The Experiences of Integrated Care by Women in Ealing & Hounslow

A report by Healthwatch Ealing and Healthwatch Hounslow

healthwatch Hounslow

healthwatch Ealing

Table of Contents:

1. Executive Summary

Healthwatch Ealing and Healthwatch Hounslow were commissioned by NHS England to undertake a piece of research into the Integrated Care System. The exploration of how women with multiple long-term health conditions, including a cardiovascular condition were currently being supported by health and social care services in both boroughs. The aim of this research was to test and inform the qualitative methodology used to assess how well local health and care providers are delivering coordinated care and thereby supporting the identification of key areas of the integrated system that require further development.

A literature review was conducted alongside a comprehensive data analysis, a series of focus groups and semi-structured interviews, and a meta-analysis to capture the theoretical pathways of integrated care for women suffering from cardiovascular issues as well as how these pathways are being realised and experienced.

The data shows that women in Ealing and Hounslow with this complex health status were frequent users of a large range of different emergency and elective secondary care services. In conjunction with the views and experiences of women that shared similarities with this experience profile, the evidence suggests that holistic care pathways must be effectively structured with accessible prevention and management strategies in place, in order to improve the health and wellbeing of these women.

Although a lack of communication, poor service provider coordination and a lack of holistic care were regularly cited by individuals, Ealing residents were notably more satisfied with the level of care that they had received.

The analysis also uncovered health inequalities with high rates of emergency admissions coming from those living in the most deprived areas, significantly higher rates of Hypertension and Coronary Heart Disease in of women of a BAME ethnicity and disproportionately more women of a BAME ethnicity with 5 or more long-term health conditions including a heart condition.

Local policy around cardiac pathways and integrated pathways of care was limited and should therefore be built upon. However, the evidence from this research points toward initial inaccessibility to services and a lack of prevention and management support as significant contributory factors to the complexities of this cohorts' health and wellbeing and not necessarily the acute and chronic care services.

This paper outlines the visions and ambitions of the NW London region as well as each local borough pertaining to the improvement of care for this experience profile, alongside recommendations on how to both further develop the methodology of this research for future use focused on tracking whether the improvements in process or planned in these boroughs are having a positive impact on patient’s perceptions and experiences of their treatment, and how the level of integration and coordination of the health and social care systems in Ealing and Hounslow could further support women with multiple long-term health conditions including a heart condition.

2. Project Background

Healthwatch Ealing and Healthwatch Hounslow have, along with a number of other Healthwatchs across England, been asked by Healthwatch England and the NHS England Improvement Team to participate in a project aimed at developing and testing a qualitative methodology to assess how well local health and care providers are delivering joined up care to individuals. The approach adopted for this project is to identify particular exemplar ‘health and care experience profiles’ and investigate from a range of perspectives how well individuals with those characteristics are being supported by health and social care systems.

As part of this work, Healthwatch Ealing and Healthwatch Hounslow have been asked to supplement the national health and care experience profile they have been allocated with local characteristics representative of the population in their areas.

The experience profile allocated to Healthwatch Ealing and Healthwatch Hounslow is a woman with multiple health conditions, including recent experience of care for a cardiovascular condition(s). This experience profile has been identified because she:

- Demonstrates the complexity of living with multiple health conditions – and therefore service users who benefit significantly from well-integrated care and support.
- Provides the opportunity to explore both integration between the different health services involved and integration with other relevant services and organisations including any relevant community support, social prescribing and/or social care services.
- Provides the opportunity to explore women’s experiences of having a cardiovascular condition, which have been typically (and incorrectly) considered to be “men’s conditions”.[1]
- Reflects a key commitment of the NHS Long Term Plan – better care for major health conditions.[2]

Further details of this experience profile, together with descriptions of their potential local characteristics, their suggested care arrangements nationally, and what they can expect in Ealing and Hounslow, are set out in Annex A. By exploring how these individuals interact with services at local level, the respective local Healthwatch can provide advice to inform Healthwatch England as to how Integrated Care Pathways are realised in practice and how Healthwatch England might adapt and develop their methodology for studying integrated care.

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[1] British Heart Foundation, Women and heart attacks (accessed 17/11/2020)

[2] NHS England (2019) NHS Long Term Plan

Research was carried out from 15th December to 31st March. To deliver a comprehensive overview of the current level of care that these women were theoretically and practically receiving, the research project was broken down into three distinct workstreams:

- A review of local policy frameworks that outline how such women can expect to be supported by health and social care services in their borough;
- An analysis of historic and current data that could provide quantitative insight into the health of women that match this profile and map out the interactions that they have had with health services;
- A series of engagement activities with women who match this experience profile, for them to share their experiences and the realities of care that are not necessarily reflected in the related data or local policy frameworks.

Healthwatch Ealing and Healthwatch Hounslow have been allocated their particular health and care experience profile due, in part, to the historic health characteristics of each borough’s population.

The next section of the report provides an overview of the literature currently available about the prevalence of cardiovascular disease and other long-term conditions often associated with cardiovascular disease, to provide a picture of the challenge faced by health and social care providers in Ealing and Hounslow.

3. Health Background in Ealing and Hounslow

A recent paper published in the British Journal of General Practice[3] explains precisely why the issue that this health and care experience profile represents is of concern. The study aimed to describe overall health and social service use and care usage patterns by patients with Heart Failure (HF)[i]. The study undertook a cross-sectional analysis of health service utilization by prevalent HF cases from January 2015 to December 2018 using an administrative dataset covering primary and secondary care, and community, mental health and social care services in North West London. The study found that health service use was high in the present population of adults in North West London living with heart failure. But it also noted that the relatively low level of GP service use, which decreased over the study period, while the relatively frequent use of emergency services and their unscheduled care in these vulnerable patients was of significant concern and could suggest challenges in access to primary care service.

The more detailed data in the report pertinent to the Ealing and Hounslow experience profile indicated that for female patients nearly 45% fell into the two most deprived living condition categories (using the IMD scale), over 30% were Black or Asian, nearly two-thirds had at least one comorbidity (with over 25% having diabetes) and at least 50% were overweight or obese. And of particular concern for our local experience profile, the study noted that those with infrequent GP consultations were more likely to be of mixed ethnicity and living in areas of higher deprivation, possibly reflecting both poor health management and low engagement of patients in their own health. Finally, the data indicated that for the population in North West London, participation in cardiac rehabilitation in the community is low. While this data was based on the patients across the whole of the North West London health district, the data available for Ealing and Hounslow is consistent, and would indicate that the challenges identified in the study are applicable to these boroughs.

3.a. Ealing

In Ealing, the most common cause of death is cardiovascular disease, accounting for approximately 31% of all deaths.[4] The latest data from the Ealing Joint Strategic Needs Assessment (JSNA) Chapter on Cardiovascular Disease[5] indicates that 9.39% (24,063) adults were affected by CVD with prevalence expected to increase for males and females within the next 10 years. According to the British Heart Foundation (BHF), approximately 30,000 people are living with a heart and circulatory disease in Ealing, 11,000 of whom are living with CHD. Furthermore, 2,800 people have been diagnosed with heart failure, approximately 4,700 individuals in Ealing have survived a stroke, 5,300 have been diagnosed with atrial fibrillation and 57,000 people in Ealing have been diagnosed with high blood

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[3] Kim, D. et al (2020). [Health service use by patients with heart failure living in a community setting: a cross-sectional analysis in North West London](). *British Journal of General Practice*, e563-e572.

[4] North West London Collaboration of Clinical Commissioning Groups (V01, 2016). NW London Sustainability and Transformation Plan

[5] Ealing Council (2014). Ealing JSNA. Chapter 7: Strengthen the Role & Impact of Ill Health Prevention. Cardiovascular Disease

pressure.[6] [7] A comparative looks across London CCGs found that Ealing had the highest incidence of CVD-related elective hospital admissions (7/1000) and a higher CVD emergency admission rate (3.8/1000) than the England average (3.3/1000). More specifically, the BHF analysis showed that in Ealing, from 2016-18, an average of 253 women per year died from all heart and circulatory diseases.

Other data confirms the scale of the challenge faced in Ealing. The ratios of recorded against expected prevalence indicate that there are about 68% of CHD, 27% of hypertension and 56% of stroke cases that remain undiagnosed in Ealing. Early mortality (under 75 years) rates in Ealing from CHD were significantly higher than the England rate at 42.3 per 100,000 people.[8] Again, admissions rates were significantly higher in Ealing for CHD than the England average with 663.7/100,000 people (1,710 admissions) compared to 470/100,000. A similar picture emerges with other cardiovascular conditions.

One of the main risk factors for heart conditions, Diabetes, is also prevalent within the community in Ealing. Including the estimated number of undiagnosed individuals, approximately 10.4% of residents suffer from Diabetes; this is driven, at least in part, by the high levels of adult obesity in the borough – 57.6%. Whether diagnosed or not, individuals with Diabetes are at a higher risk of having a heart attack or stroke. In Ealing, people with Diabetes were 138.0% more likely than people without Diabetes to have a heart attack. This was higher than the national average of 86.9%. People living in Ealing with Diabetes were also 91.5% more likely to have a stroke.[9] This was also higher than the figure for England where there was a 58.5% greater risk. In Ealing, females typically suffer less from Type I and II Diabetes while, those from minority ethnic groups make up 73.6% of the total number of individuals with Type II Diabetes.

In addition to the heightened risk of heart-related issues caused by the prevalence of Diabetes in Ealing, the borough has a higher burden of lifestyle risk factors for circulatory disease including smoking, physical inactivity, higher levels of alcohol intake and unhealthy eating. This is reflected in the broader picture around other long-term health conditions – over 66,000 adults in Ealing are currently managing one or more long-term health condition. These individuals account for 50% of all GP appointments and 70% of all inpatient bed days in Ealing[10] and 75% of total healthcare resources in NW London.[11] Perhaps unsurprisingly, The King's Fund has predicted a further increase in the number of people managing multiple long-term health conditions and a concurrent increase in the cost of health and social care.[12]

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[6] British Heart Foundation (2020). Heart & Circulatory Disease Statistics

[7] British Heart Foundation (2021). Local Health Intelligence - London Borough of Ealing; also CCG, Local heart and circulatory disease statistics

[8] Public Health England (2020). CVD Profiles – Diabetes, NHS Ealing CCG

[9] Public Health England (2020). CVD Profiles – Diabetes, NHS Ealing CCG

[10] Ealing Health and Wellbeing Board (2016). Ealing Health and Wellbeing Strategy 2016-2021

[11] North West London Collaboration of Clinical Commissioning Groups (V01, 2016). NW London Sustainability and Transformation Plan

[12] The King's Fund (2012). Long-term conditions and multi-morbidity

A further layer to the health issues are the inequalities that persist throughout the borough. According to the latest data, Ealing is the third most deprived borough in West London, with just 37% of the households in Ealing not deprived in any dimension. This is 2% points lower than London, overall.[13] What's more, 28% of Ealing households suffer from multiple indices of deprivation, with 8 out of the 23 wards falling in the 10% most deprived wards in England. Further still, Ealing has an increasingly diverse population with a steady rise projected for the BAME population,[14] currently at 52%. As indicated by previous findings, CVD and other long-term health conditions are more prevalent in BAME communities. For example, there is an increased risk of CHD and stroke in South Asians, greater risk of hypertension and stroke in African-Caribbean individuals, and higher levels of Diabetes and lower levels of advice sought out for mental health issues and cancer screening throughout BAME communities. In general, long-term health conditions also show clear disparities, increasing in instances with deprivation and among people from black and minority ethnic groups (South Asian, African and African-Caribbean descent). This is apparent when we see that among Ealing wards, Dormers Wells, Southall Broadway, Southall, Northolt West End and Norwood Green had more than expected number of CVD-related deaths.

3.b. Hounslow

Although Hounslow (270,900) has a smaller population than Ealing (342,000), the prevalence of Heart-related illness and mortality is proportionately similar. According to the British Heart Foundation, approximately 20,000 people are living in Hounslow with heart and circulatory diseases, of which 7,200 are living with CHD.[15] Approximately 1,800 people have received a diagnosis of heart failure, 3,400 have survived a stroke, 3,300 have received an atrial fibrillation diagnosis and 37,000 people in Hounslow have been diagnosed with high blood pressure. The Hounslow Joint Health and Wellbeing Strategy estimated that in Hounslow 30% of CHD cases, 45% of hypertension cases and 16.6% of diabetes cases are undiagnosed.[16] Every month in Hounslow, 35 female deaths are attributed to heart and circulatory diseases.

In 2019/20, the CHD prevalence in Hounslow was 2.3%; this figure is lower than the national average of 3.1%.[17] However, Hounslow has a high rate of CHD hospital admissions (666.8 per 100,000 people/1,310 admissions) when compared with the national average (470 per 100,000 people). Additionally, heart failure hospital admissions were 219.9 per 100,000 people/385 admissions. In Hounslow, in the same year, the London Ambulance Service transported 1,125 patients to hospital with a serious heart attack. Furthermore, the early mortality (under 75 years) CHD rate in Hounslow was 46.7 per 100,000 people - also higher than the England rate (42.3 per 100,000 people).

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[13] Ealing JSNA 2017: Population Characteristics (2017)

[14] Ealing Health and Wellbeing Board (2016). Ealing Health and Wellbeing Strategy 2016-2021

[15] British Heart Foundation (2021). Hounslow heart and circulatory disease statistics

[16] Hounslow Council (2018). Hounslow Joint Health and Wellbeing Strategy, 2018 - 2022

[17] Public Health England (2020). CVD Profiles – Heart Disease, NHS Hounslow CCG

Much like Ealing, Diabetes is prevalent within Hounslow with 9.2% of the population estimated to have Type I or II Diabetes (2019/20).[18] Diabetic residents in Hounslow are 122.2% more likely to have a heart attack and 94.1% more likely to have a stroke (2014/15). These figures are higher than the national averages of 86.9% and 58.5%, respectively. In Hounslow, Type I and Type II Diabetes are more prevalent in males rather than females. However, Type II Diabetes is more prevalent in minority ethnic groups who account for 65.1% of the cases. Additionally, the Hounslow population has a high prevalence of contributory lifestyle risk factors for cardiovascular disease. In 2015, 14.1% of adults smoked, 11.5% were diagnosed with hypertension, 29.9% were estimated to be inactive, 51.5% were estimated to have inadequate diets and 62.7% were estimated to be overweight or obese.[19]

Unlike Ealing, Hounslow's relative deprivation has increased with 16 of its Lower Super Output Areas (LSOAs) now in the most deprived 20% in England.[20] The borough of Hounslow also has a diverse community, with 50% of the population having a BAME heritage.[21] Rates of cardiovascular disease, diabetes and strokes are higher among Black and South Asian groups[22]. Cardiovascular disease accounts for 24% of ethnic minority deaths in England and Wales (2019) and BAME individuals develop diabetes at a younger age than their white counterparts. This may be partly attributed to low levels of physical activity among BAME individuals, particularly women. Additionally, obesity levels are higher among black individuals. These are both predictors of long-term health conditions.

The current data indicates that in both Ealing and Hounslow a multitude of lifestyle, environmental and fixed factors are contributing to the prevalence of heart conditions and other associated long-term health conditions. It is therefore important to understand how a coordinated health and social care service can support at-risk individuals in managing and preventing such conditions.

4. Methodology

For the purpose of this report, Cardiovascular Disease is a term used to describe conditions affecting the heart or blood vessels. This is usually due to arterial blockages and, therefore, is also associated arterial damage to the brain, kidneys and eyes.

Diseases that fall under Cardiovascular Disease include: Arrhythmia, Coronary Heart Disease, Strokes or TIAs, Cardiomyopathy, Atrial fibrillation, Peripheral Arterial Disease and Aortic Diseases, Atherosclerosis, Congenital Heart Disease, Heart Attacks and Heart Failure

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[18] Public Health England (2020). CVD Profiles – Diabetes, NHS Hounslow CCG

[19] Hounslow Council (2016). London Borough of Hounslow, JSNA, Factsheet: Cardiovascular disease, 2016/17

[20] Hounslow Council (2015). Intelligence Briefing: Indices of Deprivation

[21] Hounslow Council (2018), Future Borough Strategy, 2018 - 2035 - Hounslow Together

[22] The King's Fund (2021). The health of people from ethnic minority groups in England

4.a. Local Policy Exploration

Healthwatch England provided each Healthwatch with preliminary guidance on how to conduct local policy analysis. The policy review that was conducted by Healthwatch England looked at how guidelines implemented at national level (NICE guidance etc.) set the broader context for any related local policies that were put in place at regional or borough level. In addition, Healthwatch England provided guidance on the specific areas of focus and documentation that could be explored and used as a starting point for a literature review at local level that were applicable to the health and care experience profile. This included:

- Local Joint Strategic Needs Assessment and accompanying Health and Wellbeing documentation;
- Regional Strategic Plans (North West London);
- PHE CCG reports on health issues in question (Cardiovascular Diseases and other related diseases such as Diabetes);
- Local NHS Trust Policies.

Subsequently, a systematic literature review of publicly available documentation was conducted to identify the local policy framework that provided members of the public and health professionals with a theoretical care pathway as to how women with multiple LTCs including a heart condition are supported including how the current system supports these individuals in managing their own healthcare needs. A list of the documents explored in the policy analysis can be found in the References section of the report.

