Healthwatch Central West London

Co-ordinated care? Patients' and their carers' experiences of living with long-term health conditions in Westminster

2018

Contents

Acknowledgements

Thank you to all the members of the Advocacy Project Older Adults group who attended the Project Group for this project – we could not have done it without you! Thank you also to all the people who responded to our survey and those who gave up their time to attend focus groups.

1. Introduction

A key aspect of Healthwatch Central West London's (Healthwatch CWL) work is to provide information to the public about healthcare and changes in local provision. We also listen to people's experiences of accessing healthcare.

In 2016 – 2017 Healthwatch Central West London (Healthwatch CWL) held a series of public meetings at which we asked local people about their experiences of health and care services in their area. People told us that there was little support to help them stay well and manage their long-term health conditions. Others reported that they were unsure of how to access additional support for people living with long-term health conditions. They were concerned that friends and neighbours were slipping through the net and not getting the support they needed.

Long-term health conditions include conditions such as: Diabetes, lung and heart conditions, Multiple Sclerosis, and Muscle Skeletal Disorders, amongst others.

To find out more about what support people were receiving and what support should be available for people with long term health conditions Healthwatch CWL teamed up with the Older Adults Group at the Advocacy Project. We set up a small steering group of four older adults who advised and directed the work. We met every two weeks from April to September 2017.

The Project Group agreed that there is a need to monitor the support available to people with long term health conditions offered through GP practices to ensure that it is meeting people’s health and support needs; and to ensure that people who use the service can influence how the service is evaluated and improved.

With changes to primary care still to come there is a need for Healthwatch CWL to closely monitor whether these changes are benefiting local people. We set out to discover more about people’s current experiences of support offered through GP practices to help them manage their long-term health conditions. We created a survey and held a series of focus groups in which we talked to patients and carers about their experiences of using primary care to help them manage their, or the person they care for, long-term health condition.

This report sets out the survey responses and focus group discussions in the context of the changing environment in provision of primary care across the borough. It aims to build a comprehensive picture of patients' and carers’ views and experiences of accessing support through primary care for long-term health conditions. This will enable key decision makers, commissioners and providers to better understand the types of provision that local people need and prefer to help them stay well and manage their long-term health conditions.

The main questions explored are:

- What type of support patients received through their GP practice to help them manage their long-term health condition; and
- How easy was it for patients to get the help they need for their long-term health condition through their GP practice.

2. Methodology

What did we do?

To hear more about people's experiences of living with a long-term condition and how their GPs supported them, with the Project Group we co-designed a survey for people with long term health conditions or their carers, which was live through June to September 2017. We promoted this on our website and through partner agencies. In total, we received 45 responses.

The Project Group invited three Care Navigators from the Care Co-ordination Service provided by Central London Healthcare to tell us more about the service that they offer.

The Project Group held four focus groups in August and September 2017, which included one for carers. Participants were recruited by working with other organisations such as Open Age Westminster; Carers Network; and Breathe Easy Westminster. We spoke to 35 people in the focus groups.

Further telephone interviews were held in September – November 2017 with people with long-term health conditions or their carers living in Westminster who were identified through the survey.

The survey focused on:

- What type of support patients received through their GP practice to help them manage their long-term health condition; and
- How easy it was for patients to get the help they need for their long-term health condition through their GP practice

In the focus groups we explored this in more depth and also asked participants what could be changed so that their health needs were better met

Who did we speak to?

This report includes the views of 85 people either living with long-term health conditions or caring for someone who has a long-term health condition in Westminster. The people we spoke to each had a range of long term health conditions including Diabetes, respiratory conditions, Multiple Sclerosis, and Muscle Skeletal Disorders, amongst others. The majority (86%) of people we spoke to had had their long-term health condition for over three years

The ages of the people who engaged with us ranged from one person in the 18-25 age group to those above 80 years. Over two-thirds of people we spoke to were aged 60 years or older (77%); with just under half (49%) aged 70 years or older.

Half of the respondents to the survey stated that they were carers (50%). In the focus groups about a fifth (22%) said that they were carers. We carried out one focus group specifically for carers; this was attended by eight people.

Not all respondents to the survey informed us of which GP practice they were registered at but the 25 that did, were registered at 16 of the GP practices in Central London and two in Queen's Park and Paddington area. There was a good spread across the borough, although this was slightly weighted towards the north.

3. Background information

Healthwatch CWL held a series of focus groups and surveys in Westminster during June and July 2016. These highlighted that local people were unsure of how to access support for people who were struggling with their long-term health conditions. People were concerned that friends and neighbours were slipping through the net and not getting the support that they needed.

