoperable and solutions are needed to facilitate data sharing to support integrated / more seamless care to local people.

Key population health challenges – JSNA

- Some significant public health challenges including:
 - Obesity
 - Homelessness
 - Dementia Diagnosis
 - Support for older people
- Screening uptake worsened during the pandemic
- Crime and Vaccination uptake – Havering is better than the London average

Levelling up Funding

Compared to other Boroughs in North East London, many areas such as Primary Care and Public Health have been underfunded. Please see example below

Funding – Public Health

There is significant under funding in relation to the Public Health grant for Redbridge, compared to other NEL boroughs, as illustrated below. The percentages show the current slice of the overall pot for NEL as a proxy for the proportion of funding split. This is not decided at a NEL level and is allocated centrally.

Public Health Grants by NEL PbP		
City and Hackney	£37,573,975	22%
Barking and Dagenham	£17,787,080	11%
Havering	£11,622,333	7%
Newham	£32,612,030	19%
Redbridge	£14,576,152	9%
Tower Hamlets	£37,371,659	22%
Waltham Forest	£17,001,881	10%
£168,545,110		

Key Risks

- **With joint decision making comes joint accountability** – e.g. Do elected members / senior officers want to be part of a controversial / unpopular decision in health services – shutting A and E (please note this is not being discussed currently)
- The voice of **Place** in the provider collaboratives
- The NHS **legal duties** have changed but local government hasn't
- There are still **financial challenges** within the NHS and local authorities. The message is that the ICS is now one budget, but working in a collaborative way with penitential savings target can be challenging



In Summary

- There are now **3 main levels of the NHS**. Integrated Care System (ICS), Place, (Borough for us), Primary Care Network (PCN) / Neighbourhood
- There is a **requirement** for Local Authorities, Voluntary sector and Communities to have more input into how Health and Care works
- There is a need to **work with partners** around the wider determinants of health
- A **system wide focus** on health inequalities
- Havering has some **great relationships** already to build upon and **good progress** is being made
- Discussion needs to happen around the **decision making process** at place (e.g. officer and elected member input)

Opportunity: With the new administration, to have a joint Community and Health plan for Havering, which uses the Place Based Partnership as a vehicle for delivery.

Championing what matters to you

Annual Report 2021–22



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Message from our chairman

I would like to take this opportunity to thank all residents, patients, their family and friends, our team and the ever-dedicated volunteer members, for sharing their concerns, local issues and stories about health and social care in our borough.


This report records some of the many things that people have shared with us. Although people come to us with their concerns, some of which are in our report below, we also hear about some very caring and supportive initiatives that make us proud to be in the Borough of Havering.

I very much hope you find this report helpful and informative and please do contact us if you would like to know more about our work.




Anne-Marie Dean
Chairman,
Healthwatch Havering

Below is a comment from Sir Robert Francis QC, who is soon to retire as Chair of Healthwatch England. Sir Robert has been inspirational in developing Healthwatch and we are grateful to him for his dedication to ensuring the patient voice is heard.



The COVID-19 pandemic has thrown long-standing health inequalities into stark relief. With NHS and social care facing even longer backlogs, the unequal outcomes exposed by the pandemic are at risk of becoming worse. Local Healthwatch play an important role in helping to overcome these adversities and are uniquely placed to make a positive difference in their communities.

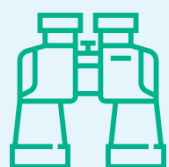
Sir Robert Francis QC, Chair of Healthwatch England



About us

Your health and social care champion

Healthwatch Havering is your local health and social care champion. From Rainham & Wennington to Havering atte Bower and everywhere in between, we make sure Council and NHS leaders and other decision makers hear your voice and use your feedback to improve care. We can also help you to find reliable and trustworthy information and advice.



Our vision

That Havering is the Place where we can all get the health and care we need.



Our mission

To ensure our residents experiences help make health and care better in our borough for everyone.



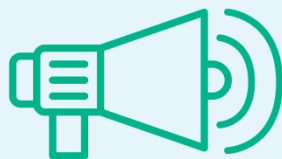
Our values

- Listening to people and making sure their voices are heard.
- Including everyone in the conversation – especially those who don't always have their voice heard.
- Analysing different people's experiences to learn how to improve care.
- Acting on feedback and driving change.
- Partnering with care providers, Government, and the voluntary sector – serving as the public's independent advocate.

Our year in review

Find out how we have engaged and supported people.

Reaching out



635 people

shared their experiences of health and social care services with us, helping to raise awareness of issues and improve care.

140 people

came to us for clear advice and information about topics such as NHS dentistry, accessing a GP and problems with hospital care

Making a difference to care



We published

6 reports

about the improvements people would like to see to health and social care services.

Our most popular report was

Community Insights on disabled residents and the Covid vaccine in North East London

which highlighted how the vaccine impacted disabled residents

Health and care that works for you



We're lucky to have

20

outstanding volunteers, who freely give up their time to make care better for our community.

We're funded by Havering Council. In 2021-22 we received:

£117,359

Which is the same amount that we received for the previous year.









We also currently employ

6 staff, all part time

who help us carry out this work.

How we’ve made a difference throughout the year

These are the sort of thing we worked on from April 2021 to March 2022.

Spring		Supporting vaccination programmes, providing support to older people and carers to attend the centres		We supported a family in their discussions with BHRUT regarding the protocol of Do Not Resuscitate DNR
Summer		We supported a disabled mum with a young baby to get transport support to specialist hospital appointments		We continued to raise concerns regarding the signage and long queues experience by patients waiting for the Urgent Treatment centre
Autumn		Teaming up with the British Red Cross, we called for improvements to make leaving hospital safer during the pandemic.		We continued our campaign to increase the access to residents for dental care. The issues was raised and acknowledged at the Health and Wellbeing Board
Winter		When people struggled to see their GP face-to-face we asked the NHS to confirm this right for all patients, resulting in updated guidance to practices.		To support the COVID-19 vaccination programme we talked to different communities to understand their hesitancy towards the vaccine and published guidance to improve trust.

Listening to your experiences

Services can't make improvements without hearing your views. That's why over the last year we have made listening to feedback from all areas of the community a priority. This allows us to understand the full picture, and feedback to services to help them improve



Long Covid – Project – Post Covid 19 Clinic

Thanks to people sharing their experience of symptoms

For some people, coronavirus (COVID-19) can cause symptoms that last weeks or months after the infection has gone. This is sometimes called post-COVID-19 syndrome or “Long COVID”

In partnership with neighbouring Healthwatch and the North East London Foundation Health Trust (NELFT) we carried out a survey into Long COVID



169 people responded, of whom 96 were Havering residents. 84% had tested positive for Covid – 41% diagnosed with Long Covid – 20% identified as carers – 77% were women – 13% were health care workers

People told us:

- **they were unsure where to access support**

‘I HAVE NOWHERE TO GO FOR HELP’

‘There’s absolutely no support, it’s like people with long covid are invisible’

- **they were in fear of being disbelieved**

‘I haven’t looked for help at the doctors in case I’m not believed.’

- **of the impact on their quality of life**

‘I’ve had no support from anyone I have gone into debt and struggling to work and feel tired all the time’

What difference did this make

- Evaluate GP diagnostic codes and simplify referral
- Widen in-person GP access to assess impact

Recommendations



- To be recognised and acknowledged
- ‘Let me know a little bit more’ – information for peace of mind
- Time limits for when to seek advice regarding loss of function




Digital – emerging and vital

One of the most important roles that a Healthwatch has is to support emerging pieces of work from all organisations across the borough which will enhance and support those people who are most vulnerable in our Havering borough.


One such emerging piece of work is how services in Havering respond and support those residents that need help and support to be able to access services in the new digital environment we all have to live in.

We are supporting the Borough's Discovery programme and have and will be using our Friends Network to help all residents to learn about the importance of having connectivity and accessibility to the internet. At our recent Away Day for our Volunteer Members we had a presentation from the Digital Portfolio team and were able to influence and discuss the issues that will improve the service for all.



‘With the internet you lose personal contact with people, you do even with your family because they email you or text you and you think it would be nice to hear your voice.’

Life Offline qualitative research, female 75+



How we will build on this years work in 2022-2023

- It will help to identify training and on-going support needs
- Ensuring that people worries about security and scamming are addressed and supported
- Ensure that all young people have the ability to learn from home using digital technology
- Increasing the opportunity for positive outcomes – on-line shopping, paying bills, keeping in touch with friends and family

Three ways we have made a difference for the community

Throughout our work we gather information about health inequalities by speaking to people whose experiences aren't often heard.



Creating empathy by bringing experiences to life

It's important for the Social and Home Care services to step back and see the bigger picture, through hearing personal experiences, and the impact on people's lives. This provides a deeper understanding than using data alone.

We have undertaken an annual independent survey of residents who are receiving care home packages of support provided by LBH. Our experienced team of volunteers use a range of over 20 questions to provide residents with every opportunity to share their experience and influence the care that they and others are receiving



Getting services to involve the public

Services need to understand the benefits of involving local people to help improve care for everyone.

This year we have been working to help re-engage patients with their GP practices. The experience of GP services has not always been positive due to Covid 19. There is lot of work being developed to help to improve the service models for both the Patient, Carers and GP practice staff. We are working with the CCG to reintroduce and support Patient Participating Groups (PPG)



Improving care over time

Change takes time. We often work behind the scenes with health and care services to consistently raise issues and push for changes.

Access to NHS dental care has been and remains a serious concern in the Borough. In 2020 we published our first report on Dental Services in Havering. The Healthwatch campaign is for accessibility and affordability for everyone. With the new NHS reforms Dental care and its funding will be part of the local Integrated Care Systems (ICS)

Advice and information

If you feel lost and don't know where to turn, Healthwatch is here for you. In times of worry or stress, we can provide confidential support and free information to help you understand your options and get the help you need. Whether it's finding an NHS dentist, how to make a complaint or needing to know more about how to live with Long Covid – you can count on us.