As part of the literature review, Healthwatch Ealing and Healthwatch Hounslow utilised their network of key health partners to provide a comprehensive overview of local care pathway policy. A list of all stakeholders that Healthwatch engaged with throughout this project can be found in Annex B.

4.b. Quantitative Data Collection

Healthwatch Ealing and Hounslow worked with the NWL CCG Collaborative to analyse the available data on this experience profile. The WSIC database was used as the source of data and a raw data set produced [Annex C] that included data on:

- All women aged 16+ with CVD long term and at least one other long-term condition (LTC) within Hounslow and Ealing
- A breakdown of other LTCs / co morbidities
- A total number of LTCs / co morbidities
- An activity count for the last 3 years, including the below:
  - A&E visits
  - Hospital admission (under cardiology / similar specialties)
  - Hospital admissions (all other specialties)
  - Outpatient attendances (cardiology)
  - Outpatient attendances (other)

- Demographic information:
    - Ethnicity
    - IMD decile
    - Electoral ward (this will be included initially and reviewed)
    - First language (where populated)
    - Religion (this will be included initially and reviewed)
    - Age ranges

4.c. Qualitative Data Collection

Patient Engagement

Four different approaches were used as part of the patient outreach and engagement strategy for this project:

- Members of staff, committee members and volunteers at each Healthwatch were asked to reach out to other colleagues, friends and family members who may have shared characteristics with this experience profile or know of other people in their social networks that did;
- Each Healthwatch used their own communication channels to promote and encourage women to participate in either a focus group discussion or a 1:1 interview (see Annex D for promotional materials including promotional poster and project brief used for outreach);
- Each Healthwatch utilised their relationships with other community groups within the borough to promote the project and the interviews to their local networks;
- Statutory organisations were asked to promote the project and the interviews through their own networks.

Focus groups

In line with government guidelines, virtual focus groups via Zoom were organised and promoted through community group networks, statutory partnerships, and Healthwatch media channels. The aim of the groups was to bring together approximately 4-8 women who have digital access and that match the experience profile.

The focus groups were semi-structured containing six open-ended questions chosen by Healthwatch Ealing and Hounslow [Annex E], based on the methodology provided by Healthwatch England [Annex F]. This structure would allow for the facilitation of organic conversation between attendees while covering the broad topics of the current health conditions experience by each woman; how they have interacted with health and social care to date; prominent concerns regarding the care that they have received; what they believe would improve the care that they receive.

The focus groups followed YVHSC guidelines for safeguarding [Annex G] to ensure that if any feedback that related to abuse or neglect was disclosed, it would be dealt with in the appropriate manner. Patients were also provided with a GDPR compliance document [Annex H] and a consent form [Annex I] outlining how their feedback will be stored and used as well as informing participants that, should they agree for their experiences to be shared via this report, that their feedback would be anonymised. Both the GDPR compliance and consent policy were reiterated at the start of each focus group, including consent by all attendees to record the focus group for transcription purposes. Facilitators of these focus groups were trained in information and signposting and participants were informed that, should any of the conversation affect them, they are free to leave temporarily or permanently and that they can speak to a trained member of staff after the focus group should they need further support. Sensory and language impairments were considered when conducting these focus groups.

1:1 Telephone Interviews

During the process of conducting the patient engagement portion of this research, some women indicated that they did not feel comfortable speaking about their conditions in a group setting. It was therefore agreed that a 1:1 telephone interview would be conducted. These interviews followed the same guidelines, regulations and procedures as the focus groups outlined above. The necessary steps were taken to ensure that individual's health and wellbeing, privacy and any safeguarding issues were prioritised. Like the focus groups, patients were informed of the GDPR compliance regulations in place and asked if they would provide their verbal consent. The 1:1 telephone interviews followed the same semi-structured interview format but, were adapted to make sure that each question was directed at the individual rather than being phrased as a question to a group of individuals.Healthwatch members of staff that conducted these interviews were trained in information and signposting, and safguarding to ensure that any participants who were affected by the conversation could be supported and direct to the best possible care. This information was mentioned at the start of the interview and reiterated at the end.

Once the interviews were complete, each woman was informed once again of the GDPR compliance rules and told that the information that they had provided would be formalised in an interview write-up that would be sent over to them via email and was subject to their approval.

Stakeholder Engagement

In addition to the interviews conducted with women who matched the health and care experience profile, healthcare professionals were interviewed to provide a thorough understanding of how the health and social care system currently supports these individuals. Professionals were given a summary of the background and purpose of the project, before being asked a series of tailored questions, pertinent to the individual's role and perspective. The individuals who participated in these interviews can be found in the stakeholder list [Annex B] with their names in bold.

5. Analysis

5.a. Local Policy

Local policy on the support for those with heart conditions and specific long-term health conditions was more readily available than policies aimed at those whose heart condition was just one aspect of their health that was chronically affected. In instances where policies have not been made clear and the documentation outlines any ambitions on ambitions for how such pathways should look in the future, any inferences or generalisations were avoided. A full list of the literature reviewed for Local Policy in the context of National guidelines can be found in the References section of the report. A detailed outline of the policy and related care pathways that are available for individuals that share similarities with the experience profile are included in the Local Experience Profile document [Annex A].

5.b. Quantitative Analysis

Upon a preliminary review of the WSIC report produced by the NWL CCG Collaborative, it was agreed between Healthwatch and the Business Intelligence team at the CCG that further amendments to the output were required. These included:

- Data suppression was applied in cases of less than (<5) patients to avoid individual identification. For analysis purposes, this where this data suppression was applied, an average of 2.5 was used to provide an approximation of instances.
- Logic was amended to the report to include women aged 16 or over with any of the following conditions AND one or more other LTC (including the five below):
    - Atrial Fibrilliation
    - Coronary Heart Disease
    - Heart Failure
    - Hypertension
    - Stroke / TIA
- First language and Religion columns were removed from the dataset.
- Electoral ward was removed from the dataset.
- IMD decile was grouped into pairs e.g. 1-2, 3-4, etc.
- Patients aged between 16 and 45 were grouped into the age range 16-45, the existing groupings remained the same.
- The total number of LTCs was grouped into 2, 3, 4 and 5+.
- Some long-term condition columns included were grouped to avoid individual identification.

5.c. Qualitative Analysis

5.c.i. Focus Groups

Two focus groups were conducted during this research. However, as none of the participants in the first focus group had any heart conditions, only the second focus group provided information relevant to the current research. As a result, only the findings from the second focus group will be included in the Findings section, below. For this focus group, diligent notes were taken by three Healthwatch employees to ensure that all information provided by participants was accurately recorded. Formal write-ups of the focus group were aggregated and subsequently subject to thematic analysis. The findings of this analysis can be found in the next section of the report.

5.c.ii. 1:1 Telephone Interviews

In addition to the women that felt more comfortable talking about their conditions on a 1:1 basis, on several occasions it became clear that it was more beneficial for both parties to speak to a member of the family rather than directly to the woman. Reasons for this included a language barrier between the woman and the interviewer, a lack of understanding around their own care and on one occasion the woman being a resident in a care home who could not be contacted directly. In all these instances the daughter who answered the questions on behalf the patient were happy to do so and clarified that they were the ones orchestrating the care and had a clear understanding of the care that their mother had received to date.

Of the 19 women that participated in a 1:1 telephone interview, 4 women (2 of whom were the daughter of the woman in question) indicated that they required support for some of the issues that they had mentioned during the interview and were subsequently provided with the necessary information by the Healthwatch member of staff.

The conditions of each woman who participated in either the focus group or a 1:1 telephone interview and the demographic breakdown of the women who provided this information can be found in the Annex (Annex J).

5.c.iii. Healthwatch Ealing Meta-analysis

After the telephone interviews and focus groups were conducted, it became apparent that there were some significant differences in the experiences of Hounslow residents that provided their feedback, compared to Ealing residents. Subsequently, to supplement and further confirm the generalisability of the qualitative insight provided by these Ealing residents, Healthwatch Ealing carried out a meta-analysis of previous Healthwatch Ealing research reports that were published during the last three years. The aim of this analysis was to identify whether there were any participants that fit our experience profile who had expressed their opinions and shared their experiences of health and social care. Although these women were not directly asked about the integration of their care, it was rationalised that the information that they shared could provide further clarity to the experiences that had been shared, into the level of coordinated support that they receive from health and social care services in the borough of Ealing.

From the previous three years (2018-2020), Healthwatch Ealing identified three research projects that received feedback from participants who shared similarities with the experience profile, alongside a cohort of participants collected from Healthwatch Ealing's quarterly Patient Experience Reports from the same time period:

> **Quarterly Patient Experience Reports –** Feedback provided to the Patient Experience Team and included in our quarterly Patient Experience Reports since January 2018.
>
> **The Housebound Project** – Obtained feedback from those who are unable to leave their homes with or without assistance due to physical and psychological illnesses (Housebound) to understand how these people are being supported by health & social care services provided by the Local Authority (LA).

The Better Lives Survey - Obtained feedback from people who use social care services in Ealing to evaluate the benefits of these services and measure their impact in terms of bettering individual's lives.

The Falls Survey - Obtained user feedback on the Strength & Balance program provided by the NHS Falls Service and a variety of other related services, to evaluate the effect they had on preventing falls and the impact they had on user's confidence.

A thematic analysis of each research project was conducted, breaking down the female population sample into five categories and exploring the themes that came from each relevant categories' responses which pertained to the current Integration Index Project. The five categories were:

- Women who reported no long-term health conditions
- Women with a long-term health condition that is not classified as a heart condition
- Women with a long-term heart condition
- Women with multiple long term health conditions without a classified heart condition
- Women with multiple long term health conditions, including a classified heart condition

5.c.iv. Stakeholder Engagement

Like the patient engagement format, diligent notes were taken during discussions with stakeholders by the interviewer (Operations Manager of Healthwatch Ealing or Healthwatch Hounslow). A similar approval procedure was also undertaken - once a formal write-up of the discussion was completed it was sent over to the individual who was free to make any changes or add any information that they deemed appropriate [Annex K]. In total, 6 healthcare professionals were willing to have an open discussion around the question:

> *"From your perspective how are individuals with long term health conditions - specifically heart conditions if possible - currently supported by services in Ealing. Given that there are a number of related diseases and comorbidities for Heart conditions do you believe the system is set up for prevention and management in a wrap-around approach that the integrated service is aiming for?"*

6. Findings

The findings are reported in the following sections:

- Local Data from WSIC
- Local Policy
- Local Experiences

6.a. Local Data

Ealing:

Out of 153,053 female residents in Ealing aged 16 years or older, approximately 10.9% (n.16,653) suffer from two or more long-term health conditions, including a cardiovascular condition. Out of the total sample population, 57% (n.9,501) of these women were of a BAME ethnicity.

This population accounted for 47,040 A&E admissions over the last three years, averaging close to 1 A&E admission per year, per patient. The highest proportion of emergency admissions were from; women of White British ethnicity, with 18.5% (n.8,698); women of Indian ethnicity, with 18.5% (n.8,684); women of Pakistani ethnicity, with 6.7% (n.3,155); and women of Black Caribbean ethnicity, with 5.9% (n.2,772).

This cohort also accounted for 25,858 cardiac admissions (23,637 outpatient and 2,221 inpatient) and 291,805 hospital admissions for other services (24,2882 outpatient, 48,923 inpatient). On average, each Ealing patient therefore had just under 2 cardiac admissions during the last three years but, over 17 admissions for other hospital services - just under 6 admissions per year. There were no significant differences between ethnicities for the number of inpatient or outpatient admissions for cardiac services or other services.

Of the total sample population, 19% (n.3,130) were living in an area of the borough with an IMD Decile of 1 or 2, with 21% (1,991) of the BAME population within this cohort falling into this category. 64% of the population within these areas is therefore of a BAME ethnicity.

In Ealing, there was significantly more women of BAME ethnicities with 5 or more LTCs including a cardiovascular condition (n.1,673) compared to women of White British ethnicity (n.636)

Hounslow:

Out of 115,015 female residents in Hounslow aged 16 years or older, approximately 11.6% (n.13,398) suffer from two or more long-term health conditions, including a cardiovascular condition. Out of the total sample population, 51% (n.6,822) of the women were of a BAME ethnicity.

This population accounted for 39,765 A&E admissions over the last three years, averaging approximately 1 A&E admission per year, per patient. The highest proportion of emergency admissions were from; women of White British ethnicity, with 27% (n.10,866); women of Indian ethnicity, with 21% (n.8,455); and women of Pakistani ethnicity, with just over 6% (n.2,428)

This cohort also accounted for 22,279 cardiac admissions (20.563 outpatient and 1,716 inpatient) and 217,231 hospital admissions for other services (181,916 outpatient, 35,315 inpatient). On average, each patient in Hounslow was admitted under 2 times for their cardiac condition during the last three years but, over 16 times for other hospital services - just over 5 admissions per year. There were no significant differences between ethnicities for the number of inpatient or outpatient admissions for cardiac services or other services.

Of the total sample population, 8.5% (n.1138) were living in an area of the borough with an IMD Decile of 1 or 2, with just over 7% (n.448) of the BAME population within this cohort falling into this category.

In Hounslow, there was also more women of BAME ethnicities with 5 or more LTCs including a cardiovascular condition (n.1174) compared to women of White British ethnicity (n.685) but to a lesser extent than Ealing.

There were no significant differences between the boroughs in the proportion of Stroke, Hypertension, Heart Failure or CHD cases. However, within each borough, there was a significant difference in the number of CHD and Hypertension cases amongst different ethnicities. In Ealing, the number of CHD cases in women of BAME ethnicities (n.1,676) was, proportionally, significantly higher than the number of CHD cases in women of British White Ethnicity (n.430). In addition, the number of Hypertension cases displayed in women of BAME ethnicities was significantly higher (n.8975) compared with cases in White British women (n.2,620). The same proportional differentiation was found in Hounslow with women of BAME ethnicities recording a higher rate of CHD (n.1,233) compared to White British women (n.517) and, significantly more cases of Hypertension with 6,443 cases compared to 2,820, respectively.

Lastly, there was a significant difference between both boroughs regarding the number of A&E admissions from the lower deciles in each borough. In Hounslow, women with multiple long-term health conditions, including a cardiovascular condition living in areas with an IMD Decile score of 1 or 2 (n.1138) accounted for 11,583 A&E admissions over the last three years and those that were living in areas with an IMD Decile of 3 or 4 (n.11,869) accounted for 37,159. In Ealing, those living in an IMD Decile area of 1 or 2 (n.3130) accounted for 9,311 A&E admissions during the last three years while those living in an area that scored 3 or 4 on the IMD Decile scale (n.11,209) accounted for 29,454 A&E admissions during the last three years.

6.b. Local Policy

1. Due to the aims and key delivery areas in the London Primary Care Framework[23] and the NW London Sustainability and Transformation Plan[24] and the similar demographic characteristics, Ealing and Hounslow share many similarities in local level policy.

2. Both Ealing and Hounslow's primary prevention strategy involves early detection of CVD and other LTCs through NHS Health Checks and use of the Patient Activation Measures (PAM) to help patients control their own care with auxiliary prevention methods coming from Diabetes Education Programmes and weight management advice from healthcare professionals.

3. The boroughs differ in their care available for those who require support from Intermediate Care after suffering from a significant cardiovascular event. Ealing has a specialised Community Cardiac Service that supports patients through rehabilitation and onto chronic care while Hounslow provides this care through the network of Hospitals that specialise in Cardiac Care.

4. As part of the rehabilitation programmes for these individuals, Ealing offers a Care Planning Coordination service that should involve multidisciplinary teams to orchestrate an individual's care. The West London NHS Trust and the Hounslow and Richmond Community Healthcare NHS Trust provide a range of integrated services that support people in their recovery and management of CVD and other LTCs through timely hospital discharge and prevention of future hospital admissions, with the West London Trust offering psychological support to residents in both boroughs.

5. As a result of funding cuts, additional community organisation led support has diminished in recent years with Primary Care opting for referrals to more sustainable National Health campaigns for advice on healthy lifestyle choices.

6. Each borough has a clear strategic aim for improving the prevention, diagnosis and support of CVD and incidences of multimorbidity. Local cardiac pathways will continue to develop, the West London Trust is rapidly restructuring its care pathways to include an embedded psychological support service for those suffering from LTCs and the NWL region is aiming to improve the efficiency of care for those who have suffered a stroke.

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[23] London Primary Care Transformation Board and Primary Care Transformation Clinical Board (2015). Transforming Primary Care in London: A Strategic Commissioning Framework

[24] North West London Collaboration of Clinical Commissioning Groups (V01, 2016). NW London Sustainability and Transformation Plan

7. Most notably, the move to a single NWL CCG and the establishment of local Integrated Care Partnerships establishes the pooling of resources that is arguably required to evolve local care pathways for these patients into the holistic and person-centered vision.

6.b. Local Experiences

6.b.i. Local Patient Experience - Thematic Analysis

The pre-specified Healthwatch England themes that were considered can be found in Annex F. There was also a process of line-by-line coding resulting in other themes emerging from the data.