At the same time care coordination services in GP practices in Westminster were changing. A new Care Coordination Service (CCS) was launched in July 2016 by Central London Healthcare (CLH). Initially this was to be a two year offer with a social prescription element being piloted in selected GP surgeries in 'Wave 1 Villages'. The social prescription offer was subsequently rolled out to most GP practices in Central London CCG.

Social prescription

"Social prescribing enables GPs, nurses and other primary care professionals to refer people to a range of local, non-clinical services. Social prescribing seeks to address people's needs in a holistic way. It also aims to support individuals to take greater control of their own health."

"Social prescribing schemes can involve a variety of activities which are typically provided by voluntary and community sector organisations. Examples include volunteering, arts activities, group learning, gardening, befriending, cookery, healthy eating advice and a range of sports."

The King's Fund[1]

Changes to local health and care systems

The Five Years Forward View[2], published by NHS England and its partners sets out the vision for the future of the NHS. It notes that 'long term conditions are now a central task of the NHS; caring for these needs requires a partnership with patients over the longer term rather than providing single, unconnected "episodes" of care.'

Both Westminster City Council and Central London CCG are working to create a local care system that is integrated across health, social care and voluntary sector partners to support people's health and wellbeing outcomes. The North West London Sustainability and Transformation Plan (STP) for the eight CCGs in the STP footprint set out that this can best be achieved through an accountable care system that incorporates an integrated system across health and care, supported by joined up funding and aligned outcomes for local people. This aim is being supported at a local Westminster borough level by the Westminster Health and Wellbeing Strategy 2017 – 2022 and Central London CCG's Primary Care Strategy.

The projected number of people living in Westminster with a range of long-term health conditions is expected to rise over the next ten to 15 years.[3] The Westminster Health and Wellbeing Strategy 2017 – 2022 has as one of its priorities a commitment to reduce the risk factors for, and improve the management of, long-term conditions. Likewise, CLCCG also has a commitment to better care for people with long-term health conditions in its Primary Care Strategy. These are set out below.

Westminster Health and Wellbeing Strategy 2017 – 2022

The Westminster Health and Wellbeing Strategy includes a specific priority aimed at improving support for people living with a long-term health condition in Westminster (Box 1). This includes a commitment to consider the experiences and needs of people with long-term conditions and working with them and their carers to develop services. There are a range of outcomes underpinning this priority, including:

- *'I have a named point of contact who understands me and my condition(s).*

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[1] https://www.kingsfund.org.uk/publications/social-prescribing
[2] https://www.england.nhs.uk/ourwork/ltc-op-eolc/ltc-eolc/our-work-on-long-term-conditions/
[3] http://www.centrallondonccg.nhs.uk/media/47656/Evidence-Base-FINAL.pdf

- *I feel that the health and care services and staff I engage with understand my specific needs and listen to me'*, and
- *'I am supported to remain independent and stay living in my own home'*.

Box 1: Westminster Health and Wellbeing Strategy 2017 – 2022

Priority 2: Reducing the risk factors for, and improving the management of, long-term conditions, such as dementia

Aim:

- Reduce the risk factors associated with long-term conditions
- Reduce the risks of developing complications from long-term conditions
- Improve care and support, and ultimately, outcomes for people with long-term conditions

Commitments include:

- Considering the experiences and needs of people with long-term conditions and their carers by working with them to develop services
- Support community resilience by ensuring that local services take into account the diversity of experience and background of people with long-term conditions and their carers
- Support the development of a health and care workforce that is agile and responsive to patient and community needs. This will include creating teams of professionals who can work across specialisms and signpost people to our community assets and facilities which can support people to improve their health and wellbeing

Outcomes:

I can access services which address all my needs and have an awareness of how my lifestyle, such as my housing situation, impacts my health and my access to services. My wider health needs, including accessing opportunities for physical activity, are addressed and supported.

I have input in the development of my care plan with my family and carers. My carers are supported to care for me and have their own needs recognised.

I have a named point of contact who understands me and my condition(s). I feel that the health and care services and staff I engage with understand my specific needs and listen to me.

I believe that the professionals involved in my care talk to each other and work as a team.

I am supported to remain independent and stay living in my own home.

Central London CCG Primary Care Strategy

Central London CCG's Primary Care Strategy also includes a specific priority for better care for people with long-term conditions (Box 2). This will be achieved through improved joint working within General Practice and with other care services. An accountable care approach will be developed to provide a unified approach.

Box 2: Central London CCG Primary Care Strategy

Central London CCG's vision

"improve the quality of care for individuals, carers, and families, empowering and supporting people to maintain independence and to lead full lives as active participants in their community".