This year we helped people by:

- Being members of a detailed clinical study on the impact of Covid 19
- Linking people to reliable information they could trust
- Supporting the COVID-19 vaccination and booster programme
- Helping people to access the services they need to support their recovery



Supporting the public health campaign – to get our jobs



Playing our part in helping at the vaccinations centres

For Havering, the vaccination programme was a vital part of the fight against Covid. As a borough we have one of the highest number of care home beds in London and a large number of our population are older people.

Our members helped at the vaccination centres, with providing transport, and importantly networking with often hard to reach communities to ensure that they had every opportunity to visit the vaccination centres

We used our Healthwatch Friends Network to publish often twice weekly information which was flowing down from the NHS and the public health team at Havering Borough Council

We worked in partnership with the local voluntary organisations to support residents and carers needs.

Volunteers

We're supported by a team of amazing volunteers who are the heart of Healthwatch Havering. Thanks to their efforts in the community, we're able to understand what is working and what needs improving in NHS and social care.

This year our volunteers:

- Helped people have their say from home, carrying out surveys over the telephone and online.
- Carried out website and telephone reviews for local services on the information they provide and assessing their accessibility.
- Continued to help with the local volunteering efforts supporting those who were self-isolating.

Become a
healthwatch
Community Champion!





Vivien

“For me I am particularly passionate about dementia care. Unless you have experience of dementia you can not imagine how unsettling and distressing it is for people who have dementia and the enormous challenges that their carers face. I regularly provide updates to our weekly meeting on the key issues that friends and neighbours affected share with me.

Dianne

“I have a background in Care Home management and this is still my passion. For me to be able to support local homes to deliver the best possible care is important. I have a role in the Enter and View visits to care homes. To ensure that I keep up to date with CQC requirements etc. I attend the Boroughs Quality and Safety meeting and the tri-borough meeting on quality and safety.




Jenny

“Like my two colleagues above I have been a Volunteer member of Healthwatch since it was created 2012. I have a schools background and I am passionate about volunteering. I have been volunteering at our local hospital for many years – for me the opportunity to make a positive contribution to a persons life – young or old – is the best feeling in the world



Do you feel inspired?

We are always on the lookout for new volunteers, so please get in touch today.

-  www.healthwatchhavering.co.uk
-  01708 303300
-  enquiries@healthwatchhavering.co.uk

Statutory statements

About us

Healthwatch Havering is the operating name of Havering Healthwatch C.I.C., a community interest company limited by guarantee, whose registered office is at Queen's Court, 2-17 Eastern Road, Romford RM1 3NH

Healthwatch Havering uses the Healthwatch Trademark when undertaking our statutory activities as covered by the licence agreement.



Finance and future priorities

To help us carry out our work we receive funding from our local authority under the Health and Social Care Act 2012.

Income		Expenditure	
Funding received from local authority	£117,359	Staff costs	£82,766
Additional funding	£2,540	Operational costs	£2,743
Taken from reserves	£565	Support and administration	£34,955
Total income	£120,464	Total expenditure	£120,464

Top three priorities for 2022–23

1. Helping GP practice Patient Experience Groups to become re-established
2. Maternity – improving local services
3. Mental Health – supporting development of street and pastoral services.

Next steps

The pandemic has shone a stark light on the impact of existing inequalities when using health and care services, highlighting the importance of championing the voices of those who all too often go unheard.

Over the coming years, our goal is to help reduce these inequalities by making sure your voice is heard, and decision makers reduce the barriers you face, regardless of whether that’s because of where you live, income or race.

The way we work

Involving volunteer members in our governance and decision-making

Our Healthwatch board consists of eleven members (two Executive Directors, two Non-Executive Directors, two staff members and five volunteers) who provide direction, oversight and scrutiny of our activities. Through 2021/22 the board met eleven times and made decisions on matters such as our finances, resuming Enter & View visits, the HWE Quality Framework and internal policies and procedures.

Every quarter, all of our volunteer members meet in a formal Members' Meeting as the ultimate decision-making body. Additional meetings are occasionally held.

We ensure wider public involvement in deciding our work priorities. During the year, we joined the prize winning North East London Healthwatch Community Insights System and now access a much broader range of opinions.

Methods and systems used across the year's work to obtain people's views and experience.

We use a wide range of approaches to ensure that as many people as possible have the opportunity to provide us with insight about their experience of health and care services. During 2021/22 we have been available by phone, by email, provided a webform on our website, provided a feedback centre/rate and review system, attended virtual meetings of community groups and forums, provided our own virtual activities and engaged with the public..

We are committed to taking additional steps to ensure we obtain the views of people from diverse backgrounds who are often not heard by health and care decision makers. This year we have done this by, for example, developing links with a local voluntary organisation that represents people of Eastern European heritage.

We ensure that this annual report is made available to as many members of the public and partner organisations as possible. We publish it on our website, send it to our Friends' Network and circulate it by email to a wide range of stakeholders.

Responses to recommendations and requests

No provider failed to respond to requests for information or recommendations.

This year, due to the COVID-19 pandemic, we did not make use of our Enter and View powers. Consequently, no recommendations or other actions resulted from this area of activity. We are planning to reintroduce visits during 2022/23.

There were no issues or recommendations escalated by our Healthwatch to the Healthwatch England Committee and so no resulting special reviews or investigations.

Health and Wellbeing Board

Healthwatch Havering is represented on the Havering Health and Wellbeing Board Anne-Marie Dean, Chair .During 2021/22 our representative has effectively carried our this role by discussion, sharing of information and attending the Health and Wellbeing Board and Havering Borough Partnership.

2021-2022 Outcomes	
Project / Activity Area	Opportunities /Changes made to services
St George’s Wellbeing Centre project	Members of the development working group; Outline Business Case for the project submitted
Dementia	Widening our involvement with local groups
St John Ambulance	Working to support and widen the work of the Community First Responder team
North East London (NEL) Healthwatch Community Insights programme	Improving our ability to use digital information to provide evidence of concerns for residents and patients
Post Covid Syndrome (Long Covid) programme	Continuing to support the work of the research team
NEL Home Care Survey on Designated Enhanced Service (GP cover for care homes)	Working jointly with Healthwatch and the ICS – 1 st stage of planning completed
Recommencing the Enter and View of Care Homes	New model for E & V designed using NHS guidance and working with the Care Homes
Pharmacy Needs Assessment	Work completed on the assessment; to be presented at Health and Wellbeing Board and Overview & Scrutiny Committee
Working with individual GP practices	Keeping in Touch with GP practices that are currently receiving local GP support
Maternity	Working with BHRUT following the CQC report on services and combining this with a wider survey with Healthwatch across NEL
Working with Havering COMPACT	Working and developing our role within the COMPACT and identifying areas for development and support



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The Experience of Post-Covid-19

A report by Healthwatch Redbridge, Havering and Barking & Dagenham, in collaboration with the NELFT Long Covid Clinic at King George Hospital, and NEL CCG



“It’s been devastating - I’m a completely different person, and have physically aged significantly.

Waiting a year for any support was too long.”

Local Resident

‘This has been infuriating. I have had no idea what to do.’

Local Resident

“There’s absolutely no support, it’s like people with Long Covid are invisible.”

Local Resident

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Demographics

Appendix 1

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1. Introduction - a new and evolving syndrome

Long COVID is a new and evolving syndrome that can greatly impact the health and quality of life of many people. The precise causes of Long COVID are not yet known and the recovery time varies for each patient.

There is evidence from other Healthwatch reports (Healthwatch Barnet, 2022) and the Royal College of Nursing (June 2022) (RCN, 2022) that treatment varies across the country, with long waits for specialist provision and disagreement about referral structures common.

2. Background - definitions, and our mandate for the work

There is no currently agreed clinical definition. However the National Institute for Health and Care Excellence recommendation (NICE, 2021) is that ‘Ongoing symptomatic COVID-19’ be used when symptoms continue after 4 weeks of contracting COVID-19 and are not explained by an alternative diagnosis; and ‘Post-COVID-19 syndrome’ is used when symptoms continue beyond 12 weeks or newer symptoms develop. Both are commonly called Long COVID.

Long COVID presents itself through a wide range of clustered symptoms. The most recent data from the Office for National Statistics show that an estimated 2 million people self-reported experiencing Long COVID symptoms as of June 2022.

To tackle the debilitating impact of the condition, the Long COVID NHS Plan for 2021/22 outlined an investment of £100 million to support patients. There are now approximately 90 Post-COVID Specialist Clinics across England that support patients where previous medical care did not aid their recovery. These specialist clinics provide physical, cognitive and psychological treatment. The plan also outlines the establishment of paediatric hubs to support children and young people suffering from Long COVID.

What we wanted to achieve

We wanted to hear and present the perspectives of local service users at key stages along the NICE clinical pathway for post-Covid-19 syndrome (*guideline NG188 11.11.21*). In summary, the prevailing context suggests a need for patient insight because:

- The reported symptoms vary widely
- As a new clinical area there remain uncertainties in treatment pathways*
- Recent clinical guidelines indicate holistic assessment and shared decision-making
- Routes of access to support are not well evaluated

- There are potential demographic factors affecting uptake of support and equality of access

We wanted to support the recent call of Healthwatch England to gather data on patient experience. We wanted to mirror the clinical pathway in our research, from seeking GP support, or not, being referred to the Long Covid clinic at King George Hospital and subsequent experience.

We wanted to clearly articulate and present Redbridge, Barking and Dagenham and Havering community patient voice to shape and develop services in this new clinical area.