Borough of Hounslow

(1) Poor communication and coordination between professionals

Communication and coordination between professionals. The system shares information through patients rather than between services

Poor communication and coordination between healthcare professionals was cited by the majority of participants, with patient 2 noting the way in which this has "hindered and delayed" her care. Examples of a complete lack of coordination between services, and professionals contradicting each other's care plans were cited by three participants. After cancellation of an eye appointment by Ashford Hospital, the Hospital instructed patient 2 to continue with their medication, whilst the GP surgery amended their prescription due to non-attendance. It was then up to the patient to mediate between services to obtain their prescription. Patient 11 described a similar experience, with Royal Brompton Hospital prescribing medication that her GP nurses later told her to discontinue as the surgery had been uninformed. Patient 9 was very distressed when told by one professional that her blood oxygen level was okay, whilst another contradicted this. The GP referral process was also cited as a barrier to adequate care by patients 2, 3 and 5. For example, the Imperial College Healthcare NHS Trust had written to patient 5's GP surgery twice regarding a referral, with no response.

Patient 12 fittingly summarised this theme, describing patients (and carers) as middle-men of their own healthcare. The experience of these women demonstrate that the implications of this theme include delays to necessary care and a disproportionate level of proactivity required from patients to receive the care they need.

(2) Lack of holistic care pathways

Care pathways often do not consider other needs and drivers of negative experiences

Another main theme was the lack of holistic care pathways. Patient 5, who has type II diabetes, high blood pressure, high cholesterol and asthma, said she is only able to discuss one condition at a time with her GP. Patient 2 expressed unhappiness at both the continual reminders that only two conditions can be discussed per GP appointment, and at the 10-minute time limit. She also stated that when she raises certain issues, their GP says it has nothing to do with them. Patient 3 noted a similar sentiment regarding professionals at West Middlesex University Hospital (WMUH). Patient 1 was led to support services such as the Integrated Neurological Services (INS), and a myotonic dystrophy support group, following a recommendation from a friend with Parkinson's and their neurologist (i.e., rather than by healthcare services in the borough). Patient 12 said that she wishes there was a relevant support group, but nothing had been recommended for her.

There was some evidence that care pathways do not always consider broader needs, such as transport and education. Patient 4 was upset that she was unable to have her heart operation at her preferred hospital because it was too far. She also experienced hospital letters as difficult to understand, and said she had to Google various words to understand them. Patient 7 experienced a two-year delay in receiving a disability badge from Hounslow Council, even though fully endorsed by her doctor. Creating more holistic care may lead to patients feeling more supported by the system. At present, patients appear frustrated at the siloed nature of care pathways.

(3) Lack of continuity of care

Patients must repeat their story unnecessarily to different healthcare professionals

Another major theme was a lack of continuity in the healthcare system. Although patient 1 felt they had received "good" treatment from University College London Hospital (UCHL) and that their services were well integrated, other experiences were not so positive. Patient 2 stated that they have to "constantly repeat" their story to professionals in different services, a frustration also expressed by patient 3 and 11. Patient 3 gave an example of a family member having to repeat everything following lack of records of a previous call made to 111 regarding the patient. Patient 1 also expressed dissatisfaction at a lack of continuity in their physiotherapy care at WMUH, where they were treated by three different physiotherapists. Potential outcomes include inefficiency and therefore unnecessary delays, as well as a lack of feeling acknowledged and important as an individual; patient 2 described being with her GP surgery for 20 years and yet feeling that her own GP surgery didn't know who she was.

(4) Distress from interactions with professionals

Lack of respect from professionals and depersonalisation

Although only referenced by a subset of participants, this theme was striking and therefore warranted inclusion. Patient 1 encountered a "very rude" consultant at Charing Cross Hospital, who told the patient to "shut up" when explaining her condition, as well as a physiotherapist telling her that they would have been referred to a consultant if they were "a 35-year-old footballer playing football three times a week". Patient 2 said that "no one acknowledges you as a human being" and that there is a "lack of respect and assistance" in GP surgeries, particularly from receptionists. Patient 9 said she had previously had bad experiences with healthcare professionals, to the extent that she feared her ailing health because she did not want those professionals being responsible for decisions about her care. She also echoed patient 2's sentiment, that patients are not treated as human beings within the borough's healthcare system. From this theme, it can be inferred that some patients feel a lack of support from services and perhaps even disengagement. This does not, however, represent the experiences of all patients interviewed, with, for example, patient 4 saying that her GP was "very good" in her communications with her.

(5) Over-involvement in own care

Patients having to manage their own care due to inadequate support from services

The HW England general theme of 'lack of involvement' i.e., patients and families not being involved in care and decision making, did not emerge. Rather, it was over-involvement in their own care, and reliance on self and family (due to lack of support from services) that was a more salient theme in this sample. Several participants explicitly stated that they have to manage their own care, with patient 1 noting a lack of understanding by services in the borough of their rare condition and patient 3 saying they wished for more involvement from their GP (i.e., checking in on them). Patient 12 stated that their doctor relies on them to decide "it's been three months, I need my blood test", when more proactive organisation by GP services would be preferable. Patient 11 stated that she does receive such communications from her GP surgery, highlighting an inconsistency in service provisions. Patient 6 also described being proactively contacted by services. Therefore, with a couple of exceptions, many participants' experiences appear to be one of lacking support from their borough's services.

(6) Lack of support for carers

Inadequate support from services transferring disproportionate burden of care to carers

Patient 12 - who has diabetes herself - is a full-time carer for her husband, who has had a stroke, two heart attacks and has COPD. She feels that she has had no support in this role, noting that she is even responsible for his physiotherapy - which causes significant friction in their relationship as she must pester him to do his exercises. She is also responsible for keeping track of his medical records and relaying information relating to his care between different departments. The story of patient 6 provides a salient example of this theme. Following a stroke, it took a year for the patient to receive a needs assessment (and this was only because a family friend within the care service was able to flag the issue). In the interim, the patient's daughters have had to provide the entire breadth of support whilst attending college and university, respectively. The detriment to one of the daughter's education has been significant and resulted in more stress for the patient and the entire family. Importantly, this theme captures the broader relational and social consequences of lack of adequate health and social care.

(7) Inadequate communication between services and patients

Patients not given adequate information or ability to contact services when necessary

Patient 5 complained that it had been a "nightmare" for them to get through to anyone on the phone at Chelsea and Westminster Hospital to book an appointment, to the extent that they had to go to the hospital in person to complete their booking. Patient 6 was provided with a telephone number for a social care provider, but the number was disconnected, and they were told by the hospital and GP that they were unable to help. The latter also illustrates theme 1, a lack of coordination between services. The fact that patients and carers are having to chase up services for adequate care again shows lack of support and the burden being transferred from system to patient. In terms of more positive experiences, patient 5 did praise the 'Patient Knows Best' system where they are able to see their appointments and scan results and noted that Chelsea and Westminster Hospital were 'good' at updating the system to keep the patient informed. In addition, Patient 2 had been provided with large print letters from the hospital to accommodate her eye condition.

Borough of Ealing

(1) Communications between professionals and patients

Predominantly positive experiences of proactive and communicative professionals

Every participant in the Ealing group cited their experiences of communications with professionals. The majority spoke positively: patients 3, 4, 7, 8 and 10 all noted that their GP surgeries were very good at communicating with them, such as proactively scheduling regular check-ups and sending leaflet and email information. Positive comments were also made about their interactions with GPs, nurses, and administrative assistants at GP surgeries; patient 7 said they had even been great during the pandemic, with the GP nurses phoning to check on her, once a fortnight. Patient 8 said the GP and other staff were very supportive and treated her like a human being, not just another case. Good communication from professionals at the hospitals was also mentioned, with, for example, patient 8 noting that her cardiologist phones every six months to check on her wellbeing. Patient 1 said she was impressed with the extensive hospital follow-ups and clear information from clinical consultants.

Patients 9 and 11 had negative experiences, with the latter never receiving an expected call from a cardiologist at Ealing Hospital despite being told (only once she chased) that she would be contacted. Patient 9 complained about having to call her GP two to three times to get an appointment, with nothing yet confirmed. Patient 1 did note one experience of poor communication whereby she was not informed that her appointment had been moved from one hospital to another. However, as above, her experiences overall were very positive.

(2) Communication and coordination between professionals

Mostly effective communication and coordination between professionals and efficient record-keeping

Communication and coordination between professionals again emerged as a main theme. In contrast to the Hounslow participants, the majority of the Ealing group (nine out of twelve) made positive comments. Patient 5 stated that she is happy with services as they are, and no further integration of care is needed. Others referred specifically to effective communications between doctors/surgeons and sisters on the ward (patient 2), between GP and pharmacy (patient 7), between a care home team and GP (patient 2), and between hospital and GP (patients 10 and 12). Patient 8 described overall coordination in care as ‘excellent’. Patients 3, 4, and 6 spoke of the efficient GP record-keeping and the way in which their notes are kept updated in relevant systems. Patient 10 noted that the hospitals are also efficient at sending letters to GPs.

There were a few negative comments regarding the lack of coordination between services. Patient 1 described a lack of coordination between pharmacy and hospital, which she found frustrating when trying to obtain her medication; patient 10 booked a blood test with her GP, only to be told by the nurse (who had not been informed by the GP) that she didn’t require a blood test. Patient 11 made a broad remark regarding the lack of coordination between primary and secondary care, but no detail was given.

(3) Holistic care pathways

Mixed experiences of care pathways as holistic

A few participants cited experiences indicative of holistic care pathways in the borough. Patient 3 said there was a good holistic approach and that “they deal with all my health conditions”. Patient 8’s GP not only referred her to a diabetes programme and coordinated her physiotherapy care, but even arranged her transportation for hospital appointments. Patient 4 described her care services as fantastic and noted integration and support from council services who regularly check her alarm system and provide financial support.

On the other hand, two of the participants described poor experiences. Patient 9 felt that they were ‘over a barrel’ with their care, because although unhappy with their GP - who they describe as “really bad”, they don’t feel able to change because it would be difficult to find another who speaks their first language of Punjabi. Patient 1 criticised the volume and content of hospital letters and said she found the NHS jargon overwhelming. These examples demonstrate that care pathways may not always consider other needs and drivers of negative experiences, such as language.

(4) Involvement of patients and family

Mixed experiences of patient involvement in own care

Several participants discussed their levels of involvement with their care. Patients 1, 4, 5 and 10 all felt sufficiently included in their care planning and decision-making, whilst patient 11 stated that she did not feel involved in her own care, in relation to the support she needed from Ealing Hospital. Patient 9 was highly critical of her GP and felt her or her family’s opinion about her care was never taken into consideration.

(5) Inadequate physiotherapy services

Lack of patient access to quality physiotherapy services

Finally, a minor theme that emerged was an inadequacy of physiotherapy services, which was referenced by four of the participants. Patient 2 is in a care home, and although given exercises by her physiotherapist felt a lack of support in executing them. Nobody at the care home helps her and the only time she receives support is when her family visit (and this has also been restricted due to the pandemic). Patient 3 was previously happy with physiotherapy services, but since lockdown has noted a lack of care and lack of communication between physiotherapist and GP. Patient 8 also had their physiotherapy stopped because of the pandemic. Patient 9 (and her daughter) felt that the physiotherapy received was substandard with sessions regularly cancelled and when they did happen, they were too short. This was after the patient’s stroke three years ago and, therefore, could not be attributed to the impact of the pandemic.

6.b.ii. Healthwatch Ealing Meta-analysis

Quarterly Patient Experience Reports *(2018-2020)*

From the cohort of women who identified themselves as having multiple long-term health conditions, including a heart condition (n.24), several key themes were extrapolated from their service feedback which pertained to the integration of care.

Communication – Women from this cohort consistently identified a lack of communication from health and social care services as an issue. This included social care services, with women stating that their ‘social worker did not provide any contact details’ and that there is ‘no communication... about the social care services.’. Unannounced social care worker visits were regularly referenced by these women, further highlighting the shortfalls of provider-to-patient communication and inclusion. In relation to GP services women indicated that communication between all staff and patients is ‘very poor’ and that staff ‘never communicate well regarding the rescheduling of appointments.’.

Patient Involvement – For both social care and health care services, a lack of involvement in one's own care plan was consistently identified within these patient’s feedback. One woman stated that ‘the social worker takes decisions for my care plan. They never involved me or my family...’ while another highlighted more patient involvement as the ‘one thing’ that could improve social care services. Once again, this issue was also identified in primary care services with one woman indicating that they have been subject to ‘biased decision making with no justifiable solutions to meet the needs of a patient’ and another woman stating that even though she had told her GP surgery that she felt uncomfortable with a male doctor, her request for a female doctor was not met.

Continuity in Care – Feedback from this group of women regularly highlighted a lack of continuity in doctors and social workers as the cause of the sub-standard healthcare that they believed they had received. One woman even mentioned that she thought some social workers were good at their job, however, the next visit would be a different one. The same situation can be seen in primary care with a ‘no continuity in care’ that means that, in some cases, ‘medical records are not reviewed properly and can make prescribing more difficult.’ This point was reinforced by another woman who mentioned that upon trying to order a repeat prescription the nurse indicated that ‘it goes to a different company and it all gets muddled up.’. While most of the time this lack of continuity leads to having to relay their own medical history one woman stated that this had resulted in a more serious incident of her GP ‘losing some of my documentation... and took a long time to rectify.’.

Referrals and Follow ups – Another indication of a lack of coordination and integration can be seen in this theme. While some women suggested that the referral procedure took a ‘long period’ others state that ‘there were no referrals or follow ups to help’. This woman was still concerned about her health condition and therefore ‘had to contact another hospital to see a specialist' without the support of the healthcare system. Further still although longer referral periods do often occur, one woman indicated that she had to 'wait 6 months as they had no record of my appointment. They do not update me on my condition.'.

One woman was positive about the referral process, stating that her appointment with the cardiologist was organised very promptly by her GP after which they were 'able to diagnose me and tell me I have a hole in my heart.'. However, one woman commented that the next stage of this care pathway, the Community Cardiac Service was not delivered to the best standard: 'I attend the heart clinic which I find a very poor service. I had no name on my letter on who I was going to see.'

Falls Survey: *Review of Falls Prevention Services (March 2018- March 2019)*

Of the women who completed all the relevant responses (n.424), 19% (n.79) had multiple long term health conditions without a heart condition and 4% (n.18) had multiple long term health conditions, including a heart condition.

Thematic Analysis:

Several key themes were identified in the feedback given for Falls services by women with multiple long term health conditions, including a heart condition. A lack of access to services due to proximity was highlighted on a few occasions with one woman indicating it was difficult to get to exercise classes via 'transport due to my heart condition' and another stating that the classes were 'too far away' and that she wished classes were 'organised in Ealing as well' indicating that patients had to travel out of borough for classes. In addition, women in this category indicated that there was a lack of information about classes First, these service users generally experienced unsatisfactory levels of communication. Second, participants highlighted a lack of information of such rehabilitation services with one woman stating that she had '...no information about where to approach to regain my confidence and strength after my heart surgery'. Lastly, a common theme identified in the responses from this group of women was a lack of coordination and integration of services with one woman stating that there is a lack of follow up and she was unaware of the next steps she needed to take to recover from a stroke and another stating that she thought 'services should all link up after they (patients) are discharged from hospital...'.

Better Lives Survey: *Reviewing experiences of Social care reviews and reassessments (April 2019 – August 2019)*

Of the women who completed all the relevant responses (n.53), 45% (n.24) of women had multiple long term health conditions without a heart condition and 8% (n.4) of women had multiple long term health conditions, including a heart condition.

Thematic Analysis:

In the Better Lives Survey, the themes that were identified in the responses from women with multiple long term health conditions, including a heart condition were like that of the Falls Survey. Women regularly referenced a lack of communication with women receiving 'no updates' on activities in the community and one woman stating that '...they did not inform me about anything.' Additionally, a lack of support for individuals in some instances seemed to have led to a lack of involvement in patient's care as one woman stated that she 'did not feel that I wasn't involved in the planning for my support since I couldn't understand properly. And I was asking for extra help, but she said that it's not possible.'

Housebound Project: *Research on Quality & Delivery of Health & Social Care Services of Housebound Individuals (October 2019 – March 2020)*

Of the 50 women in the sample population, 36 women indicated that they had some sort of long-term health condition. Of these, 31% (n.11) of women had multiple long term health conditions without a heart condition and 11% (n.4) of women had multiple long term health conditions, including a heart condition.

Thematic Analysis:

Women that identified as having multiple long term health conditions including a heart condition highlighted a lack of support from health and social care services with several individuals stating that they had not received the appropriate assisted living equipment and a lack of holistic coordination in care with one woman stating that the 'district nurse communicates to the GP about my health condition, but they are not communicating with us.'

6.b.iv. Local Stakeholder Engagement

A total of 6 healthcare professionals from across the boroughs of Ealing and Hounslow provided their opinions and shared their experiences of how the Health and Social Care services within each borough supports its residents who fit the experience profile.

Dr. Fragoyannis highlighted the integration of IT systems within Ealing and subsequently NW London as one of the leading reasons for a robust and coordinated cardiovascular service in the borough. The use of SystemOne across NWL CCGs is both universally accessible and amendable allowing patient's data to be reviewed and updated by any healthcare professional. This centralised database enables individual healthcare and referral pathway monitoring, providing an integrated and tailored level of care. SystemOne is supported by the Whole System Integrated Care (WSIC) database that enables further analysis of population and sub-populations to understand the demographic distribution and prevalence of conditions like any heart-related conditions to understand how the healthcare system can target increased support specific communities.