Specific local priorities include:

- Improving health and wellbeing
- Better care for people with long-term conditions
- Better care for older people

These priorities will be delivered through:

A new approach to providing health and care that:

- Prioritises more joint working within general practice and with other care services wrapped around the registered lists of groups of practices
- From primary care upwards, develops an accountable care approach that underpins a unified approach to all care delivered within Westminster
- Increases payments based on outcomes rather than activity

GP practices in the London Borough of Westminster

The London Borough of Westminster has 34 GP practices covered by Central London Clinical Commissioning Group. A further ten GP practices in Queen's Park and Paddington are covered by West London Clinical Commissioning Group. Each of these CCGs has commissioned a different type of primary care support for people living with long-term health conditions. Central London CCG commissions the Care Co-ordination Service provided by Central London Healthcare. Queen's Park and Paddington patients are covered by West London CCG's My Care, My Way provision.

Care Co-ordination Service

The Care Co-ordination Service (CCS) provides administrative support for GPs and care navigation for patients in some practices. It provides care planning support for people with complex and long-term conditions. It replaces the Patient Referral System and all patients should be able to access it to assist them in booking referral appointments. Extra support through proactive care is provided to:

- Anyone over the age of 65 years
- Anyone over the age of 18 who has one or more long-term condition
- Anyone whose clinician agrees they would benefit from the service

The CCS provides support to 33 GP practices in Central London, divided into nine villages. Three villages were part of Wave 1 and received an enhanced service that included access to a Care Navigator who provided a social prescription function.

Care Navigators mostly contact patients by telephone; this is done at the request of the GP who remains responsible for that patient's care. Care navigators can link patients into local community and voluntary organisations to help them manage their long-term health condition. They can also contribute to preparing a care plan. They are not a named person for the patient to contact, although they may help to co-ordinate services.

We included a question in our survey that explored whether respondents had benefited from a range of options that mapped onto the tasks identified as being part of the Care Co-ordination Service commissioned by Central London CCG (Box 3).

However, not all survey respondents or focus group participants told us which GP surgery they were registered with and were not always aware of the names of the service they receive, or which CCG was their local commissioner. As a result, it is not possible to be clear which provision was being referred to. Therefore, this report does not offer a view on how well the CCS is helping to support people living with long-term health needs.

Box 3

Survey Question 3: Which of the following has your GP, or someone from your GP practice helped you with? Please tick all that apply.

- Help to create a care plan that was tailored to your health needs and goals
- Booking and co-ordinating your appointments
- Referring you to services identified in your care plan
- Being a single point of contact for all your referral, care plan and co-ordination queries
- Assisting you to better maintain and improve your health and wellbeing
- Contacting you regularly to see how you are getting on and providing encouragement
- Giving you extra support when you feel your health was getting worse and when you needed help to improve or maintain it
- Providing assistance for you when you are struggling to co-ordinate care for yourself
- Telling you about community-based wellbeing services or activities

My Care, My Way

The London Borough of Westminster also includes the Queen’s Park and Paddington area. This part of the borough contains about a quarter of the GPs in Westminster (ten) who come under West London CCG. Older patients can access My Care, My Way, which specifically supports the health and wellbeing of local people who are aged 65 and over to help keep them well, closer to home. It is a multi-organisation collaboration led by West London CCG and includes GP surgeries, hospitals, local community and social care services as well as local voluntary organisations.

Two respondents to our survey stated that they were registered at GP practice covered by West London CCG. One had been referred to My Care, My Way. This respondent had received physiotherapy, had been contacted at times when they needed some additional support and were visited by District Nurses twice weekly. They reported that it was easy for them to get the help they needed.

However, the other respondent registered at GP practice covered by West London CCG had received no support and reported that they found it very difficult to access the help they needed.