3. Methodology and Collaboration with NHS partners

We had three main strands of data collection:

- Tri-Borough survey with free text comments for additional qualitative analysis, promoted by the NEL CCG Comms team; NELFT Long Covid service comms team; NELFT patient experience and expert patients comms team; BHRUT Long Covid Clinic; and our local Healthwatch comms teams.
- 10 In-depth interviews with local service users who identify as experiencing Long Covid, accessed through the survey and by referral from the Clinic and other local contacts.
- 4 Interviews with local GP's and a further focus group with their service leaders, in conjunction with Dr Adam Ainley, Clinical Lead of the BHRUT Long Covid service

The survey was designed in collaboration with the NELFT Long Covid service and BHRUT Clinic, with a focus on inequalities and deprivation. Although this took slightly longer, the wide reach of the survey and the broad use of the data have proved beneficial to increasing knowledge and insight into local service user experience and also the direct shaping of the service. Changes were made in the light of interim findings.

Impact of interim findings - service change

Interim findings were presented when the survey had been open for one month to:

- Dr Ainley and the Long Covid Clinic
- NELFT Long Covid service
- BHR ICP Complex Care and Whole Systems Pathways Operational working group transformation Board meeting

At these meetings, the complexities of access to support and specialist provision highlighted in the findings below were identified. Many free text comments identified that service users were being told by GPs that they had to wait for one year with symptoms before referral. A potential confusion was identified, between a 12-week referral window and a 12-month structure. This led to primary care training webinars being designed and delivered by the Long Covid service. Additionally, the referral form from NHSE was simplified to make the referral structure easier for GPs. At the same time we were asked to develop a quality of life impact scale from the data for the syndrome. This was then used in requesting access to further funding for Long Covid in the year to come.

Over the course of the 8 week survey there was also an increase in diagnosis of Post-Covid-19 syndrome from 32% to 44% and a corresponding increase in visibility of the highly-rated Long Covid clinic by 6%. Ikenna Obianwa, Planned Care Programme Manager for North East London Clinical Commissioning Group, introduces this impact:

‘The partnership between Healthwatch and NELCCG has been helpful in generating understanding of local patient experience of Post-Covid-19 syndrome (Long COVID), with a high quality of life impact and complexities of access to our specialist provision. It has been good to see the high value given by patients to the Long COVID Clinic here at King George Hospital in the survey and interviews. We are working to increase the referrals to this clinic as a system in the light of the findings, and are pleased to see recent data suggesting this is now taking place.’

4th July 2022

5. Executive Summary of Findings

During March - June 2022, 169 people from North East London completed our survey on Post-Covid Syndrome. 10 service users gave in-depth interviews and 4 GPs gave interviews.

This is a summary of key findings - see section 6 for the analysis in full.

Key Findings

General

- A clear majority of respondents (87%) have tested positive for Covid-19, while under half (44%) have been diagnosed with Long Covid.
- On impact on daily living, most (93%) feel that life has become less enjoyable, with two thirds (76%) finding it more difficult to undertake hobbies.
- Half of all respondents (50%) say their ability to work has been affected.

Services

- Respondents are almost twice as likely to seek self-help, than consult with their GP.
- Just under a third of respondents (30%) have accessed a designated service for Long Covid.
- A majority feel that hospital and community based services have not been helpful (54%), while a similar number (54%) say that primary care services have not helped.
- Around a quarter of respondents (27%) have been referred to receive support.
- Almost a fifth (18%) have self-referred, or found support elsewhere.
- A third of respondents (35%) have heard of the Long Covid Clinic.
- Just under three quarters (70%) say their physical support needs are unmet, while 71% indicate that their mental health needs have not been met.

Health inequalities

Although we had a relatively small number of survey respondents who were from Bangladeshi, Pakistani, Black African, and Caribbean backgrounds (8%), it is worth noting that in every area of life, respondents from these communities identified a greater effect on their day to day lives. Particularly of note is in the areas of self-care and caring for others.

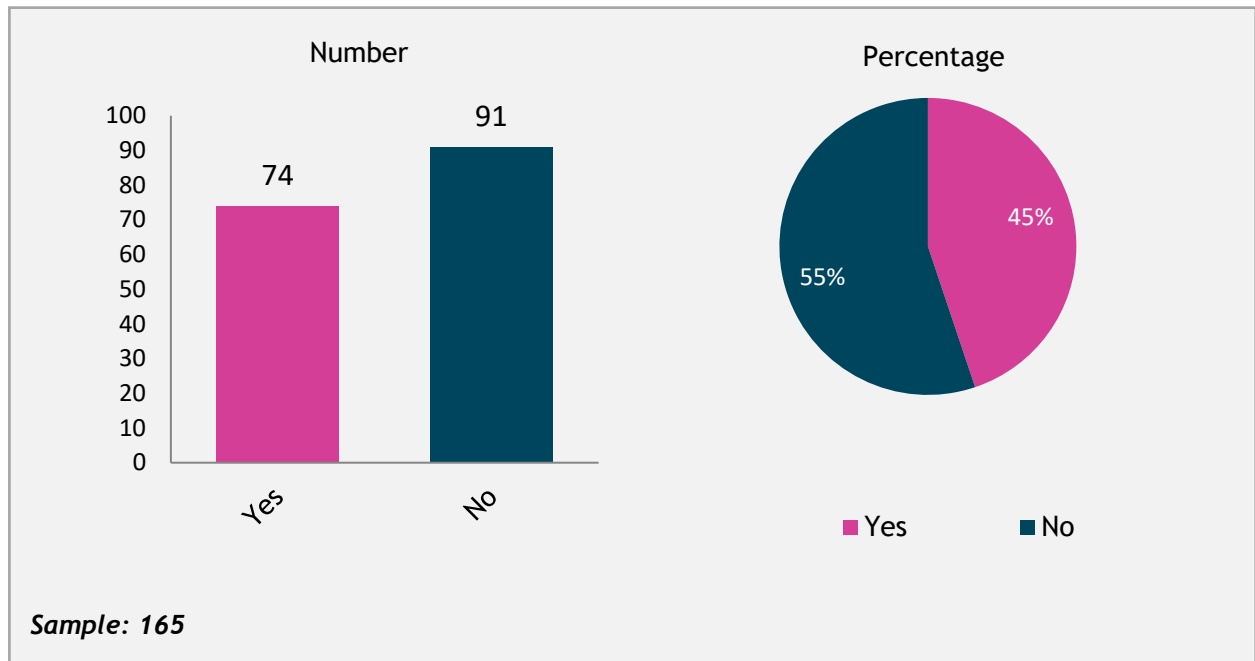
What are people saying?

- As the condition is relatively new, many doubt the effectiveness of interventions and some, citing ‘overstretched services’ are fearful of being a burden on the NHS.
- Levels of information on what support is available are said to be lacking.
- While some people feel their GP would be sympathetic, others fear that symptoms may be dismissed. The ability to obtain appointments is a key issue.
- Waiting lists for the Long Covid Clinic are reportedly around a year. It is commented that children, or those without a diagnosis, are not eligible.
- We hear that waiting lists for general support have been ‘too long’, and services offered have been generic, with ‘one-to-one’ options lacking.
- It is also suggested that packages, such as a six week mobility class are insufficient, and therefore ineffective.
- Those with caring responsibilities have found it difficult to support themselves and also their loved ones.

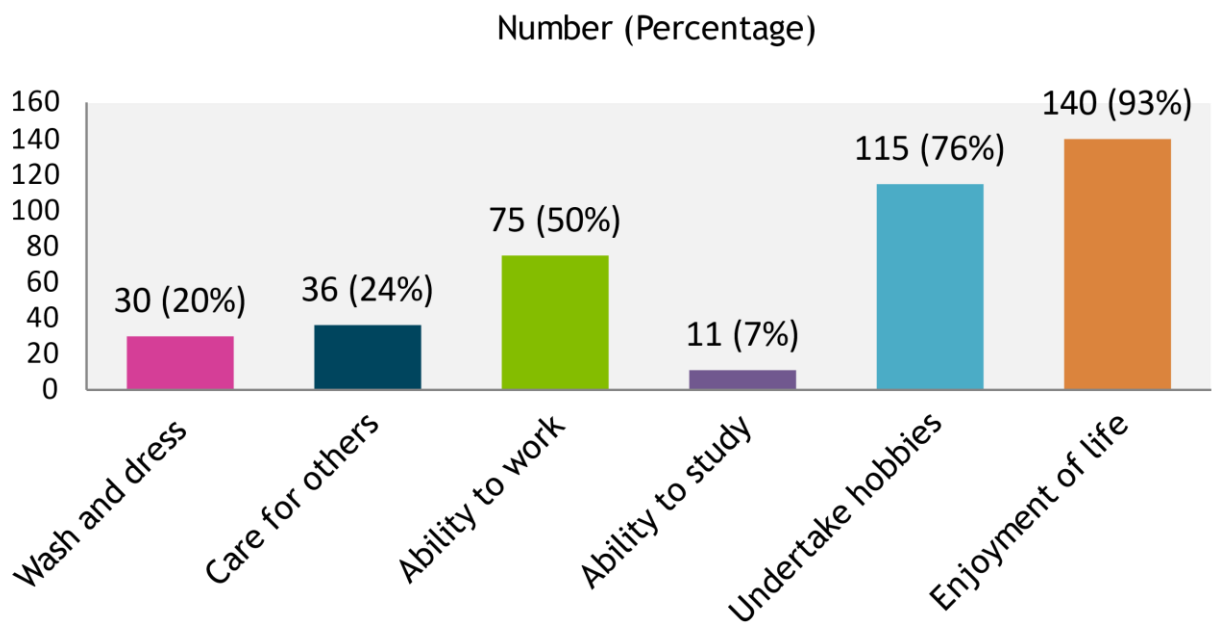
6. Analysis of survey feedback

During March - June 2022, 169 people from North East London completed our survey on Post-Covid Syndrome. 86% of people had been diagnosed with Covid-19. The key survey questions are illustrated below:

6.1 Have you been diagnosed with Post-Covid-19 syndrome (Long Covid)?

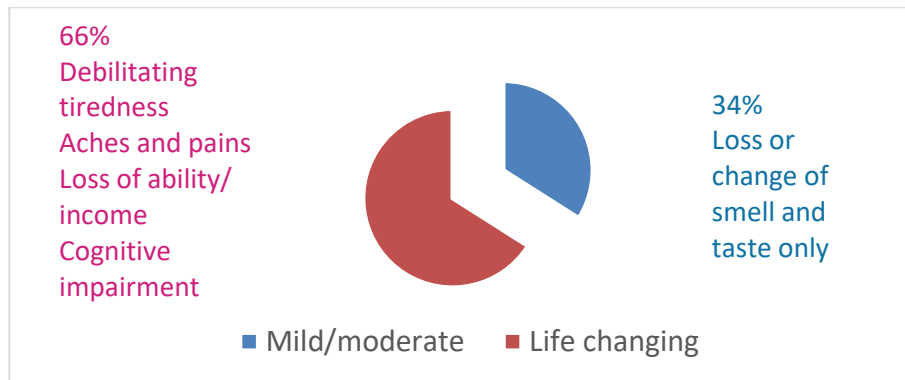


6.2 Has Post Covid syndrome (Long Covid) affected your day to day living in any of these areas?



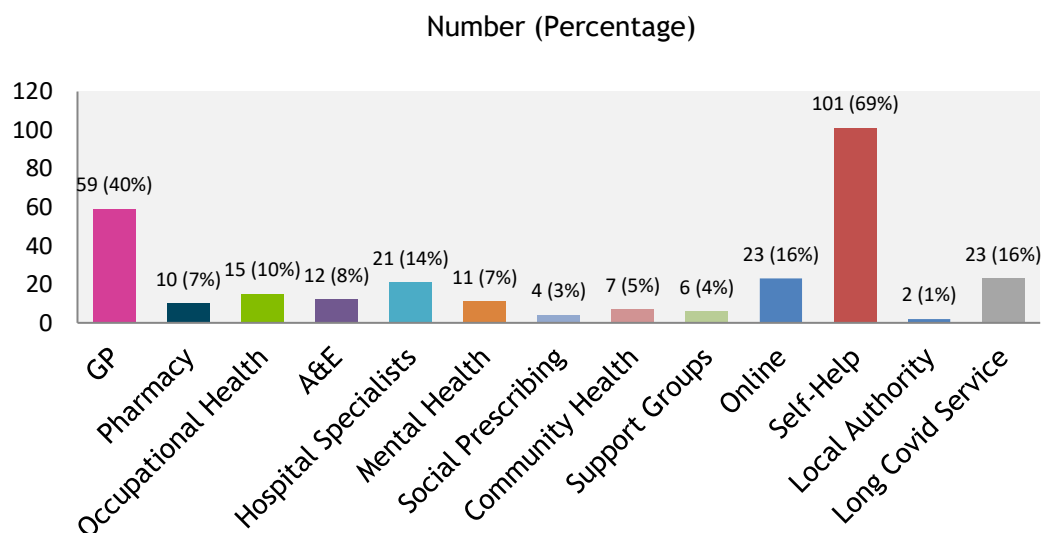
When looking at effects on daily living, a majority (93%) feel that life has become less enjoyable, with three quarters (76%) finding it more difficult to undertake hobbies. Half of all respondents (50%) say their ability to work has also been affected.

6.2.1 Quality of life scale, derived from qualitative free text comments



We looked at each comment about impact in the free text responses, using a qualitative scale of single issue symptoms as mild/moderate and multiple impact symptoms as life changing. We can see more of the high impact of Post-Covid-19, with 66% of all respondents identifying life-changing symptoms. This also linked to the high levels of anxiety found in the in-depth interviews.

6.3 Where have you found support for Post Covid Syndrome (Long Covid)?



Respondents are almost twice as likely to seek self-help, than consult with their GP.

As the condition is relatively new, many doubt the effectiveness of referrals or interventions and some, citing 'overstretched services' are fearful of being a burden on the NHS. Levels of information, on what support is available are said to be lacking.

An increasing number of respondents (16%) have accessed a designated service for Long Covid. The survey began with this figure at 10%.

Selected Comments

"No one seems to know how to help and I understand that it is because we are all still learning about Long Covid symptoms."

"My wife and I were told the medical community are still learning about the effects so nothing they could do."

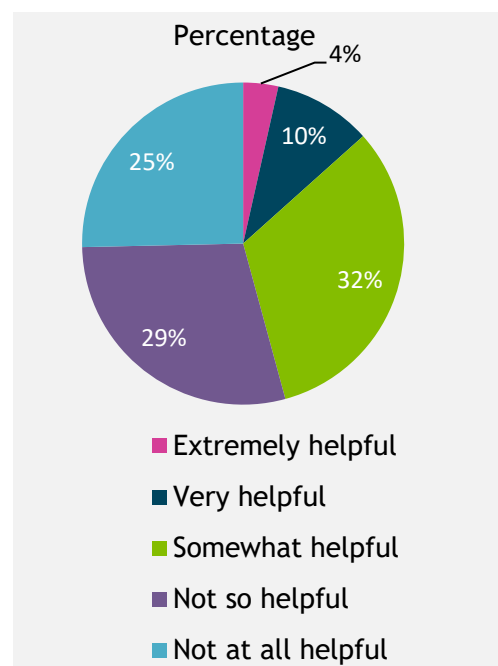
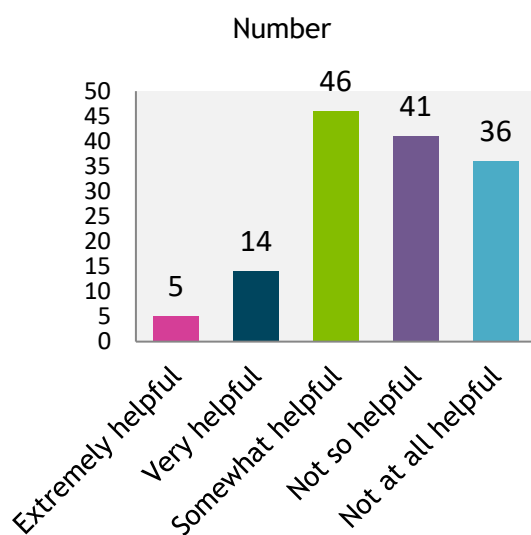
"Like most people I know - we just carried on without any seeking any NHS help."

"No additional help outside of family was asked for. With all the NHS departments being pushed to their limits my family stepped in to help."

"No one really offered support at all and just told you will eventually recover..."

"I did not know where to find help."

6.4 How helpful did you find the experience of using primary care, if applicable?



Just over half of respondents (54%) feel that primary care services have not been helpful.

Accessibility is a key issue, with congested telephone lines and long waits for appointments commonly reported.

While some people feel their GP would be sympathetic, others fear that symptoms may be dismissed. Support is commented to be lacking in cases, with patients told to 'get on with it'.

Selected Comments

"I haven't sought post Covid support as it is almost impossible to get through to my doctor's surgery. With the help of my family, I am getting by."

"Waiting weeks for a telephone appointment to speak with my GP."

"My doctors have been very helpful, they've sent me for chest X-rays, scans blood tests etc and have listened to me when I've tried to explain how I feel without making me feel like I was imagining things."

"My doctor and staff at the surgery have been marvelous without their help I don't think I would have got through this."

"I haven't looked for help at the doctors in case I'm not believed."

"My GP has been good. But I have generally been told to get on with it." "I have continuously tried to talk to my doctor but they won't even answer the phones."

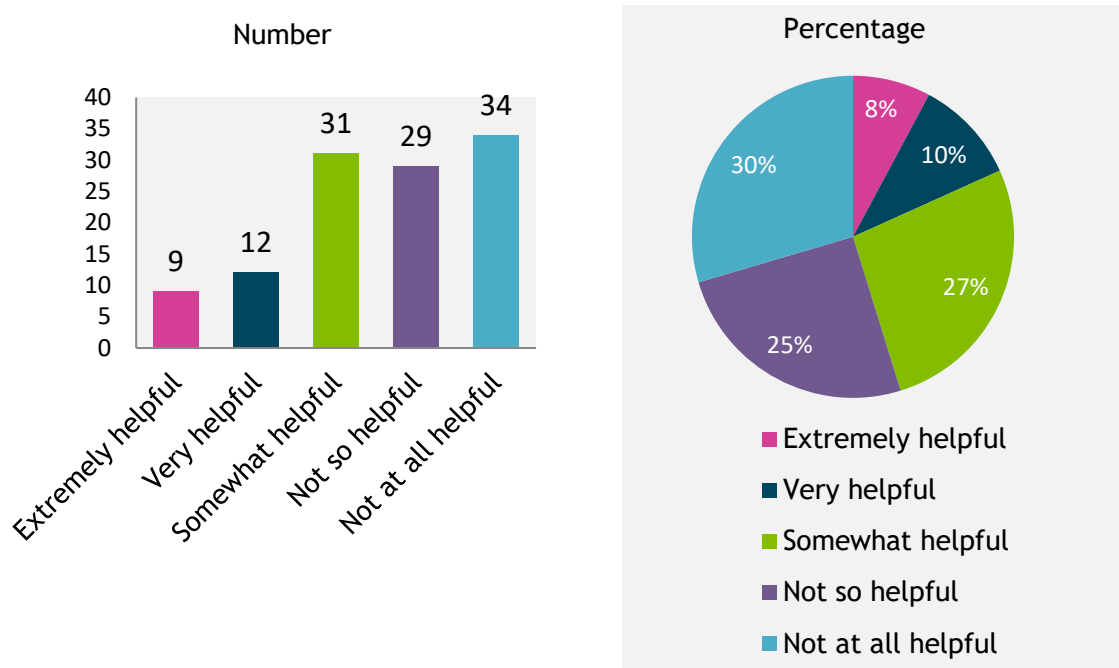
"Tried contacting the GP, a waste of time, cannot sit on the phone at 8am to get an appointment, tried 111 and just as bad. No hub appointments available."

"I was unable to see my GP for a long while - could not get an appointment, which delayed me being able to talk to someone about how Covid is impacting my health and get help."

"I feel as though all of the doctors that I spoke to weren't really interested in what I was telling them about how unwell I was or how I was feeling, there was little to no help given, in the end I stopped calling them."