For Hounslow, patients are referred through several routes to the Rapid Access Chest Pain Clinic (RACPC) at West Middlesex University Hospital. The service provides; Rapid assessment and diagnosis of patients with suspected angina; Information on treatment options and development of a management plan; and an estimate of overall cardiac risk and information on individual risk factors.

Patients can then be referred via their GP, Ambulatory Emergency Care and A&E. The specialist nurses indicated that it is very common to see patients come through the RACP clinics have multiple risk factors e.g., obesity, diabetes, high blood pressure, hypertension. The Cardiology department at West Middlesex University Hospital diagnose and manage both acute (severe and sudden) and chronic (worsens over time) health conditions related to the heart. They treat people requiring both inpatient and outpatient care and support. Patients requiring admission are seen in the Cardiac Care Unit and if a person requires very specialist cardiac support, this is provided via The Royal Brompton and Hammersmith hospitals. This network of hospital services is also subsequently support by West Middlesex University Hospital's Cardiac Prevention and Rehabilitation service that helps people return to health after their treatment.

Ealing's position as a leading example of integrated care is apparent at the next stage of the referral pathway as it was the first NHS CCG in England to successfully develop and launch a Community Cardiology Service. Dr. Fragoyannis stated that this service has clearly defined pathways for all common conditions. Dr. Fragoyannis subsequently stated that in his opinion as commissioning lead of the service for the past decade, he has seen no differences in the level of cardiac care received by women compared to men. Both specialist nurses from Hounslow agreed with this sentiment, stating that this was a misconception, and that the data does not indicate an unequal service when comparing genders. What they are starting to see in Hounslow is a disproportionate increase in the number of women from a South Asian background using their services.

There was, however, evidence from both boroughs that the delivery of a comprehensive pathway of care for these women had not yet been fully achieved. For example, Ms. Sargent noted that while there are service specification pathways for other conditions, such as the Community Neuro Stroke Rehabilitation Pathway [Annex L], there is no such documented pathway for Cardiac conditions. In addition, Dr. Ip suggested that the resources within the community needed to be improved as well as the knowledge amongst healthcare professionals of what is available in the community. Furthermore, as the care in both boroughs that individuals receive once acute care is required was effective, Dr. Fragoyannis suggested that the misconceptions around a lack of care for such woman could stem from an initial lack of access for these women to preventative support. Dr. Chauhan highlighted the lack of timely diagnosis for heart and CVD-related long-term health conditions. For instance, women with diabetes often remain undiagnosed until a serious cardiac event occurs. Dr. Chauhan went on to say that the lack of diagnosis, lack of an efficient and signposted care pathway, and a lack of pre- and post-infarction support services combine to undermine the effective management of long-term health conditions, particularly those related to cardiovascular health.

Both Nurse Shotter Weetman and Nurse Kaba highlighted the importance of improving prevention in Hounslow as services can increase capacity and resources as the pressures of the pandemic begin to ease. They have already launched several prevention initiatives, focusing on health promotion and cardiac care and working in partnership with Hounslow and Richmond Community Healthcare Trust to deliver 'Right Lifestyle' Roadshows to help improve resident's health and lifestyle.

Dr. Fragoyannis stated that work to further build on the efficiency and effectiveness of the Community Cardiac Service in Ealing continues while it is also being used as a service template for the other boroughs, within the region. Concurrently, Ms. Sargent suggested that as the impact of COVID begins to ease, Ealing Community Partners can start to turn their attention back to the integration of treatment and rehabilitation services into a more holistic pathway. This has already begun in certain areas of work with plans to extend this work across both boroughs under the West London NHS Trust. A coproduction group of professionals and service users has been formed to address how pain management and psychological services need to be integrated into rehabilitation services for physical conditions and a psychologist has now been appointed within the Pain Management service in Musculoskeletal team with the hiring process currently underway for the same position in the Diabetes and Cardiology teams as well. Furthermore, Ms. Sargent and Dr. Ip outlined a holistic service that individuals could be referred to for the breadth of their health and wellbeing issues representing a tri-aspect care service that would provide individuals with access to support for their mental and physical wellbeing as well as involving PCN Social Prescribers to provide support for other contributory health and lifestyle factors. Both Ms. Sargant and Dr. Ip indicated that the utilisation of other care services within a stepped approach; including IAPT, community sector organisations and Social Prescribers, would be crucial to ensuring that patient's needs are met while ensuring that the pressures on primary secondary care services are more reasonably distributed. However, as Dr. Chauhan pointed out this would require a support for community organisations to offer such services and a strong knowledge base for GPs to improve the local referral process.

7. Conclusions

The findings from this report provide a robust evidence base demonstrating the need to improve the holistic care pathways within the boroughs of Ealing and Hounslow for women with multimorbidities, including a cardiovascular condition. The data shows that this relatively small cohort of each borough generate a sizeable amount of emergency and planned visits, using a significant amount of NHS resources as a result.

The data highlights several inequalities within this population sample that require further exploration. First, the significant proportion of A&E visits from individuals living in the most deprived areas in Hounslow seem to suggest that women living in these areas require a great deal more support from health and social care services to both manage any long-term health conditions they have and prevent any further ones from developing. Furthermore, a significant percentage of Ealing residents who fit this Profile were of a BAME ethnicity, making up the majority of those living in the most deprived areas in the borough. Further still, in both boroughs there were more women of a BAME ethnicity suffering from 5 or more long-term health conditions, including a cardiovascular condition, compared to White British women. In conjunction with the finding that women of BAME ethnicities in both boroughs had a significantly higher incidence of CHD and Hypertension, the data highlights clear disparities between the health of those of a BAME ethnicity and White British women, particularly those living in deprived areas.

Overall, the data reinforces the previous literature on women in NWL with multiple LTCs, indicating that a lack of - or underdeveloped - holistic approach to care in Ealing and Hounslow may, in part, be responsible for the significant use of NHS resources by this cohort of women. In particular, the significant number of BAME women in this cohort with Hypertension may suggest that there is a delay in the health and social care support that these women are receiving. By introducing more coordinated and integrated care pathways that provided primary care prevention and management for those that need it most, there is a strong argument that individuals would rely less on acute care for their health and wellbeing.

Despite the clear prevalence of multimorbidity in women and the impact that this has on the health and social care system, there does not appear to be any clear policy regarding the treatment of women that match this experience profile. Integrated care pathways, particularly around Cardiac conditions are still under development and were impacted by the COVID-19 pandemic. The data suggests that it is arguably a lack of initial access to services that is having a significant impact on these women's health and therefore clearer policy around the primary care support that individuals should receive in relation to prevention and management strategies may be most useful. These findings from the data and the patient engagement are somewhat echoed by Dr. Fragoyannis' statement that services across the NWL region, particularly that of the Community Cardiology Service in Ealing, have been designed to ensure that there is no variation in the standard of treatment that people receive once they have become a patient. Although further exploration is needed, this lack of access to prevention and management services may provide an explanation as to why women are less likely to achieve heart-related treatment targets, compared to men.[25]

While the data provides evidence to suggest that improvements in the treatment and care for women who match this experience profile is required, the findings from the thematic analysis of patient's experiences from Ealing and Hounslow outline the specific areas in which treatment and care could be improved. The themes that were identified illustrated the broad issues that individuals face as well as the more intricate issues that highlight gaps in borough services and, consequently, impact individual health.

The identification of an overall lack of awareness from Hounslow patients regarding the status, direction or purpose of their care suggests that there is a real need to integrate the

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[25] Zhao, M., Vaartjes, I., Graham, I., et al (2017). Sex differences in risk factor management of coronary heart disease across three regions. Heart. 103:1587-1594.

patient more, within their own care. Hounslow's significantly higher levels of A&E admissions from its most deprived areas compared to Ealing arguably reinforces this. This suggests a lack of coordination, communication and holistic care. This could be addressed by improving the communication between healthcare professionals and patients, as evidenced by the experiences of Ealing patients. This includes the frequency of communication as well as the omission of medical phraseology, the translation of materials to patient's preferred language and the provision of appropriate lines of communication. The latter was most prominently highlighted by a Hounslow resident who, prior to the pandemic, was provided with disconnected contact numbers for social care services that she required due to a Stroke. Providing patients with a convenient contact that can assist in the coordination of their care is crucial to integrating services and involving patients in their own care through effective provider-to-patient communication. As Dr. Ip mentioned in her views of the issues that may currently affect the integration of healthcare services in Ealing, transparency from services is crucial to coordination and making sure that patients are aware of the care they are receiving - it is vital to the effectiveness of their healthcare for patients to be made aware of changes and updates.

In Hounslow, the requirement for patients to coordinate their own care demonstrates a lack of proactivity from health and social care systems and a poor level of coordination between services. This lack of support from primary care is arguably translated in the prevalence of hospital admissions we see across both boroughs. Patients felt fatigued and disenfranchised because of the need to frequently relay their own medical history and as the experiences demonstrated caused feelings of hopelessness, a lack of a respect for their own opinions on their care, and even a sense of depersonalisation.

Furthermore, the indication that between and within boroughs some patients experienced adequate proactivity and felt satisfied and heard with the coordinated care they receive, suggests that there is ample room for reducing the variation in care for individuals with multi-morbidities and improving the continuity in service delivery to meet the required standard for every patient. Once again, the level of communication between healthcare professionals was identified as an issue prior to the pandemic and therefore highlights systemic gaps in provisions rather than outcomes of any COVID-related pressures. Not only does this lead to patients receiving inefficient care and having to act as middlemen for their own treatment, but it has also potentially threatening implications to an individual's health as the experience of some Hounslow women would seem to suggest.

The contrasting level of coordination of care in Ealing compared to Hounslow is of significant interest. This could be a result of several contributory factors. For example, one patient highlighted the proficiency of Ealing's Community Cardiac Care service and others referenced sufficient GP support. This could also be a result of the implementation of IT systems in Ealing, the training available to healthcare professionals and the clear referral route in Ealing for individuals suffering from Cardiovascular related issues that Dr. Fragoyannis referred to. However, the Meta-analysis of previous Healthwatch Ealing research uncovered several issues, such as a lack of coordination, continuity in care and communication from healthcare professionals, which seem to suggest that these issues remain pertinent across the NW London region. Given that these issues were regularly cited in reference to poor reablement or rehabilitation services this would suggest that the lack of multidisciplinary health care and the more general lack of coordinated care for those with multiple long-term health conditions is having an impact on the wellbeing of female residents.

The evidence from patient engagement indicated that, across both boroughs, further work needs to be done to consider the wider determinants of health. As well as patients' social care needs sometimes not being met, patients in Hounslow regularly indicated that their time with GPs was both temporally restricted and allocated to just one or two health concerns suggesting the absence of any holistic care. Patient's experiences from both Ealing and Hounslow suggested that there was also a gap in services due to a lack of coordination between healthcare professionals and local authorities and subsequently, wider determinants of treatment and care, such as travel to health sites were not being taken into account.

Lastly, it should be noted that specific Mental Health issues were not referenced by patients. However, patients from both boroughs regularly referred to the lack of support as 'frustrating', 'worrying' and stress-inducing. Reasons for the lack of mental health issues or support may be due to the fact that, for some communities it is not culturally or socially acceptable to raise the issue. It also reflects the fact that, overall, we view mental health issues as separate from physical ones and there is a lack of concurrent mental health support for those managing long-term issues and therefore patients don't even think to ask for it or mention that there psychological wellbeing is also of concern to them. Notably, those that were carers and who were interviewed on behalf of a patient (or in one case she also happened to be a carer) all referenced the psychological and emotional impact it was having on the patient and those that care for them. A number felt there was little regard for their wellbeing and that the fact that they are able to provide such care for their family member works against them as they then do not seem to get the provisions of social care services. The indication from the relevant literature and from the interviewed healthcare professionals, that coordination and integration between mental health support services and physical rehabilitation is high on the list of priorities for healthcare in both Ealing and Hounslow is therefore welcome and should go further to ensure that family carers receive a similar level of psychological support.

The findings seem to indicate that access to services remains a concern within both boroughs. Although the patient engagement for Ealing indicates that, once referred onto the appropriate care, patients can and do receive sufficient support, the evidence provided in this report does not include the experiences and opinions of those that remain undiagnosed or simply do not have access to any services. Therefore, when reviewing the areas of improvement for a coordinated care service, addressing barriers to access must be at the core of any future developments. Future visions outlined by the NWL region as a whole and each borough individually include such aims.

As the pandemic halted any major developments to these pathways, promising plans to improve the coordination of services across NWL are due to recommence, with direct implications for intermediate cardiac care and the integration of psychological therapies within such services. However, the practical implementation of these improvements requires an increase in the level of coordination between health and voluntary sectors to increase awareness amongst communities of women particularly affected by multiple LTCs including cardiovascular conditions. For the region, this could include the creation of a cardiac care pathway like the Neuro Stroke Specification [Annex L] and the Diabetes Guidelines. In Hounslow, the evidence suggests that the first step toward this awareness could come from the improvement in Primary care coordination and that this would be supported via a degree of proactivity that is cost efficient, a knowledge base of borough level and regional support, a single point of access for the multitude of issues faced.

What remains unclear is how community sector support, outlined by Dr. Chauhan, will bolster and support the easing of pressure on the NHS, reducing public spend and the utilisation of the network of care within each borough. When considering how a community led prevention and management programme should look, focused attention must be paid to communities that reflect the level of inequalities seen in this research.

8. Recommendations

This section provides two set of recommendations on how to better care for these women. This includes a set of recommendations on how to improve the experience profile methodology of the work that has been conducted and a set of recommendations that detail how care in both Ealing and Hounslow can be developed into a more coordinated and person-centred system:

- **Recommendation 1**: *Further Experience Profile specifications*

Although it was difficult to form any robust conclusions from the patient engagement on whether there was a disproportionate number of women suffering from multiple LTCs and a heart condition from a specific ethnicity, the demographic and prevalence data for both Ealing and Hounslow indicated that the experience profile represented in this report could be further defined as a woman of a BAME ethnicity living in an area with a significant level of deprivation. This would return a smaller cohort of women; however, it would be a step worth considering in order to be able to truly understand the complex and often multifaceted nature of how these communities, who are so disproportionately affected by health issues relating to cardiovascular disease, are accessing services.

- **Recommendation 2**: *Longitudinal monitoring*

Another recommendation for the implementation of this methodology is for a longitudinal monitoring component to be established to understand the journey of this experience profiles relationship with health and social care. This would enable further insight into how coordination transforms over time for a particular panel of individuals and will provide closer to real time evidence of when the necessary level of coordination suffers and what the key drivers are behind this.

- **Recommendation 3**: *Quantitative measures*

In conjunction with Recommendation 2, an accompanying set of standardised quantitative questions that produce a score at specific timestamps in an individual's care would support the analysis of emerging trends and provide an efficient method of identifying areas of development that could be further supplemented by individual's shared experiences if further insight into specific circumstances is required.

In addition, several areas were identified that could improve the level of coordination within health and social care in Ealing and Hounslow:

- **Recommendation 4**: *Local awareness campaigns for CVD and heart related conditions*

The findings from this report and the views of healthcare professionals from both boroughs showed that issues with receiving the appropriate care may be due, in part, to a lack of awareness of conditions (undiagnosed cases) and the care pathways that are in place to support the management of conditions. It is recommended that Ealing and Hounslow refer to the case studies conducted in Blackpool[26] and Lambeth[27] to increase resident's awareness of the causes and available treatments for CVD and other heart related conditions. These awareness campaigns must be specifically targeted toward women and would require collaboration with the community to ensure that the messages being distributed were accessible through different languages, free from any unnecessary medical ‘jargon’ and culturally apt. It was highlighted in both Ealing and Hounslow that any differentiation in gender may be a result of a general lack of access to care rather than the performance of the care services themselves.

- **Recommendation 5**: *A stepped approach to coordinated care*

For Ealing and Hounslow, the implementation of MDT teams with a stepped approach to coordinated care and rehab, including psychological support and wider issue support from Social Prescribers would benefit individuals who match this experience profile. Successful MDTs will require cooperation, coordination, and communication across health services and such care is likely to be more effective if targeted at specific functional difficulties such as universal access to physical therapy, as the findings indicate that this is somewhat lacking. A need exists to clearly identify patients with multimorbidity and to develop cost-effective and specifically targeted interventions that can improve health outcomes depending on the severity and stage of their conditions, for example the use of community-led support groups could be prescribed to those who show signs of a mild impact on their psychological

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[26] Public Health England (2014). Blackpool: identify and treat people with undiagnosed high blood pressure

[27] Lambeth CCG (2017). Hypertension: Improving blood pressure management in primary care.

wellbeing while those identified as having a more severe diagnosed mental health condition would require access to the IAPT-LTC[28] service that the West London Trust are expected to implement within their care pathways. Evidence-based guidance regarding the operationalization of integrated care between cardiac services and other LTC services – including pathways between local and specialist centres – for all women with cardiac disease is required.