4. GP practice support for people living with long-term health conditions

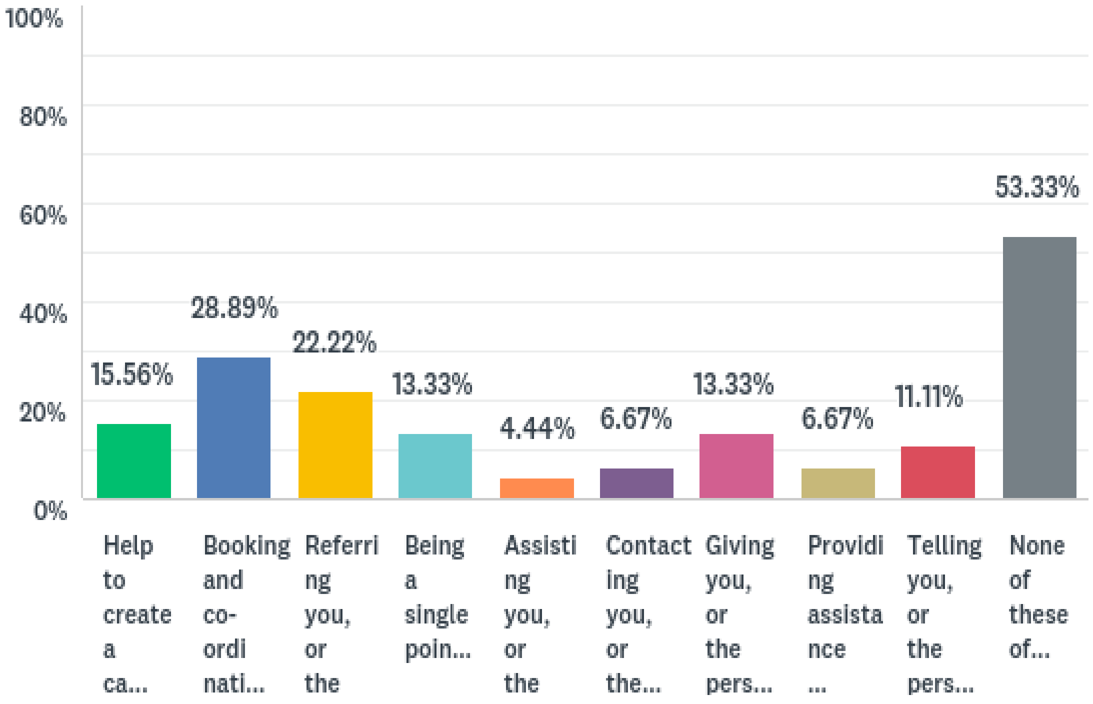
What type of help do patients with long-term health conditions receive from their GP practice?

We asked people what type of support they received to help them manage their long-term health condition. In our survey we listed a range of different options based on those offered through the Care Co-ordination Service:

Support offered	**Number of respondents out of 45**
Help to create a care plan that was tailored to your health needs and goals	7
Booking and co-ordinating your appointments	13
Referring you to services identified in your care plan	10
Being a single point of contact for all your referral, care plan and co-ordination queries	6
Assisting you to better maintain and improve your health and wellbeing	2
Contacting you regularly to see how you are getting on and providing encouragement	3
Giving you extra support when you feel your health was getting worse and when you needed help to improve or maintain it	6
Providing assistance for you when you are struggling to co-ordinate care for yourself	3
Telling you about community-based wellbeing services or activities	5
None of the above	24

As can be seen, **just over half** of all respondents **had not received any** of the options listed above. Over a quarter (28.9%) had had help with booking and co-ordinating appointments and just under a quarter (22%) had been referred to services in their care plan. In the focus groups, a number of participants stated that this had been better under the Patient Referral System.

Most notably, only two respondents had been offered help to maintain and improve their health and wellbeing. Only three had felt that they had received assistance when they were struggling to co-ordinate their own care or had been contacted to see how they were getting on.



Graph: What type of help do patients with long-term health conditions receive from their GP practice?

Care Co-ordination Service Wave 1 Village GP practices

As each of these tasks were identified as being part of the Care Co-ordination Service offered through all Wave 1 Village GP practices, we looked at what our data could tell us about the support that people registered at these GP practices received.

Not all respondents to the survey informed us of which GP practice they were registered at; however, **12 did tell us that they were registered at GP practices in one of the Wave 1 Villages**.

One of the 12 respondents said they had received **all the support options** in the question; a further four respondents had received at least one of the options with help to book and co-ordinate appointments the most frequently chosen option.

However, **eight of the 12 people (66.6%)** registered with a GP practice in a Wave 1 Village had received **none of the options** set out and rated it as **difficult or very difficult** to get the support they need. This compares to just over half (53.3%) of all respondents as a whole.

We took a closer look at the open responses that the 12 people who were registered with GP practices in the Wave 1 Villages gave, to build up a more comprehensive picture of the type of support they were receiving and any difficulties they encountered.

Assistance to maintain health and wellbeing

Concerns were raised about managing regular medication and about how well these were monitored:

- “I am currently struggling to get a medication review, after four years on the same dose and medication and it seems impossible.”

There were also questions about what health conditions can be managed through primary care and how patients with other conditions can be supported:

- “Not all long-term conditions and disabilities are included in primary care services. This is a real problem for those patients who live far from a hospital.”

Extra support when health is worsening

We heard of some good experiences where people were able to access the help they needed:

- “I put easy rather than ok although it is not always easy to get an appointment to see the GP who knows me most. Having said that a doctor will phone you on the day and see how to help me and will refer me on if necessary.”

However, others found it hard to get support when they were unwell:

- “Support is fine when health is reasonably good, but not so during a bad experience for 3 months - told ‘but you have an incurable progressive condition’.”

And worryingly, it appeared to be hard to get a home visit even when that was the advice they had received from NHS England:

- “Forced to attend GP appointments in winter when weather is just above freezing, which is against advice and alerts I get from NHS England via email..”
- “Unable to arrange an appointment at time of being unwell. Constantly refused home support including INR test by district nurse.”