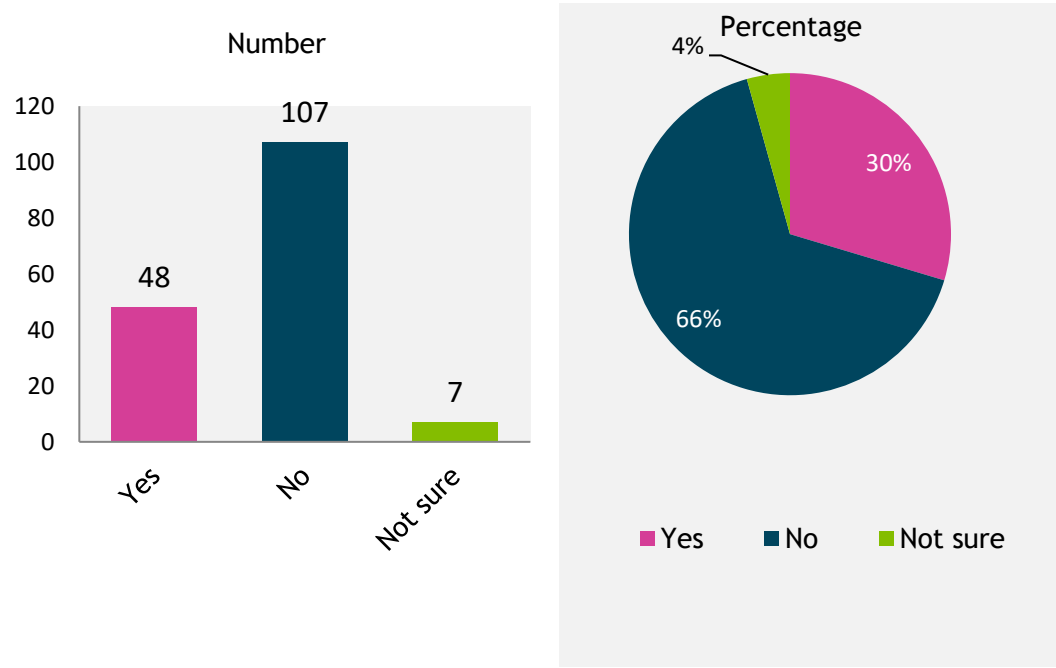
"I've mentioned to the GP about a lack of energy, fatigue, loss of taste and smell and headaches and he didn't act."

6.5 How helpful did you find the experience of using hospital or community care, if applicable?



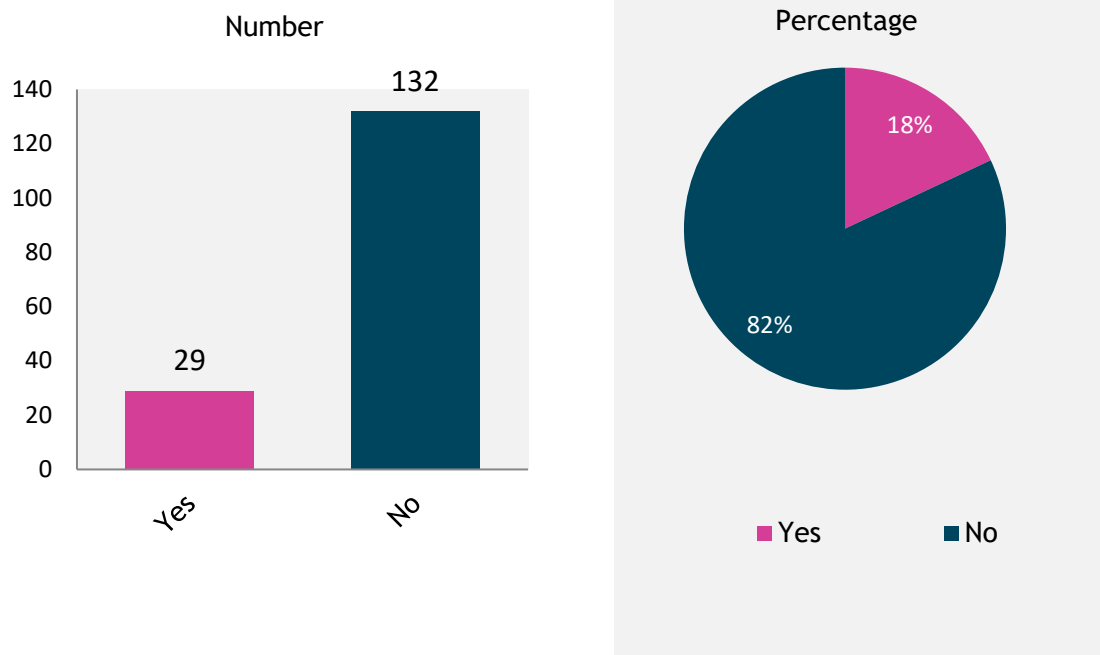
A majority of respondents (55%) feel that hospital or community based services have not been helpful.

6.6 Have you been referred to support for Post-Covid-19 Syndrome (Long Covid)?



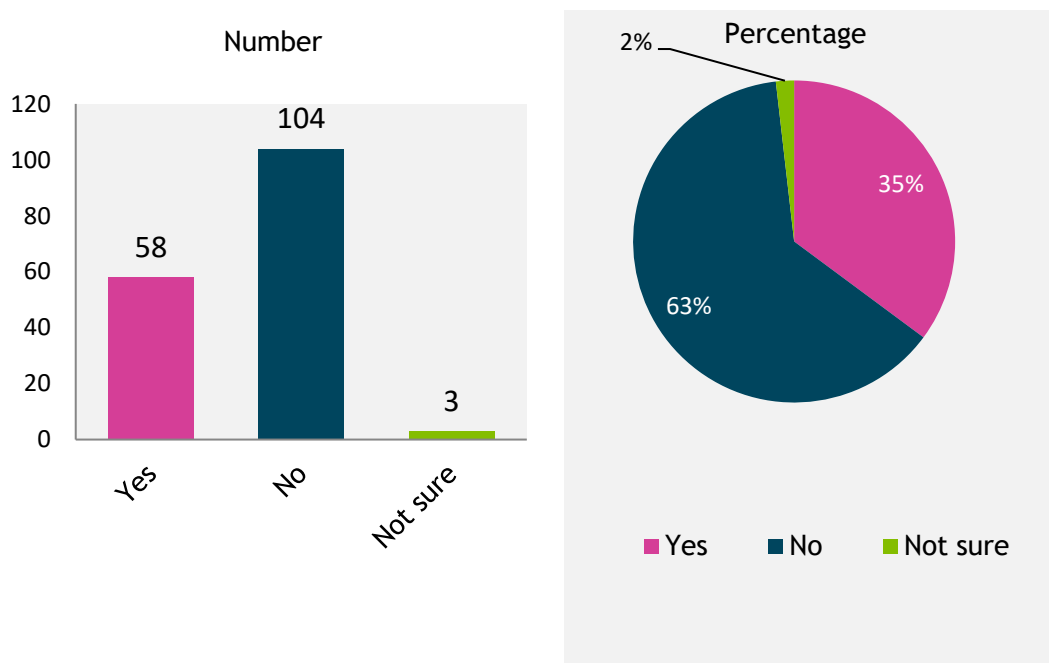
Just under a third of respondents (30%) have been referred to receive support.

6.7 Have you self-referred or found support elsewhere?



Around a fifth (18%) have self-referred, or found support elsewhere, with online resources, physiotherapy and community mental health services among the options mentioned. Some people have utilised their private medical insurance.

6.8 Have you heard of the Post-Covid-19 (Long Covid) Clinic provided by NELFT?



Highly rated specialist provision with long access

A third of respondents (35%) have heard of the Long Covid Clinic, operated by NELFT (North East London NHS Foundation Trust).

Those with experience of the service report waiting lists of around a year. Treatment and sessions are highly valued, along with a phone app which offers some support while on the waiting list.

In some cases, people have had to be proactive in chasing referrals, we also hear that children, and those without official diagnosis are not eligible. Awareness levels of the service are lacking in cases.

Selected Comments

"Took a year to get seen by someone from the Long Covid Clinic and still to this day haven't been seen by a doctor. That said, the phone app has provided me with support."

"Waited a long time for the Long Covid Clinic but was glad to have attended the sessions."

"Being referred to the Long Covid Clinic helped a lot."

"No support for the first year, until I got on the Long Covid Clinic, which I had to chase because no one was interested in helping."

"My experience has been terrible in seeking help and support. My parents have had to pay for private consultations as I was turned away from the Long Covid Clinic due to being under 18."

"I feel that those of us who contracted Covid-19 so early on that we were not able to be tested for it, have not had the support we could have had, as we have not been able to prove that we had the infection."

"I did not know that there was a Long Covid Clinic so have not been referred to it, and would like to be assessed by clinic."

"Still haven't had an appointment over a year later."