- **Recommendation 6**: *Transparent pathways*

Pathways for individuals suffering from Cardiovascular conditions and/or multiple LTCs should have access to documented care pathways that they are able to refer to, much like that of the Diabetes guidelines. This provides useful support for healthcare professionals as well as facilitating a transparent relationship between these professionals and patients. Once again, for these pathways to be entirely transparent, the language used must be understood by the patient and not just the professionals. Pathways should have a strong focus on available prevention and management strategies for individuals to support their own care as well as being supported through health and social care services, such as a single point of access support hub for patients to be directed to the appropriate contact. A single access hub like this would allow for further efficiency in access and delivery of services, a greater degree of coordination between services and a level of transparency that would allow patients to feel more involved in their care if they are able to contact services as and when they need.

- **Recommendation 7**: *Apply learnings from Ealing to Hounslow's care*

From the experiences shared by local residents, it is apparent that Hounslow must understand the specific instances in which Ealing is successfully coordinating care to further improve its offering. Most notably, Ealing could be used as a template for other borough in the NWL region including Hounslow on how to instil effective communication pathways both between professionals and with patients. As this appears to be the root cause of many of the issues pertaining to a lack of integration it seems an appropriate aspect of care to focus on, making GPs aware of how they can provide proactive care to individuals and act as an enabler for additional care.

In addition, the success of the Community Cardiac Service in Ealing and the utilisation of the related IT systems including SystemOne and the WSIC database should support planning for the borough of Hounslow on how to provide more effective and efficient care for those suffering from Cardiovascular conditions. However, the patient engagement and meta-analysis does show that Ealing still has room for improvement in this area and therefore it is recommended that Ealing too, explore instances of good practice and how this can be

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[28] National Collaborating Centre for Mental Health (2018). The Improving Access to Psychological Therapies (IAPT) Pathway for People with Long-term Physical Health Conditions and Medically Unexplained Symptoms, Full Implementation Guidance

implemented throughout the borough to reduce variation and inequalities in care for those with multiple LTCs. This should involve continuity in care with patients able to regularly see the same healthcare professional as well as continuity across professionals through global access to patients records to prevent any need to reassess or for the patient to be the middleman in their own care.

- **Recommendation 8**: *Improve knowledge of GPs for a holistic care pathway*

Further training and education for GPs that outlines the road map of care pathways in Ealing and Hounslow would enable a more coordinated service. This increased and standardised level of knowledge of what health and social care and community sector organisations are appropriate to refer an individual to would ensure a proactive level of care was being delivered while simultaneously providing the individual with the resources to successfully manage their own care. In addition to health issues, this education and training should also inform GPs on the provisions of Local Healthwatch as well as other information & signposting services and advocacy services that could help individuals with wider determinants of health and wellbeing.

- **Recommendation 9**: *Support for family members and informal carers*

Recognition of Informal Carers as part of the health management structure for individuals who match this Profile. This means social support, psychological support, transparency of the patient’s needs, support with medical records/ information that can be confusing.

- **Recommendation 10**: *Community-led healthy lifestyle programmes*

Community services that are supported by Statutory organisations to deliver a holistic approach family service that includes accredited education, physical and mental health and wellbeing programmes. Must include output and outcome measures. For example, general practice nurses may target recently diagnosed patients who in theory would have fewer comorbidities and provide them with early education and self-management programmes, which may include additional telephone and/or specialist community support for those with lower socioeconomic status. The use of community support is integral to the implementation of such awareness campaigns and educational programmes and findings suggest that if Hounslow and Ealing were able to emulate the holistic approach of the decommissioned Ealing Health Lifestyle Programme the boroughs would see a reduction in the utilisation of health services, but also an improvement in patient wellbeing and result in large cost savings for the NHS.

9. Limitations

During this research project, several limitations were encountered. First, it is important to understand the context in which this research was conducted. Amid the global COVID-19 Pandemic, England was still under government enforced lockdown restrictions. This prevented Healthwatch Ealing and Hounslow from conducting its usual face-to-face, community engagement and outreach that would ordinarily play an integral part in the promotion and outputs of a project of this size. In accordance with government guidelines Healthwatch Ealing and Healthwatch Hounslow employed an adapted digital approach to patient and stakeholder outreach. It can be argued that a greater number of women would have participated in this project if it were conducted in more normal circumstances. Several reasons are posited to contribute to this including; a lack of understanding of the project by patients, particularly given the specific criteria that made individuals eligible for participation; a fairly narrow cohort of individuals that were eligible for participation that more personal outreach could have further explained the nature of the study and what we were asking of them; and the lack of 'ad-hoc' engagement that is commonplace in face-to-face outreach at hospitals, GP surgeries and other primary care services in each borough. Finding a suitable time to schedule a Zoom focus group for or call patients at a time that was convenient for them may have brought an added level of difficulty and as we know that women who match this Profile, are disproportionately from areas of deprivation, older age groups and of black or other minority ethnic groups it can be argued that the individuals we were hoping to speak to, could not access Zoom due to digital isolation and therefore may even have not have been made aware of the research project where they would have been if we were attending their community groups.

Another distinct, but related, limitation was the engagement with stakeholders and other healthcare professionals during this time. Given the breadth of the research it was pivotal that Healthwatch secured the support of statutory organisations for assistance in the data analysis and local policy review sections of the research and the support of both statutory and community services in promoting the focus groups and interview to bolster the third and final section of the research. Given that all organisations main priority at this stage was handling the fallout from the pandemic, adjusting to the new way of working and then subsequently ensuring that the vaccination rollout was successful, this project, understandably, did not receive the support that it required. It can be argued that had we received the full support of community organsiations for the promotion of the interviews and focus groups and had statutory organisations been able to dedicate more time and resources to supporting this project, it would have made the project easier, if not more effective.

Although this digital approach presented several barriers to patient and stakeholder engagement, Healthwatch Ealing and Healthwatch Hounslow overcame these through extensive community outreach and the subsequent support of stakeholders and community partners.

One limitation more directly related to the research conduction process itself was that often, women were unable to provide a certain level of detail regarding their care. This could have been due to their health condition or the fact that most of the women we interviewed were older in age but, paradoxically, it could have been due to a lack of understanding of their own care. It can be argued that this is a telling sign of the lack of coordination of the integrated pathways and involvement in their care – both forming the basis of our recommendations for how to develop Integrated Care Pathways. It therefore became difficult in some situations to truly identify the issue, department, health requirements or area of good practice that the patient was alluding to.

Despite the limitations outlined, Healthwatch Ealing and Healthwatch Hounslow were able to obtain a wealth of insight into how women were currently being supported by health and social care across Ealing and Hounslow and how they believed that this support could be further improved in relation to the integration and coordination of services.

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Annex

ANNEX A: Ealing and Hounslow Integration Health and Care Experience Profile

- Attached separately

ANNEX B: Stakeholder engagement audit

Ealing

Stakeholder	
Ealing Clinical Commissioning Group	Judith George, Engagement and Equalities Officer, NHS Hounslow and Ealing Clinical Commissioning Groups Neha Unadkat, Joint Acting Managing Director Ealing CCG **Dr. Alex Fragoyannis**, GP Commissioning Lead for Cardiac Services Manisha Parmer, Ealing CCG Primary Care Programme Delivery Manager Aydid Cabdillahi, Programme Delivery Manager Primary Care , NHS Ealing CCG Danielle Bates, Primary Care Officer, NHS Ealing Clinical Commissioning Group – PCCC administrator Caroline O'Leary, Social Prescriber - Community Link Worker, Ealing PCN
North West London Collaboration of Clinical Commissioning Groups, Business Intelligence Team	Kavitha Saravanakumar, Associate Director of Business Intelligence, North West London Collaboration of Clinical Commissioning Groups Owain Griffiths, Business Intelligence, North West London Collaboration of Clinical Commissioning Groups
West London NHS Trust (Ealing Community Partners)	Chris Hilton, Clinical Director for Integrated Care Services **Dr. Lyndsay Ip**, Consultant Psychologist (Pain management, integration of physical and mental health), Ealing Community Partners **Zoe Sargent**, Associate Director of Community Services and Children's Strategic Lead, Ealing Community Partners and Central and North West London NHS Foundation Trust Peter Wilde, Service Manager, Intermediate Care Services, Ealing Community Partners

	Ann Francis-Wilding, Team Leader, Ealing Care Coordination Services, Ealing Community Partners
Ealing Public Health	Jade Clark, Programme Manager - Predictive Prevention, Programmes and Priorities Division **Dr. Sapna Chauhan**, Senior Public Health Specialist Ealing Maddy Gupta-Wright, Consultant in Public Health Ealing Wendy Meredith, Consultant in Public Health Anna Bryden, Director of Public Health
London North West University Hospital NHS Trust (LNWH)	Rachel Tunstall, General Manager Cardiology and Dermatology Anjali Patel, Patient Experience Manager
LNWH Cardiac Research Department, Cardiac Research Charity	Ann Banfield, Business Manager, Cardiac Research UK coordinator
Imperial College Health Partners	Chris Marot, Office Manager Professor Alex Bottle, Chair in Medical Statistics, Co-director, Dr Foster Unit, School of Public Health
Ealing Council	Kashmir Takhar, Older Adults' Commissioner, Ealing Adults' Services Moira Mercer, Head of Communications Edel Meremikwu, Media and Communications Officer
Healthwatch England	Olly Grice, Collaboration and Regional Network (South) Manager Jacob Lant, Martha Jesson, Senior Research Analyst
NHS England & NHS Improvement	Nick Hassey, Senior Programme Manager, Primary Care & System Transformation Ros Spinks, Carers Regional Lead

	Michelle Mello, Clinical Quality Director
Age UK Ealing	Reginal Parkinson, CEO
GOS&D	Sharmarke Diriye, Programmes Lead
The Advocacy Project	Jo Kay, Governance and Project Coordinator
Ealing Community Network	General Enquiry
Southall Black Sisters	General Enquiry
Southall Community Alliance	General Enquiry
Mulberry Centre	General Enquiry
Marie Curie Ealing	General Enquiry
Ealing Maternity Groups	General Enquiry
Heart Links	General Enquiry
Ealing Support for Independent Living (ESIL)	General Enquiry
Let's Go Southall	General Enquiry
Solace	General Enquiry

Hounslow

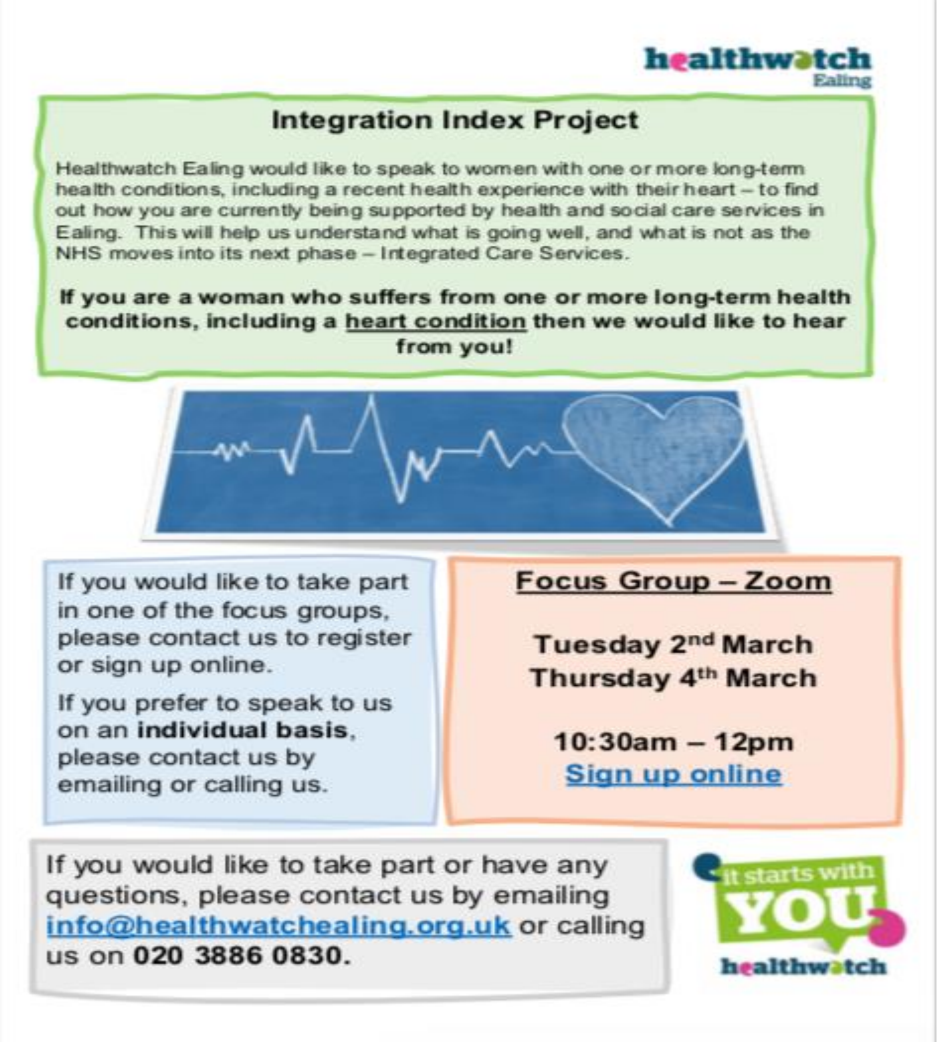
Stakeholder	
Hounslow Clinical Commissioning Group	• Sarah – Engagement and Equalities Manager (Hounslow and Ealing) • Judi – Engagement and Equalities Officer
Hounslow and Richmond Community Healthcare NHS Trust	• Robin – Patient Experience and Involvement Manager • Fiona - Director of Communications Hounslow and Richmond Community Healthcare
Hounslow Public Health	• Buvana – Senior Public Health Commissioning Manager – Primary Care
Chelsea and Westminster Hospital NHS Foundation Trust	• Vanessa – Deputy Chief Nurse • **Cas Shotter Weetman,** Lead Specialist Nurse Cardiology at West Middlesex University Hospital • **Agnes Kaba,** Clinical Nurse Specialist, Rapid Access Chest Pain Services Lead at West Middlesex University Hospital

Integrated Care Partnership Comms and Engagement	General Enquiry
Hounslow Somali Group	General Enquiry
Hounslow Tamil Group	General Enquiry
Afghanistan & Central Asian Association (ACAA)	General Enquiry
Woman Specific Groups	General Enquiry
Heart of Hounslow:	• The Practice • Green Practice • Chestnut Practice • Bluewing Surgery
Chiswick Health Centre:	• Chiswick Health Practice • West4GPs • Chiswick Family Doctors Practice
Brentford Health Centre:	• Albany Practice • Brentford Family Practice • Brentford Group Practice
Feltham Health Centre:	• The Practice • Queens Park Medical Centre • St. David's Practice
Firstcare Practice	• Saira – Practice Manager
Hounslow Carers Forum	• Lyn – LBH Carers Adviser • Caroline – Community Information Manager
Hounslow COPD Group	• Roger – Chair
Hounslow Social Prescribing	General Enquiry
LBH My Independent Service	General Enquiry
One You Hounslow	• Rasneet – Wellbeing Coordinator
Hounslow IAPT	• Bev – Joint Deputy Clinical Lead & accredited therapist and supervisor (BABCP)
Speak Out in Hounslow	• Sarfraz – Campaigns and Advice Coordinator
Age UK Hounslow	General Enquiry
LGBTQ Group	General Enquiry

ANNEX C: WSIC data on experience profile 5 from the NWL CCG Collaborative Business Intelligence Team

Attached separately and available upon request.

ANNEX D1: Promotional Poster for Focus groups - Ealing Example.



healthwatch Ealing

Integration Index Project

Healthwatch Ealing would like to speak to women with one or more long-term health conditions, including a recent health experience with their heart – to find out how you are currently being supported by health and social care services in Ealing. This will help us understand what is going well, and what is not as the NHS moves into its next phase – Integrated Care Services.

If you are a woman who suffers from one or more long-term health conditions, including a heart condition then we would like to hear from you!

If you would like to take part in one of the focus groups, please contact us to register or sign up online.

If you prefer to speak to us on an **individual basis**, please contact us by emailing or calling us.

Focus Group – Zoom

Tuesday 2nd March
Thursday 4th March

10:30am – 12pm
Sign up online

If you would like to take part or have any questions, please contact us by emailing info@healthwatchealing.org.uk or calling us on **020 3886 0830.**

ANNEX D2: Project Brief for Statutory and Community Organisation Outreach

Healthwatch Ealing Integration Index Project

The NHS in England wants to provide people with the best care possible. To do this it is important that hospitals, GP surgeries and community services, like physiotherapists, pharmacies and mental health services, always work well together.

These NHS services also must work well with local social care services, such as care homes and care provided in people’s own homes, to ensure the help people receive supports all their needs.

This approach often requires the NHS to think about the role of other public services including things like housing, benefits, transport and education. All these things play a vital role in supporting people’s general wellbeing as well as their health. For the people receiving care it should feel like they are being supported by one big organisation which is thinking about all their needs and responding together as one.

HOW DO WE GET TO A WORLD THAT LOOKS LIKE THIS?

The NHS has been thinking about how to provide care in this way for some time, and important changes have been made already.

But to know if these are working, they need to hear from people about their experiences of care. This is what the 'Integration Index' is all about.

WHAT IS HEALTHWATCH EALING'S ROLE IN THE INTEGRATION INDEX PROJECT?