There were also concerns about accessing a GP when needed at weekends:

- “When my (adult) son aspirates I need immediate help like antibiotics for chest infections as sometimes I have to wait weekends to pass then he has to be seen so it drags on and my son’s suffering is unbearable.”

Single point of contact

The importance of having one person who knows and understands their health conditions was flagged:

- “She knows me, I trust her and can check things out with her. I don’t like to talk to loads of different people.”

Integration of health, care and community services

We heard of some good experiences of where services had worked well together:

- “Staff are all helpful and considerate and always able to help me find what I need, for example information from the Maggie Centre at Charing Cross hospital.”
- “My GP is available to review the medicines after discharge of hospital with too many medicines as recommended by the Hospital and would refer to Secondary Health Care Team to review or prompt to take action.”

For others, their experiences were less positive:

- “No support at all as community services reserved for COPD and Asthma patients. I have breathing problems but not those, so nothing is there for me.”

We asked for more information on people’s experiences of support through their GP practice:

Assistance to maintain health and wellbeing

Some people had good experiences of their GP helping them to maintain their health:

- “My GP knows me well and can see when I am not good. He always asks – ‘how are you, is there anything else you need?’ (Focus group participant).

Others were concerned about whether a GP was the right person to help with their condition:

- “Do GP’s have specialised knowledge on conditions? They lack the in depth understanding of Dementia”, (Focus group participant).

Integration of health, care and community support

People discussed the **lack of integration or coordination between services**, stating that they had to call several services to get hold of one service:

- “I have been passed on from one service to another. GPs are unable to signpost people to the right kind of services, they don’t know what is available – how can they? I wish they did!”, (Focus group participant).
- “I had to make several phone calls before finding out my elderly mother needed to access an Admiral Nurse. I didn’t know about this, they could have just told me, but I had to keep ringing for help”, (Focus group participant).

There were also concerns that services did not seem to communicate well with each other:

- “The lines are not all joined up. I have to remember for my mother and follow up. There needs to be better communication between doctor, chemist and district nurses. For example, district nurses frequently turn up to see my mother when she is at the day centre - they should collate information that is regular”, (Focus group participant).

- “Mum needed her feet doing, took a few calls and some confusion from GP to service, which mum only luckily got due to cancellation. Was a bit confusing and I (her daughter) had to chase it up. That service no longer available. Post stroke feet very important. The treatment was very helpful” (Survey respondent).

However, there were some positive experiences where support had been available following a hospital admission:

- “If you need help home visit district nurse they are good. Mum had a Neuro rehab team after hospital who were fantastic and most of ongoing stuff came from them”, (Survey respondent).
- “I see the GP for my prescription, they are supportive. Pharmacy delivers my prescription” (Focus group participant).

One person with a Central London CCG GP had heard from a friend about My Care, My Way:

- “West London CCG have a Care Navigator system that was co-produced by patients and carers, it is good”, (Focus group participant).

Support for Care Plans

Care plans were discussed in each of the focus groups, with only two participants stating that they had a care plan:

- “I have a care plan that my GP arranged with me. I know him well, he has been my GP for 40 years, that is important, we know each other”, (Focus group participant).
- “I had a care plan from the hospital when I was discharged. My GP ignored it and said, ‘Oh no, you don’t need that’. GPs should listen to hospital consultants. The care plan was never used”, (Focus group participant).

Most focus group participants **did not know about care plans**, had never been offered one by their GP, and did not know how to get one:

- “What is a care plan, what does it cover?”, (Focus group participant).
- “How do I know if I should have one? No one has ever mentioned it to me, now I don’t know if I should ask!”, (Focus group participant).

Single point of contact

The importance of having a single point of contact was mentioned to help manage different appointments and maintain focus:

- “As mum’s carer I organise everything and one point of contact would be helpful for all things. Once discharged from them it's a matter of joining up dots and having energy to keep on it”, (Survey respondent).

However, the single point of contact needed to have some authority:

- “There is a new Healthcare Assistant in charge of care planning and now there is no priority for appointments for people over 75. It is hard to get help when I need it”, (Survey respondent).

How Easy or Difficult is it for patients to get the support they need for their long-term health condition through their GP practice?

In our survey **about a third** of respondents said that it was Very Easy, Easy, or OK, **two thirds** said that it was **Difficult**, or **Very Difficult**.

Very Easy	13.33%
Easy	11.11%
OK	6.67%
Difficult	31.11%
Very Difficult	37.78%

We asked for more information on why they had picked each option in the survey and also discussed this in the focus groups. Those that found it **Very Easy, Easy, or OK** stated that:

- “My GP is very good and I’m one of the lucky ones”, (Survey respondent).
- “I get support when I need it”, (Survey respondent).
- “GPs are helpful on the phone but do not visit”, (Survey respondent).