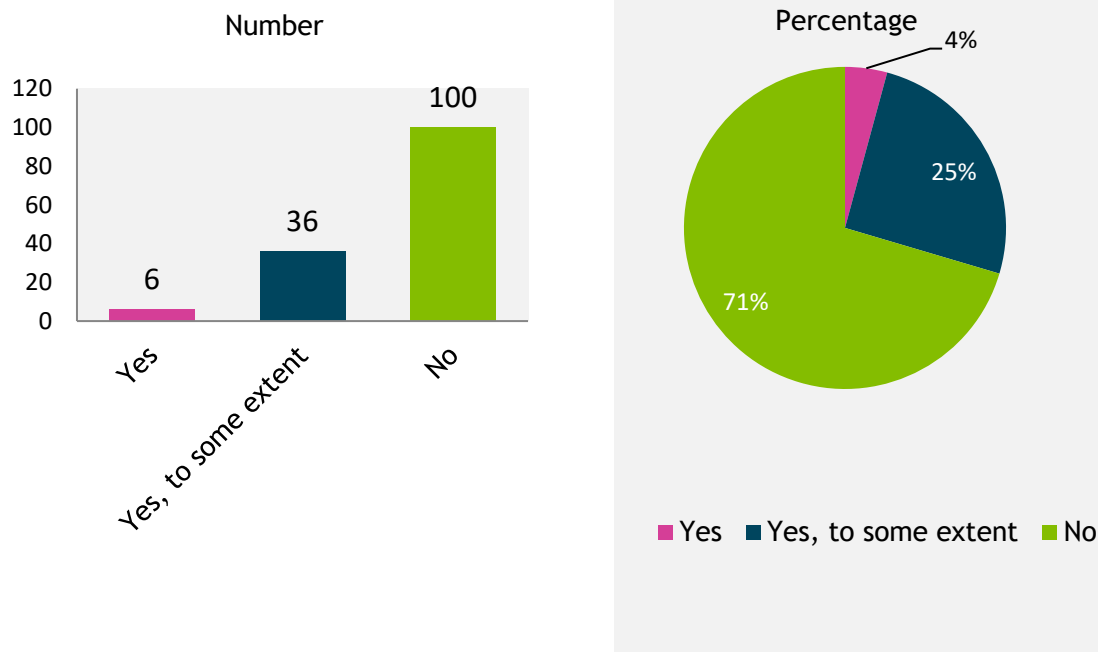
"Took a year to get into the Long Covid system."

"Referred to the Long Covid Clinic in December, appointment given for March then cancelled and offered for April."

"My son isn't able to get access."

"All professionals from the Long Covid team have been very supportive and informative."

6.9 In the support that you have received for Post Covid Syndrome, have your physical support needs been met?



Approximately three quarters of respondents (71%) say their physical support needs are unmet.

We hear that waiting lists have been ‘too long’, and support offered has been generic, with ‘one-to-one’ options lacking. It is also suggested that packages, such as a six week mobility class are insufficient, and therefore ineffective.

Those with caring responsibilities have found it difficult to support themselves and also their loved ones.

Selected Comments

“I don’t think I’ve had the help I’ve needed. The wait has also been too long.”

“Most online sessions are about fatigue and breathing issues which I completely understand. But personally this does not meet my need.”

“No one-to-one.”

“I was discharged even though still not walking properly.”

“It’s been difficult as well seeking support as I am supporting my Mum who is under palliative care for cancer that has now reached her heart. I don’t have enough time for me.”

“I have experienced a range of symptoms and medical staff at the hospital and my GP simply say it’s Long Covid and there is no solution.”

“No real support provided. Told to use inhalers and Google breathing exercises.”

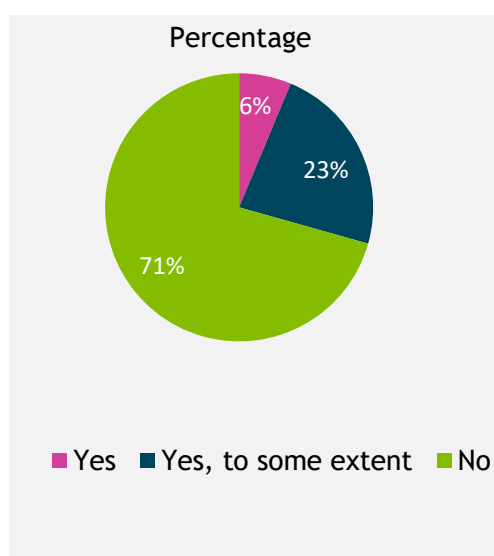
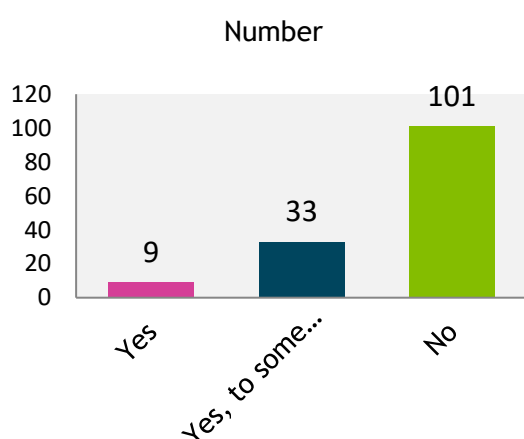
“There’s absolutely no support, it’s like people with Long Covid are invisible.”

“I was never diagnosed with Long Covid, even though I have long term affects after having Covid. So I wasn’t offered support.”

“I’ve had to research a lot of the stuff myself and then ask for tests.”

“At times it was difficult to access the support required but now I have it’s much better.”

6.10 In the support that you have received for Post Covid Syndrome, have your mental health support needs been met?



A similar number (71%) feel that their mental health needs have not been met.

Long waiting lists for mental health support are reported.

Selected Comments

“Dealing with the mental effects has been most difficult. I’ve struggled to find support in this respect - there are long waiting lists.”

6.11 In-depth interview analysis

10 interviews were conducted by telephone, 7 from the survey itself and 3 by word of mouth. The themes matched the free text data in the survey:

- *Self-doubt and loss of confidence*
- *Uncertainty as to the nature and designated symptoms of Post-Covid-19 syndrome*
- *Confusion and frustration in access*
- *Distress and severe disease impact*
- *Unsure if the issues are worthy of medical attention (eg loss of smell for two years)*

A strong theme in each interview was that service users were unsure of their own views of the syndrome, and of their health. They were often seeking reassurance and mentioned that the research call had been the first time they had been able to speak about their symptoms. This led to questions being posed to the researcher rather than questions answered. It was difficult to signpost people to services as they articulated the many barriers they had encountered already.

Recommendations made in the interviews:

- *To be recognized and acknowledged*
- *Information for peace of mind*
- *Time limits for when to seek advice regarding loss of function*

It is interesting to note that the Long Covid clinic provides reassurance and support in exactly these areas. None of the service users interviewed had been able to access the Long Covid clinic, but this is representative of the participants as a whole.

6.12 GP perspective

It was extremely difficult to find GP's who would be willing to share their experiences. However, the Long Covid service and Clinic put out requests to their GP intranet portals to facilitate this process. To date, we have been offered a meeting with Londonwide Local Medical Committees to meet GPs in the area. This is still to take place. 4 GPs were interviewed with the following themes:

- *Feeling overwhelmed*
- *Dealing with intense patient anger*
- *Subject to constant changes in referral structures for Post-Covid-19*
- *Perceptions of inappropriate requests for referral*
- *Feeling under intense scrutiny*

It was salutary to hear, although in a very small sample, that on occasions GPs were going home in tears, needing the support of colleagues and considering leaving the profession. Signposting was again difficult as GPs identified that they are often operating in isolated situations without time to access support for themselves.

7. Health Inequalities

There is clear evidence that COVID-19 does not affect all population groups equally. There has been a disproportionate effect on people from Bangladeshi, Pakistani, Black African and Caribbean backgrounds.

We analysed the responses provided by people from those communities and compared them to the responses given by people from White communities.

Although we had a relatively small number of survey respondents who were from Bangladeshi, Pakistani, Black African, and Caribbean backgrounds (8%), it is worth noting that in every area of life, respondents from these communities identified a greater effect on their day to day lives. Particularly of note is in the areas of self-care and caring for others.

8. Conclusions and Recommendations

The specialist provision for Post-Covid-19 syndrome is exceptionally well evaluated by service users. The multi-disciplinary nature of the team is especially appreciated, as the symptoms seem to be managed best by a multi-faceted holistic approach. However, there are acute access difficulties in being referred to the Clinic. These include conflicting information being given to service users across primary care; fear of being disbelieved and in fact having symptoms dismissed during consultations; and a long wait for referral. These difficulties are compounded by a high quality of life impact taking away enjoyment of life and reducing capacity to work by 50% in our survey respondents. There was a high level of distress in the in-depth interviews, affecting relationships in every sphere of life.

However, the interim findings of this report were shared with clinical colleagues both in primary care and in the Long Covid service and clinic. This led to immediate changes to the service, of a simplified referral system for GPs and a series of primary care webinars delivered to GP intranet portals within the survey window. An increase in the Post-Covid diagnosis rate was noted in the penultimate weeks of the survey, and also an increase in visibility of the Long Covid clinic itself. Whilst not able to directly correlate, the changes made did seem to impact the experience of service users.

Dr Adam Ainley, Consultant Respiratory Physician and Clinical Lead for the BHRUT Long Covid clinic, commented:

'The partnership between Healthwatch and members of the BHRUT/NELFT Long Covid service has been useful in exploring patient experience and in particular, access to support. We have been able to respond to challenges evident in patient interviews by increasing awareness of our specialist clinic at King George and working with stakeholders to simplify the referral process. It has been good to see an increased visibility of the clinic during the data collection window and increase in the number of patients getting support. I look forward to similar research across North East London as the project is rolled out.'