Healthwatch Ealing has the task of speaking to a specific type of person - Women with multiple long-term health conditions, including a recent health experience with their heart - to find out how these women are currently being supported by health and social care services in Ealing.

This research is being split over two parts, being carried out over the next couple of months:

1. Working with the NHS and Ealing CCG to analyse how services that support people with long-term health conditions are being used by the public.
2. Listen to women in the borough that fit this description, hearing their views and understanding their experiences.

This research is designed to help the NHS and its local partners to understand why things might not be working well and then work with local people to fix things.

HOW CAN YOU HELP?

With the help and support of community groups in the borough, we are hoping to promote these focus groups to women that fit the description above. Once Individuals express their interest by emailing us at info@healthwatchealing.org.uk or calling us on **02038860830** we will send them all the information that they need to join the Zoom focus group.

We would like to welcome any women that have multiple long-term health conditions, particularly individuals that are managing heart/cardiovascular conditions, to join one of our focus groups. These focus groups will take place during the first week of March.

In these online focus groups, we will ask attendees a few questions to encourage an open discussion in which everyone can share their personal experiences with health and social care in Ealing. We will then ask attendees if they have any ideas for improvement and we will expect the NHS to make these changes wherever possible. There will then be a final meeting held later in the process to ask people if their experiences have improved.

If you have any questions please do let us know by emailing info@healthwatchealing.org.uk or calling us on **02038860830.**

Thank you in advance for your support,

ANNEX E: Information and question template for focus groups and 1:1 telephone interviews

Integrated Index Project Focus Group Question Template

Who to Recruit:

Health and Care Experience Profile - Women with multiple health needs including a recent experience of a cardiovascular condition

Specific health needs in addition to CVD/ Heart condition – Diabetes, Obesity, Pregnant, Smokers, Mental Health Issues, MSK, Kidney disease, Cancer, Frail or Housebound, COPD or other respiratory conditions, Drug or Alcohol misuse, etc.

Focus Groups

When: Mid-February to Early March

How: Promoted through community group network, Statutory partnerships, our own media channels

Where: Zoom via Eventbrite

Who: 4-8 women that have digital access and that match the health and care experience profile including those from protected characteristic groups.

What: The focus group can last approximately an hour, following the line of questioning in this template but also facilitating natural conversation between attendees. This should broadly cover; 1) a description of their current health status; 2) how they have interacted with health and social care to date; 3) prominent concerns regarding the care that they have received; 4) what they believe would improve the care that they receive.

Must obtain consent by all for information and recording. Must inform ppts that if anything becomes too triggering that they can leave or have a minute out of the conversation at any time. Can also include polls for closed questions and need to gather demographic information from everyone. Can send an online confidentiality agreement including demographic monitoring questions ahead of time. Alternatively, can read the agreement at the start of the focus group.

Account for needs such as sensory impairment, language.

Risk assessment carried out beforehand to ensure the physical, emotional and mental wellbeing of participants, staff and volunteers is considered. Let participants know that they can speak to staff afterwards if they need to regarding any support, information and or signposting. Include contacts on the slideshow that individuals could contact if the conversation raised any questions. Can log these as information and signposting afterward.

Follow YVHSC guidelines for safeguarding if any feedback that relates to abuse or neglect is disclosed.

1:1 Telephone Interviews

Interviewers must be well-versed in current landscape of care for this health and care experience profile in order to uncover necessary information.

When: Mid-February to Mid-March

How: Promotion through community groups and Statutory Partners, tri-borough webinar. Individuals can call our number provided, can email their phone number to indicate they wish to receive a call, given numbers directly from community groups (non-compliant with GDPR).

Where: Via telephone, HWE line

Who: Women that match the health and care experience profile but, do not have digital access to Zoom focus groups.

What: Semi-structured interview with a clear line of open questioning and room for expanding the conversation. Must gather demographic information and obtain consent

Questions:

1. Tell me about your conditions and what services you require support from
2. To what extent have you been involved in your care – care planning, decision making, how have your family, carers, loved ones been involved?
3. How well do the different health and social care professionals involved in your care work together?
4. What do you think have been the barriers, if any, for implementing effective integrated care and support for your condition(s)?
5. Explain what Polypharmacy is and then ask if they have experienced polypharmacy and can they outline how this has impacted the way they interact with services or the support they receive
6. Has anyone (*have you*) utilised rehabilitation services? If so, what are their experiences e.g. information sharing; Being supported by multidisciplinary teams?

ANNEX F: Healthwatch England methodology on conducting a focus group.

About the guide

This is a topic discussion guide to assist Healthwatch to undertake a focus group which will test health and care experience profiles as part of the NHSE Integration Index.

Background

Healthwatch have been asked to undertake a number of focus groups to gather feedback from people about their experiences of integration of health and social care services.

To help, Healthwatch England have developed a topic guide to assist in testing the health and care experience profiles with various groups of people. These include:

- Children and young people with mental health support needs who are becoming adults
- People with diabetes who are of South Asian origin
- People with learning disabilities who have recently been in hospital
- Black men with a number of health needs including a recent experience of cancer
- Women with a number of health needs including a recent experience of a heart condition

Healthwatch can use the guides to further develop them so that they are specific for their target group. Please note that we have supplied some suggestions about activities that you could undertake to engage attendees and generate conversation – these are not prescribed.

The guide will give you:

- Key factors to consider when speaking to people about different topics and themes.
- An outline of discussion points that will ensure that all key areas are covered.
- Options for activities to keep members of the event engaged and encourage interaction.
- Timings and a sensible flow to the event that will ensure that attendees progress from one session to another.

Top tips for running a face-to-face or online focus group

1. **Be prepared.** Make sure you have all the resource necessary to undertake good and interactive activities that generate discussion, such as flipcharts, pens, post it notes. You may want to record the session and take photographs, although you will need to obtain consent.

   However, if you are conducting an online focus group, make sure you test your online platform, such as Microsoft Teams, with your team so that you are familiar with it. It’s also important to instruct your attendees on how to join sessions and use functions within the meeting. You can show a slide at the start of online events with “housekeeping” rules to show how to use functions.

   It may be useful to test your agenda/script and assess your timings. Typically, an online focus groups should last between 60-90 minutes. Any longer and attendees may find it difficult to stay focused with other distractions at home.

Know your objectives and prepare discussion points so that you can keep the conversation flowing and add in useful prompts.

Consider whether you will need to use interpreting and translation services. These can be used for both online and in-person focus groups.

2. **Provide visual aids.** Booklets per table with the sessions outlined will help keep participants on track. Slides outlining session objectives are an ideal way to engage attendees at the outset or to remind them of the tasks set.

   If you are conducting an online focus group, you can:

   - Share your slides and other documents on the screen for all attendees ahead of time or during the session
   - Ask people to have a note-pad with them so they can hold up short answers to questions
   - Allow others to share their screens
   - Use online collaborative tools e.g. interactive whiteboards
   - Share visual aids and resources before the session
3. **Choose your facilitators well.** Getting the right people to lead the event is essential. If you have table facilitators make sure they are well briefed so that they can support their tables well and share useful insight with the rest of your attendees.
4. **Getting the right mix of people.** Think about your objectives and who you need to engage to achieve them. It's a really good idea to screen your attendees using a basic questionnaire in advance so you can prepare properly for your audience. This will give you the best foundation for effective engagement. Tailor your lines of enquiry and questions accordingly.
5. **Recruiting the ideal number of people.** The size of the focus groups is often dependent on the local population and representation of certain groups of people. However, an ideal number for each focus group would be between 5-8 people, both in person and online. More than this could make it difficult for you to ensure everyone is able to make a contribution. Below 4 people could limit discussions and impact the quality of information.

   Alternatively, you can run multiple smaller focus groups as opposed to one large one, if needed.

6. **Collect demographic information.** You should collect demographic information from focus group attendees, especially as integration of services will affect all aspects of people's lives and needs. For example, collecting information about people's health conditions which will help to identify good practice examples. We must ask participants' specific cultural identity. For example, South Asian people are not homogenous and there are cultural differences between countries and communities such as in India, Pakistan and Bangladesh. It is important to allow people to self-identify, as always.
7. **Get consent.** Compelling stories can drive system change, make sure you get the right consent from attendees when collecting personal identifiable data so you can use the feedback they provide effectively. Use a consent form, perhaps as part of your screening questionnaire. Make sure you remind attendees that their data will be managed well. If you intend to record the focus groups before typing up a transcript, you will need to obtain consent from the interviewee and tell them how the recording will be used and how the data will be processed and stored, in accordance with GPDR. You will need to state how Healthwatch England intends to use the information obtained from the focus groups.

   If you are running a focus group virtually, you can send an online confidentiality agreement which can be signed ahead of time. Alternatively, you can read the agreement before you start the session and ask each participant to agree by voice and record the answer.

8. **Take care of your attendees.** Make sure you have thought about the needs of your attendees. This can be about accounting for sensory impairments, using the right language that is accessible or thinking about how they will react and respond to the conversation. This forms part of an overall risk assessment, make it clear that their needs are first and foremost in your mind. See below.

Thinking about your event participants

You may have people at your event who have mental health conditions or challenges. It is important to note that talking about experiences of mental health issues may be triggering for both participants and facilitators. They should inform participants that they can step out at any time and that they can join in the discussion as much or little as they wish. The facilitator should have the opportunity afterwards to debrief and discuss the session with another member of staff if they wish.

It would be useful to have appropriate signposting details at hand if you are concerned that a participant is currently struggling with their mental health. If someone discloses that they are at risk of harming themselves then follow your Healthwatch safeguarding procedure and contact the appropriate mental health crisis service. This procedure should be outlined when discussing confidentiality of information at the beginning of the session.

Wellbeing

A risk assessment should be carried out before an event to ensure the physical, emotional and mental wellbeing of participants, staff and volunteers is considered. Be aware that talking about poor experiences or poor health could be upsetting for people. Let people know they can leave the session whenever they need to or talk to a member of staff afterwards if they need more support. You may want to take along or send some leaflets or materials to help you signpost people to local support services.

Safeguarding

It is important that you follow your organisation's safeguarding policy and procedures if you hear any feedback that relates to abuse or neglect of a vulnerable person, or if someone discloses a safeguarding concern to you.

General themes relating to integration:

Communication: Communication and coordination between professionals. The system shares information through patients rather than between services

Lack of information: Professionals not having the information they need to treat those in front of them

Lack of continuity of care: Patients having to repeat their story unnecessarily to different professionals

Lack of involvement: Patients and families not being involved in care and decision making

Lack of holistic care pathways: Care pathways can sometimes not consider other needs and divers of negative experiences

Focus Group Outline	Proposed Content
Introductions	The purpose of this session is to give attendees enough information to help them understand why we are engaging with them and what we will be doing with the information that they share. It is also important to take your participants through the session and what you will be doing. All housekeeping should be covered here as well as how information will be shared so that people know that their data will be kept secure and anonymised where required. Ideally attendees will have completed and signed a form prior to attending the event that informs them about what they will be contributing and why, and which obtains the necessary consents. Our priority is to listen to people, so it is important to keep this session succinct. Explain the ground rules for participating in focus groups: • One person speaks at a time – there may be a temptation to jump in when someone is talking but please wait until they have finished • There are no right or wrong answers • You do not have to speak in any particular order • You do not have to agree with the views of other people in the group You should ask if anyone has any questions before you move on.
General points to cover	Tell me about your conditions and what services you require support from To what extent have you been involved in your care – care planning, decision making, how have your family, carers, loved ones been involved? How well do the different health and social care professionals involved in your care work together? What do you think have been the barriers, if any, for implementing effective integrated care and support for your condition(s)?
Specific points to cover	Children and young people with mental health support needs who are becoming adults: Explore how GPs have been involved in their care – GPs have a key role as the single service that does not change as a result of reaching adulthood Any support through educational settings? Particularly supporting young people in securing employment How often/how many times participating young people feel they have had to "start from scratch" with the people involved in their care and support (e.g. repeating their story, symptoms etc.) People with diabetes who are of South Asian origin: In relation to health inequalities and dietary/nutritional advice received, did people feel it was culturally appropriate? Did the person advising them understand the cultural implications surrounding dietary advice? Explore areas around translation, if appropriate, and information sharing to assess understanding of staff and patients Have people been supported in the community (e.g. language/messaging about diabetes in the community, places of worship, community events)[1]

	People with learning disabilities who have recently been in hospital Explore people's living situations (e.g. supported housing, do they live with their families?) Implications of carers – are they involved in their care? How do they support the focus group attendee? Black men with a number of health needs including a recent experience of cancer How has GP or community services supported the person through their cancer journey? Explore experiences of screening processes, support and referrals. Was information shared across services? Has anyone utilised social prescribing? How was this accessed? Has this been helpful e.g. health promotion, prevention? Explore any discussions around interactions between cancer treatments and treatments for other health conditions? E.g. was this discussed with a health professional? Women with a number of health needs including a recent experience of a heart condition Explore whether people are experiencing polypharmacy and how this has impacted the way they interact with services or the support they receive Has anyone utilised rehabilitation services? If so, what are their experiences e.g. information sharing; Being supported by multidisciplinary teams?
Closing	In closing the session thank everyone for attending and summarise the learning for the day. Attendees will need to know what happens next as well as timeframes.

Write your report based on the results of the focus group. Please remember to maintain confidentiality of the participating individuals by not disclosing their names.

ANNEX G: Your Voice Health and Social Care Safeguarding Guidelines (link) and the Safeguarding Incident Recording Sheet.

https://static1.squarespace.com/static/5d10de2a70b70c0001665b6f/t/5f44d0e06f784a6c15ea6817/1598345440720/Safeguarding-Policy.pdf

Safeguarding incident/concern recording sheet

In the event of a disclosure, all staff and volunteers should behave in the following way:

- Stay calm;
- Do not press for information by questioning the individual. Encourage the person to talk, listen and remember what they say;
- Do not express disbelief, anger, embarrassment, shock or fear;
- Reassure the individual and tell them you are glad they are speaking to you and that you know it is not their fault;
- Never promise to keep a secret;
- When appropriate write down what has happened on the safeguarding incident form and where possible, recount any conversations verbatim;
- Inform your superior at the earliest opportunity and hand in this form to them.

PLEASE NOTE – THE DETAILS RECORDED IN THIS FORM WILL BE STORED IN A CONFIDENTIAL FILE. DETAILS INCLUDED IN THIS RECORDING SHEET WILL ONLY BE SHARED WHEN NECESSARY FOR THE PROTECTION ON THE INDIVIDUAL.

Date of recording: **Date of incident (if applicable):**	**Name of Staff / Volunteer Reporting**: **Location:**
Nature of concern:	
Actions taken	
Outcome (to be completed by the CEO/lead safeguarding officer)	

ANNEX H: Healthwatch Ealing example of GDPR compliance

Integration Index Project - GDPR Compliance Guidelines

The **General Data Protection Regulation (GDPR)** is a legal framework that sets guidelines for the collection and processing of personal information from individuals who live in the European Union (EU).

Importance: **GDPR** is important because it improves the protection of European data subjects' rights and clarifies what companies that process personal data must do to safeguard these rights.

About Us: ***Healthwatch* Ealing** is the independent consumer champion for health and social care in the borough that deal with data relating to EU citizens and comply with the new GDPR guidelines. We appreciate the impact this is likely to have and identify areas that could cause compliance problems under the GDPR.

Personal Data Breach: We understand and take the responsibility to protect your personal information such as your contact details, name and the location from the consequences of **the personal data breach**.

Information: The information provided by you for Integration Index Care Research Project will be used for research purposes only and will not be used to personally identify you.

The information you give today will be held in a secure database; you have all the rights to ask for removing your personal at any time. We take consent of every individual before the collection of feedback.

We abide by the user rights under the GDPR and the compliances.

The Eight User Rights Under the GDPR:

- The Right to Information.
- The Right of Access.
- The Right to Rectification.
- The Right to Erasure.
- The Right to Restriction of Processing.
- The Right to Data Portability.
- The Right to Object.
- The Right to Avoid Automated Decision-Making

If you have any questions, regarding your GDPR please do let us know by emailing info@healthwatchealing.org.uk or calling us on **02038860830**.

ANNEX I: Healthwatch Ealing example of Consent Form

Consent to participate in the Integration Index Project

An independent review of Health and Social Care services in Ealing [Hounslow] being carried out by Healthwatch Ealing [Hounslow] on behalf of Healthwatch England and NHS England.

The purpose of the review is to find out how useful and how effective the health and social care services are, from the perspective of service users.

By signing this form:
I consent to Healthwatch Ealing [Hounslow] using my opinion and experience that I have shared for the purpose of this research.
I understand that I am sharing my feedback and experience of health and social care services in Ealing [Hounslow] to support the national development of health and social care services.
I understand that when Healthwatch Ealing [Hounslow contacts me, I am not obliged to take part in the review. My participation is voluntary.
I understand that if I choose to participate, my experiences and thoughts will be shared and collated into a final report for publication.
I understand that my experiences and comments will be anonymised and I will not be identifiable in any report.

Please print your name ____

Please Sign your name ____

Date __________

*For this research project, the above is to be read out to participants and verbal confirmation will be taken as granted consent.