For those who found it **Difficult, or Very Difficult**, their responses included:

- “GP has a busy surgery and they have too many people to see at any time, patients are given very little time individually”, (Survey respondent).
- “It’s currently very difficult to get any response from the GPs at the surgery I use at all. I am currently struggling to get a medication review, after four

years on the same dose and medication, it seems impossible", (Survey respondent).

- "Not all long-term health conditions and disabilities are included in primary care services. This is a real problem for those patients who live far away from a hospital", (Focus group participant).

What experiences did patients have in trying to get support for their long-term health condition through their GP practice?

We heard that some people had **good relationships with their GP:**

- "We talked about things; we know each other well", (Survey respondent).
- "…if I need something my GP practice is very good if the GP knows my son very well (son has complex health needs). Sometimes with a new GP I have to explain a bit more, but I feel every GP should know my son's condition without my explanation – it should be available for them in his records", (Focus group participant).

Attitude of staff working primary care settings

However, others had experienced **difficulties**. In the focus groups participants talked about the **attitude** of GPs, consultants, doctors in Urgent Care settings and other GP practice staff. One participant talked about hearing a Practice Manager openly saying that they did not believe in care co-ordination or double appointments for elderly patients. Others had similar experiences:

- "Doctors can have a poor attitude towards the elderly patients, we become a burden" (Focus group participant).
- "They say, 'you are old, what do you expect?' but I am trying to say this is something that I need them to do something about. They don't listen" (Focus group respondent).
- "When I phone them or visit them on my mother's behalf they seem surprised that she is still alive. She has a range of complex conditions. They do not know enough about Dementia, cannot help with mobility issues or support with her heart condition. They know nothing about what other support is out there in the community" (Survey respondent).
- "The person I care for complained that the GP does not look at them rather concentrate on the computer screen, it becomes tick box exercise rather than human contact. GP has busy surgery and they have too many people to see at any time, patients are given very little time individually" (Survey respondent).

Booking appointments to see GP

In both the focus groups and telephone interview people talked about **difficulties making appointments:**

- “We can hardly get through to the phone to get appointments. We hang on for 30 to 45 minutes and when we get through, most of the time all appointments are gone, or our GP is not available. For 10,000 patients, there should be more than two people answering the phone”, (Survey respondent).
- “Making appointments is difficult. Queuing in the rain and cold with an exacerbation for 30 minutes for same day appointment. Phoning at 8am is permanently engaged. 111 said they did not have access to weekend appointments”, (Telephone interviewee).

The importance of seeing **the same GP,** who knows the patient was often mentioned in both the focus groups and the survey:

- “No one is giving me support so it is difficult. Takes months to see the same GP who knows me – this is important to me; they work part-time”, (Survey respondent).
- “It feels like people go through a system, there’s no personal touch. I want to see someone I know, who knows me”, (Focus group participant).

Pressure on GP’s time

From the discussions in the focus groups it was clear that patients are aware of pressures that GP practices may be under:

- “GPs have a lot of patients on their books, no wonder it is hard to get an appointment”, (Focus group participant).
- “Care Co-ordinators are only at my GP surgery for one day each week and therefore have limited time, what can they do in that time?”, (Focus group participant).
- “Consultations with GPs are time limited and it’s difficult to discuss my health issue in detail”, (Focus group participant).

What did carers tell us?

Amongst carers there was a high level of dissatisfaction with the support they received from their GP practice, with the general feeling being that there was limited provision available for them.

One participant’s mother who was in her 90s and has Dementia, lives in Westminster but she herself lives in the North of England, travelling to care for her mother three times a week. She is not considered a carer by her own GP because her mother lives in a different area, so she receives no support for her caring role. She has been unable to access support for carers local to her mother in Westminster.

- “My mother’s GPs have provided very little support; I had a call from a ‘care navigator’ only once. The issue raised with the care navigator was about making adaptations in the property. The care navigator’s response was that it was not within their remit; they didn't tell me where I could access help. There was no signposting. I finally got information to contact the Occupational Therapy team through another source", (Focus group participant).

- "We get ignored by the GP. We don't have access to medical records and if they (GPs) don't talk directly to us, then we don't have the information either. My husband won't always tell me what I need to know – so what am I meant to do?", (Focus group participant).

Carers also told us through the survey that it was hard for them to get the help they needed through their GP surgery:

- "I'm the carer. I feel that the GP and all concerned leave too much up to me. I feel that there should be better co-ordination and it should not all fall on my shoulders", (Survey respondent).
- "Referrals have long waiting lists. GP surgery is always busy. GP waits for a crisis situation before the matter is taken seriously. The person I care for has been complaining about black outs and irregular heartbeat, but GP did not take any action, they had a seizure and ended up in hospital. If action was taken sooner and they were taken seriously, perhaps the hospital admission could have been prevented", (Survey respondent).
- "Soldiering on month after month, year after year, managing care for my husband is very demoralising. I am over 70 myself and wonder how much longer before my own health degenerates" (Survey respondent).