In summary, our findings are:

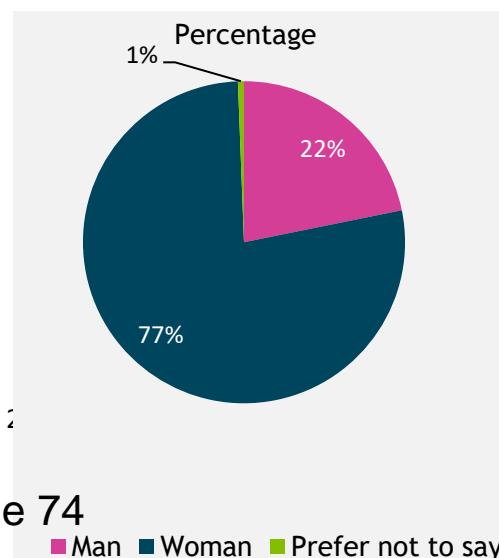
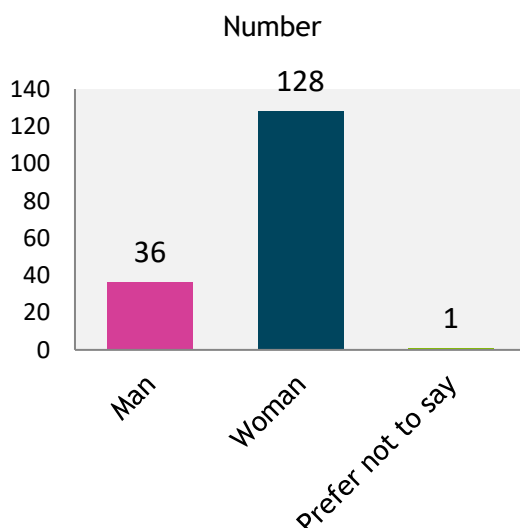
- *Although a 'niche' clinical area there is high disease impact*
- *Well-evaluated specialist clinical provision*
- *Extreme access difficulties are being experienced by service users, which is causing distress and exacerbating high levels of anxiety*

Recommendations:

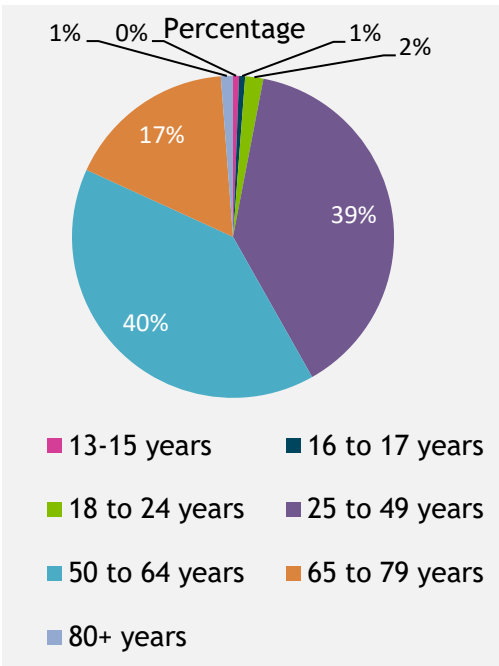
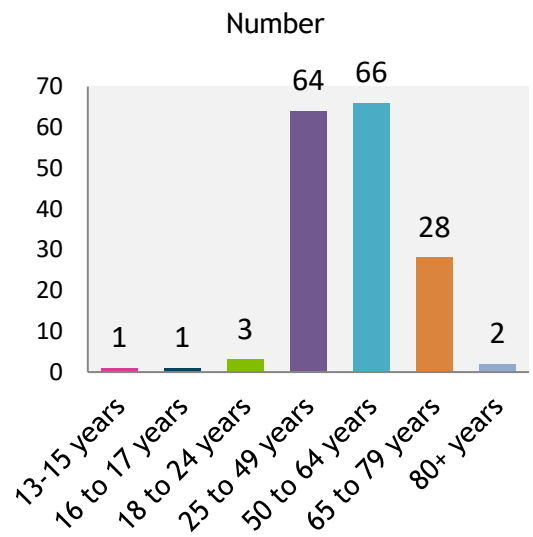
- *Referral structures continue to be simplified*
- *Community intelligence gathering across NEL to replicate the project - this is currently underway in City & Hackney and Newham*
- *Widen in-person GP access to assess impact*
- *Increase promotion of the Long Covid service in social media communications*

APPENDIX 1 DEMOGRAPHIC DATA

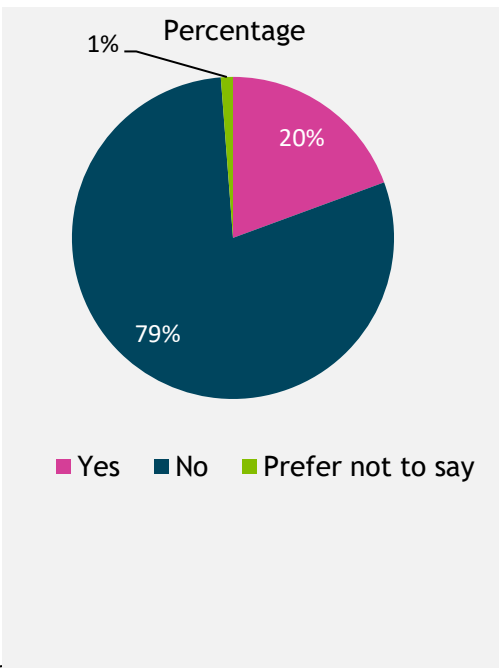
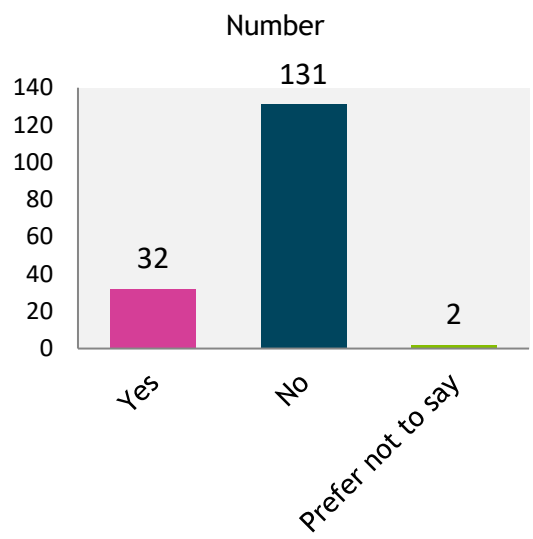
1. Gender



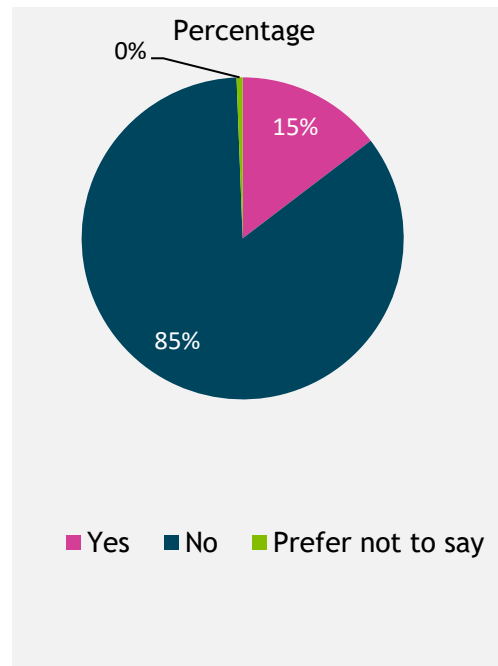
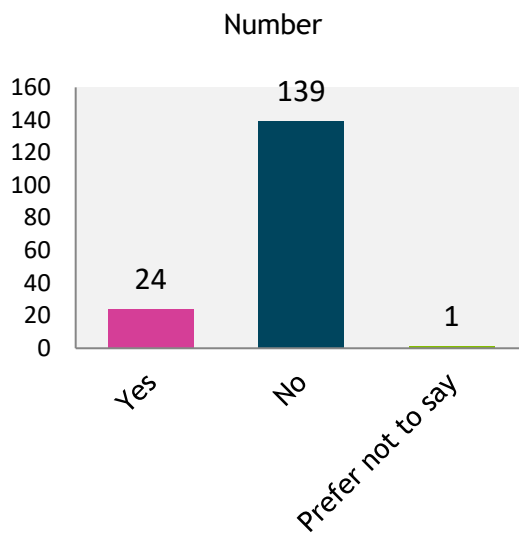
2. Age



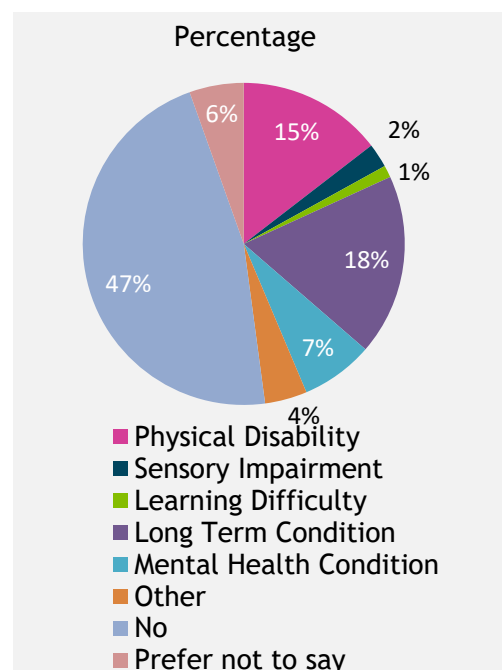
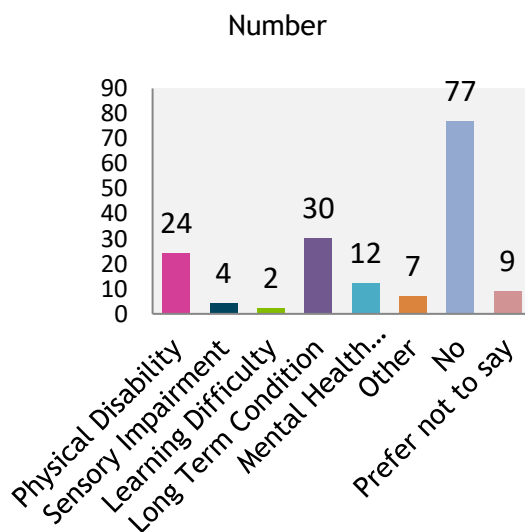
3. Are you a carer?