ANNEX J: Patient health conditions and demographic breakdown

Borough of Hounslow

Patient 1: Myotonic dystrophy, heart condition, blood clotting condition.
Patient 2: Diabetes, high blood pressure, high cholesterol, eye problems including glaucoma.
Patient 3: Type 2 diabetes, high blood pressure, high cholesterol, asthma.
Patient 4: Rheumatic heart disease, fibromyalgia, Paget's disease, paroxysmal hemicrania, chronic breast and back pain.
Patient 5: Endometriosis, fatigue, chronic back and abdominal pain.
Patient 6: Stroke, high blood pressure, arthritis.
Patient 7: Stroke (and associated lack of mobility), type II diabetes, arthritis.
Focus group:
Patient 8: Osteoarthritis in hip.
Patient 9: Osteoporosis, COPD, kidney failure, bipolar disorder.
Patient 10: Kidney stones.
Patient 11: Heart condition, respiratory lung disease.
Patient 12: Type II diabetes (and carer for husband with stroke, COPD, heart attack).

Borough of Ealing

Patient 1: Heart palpitations, lung condition, Covid-19.
Patient 2: Stroke, angina, heart disease, high blood pressure, high cholesterol, joint issues in her knees, leaving her wheelchair bound.
Patient 3: Rheumatoid arthritis, high blood pressure.
Patient 4: High blood pressure, high cholesterol, glaucoma.
Patient 5: Diabetes, asthma, high blood pressure.
Patient 6: Asthma, eye condition, hereditary ATTR amyloidosis.
Patient 7: High blood pressure and diabetes.
Patient 8: Ear, nose and throat issues, heart condition, spinal problems, pelvic problems, Type II diabetes.
Patient 9: Stroke, lung condition, dry eyes and mouth.
Patient 10: Atrial fibrillation, sleep apnoea.
Patient 11: Atrial fibrillation, arthritis, carpal tunnel, diverticulitis.
Patient 12: Coronary heart disease, cataracts, swollen feet.

Demographic data was collected for eight of the participants:

Age	**Ethnicity**	**Residence**
74	Indian	Southall
84	Black Caribbean	Greenford
76	Pakistani	Southall
32	Middle Eastern	Acton
82	Irish	West Ealing
79	African	West Ealing
82	African	Northolt
80	Caribbean	Greenford

ANNEX K: Stakeholder discussions summary write-up

Question

From your perspective how are individuals with long term health conditions - specifically heart conditions if possible - currently supported by services in Ealing. Given that there are a number of related diseases and comorbidities for Heart conditions do you believe the system is set up for prevention and management in a wrap-around approach that the integrated service is aiming for?

Stakeholders:

- **Dr Alex Fragoyannis,**

Ealing CCG Cardiology Lead, GP Partner - Corfton Road Surgery, Governing Board Member - Ealing CCG (IT co-lead, Cardiology, Anticoagulation, Dermatology, Referral Management, Planned Care)

- **Dr. Sapna Chauhan**

Senior Public Health Specialist, Lead on NHS Health Checks in Ealing, Author of the Ealing JSNA reports on Cardiovascular DIsease (2015) and Diabetes (2014)

- **Zoe Sargent**

Associate Director of Community Services for London and Children's Strategic Lead, Ealing Community Partners and Central & North West London NHS Trust

- **Dr. Lindsay Ip**

Consultant Psychologist, Ealing Community Partners

- **Hounslow Nurse**

Summary of discussions:

Dr. Fragoyannis highlighted the integration of IT systems within Ealing and subsequently NW London as one of the leading reasons for a robust and coordinated cardiovascular service in the borough. The use of SystemOne across NWL CCGs is both universally accessible and amendable allowing patient's data to be reviewed and updated by any healthcare professional. This centralised database enables individual healthcare and referral pathway monitoring, providing an integrated and tailored level of care. SystemOne is supported by the Whole System Integrated Care (WSIC) database that enables further analysis of population and sub-populations to understand the demographic distribution and prevalence of conditions like any heart-related conditions to understand how the healthcare system can target increased support specific communities.

For Hounslow, patients are referred through several routes to the Rapid Access Chest Pain Clinic (RACPC) at West Middlesex University Hospital. The service provides; Rapid assessment and diagnosis of patients with suspected angina; Information on treatment options and development of a management plan; and an estimate of overall cardiac risk and information on individual risk factors.

Patients can then be referred via their GP, Ambulatory Emergency Care and A&E. The specialist nurses indicated that it is very common to see patients come through the RACP clinics have multiple risk factors e.g., obesity, diabetes, high blood pressure, hypertension. The Cardiology department at West Middlesex University Hospital diagnose and manage both acute (severe and sudden) and chronic (worsens over time) health conditions related to the heart. They treat people requiring both inpatient and outpatient care and support. Patients requiring admission are seen in the Cardiac Care Unit and if a person requires very specialist cardiac support, this is provided via The Royal Brompton and Hammersmith hospitals. This network of hospital services is also subsequently support by West Middlesex University Hospital's Cardiac Prevention and Rehabilitation service that helps people return to health after their treatment.

Ealing's position as somewhat of a leading example of integrated care is apparent at the next stage of the referral pathway as it was the first NHS CCG in England to successfully develop and launch a community cardiology service. Dr Fragoyannis stated that this service has clearly defined pathways for all common conditions making it a template for all other NWL CCGs and one of the most common pathway driven areas of healthcare that the NWL CCGs have alongside Diabetes.

Instead of patients being referred to a hospital in Ealing they go to Hanwell health centre. Zoe Sargant indicated that the Cardiac care pathway referral process can take between 2hrs to 6-weeks depending on the severity and urgency of the issue. The intricacies of the services are a result of being created by leading. For example, Dr. Fragoyannis mentioned that the cardiology service staff structure ensures that patients only ever see senior doctors with ample training. This training has been part of the concerted efforts within Ealing and throughout the NWL CCGs to educate GPs on cardiology. However, Ms. Sargent alluded to the fact that while there are services specification pathways for other conditions, such as the Community Neuro Stroke Rehabilitation Pathway, there is no such documented pathway for Cardiac conditions.

Dr. Lindsay Ip outlined the most prevalent mental health issues in those with cardiac conditions including depression, anxiety and post-traumatic stress. A major life event related to the heart such as a Myocardial Infarction can leave individuals feeling fragile and as if their identity has changed. This can also relate to feelings of anxiety as individuals are worried about exerting themselves physically in case this causes a similar event. The cycle continues as those who become anxious and subsequently struggle to breath will then worry that this anxiety-related breathlessness will result in a heart event. Devices such as Pacemakers also often brings psychological stress including anxiety and feelings of a change in capability.

Dr. Fragoyannis recognised the variation that would occur for women with heart conditions across the NWL region due to the level of specialisation of services and that this may well lead to the inequalities in health outcomes. In addition, boroughs that do not have this level of specialised community services have extended waiting times for patients which again, can contribute to this inequity in care from one borough to the next. For example, Hounslow doesn't have a similar community cardiology service but does work well with hospital trusts for efficient referrals and coordinated care at West Middlesex Hospital.

However, at borough level, Dr. Fragoyannis mentioned that Ealing CCG and the commissioned local healthcare providers had an agreed policy on low waiting times and that the coordination in care between primary care and the cardiology community service has allowed for efficient and effective care for residents suffering from heart conditions.

The shared system, departmental administration teams and email referral process allows for less duplication in work, more efficient and personalised follow-ups from the relevant cardiology department and ability for healthcare professionals involved in an individual's care (GPs, Clinicians, etc.) to access the same data for a quicker progression of an individual's treatment and care. Further efficiencies within the service pathway comes from conducting any pre-diagnostic interviews prior to preliminary testing via telephone or video before employing a ‘one-stop shop’ style of testing, enabling Echo scans, ECGs, Blood tests etc all to be carried out during one appointment. After preliminary tests, consultants triage all referrals using the same database and email system. Finally, GPs only refer patients that truly need the support of the community cardiology service to prevent overwhelming the service, utilising specialist’s care efficiently and utilise other services in circumstances where patients need less support such as medication prescriptions or community group support for self-management of conditions.

There was, however, evidence from both boroughs that the delivery of a comprehensive pathway of care for these women had not yet been fully achieved. For example, Ms. Sargent noted that while there are service specification pathways for other conditions, such as the Community Neuro Stroke Rehabilitation Pathway [Annex L], there is no such documented pathway for Cardiac conditions. In addition, Dr. Ip suggested that the resources within the community needed to be improved as well as the knowledge amongst healthcare professionals of what is available in the community. Furthermore, as the care in both boroughs that individuals receive once acute care is required was effective, Dr. Fragoyannis suggested that the misconceptions around a lack of care for such woman could stem from an initial lack of access for these women to preventative support. Dr. Chauhan highlighted the lack of timely diagnosis for heart and CVD-related long-term health conditions. For instance, women with diabetes often remain undiagnosed until a serious cardiac event occurs. Dr. Chauhan went on to say that the lack of diagnosis, lack of an efficient and signposted care pathway, and a lack of pre- and post-infarction support services combine to undermine the effective management of long-term health conditions, particularly those related to cardiovascular health. Addressing these issues would significantly reduce unplanned hospital admissions.

Both Nurse Shotter Weetman and Nurse Kaba highlighted the importance of improving prevention in Hounslow as services are able to increase capacity and resources as the pressures of the pandemic begin to eas. They have already launch several prevention initiatives, focusing on health promotion and cardiac care and working in partnership with Hounslow and Richmond Community Healthcare Trust to deliver ‘Right Lifestyle’ Roadshows to help improve resident’s health and lifestyle.

Dr Fragoyannis also alluded to what he perceives may be the root cause of any inequalities seen in Cardiac care. As the commissioner for cardiology services in Ealing over the last 10 years he has seen no worse outcomes or management in women compared to men. The design of the service was not set up to lead to inequalities and that these would stem from more systemic issues, such as general access to services, language barriers or cultural differences in accessing healthcare for women of different ethnicities. However, Ms Sargent recognised the fragmented approach to rehabilitation when it came to the experience profile in question, stating that a patient could be on two pathways, regular physiotherapy as well as rehabilitation for a pulmonary or heart related condition. This results in duplication as patients will have to go through the initial assessment for each branch of rehabilitation that they are attending, in addition to going through their medical history again upon readmission to a rehabilitation service, should another health event occur after their rehabilitation was initially completed.

The discussion with Dr. Chauhan highlighted the systemic issues that Dr Fragoyannis mentioned. Dr Chauhan stated that her findings for the 2014/15 Cardiovascular and Diabetes chapters of the Ealing JSNA that she wrote were still just as pertinent today and that the increased rate of CVD within the more deprived areas of Ealing (Southall, Northolt and Greenford) were likely a result of a multitude of interacting health and lifestyle factors. One contributory factor that Dr. Chauhan highlighted was the lack of timely diagnosis for heart and CVD-related long-term health conditions. For instance, Diabetes is notoriously undiagnosed and is often only identified once a serious cardiac event, such as a Myocardial Infarction occurs.

As lead on Ealing's NHS Health Checks service, Dr. Chauhan stated that these checks are currently the only gateway to diagnosis for women and that individuals who are diagnosed are promptly put on a register that indicates the patient is at risk of developing or has developed a CVD. However, while pre-diabetics, who go on an equivalent register are referred to the 9-month NWL Diabetes Prevention Programme, there is no such programme for those at risk of heart-related conditions. While it was recognised that Diabetes care is a crucial component of care for women with a heart condition, Dr. Chauhan also highlighted that unlike the substantial Diabetes Care Pathway[1]there is no such pathway for patients suffering from a CVD.

The lack of prevention and management strategies within the borough was also a concerning aspect of CVD-related care for Dr. Chauhan. While there is some community support for individuals in the form of healthy walks, the support required from statutory bodies was questioned. While Diabetes education programmes are a clear and effective referral path for GPs, CVD-specific community lifestyle programmes have been decommissioned including the Healthy Walks programme run by the Southall Community Alliance. Dr. Chauhan indicated that this leads to inconsistencies in the level of care that individuals receive as not only are the support pathways scarce but the lack of clear referral pathway and resulting gap in knowledge for GPs who are supporting a woman who matches the experience profile is lacking. GPs are not up to date with what is on offer at a local level and therefore simply refer individuals to national websites for more information as this is a more sustainable, yet generic, 'pathway'.

Furthermore, Dr. Ip echoed that the resources within the community need to be improved as well as the knowledge amongst healthcare professionals of what is available in the community. This is still largely individualised and relies on the knowledge and interest of the healthcare professional that a patient is in contact with. Community support groups are hugely appreciative of this support/advertisement and therefore building on this link between healthcare and the voluntary sector is crucial to improving integrated care and self-management of LTCs. This would enable a shared workload across primary, secondary and community care based on the extent of an individual's health needs, thereby creating a more sustainable system in which partners support each other.

Dr. Chauhan also highlighted the now decommissioned Ealing Healthy Lifestyle Programme (EHLP) as an example of a highly successful community intervention strategy that did prove both statistically successful and received highly positive feedback. The EHLP was a 12-week programme that patients were referred to when, amongst other indicators, they received a high CVD risk score at their NHS Health Check or annual checkup. The success of the EHLP down to its family-based intervention approach and high degree of social interaction. Professional instructors were brought on that supported development over the 12 weeks as well as addressed any barriers and it was all done in a social setting with gym halls being hired out to facilitate EHLP sessions. In addition, the EHLP had a follow up mechanism whereby GPs were informed of the patients' completion of the 12-week course and patients were able to leave their feedback on the programme, producing outcomes and outputs demonstrating what the programme and the individuals had achieved.

When it comes to the need for integration and coordination of support, Dr. Ip had a particularly insightful perspective. Lindsay stated that approximately one third of individuals with long-term health conditions also suffer from mental health issues and that if they do indeed suffer from both, outcomes are far worse in terms of mortality rates and they are 2-3 times more likely to use emergency services. The resulting mental health support required to support individuals with LTCs equates to approximately £10 billion, making integration of physical LTC rehabilitation and psychological therapy one of the biggest value propositions for the NHS. The work being done by Kings Health Partners - combining both physical and psychological support into a dual-aspect, Healthy Mind and Body programme.

Within Ealing, Dr. Ip stated that local healthcare provides psychological support to those who have LTCs via Ealing Community Partners, under the West London Mental Health Trust. Dr. Ip mentioned that rehabilitation is still fragmented both in terms of the care people receive and physical location of said care. In addition, patients have regularly highlighted the need for improvements in communication saying that it would be accepted - to a certain extent - if services weren't optimal, as long as patients felt that they were being included in their care planning, that the services were held to a standard of transparency and that through both means, patient were respected.

With the current COVID-19 pandemic in mind, Clinical Health Psychologists within the ECP are developing the capacity to see patients with Long COVID with Community MDTs currently dedicated to assessing those with Long COVID for the full range of symptoms including any psychological symptoms. GPs can currently refer individuals to this MDT assessment service.

At this point they are trying to combine all rehabilitation services under one umbrella service - Ealing Adult Community Rehabilitation Services - for a holistic approach that will transfer patients to the most appropriate specialty teams and MDT. Ealing Community Partners were due to start the integration of treatment and rehabilitation last March but, due to COVID was put on hold. Much of this restructuring of services is going to involve coproduction and codesign with patients themselves, particularly to understand the challenges they face, the need for a psychological branch within the care package that they receive and how individuals propose that a holistic MDT service would prioritise patient conditions, should they require support for multiple LTCs. This has already begun in certain areas of work with plans to extend this work across both boroughs under the West London NHS Trust.

As an indication of what this would look like Dr. Ip used the example of a patient with a heart condition being referred by cardiologists/ GPs to a rehabilitation service that provided holistic care and support for managing this condition and others by a service that has the capacity and resources to support those with multiple LTCs including pain management services and psychological therapy for mental health conditions that result from physical ones. Ms. Sargent mentioned that the Clincial Director at the ECP, Chris Hilton has been proactive in integrating psychological elements with physical rehab and this was confirmed by Dr. Ip who stated that there is already a psychologist within the Pain Management service in Musculoskeletal team and that the ECP are currently in the process of hiring a psychologist to work alongside Diabetes and Cardiologist teams as well.

Dr. Ip indicated that this care, eventually would become a tri-aspect care service that would provide individuals with access to support for their mental and physical wellbeing as well as utilising PCN link workers to provide support for other contributory health and lifestyle factors. This would ensure that these social prescribers are being optimally utilised and would provide evidence that more funding needed to be available to increase their numbers above just one per PCN.

Dr. Ip highlighted a few barriers to overcome for this integration to take place. One practical factor that this care would need to address is the space for a co-located clinic to enable patient access to the different aspects of care all in the same location. Dr. Ip also stated that as capacity would undoubtedly pose an issue, a stepped-care approach would need to be taken, seeing patients with relatively more complex needs but also providing fundamental support for those considered to have mild to moderate needs.

In relation to the integration of physical and psychological therapy, another question that Dr. Ip believes needs addressing is “How do we make this change systemic?” One suggested approach was looking at how communication is made clearer, possibly through a series of education and training for clinicians that demonstrates how to conduct a mental health screening for such patients and provide the necessary psychological care to these individuals. Dr. Ip mentioned that this is something that the Diabetes team in Ealing is eager to employ. Additionally, all these patients who are screened, regardless of their need for immediate mental health support should receive psychologically informed materials. Within the stepped approach, IAPT could support those with relatively less severe mental health issues and then those with moderate to complex issues that impact individual’s ability to self-manage would be suitable for more embedded psychological therapy as part of their LTC rehabilitation.