One carer in a focus group did say that the GP surgery had been helpful as the person he cared for had Dementia. He also got support for himself as a carer. However, he had been registered with the surgery for 40 years and had a positive relationship with the doctor.

Support for mental health conditions and wellbeing

How well people's mental health and wellbeing was supported by their GP practice was mentioned. We heard that people struggled to get help when it was needed and at times got sent from one service to another, with the GP unable to meet their needs:

- "It's hard to write about. My diabetes services are WELL co-ordinated. Not so mental health services re. my partner's apparent early onset Dementia (still uncertain what's going on). I feel like we have been left dangling, offered self-referral to IAPT", (Survey respondent).
- "They aren't much help and we get pushed from GP to local mental health care providers - 'oh that's a physical problem'; 'oh that's a mental health problem'. Person needs to be treated as a WHOLE", (Focus group participant).
- "I recently contacted Mind for help with depression as GP request for this was not forthcoming", (Survey respondent).

What support do patients with long term health conditions expect from their GP practices?

We asked people attending the focus groups what could change to make the support they receive through their GPs better. The discussions were wide ranging, but there was some agreement:

Communication and information

There were concerns raised about GPs and consultants not communicating well with each other and at times disagreeing on diagnosis. In addition, communication from the GP surgery to patients can be poor and information given not helpful:

- "I received a booklet from my GP surgery on physiotherapy. The booklet was really badly designed and was not useful."

Face-to-face support was not always available, with more support now being offered over the phone or through booklets/written information. This meant that not all diagnosis could be discussed in detail.

There was also general consensus that people should take personal responsibility for managing their own health conditions, but that support was needed to help with this. GP practices need to operate in a way that supports this, including sending reminders for appointments in formats that are accessible to the patient. The focus groups were split on whether a text message was useful for this, suggesting that patients need to be offered a choice.

Furthermore, there was a demand for more information on how to self-manage their conditions and where to get additional support.

Involving patients

Patient Participation Groups (PPGs) were flagged as ways for patients to really make a difference to what services and support was on offer at their GP practice. However, very few participants were aware of PPGs and did not know how to contact theirs. Amongst those that were part of the PPG at their GP practice, there was a view that they were not well supported, and that Practice Managers need to know that they should put resources into them:

- "I attend my PPG but there's normally only three of us and nothing changes. They just give us a room then don't listen to what we say."

Integration of health, care and community support

There was frustration that different services were not talking to each other, resulting in people having two or more appointments booked at the same time, in different locations. Or having appointments for different clinics at the same place but on different days:

- “It’s hard for me to get the bus there, then it’s a bit of a walk. Why do I have to go three times in one week when I could do them all on one day? They are right next to each other!”

Focus group participants had not heard of ‘social prescribing’ and there had been little information given to people about community or voluntary services that could help them manage their health condition, or support their mental wellbeing:

- “Some weeks I don’t go out for days at a time. There must be things I could do but I don’t know. Those are the days I hate, makes my feet hurt more – no distraction see.”

A single point of contact

There was a general consensus that the single thing that would make the most difference would be to have a named person who could be contacted when more help was needed or when information about their condition was needed:

- “Mostly I manage, I get by, but those times when I’m not managing, or my prescription has changed, or I have a new thing going on, then I really want someone I can just ring or drop in to see. Someone who knows me and what I’ve been through.”

Peer support

There was interest in local peer to peer support possibilities for patients with specific conditions, with some oversight from the GP practice. This would allow people to share their experiences and learn from each other:

- “I’ve learnt more from being at this focus group and talking to other people than I ever do at the doctors! We’re all kept apart but we could help each other – all we need is a room. And a cup of tea and biscuits!”

What would help patients and carers manage their long-term health condition?

Focus groups participants had plenty of thoughts on what could change to make the support they receive through their GPs better:

- “Better communication for those over the age of 75’s - a letter can be sent annually to those over the age of 75 with all the necessary information such as vaccines or other services they are entitled to.”

- “A Yearly Health MOT check for patients over the age of 75.”

- “GP’s should prioritise the elderly and offer support to make appointments.”

- “All GP surgeries need to have some standard practices about how services are co-ordinated.”

- “Dedicated time for consultation with the doctor so that you’re not being rushed.”

- “Patients with long-term health conditions can be sent a letter with information on services available, and not just health services, all the other wellbeing ones as well.”

- “Linking together all wellbeing services and letting patients know about them, including nutrition and exercise.”

- “To look after my mental wellbeing alongside my physical health.”