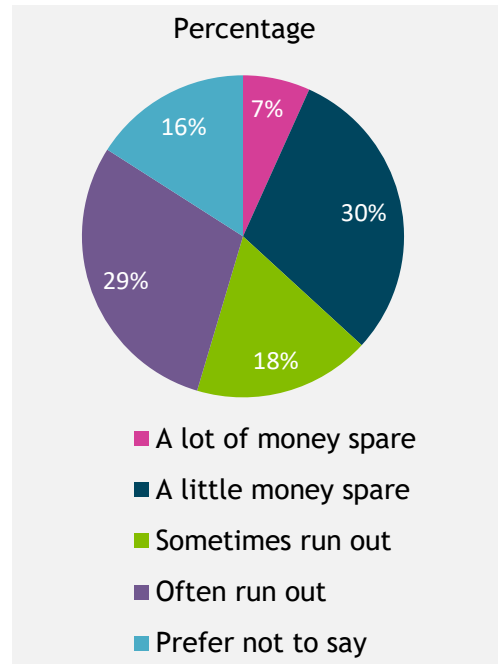
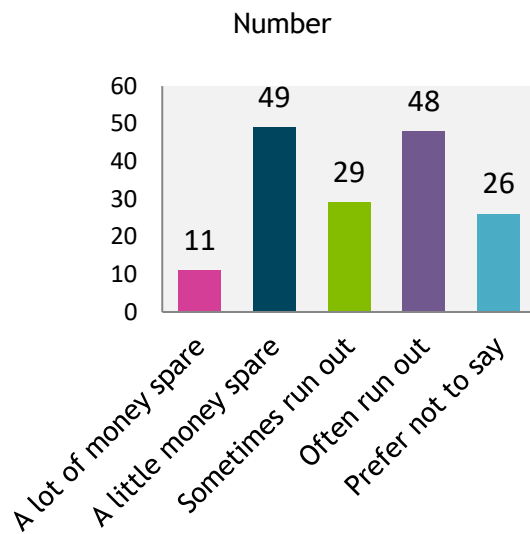
4. Are you a healthcare worker?



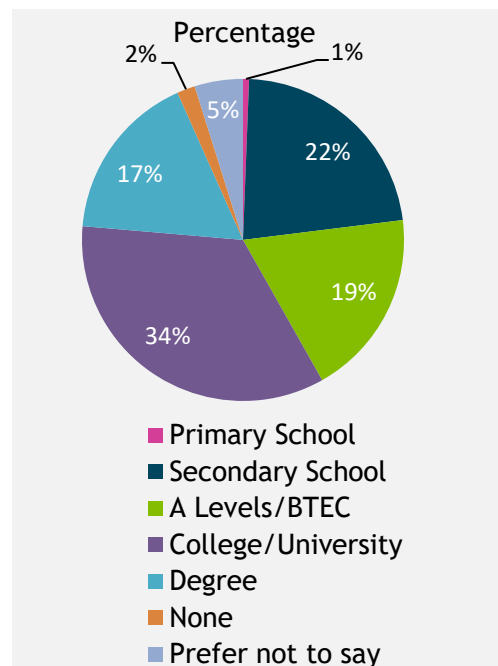
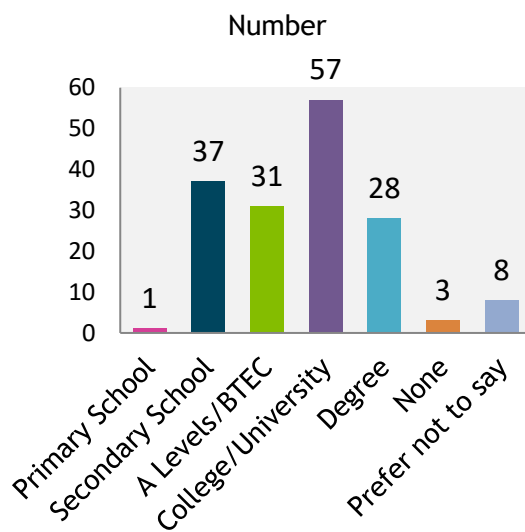
5. Do you have a disability or long term condition?



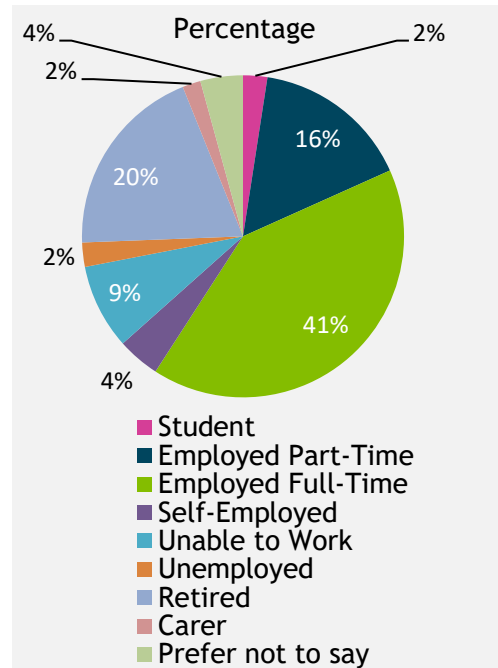
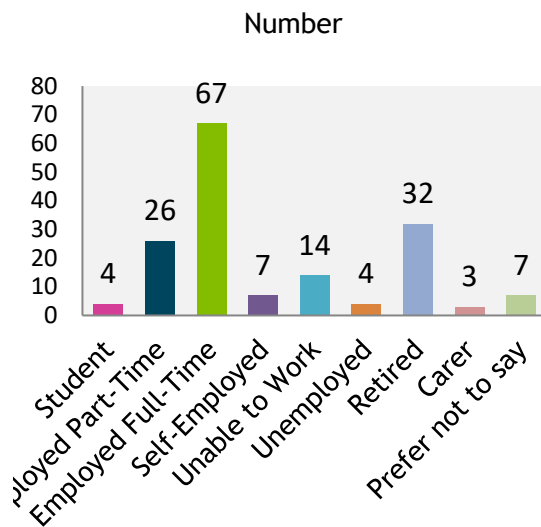
6. What is your money situation?



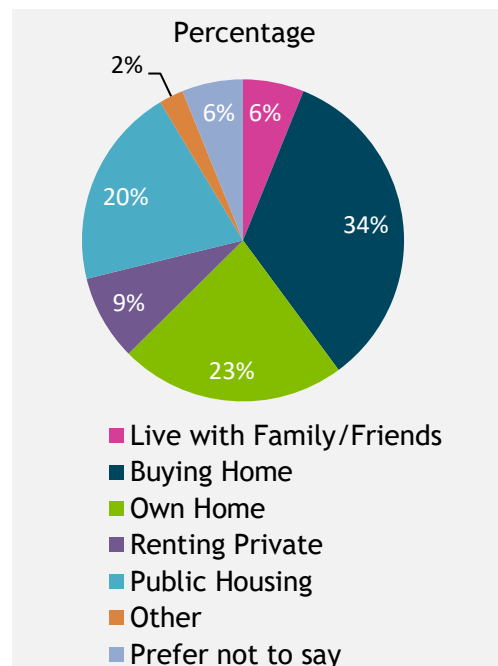
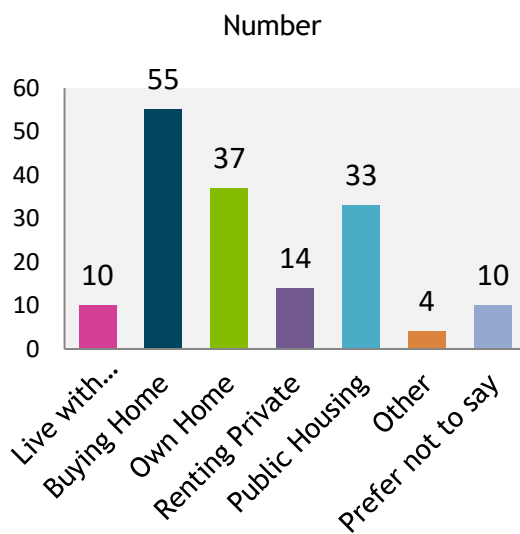
7. What is the highest level of education you have completed?



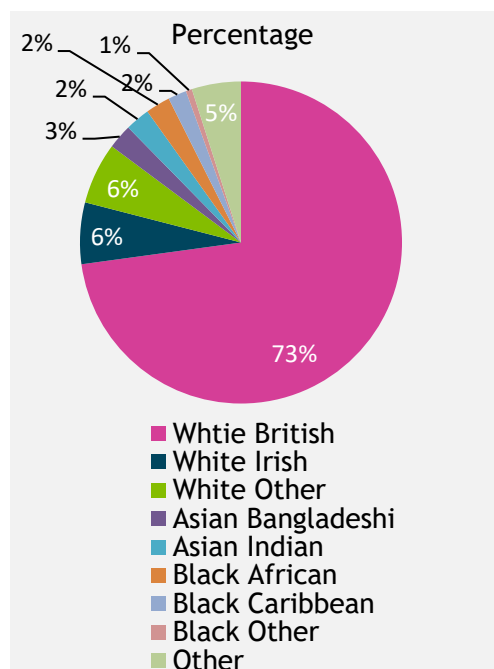
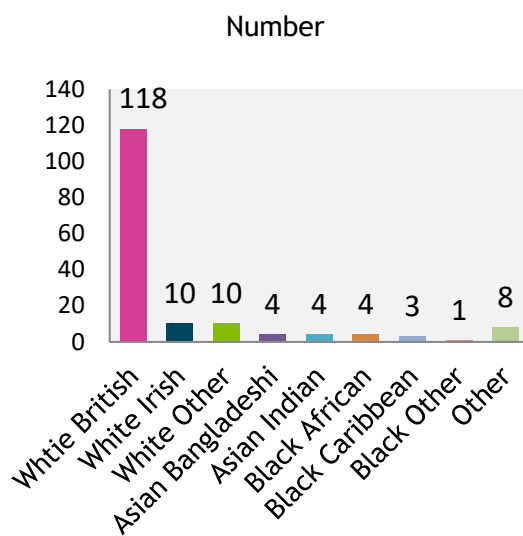
8. What is your employment status?



9. What type of housing do you live in/what is your housing tenure?



10. What is your ethnicity?



Glossary

NELFT

North East London NHS Foundation Trust

Distribution and comment

This report is available to the general public, and is shared with our statutory and community partners. Accessible formats are available.

If you have any comments on this report or wish to share your views and experiences, please contact us.

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