Annex L: Community Neuro Stroke Rehabilitation Specification Pathway

SERVICE SPECIFICATION

Specification Number No.	7
Service	Community Neuro Stroke Rehabilitation Adult
Commissioner Lead	Ealing CCG
Provider Lead	
Period	

1. Purpose

1.1 Introduction

Ealing has an estimated MS population of 330 & an MND population of 20. There are approximately 21 people newly diagnosed with MS & 6 with MND per annum. To ensure that specialist community rehabilitation with co-ordinated neurological care is in place for these populations.

The community stroke team receives approximately 250 – 300 referrals per year from discharging stroke units

1.2 Service Aims

Provision of a specialist multi-disciplinary team comprising of physiotherapy, occupational therapy, speech & language therapy, counselling, specialist nursing and clinical psychology. To provide community care for patients with neurological conditions (progressive & acquired), including stroke.

To provide a specialist and co-ordinated, community service for Ealing service-users, with alignment to social care.

Provision of therapeutic rehabilitation, information, support, and advice at all stages of these various neurological conditions.

1.3 North West London Strategic Context

The North West London STP is focused on delivering care closer to home and supporting patients in the community. Ealing have invested significantly to enable responsive services that have shifted settings of care into the community. Key initiatives that have been implemented locally include:

- The Ealing Integrated Model of Care - Joint Care Teams are created with Care Co-ordinators
- Intermediate care services – jointly commissioned with the London Borough of Ealing, providing consultant-led rapid intervention and close collaboration between reablement and rehabilitation to significantly reduce non-elective admissions and facilitate more complex discharges.
- Ealing Standard - to enable more planned care to be delivered close to patients through primary care.

1.3 Evidence Base - National & Local

- National Clinical Guidelines for Stroke (2016)
- NICE Guidelines for Stroke Rehab in Adults (2013)
- NICE Guidelines for Motor Neurone Disease (2016)
- NICE Guidelines for Parkinson’s Disease in Adults (2017)
- NICE Guidelines for Multiple Sclerosis (2014)
- Stroke Strategy for London (2008)
- NWL Five Year Forward View (current)

2. Scope

NHS Outcomes Framework Domains & Indicators

Domain 1	**Preventing people from dying prematurely**	✓
Domain 2	**Enhancing quality of life for people with long-term conditions**	✓
Domain 3	**Helping people to recover from episodes of ill-health or following injury**	✓
Domain 4	**Ensuring people have a positive experience of care**	✓
Domain 5	**Treating and caring for people in safe environment and protecting them from avoidable harm**	✓

2.2 Principles underpinning the Clinical Model

The clinical model has been developed based on the information set out and according to a set of design principles that have been developed in conjunction with local clinicians and which reflect the outputs from previous engagement events with service users.

Principle 1: Community services should work seamlessly alongside primary care

- Population health management in primary care can shape how best to use community-based services for individual patients
- Emphasis on primary prevention (proactive rather than reactive)
- Establish and use formal & informal communication channels between care professionals
- Understanding of pathways to ensure appropriate referral
- Aligning with sector-wide pathways where available,
- Continuing trend of decentralising model of care for LTCs e.g. specialist nursing provided in community
- Education/training on disease conditions so primary and community professionals are working with same approaches to care
- Regular Multi-disciplinary team (MDT) and Joint Care Team (JCT) meetings
- Responsive to feedback from primary care, and adaptable to ensure seamless and integrated care pathways between primary and community services are evident

Principle 2: Community care should be truly 'community' and have a strong sense of local place

- Familiar, consistent local teams working with primary care teams to build relationships and trust, and familiarity with the local patient populations
- Bases/hubs for specific services e.g. palliative care, diabetes, MSK interface, Tissue Viability services
- If services centralised, they should still feel local to the patient
- Good in-reach service into the hospital setting, with escalation policy
- Services are tailored to the needs of the local population, with a workforce that are reflective of the local population
- Services that recognise the value of non-statutory services in the borough and how they can help service users

Principle 3: Care should be based on what matters to each patient

- Care should be planned around and delivered in the context of achieving the goals that matter to patients
- Care should help patients feel empowered and enabled
- It should encourage and facilitate self-management and embrace health literacy as an approach to knowing how best to adapt care to suit individuals
- Patients who already have relationships with specific teams e.g. cancer, Parkinsons, should be able to self-refer to those teams

- From the patient's perspective, care should feel coordinated

Principle 4: The type and route of care delivery should suit the type and preferences of patients. This can mean different modalities for different types of patients.

- Patient segmentation is done not just on clinical or health need, but on personal characteristics, such as: familiarity with technology; school and/or work commitments; caring responsibilities; patient activation levels
- Make routine the use (for suitable patient cohorts) of online apps, web videos, and other non-face to face routes to care
- Pay particular regard to vulnerable populations, e.g. nursing homes, adolescents and young adults

Principle 5: Professionals providing community-based care are delivering at the top end of their licence, enabling primary care to focus on population health management and acute teams to focus on people requiring specialist provision

- Use of best practice from elsewhere such as Home First
- Joint learning and trust at clinical level to enable appropriate transition out of hospital and into community-based care
- Knowing what 'normal' is for each patient
- Building awareness of models of care available in community with acute team colleagues, and vice versa to ensure best use of mutual resources
- Community services actively in-reaching to acute care

Principle 6: Services are delivered in a way that constantly improves health outcomes of the population, by providing high quality of care, efficiently and within financial control targets

- There is accountability for achieving high quality of care for the population of Ealing working with primary care, commissioners and all other providers in the local health and care system
- Services are delivered as efficiently as possible, without compromising on quality of care, wellbeing of workforce and in a way that unnecessarily impacts on waiting times
- Staff are empowered to innovate and work across teams to deliver a holistic approach to the needs to individuals
- The provider and the commissioner work using open book principles particularly around the financial elements.

3. Service description/care pathway

3.1 General Overview

- The Community Neuro & Stroke Rehabilitation Service will provide a responsive & specialist community neurological rehabilitation, to patients with these conditions through a multi-disciplinary and multi-agency framework.
- To provide a single care pathway for patients with progressive and acquired neurological conditions
- To work as part of an integrated care pathway for people who have suffered a stroke, spanning hyper-acute, acute, non-acute settings and community settings.

3.2 Objectives

- To maximise the functional independence of service-users whether at home, in the community or in the workplace.
- To help service-users to manage & remain at home and therefore reduce unplanned hospital admissions due to secondary complications.
- To enable people to lead fulfilled lives at home, work and within the community**.**
- Provide specialist vocational, work retention or returning to work programmes.
- To establish community multi-disciplinary/consultant review clinics for people with MS / all long term neurological conditions

To provide a specialist MS nurse function delivering:

- Provide clinics for relapse management, newly-diagnosed patients, patients on disease-modifying drugs,
- To co-ordinate care in the community
- Establishing links between health and social care.
- To align service with the Independent Living Team social worker to provide specialist knowledge (i.e. housing, benefits and access to respite). To include work around newly-diagnosed & complex patients.
- To develop expert patient and carer programmes, in conjunction with other local services, and to make these programmes available to the target groups.

3.3 Service Description

A community rehabilitation service to support Ealing service-users with progressive and acquired neurological conditions such as stroke, traumatic brain injury, spinal cord injury, and progressive neurological conditions such as Parkinson's Disease, Multiple Sclerosis, Motor Neurone Disease The provision of community-based & out-patient goal based rehabilitation and disability management service.

- Consultant & nurse-led MS clinics.
- Provision of counselling & clinical psychology.
- Alignment to social care support. Vocational rehabilitation service to support return to work or other activities

- Early supported discharge service for all patients leaving acute hospital to support home discharge and reduced acute hospital length of stay
- Build relationships with voluntary sector to support the patient cohort.
- All service-users with English as a second language will have access to local interpreter services.
- The Community Neuro & Stroke Rehabilitation team provides a community domiciliary service and as such has the flexibility to provide appointments at the most beneficial location to the service-user or at a location that is clinically indicated.

3.4 Pathways

Community Neuro & Stroke Rehabilitation will work to locally agreed pathways e.g. for Multiple Sclerosis (MS), Parkinsons Disease (PD) and Motor Neurone Disease (MND).

Community Neuro & Stroke Rehabilitation will work contribute to the development of a local community stroke pathway, in line with NW London and HfL stroke strategy

Community Neuro & Stroke Rehabilitation will ensure that the pathways are streamlined, that they facilitate easy referral and take-up by the service and they systematically work to support the CCGs wider efforts to improve health, wellbeing and independence.

3.5 Whole System Relationships

The service will work jointly with local services to support patients transferring into the community, including:

- Hyper acute stroke units
- Stroke units
- North West London Regional Neurological Rehabilitation Unit
- Acute multiple sclerosis specialist clinics to support
- Community neuro and general rehabilitation beds
- Intermediate Care Service
- Wider community services
- Voluntary sector providers
- Nursing and residential homes
- Social care

3.6 Relevant Clinical Networks and Screening Programmes

The Community Neuro & Stroke Rehabilitation team will work closely & forge pathways with regional specialist neurological centres including Charing Cross Hospital and University College London Hospitals Trust.

3.7 Technology

Central to new ways of working and changing population needs is the effective and innovative use of technology. The service should demonstrate how it intends to utilise the key strands outlined below:

Personal Information Technology - for use by patients/carers of personal technology including apps and networking via personal devices.

Telehealth - The use of technology by patients/carers to support self-care including monitoring, home testing and intervention, where relevant.

Electronic care record – the use of a care record that is accessible by different professionals, across organisations and by the patient

Mobile working – the use of technology by staff to enable them to work remotely within the community reducing the need to return to base and increasing the effectiveness of patient contact through access to the latest clinical information

Workload management – the use of data and technology to plan and monitor workload allocation in order to ensure effective and efficient use of resources.

The service should have a clear strategy for the use technology. Field staff at all levels should be involved in regular activity and outcome review. The service will contribute to monthly dashboards held at network level

3.8 Expected Outcomes

- Decreased reliance on secondary care This to include:
- reduction in unplanned hospital admissions & length of stay
- reduction in initial and follow-up hospital consultant appointments – both at EHT & out-of-area acute settings
- reduction in A&E attendances for patients with long term neurological conditions
- reduction in prolonged length of acute hospital stay when admission is necessary

3.8 Workforce skills

It is not the intention of the Commissioner to prescribe the exact make up or structure of the team delivering this work. Whilst it is important for the provider to ensure the appropriate skills are available to undertake work and provide a safe service in line with agreed guidance and standards, the Provider will be expected to explore innovative ways of making use of personnel and of working with other disciplines e.g. in group activity especially where this may support parents and children and young people who are waiting for fuller assessments.

The Commissioner will expect an open and transparent relationship with the Provider in which it is clear at any time how resources are being used on staffing, the impact of vacancies or staff absence and the measures that are being taken to address issues. The Provider will promote a style of leadership that enables rapid and flexible responses. The Provider will be required to demonstrate the steps it is taking to promote and sustain the right workforce.

3.9 Referral Criteria

Referral criteria & sources for stroke	• The service will accept referrals from designated HASU/SUs and Clayponds Hospital. • Referrals taken from all health sources including Consultant, GP, therapists& Community Nursing.
Referral criteria & sources for progressive neurological conditions	• The service is open to all people with a confirmed diagnosis or strongly suspected diagnosis of a neurological diagnosis • Need to be registered with an Ealing GP. • To be over the age of 18 years. • Referrals taken from all health sources including Consultant, GP, therapists, MS nurses, community nursing. • Patients are able to self-refer once known to the service.
Referral route	• Primary Care • Secondary care. • Community services
Clinical Exclusion Criteria	• Patients with unresolved medical conditions. • Crisis intervention / 24 nursing or medical care. • Patients under the age of 18 years.

3.10 Promotion of Self referral

A continuous increase in service-users self-management through improved awareness of services provided, by increasing self-referral levels into the Community Neuro & Stroke Rehabilitation service

- Demonstrate ability to case-manage complex service-users in the community and to reduce secondary care & out-of-area costs.
- Provision of rehabilitation programmes that help achieve maximum function, improve confidence and promote self-management, facilitate safe & independent living at home– this measured through PROMs (patient-reported outcome measures).
- Community Neuro & Stroke Rehabilitation Support service users to retain or find new employment.
- Alleviate or reduce specific effects of impairment, disability or decline.
- To capture & demonstrate service user satisfaction feedback; monitor & act upon through annual service reviews
- Equip Community Neuro & Stroke Rehabilitation carers of service users with the knowledge and skills necessary to care for their relatives, and recognise when to re-refer to appropriate services

As of October 2019 all referrals will be via the Ealing Single Point of Access (SPA)

3.11 Broader Inclusion Criteria

- Patients registered with an Ealing GP practice, and residing (temporarily or permanently) within 1mile from the boundaries of Ealing who are eligible to receive NHS care
- Patients who reside within the boundaries of Ealing who are not registered to a GP

Exceptions to the above will be:

- Provision of services by the London Borough of Ealing as a component of an integrated services or specification, which require patients to be resident in the London Borough of Ealing
- Specific cohorts of patients whereby reciprocal arrangements may be in place for provision e.g. looked after children

Exclusion Criteria:

- Any patient residing outside of the Borough of Ealing who is not registered with an Ealing GP practice

3.12 Discharge Criteria & Planning

- There will be no pre-set, pre-determined time limitation for duration of Community Neuro & Stroke Rehabilitation input, however, goals initially set are to be periodically reviewed and discussed. This allows for co-ordinated future planning by therapist/nurse/enablement officer and client/family/carer. Goal Attainment Scale (GAS) outcome measures are used where indicated.

- For patients who have suffered a stroke and who do not currently have one of the other two progressive neurological conditions, Community Neuro & Stroke Rehabilitation will provide input at 6 months then yearly or as latest evidence suggests.

- When identified rehabilitation goals have been met or the potential for achieving the goals reached, the decision to complete an episode of treatment will be made in conjunction with the service-user.

- At discharge, service-users are to be provided with a discharge report and onward referral to any appropriate service.

- A satisfaction survey will be undertaken of all service-users [and/or their relatives/carers/advocates] as part of the discharge process

- An ‘at risk’ register will be established for vulnerable service-users e.g. decreased cognition, reduced family support/advocacy in place, previous frequent hospital admission. Such service-users to have an allocated key-worker within Community Neuro & Stroke Rehabilitation, to enable monitoring at agreed regular intervals. As per Best Practise suggests London Strategic Neuroscience network LTC register with an annual review, triage post telephone call or in clinic.

- Any appropriate information required by other health and social care agencies as part of the service-user’s on-going care will be provided to said agency subject to the service-user’s [or their legal advocate’s] permission.

- All discharge correspondence completed within 3 days of discharge.

3.13 Self-Care and Patient and Carer Information

The Community Neuro & Stroke Rehabilitation service places a strong emphasis on service-user (and family/carer) education and therefore self-management & self-care. Where this is not possible e.g. social isolation, decreased understanding, then a review support system is put in place.

To this effect, Community Neuro & Stroke Rehabilitation service will ensure that adequate information is available in the appropriate format for service users and their family/cares to address their health, social, emotional or psychological needs.

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To this effect, Community Neuro & Stroke Rehabilitation service will ensure that adequate information is available in the appropriate format for service users and their family/cares to address their health, social, emotional or psychological needs.

4. Waiting Time Thresholds

Referral Response Thresholds

Emergency (supported discharge suitable for ESD)	48 Hours
Urgent	2 Weeks
Routine	4 Weeks

5. Applicable Quality Requirements

5.1 Applicable Quality Requirements (See Schedule 4A-C)

1.2 Applicable CQUIN goals (See Schedule 4D)

6. Location of Provider Premises & Hours of Operation

6.1 Location

The service will operate from the current provider location until further agreement post transformation.

Current Location: Clayponds Hospital and Ealing Hospital

The service is provided in a range of community settings as appropriate to meet the outcomes for the patient within the 7 Ealing GP networks. The service will provide sufficient assessment and treatment clinics to meet the demand for the service and to allow equitable access for all residents.

6.2 Days and hours of operation

Initially the provider will follow the current hours of operational until further agreement post transformation

Future operational hours post transformation

In line with the 7 day service initiative, and extended hours operated by GP access clinics, all adult community provision delivering non-urgent care will provide care between 0800 and 2000, 7 days a week. In year one this will be delivered as per current specifications and for year 2 the provider and commissioner will agree a transformation plan to reach 7 day care delivered between 08:00 and 20:00.

Community services providing unplanned care will provide a service 24 hours per day, 7 days a week, 365 days a year. The provider will need to determine the optimal staffing structure for the 24 hour period (and adjust for seasonality as appropriate) ensuring that capacity is matching demand throughout the 24/7/365 period. It is expected that the care overnight will include the ability to respond in a crisis.

The bidder will be required to set out its plans to be able to achieve this during year one and by October 1 2019. Until October 1st 2019 services should be delivered as per the current specifications.

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[i] *The North West London health district includes Ealing and Hounslow, as well as Brent, Hammersmith and Fulham, Harrow, Hillingdon and Westminster (the Royal Borough of Kensington & Chelsea and Queens Park & Paddington)*