- “A named Co-ordinator based with my GP who I can contact directly and meet with if I need to.”

- “Someone to talk to after the consultation so I can check that I have understood and know what I need to do.”

- “It would be good to get reminders from GP surgeries to make appointments.”

- “A care plan should include practical support. It should also include an indication of what health changes to expect and forward planning for progressive conditions for carers.”

- “Carers need their own care navigator, who looks out for their support needs.”

6. Conclusions and Recommendations

This report aimed to provide a picture of the experiences of people living with long-term health conditions and their carers in Westminster. The main questions explored are:

- What type of support patients received through their GP practice to help them manage their long-term health condition; and

- How easy it was for patients to get the help they need for their long-term health condition through their GP practice.

We heard mixed experiences of the type of support available through GP practices to support people to manage their long-term health conditions. It was very apparent in focus group discussions that the support on offer varied depending on which GP practice participants were registered at.

We heard that some patients and carers have good experiences of receiving help to manage long-term health conditions. The relationship built up with the GP and having a personalised response to their health or care needs seemed to be key to this.

However, two-thirds of our survey respondents said that they found it hard to get the help they needed to manage their long-term health condition from their GP practice. They, and the focus group participants highlighted a range of difficulties that they encountered.

As local health systems are changing in Westminster through Central London CCG's proposed Primary Care Strategy and the development of different accountable care partnerships to deliver a more integrated health and care offer for local residents, it is important that the voices of patients and carers are kept central to considerations of new ways of working, and when commissioning and evaluating services. We have heard from patients and carers about their experiences of living with, or caring for someone with, a long-term health condition in the borough of Westminster and their aspirations of how the health care and support they receive could be improved.

1. Clear patient pathway

Patients and carers would like services to work better together. Patients and carers manage their different appointments themselves and medical professionals are not always aware of other clinicians involved with the healthcare of the patient.

Patients and carers also wanted medical professionals to be better at communicating with each other: to share information about individual patients so that support was better co-ordinated; to inform each other what their role was; and to be clear what the service they worked for could offer.

Patients and carers would like more information about health and wellbeing support available from community and voluntary organisations. This support could help them better manage their, or the person's they care for, health conditions. It could also help them build relationships with others in their local community with whom they could share information, offer support and reduce their isolation.

Managing a long-term health condition requires patients and carers to have good, accessible and clear information about their health condition and what help is available. This includes information about how their, or the person they care for, health condition is likely to progress and how to get additional support when it is needed.

Patients and carers told us that the single thing that would make the most difference to how well they were able to manage their long-term health condition would be to have a named person who could be contacted when more help was needed or when they needed more information about their health condition.

Recommendation 1: GP practices give patients and carers with long-term health conditions clear information about the support they will receive to help them manage their health condition.

This should include information on:

- Who is eligible to receive additional support to help them manage their long-term health conditions
- What support can be offered through the GP practice
- How to ask for extra support to manage a long-term health condition from their GP practice
- How their GP will consult with them to help them to identify what help they need and what support is available.
- How the GP and other health and care professionals will ensure a personalised approach is taken so that the patient is in charge of the care they receive to manage their long-term health condition
- How the GP practice will co-ordinate their care with other healthcare professionals and how this will be communicated to the patient

Once a patient is receiving additional support, their care plan should clearly state:

- Who their named contact is that they can go to for further information and advice. Any changes to this should be clearly communicated to the patient
- Details on how to contact their named healthcare professional
- Information about their long-term health condition and self-care advice
- What health and care services they are receiving and how to contact them
- How to access other local community support and resources

2. Patient Participation Groups

Patients and carers would like to be more involved in deciding and evaluating what help was available for people with long-term health conditions through the GP practice. People wanted to be asked their opinions about what support was on offer and what could be done differently.

When informed about Patient Participation Groups (PPGs), many focus group participants felt that these would be good fora for them to feed in information about their experiences of the support available at their GP practice and to express an opinion on what could be changed to improve provision.

Recommendation 2: GP practices are supported by the CCG to develop PPGs in their practice and to demonstrate how they have listened to patients and carers, and made changes based on their experiences.

Recommendation 3: Recruitment and engagement of new and existing PPG members should target patients with long-term health conditions and their carers.

Recommendation 4: PPG members should be given opportunities to share their experiences at a wider CCG level through engagement in the new Primary Care Homes as they are formed so that patient experience is used to shape service provision, communication and improvements.

3. Support for mental health conditions and wellbeing

Patients and carers struggled to get help for their mental health and wellbeing when it was needed and at times got sent from one service to another, with the GP unable to meet their needs.

Recommendation 5: Patients with long-term health conditions and their carers are regularly asked about their mental wellbeing and are referred to mental health support where needed and signposted to community and voluntary organisations that offer services to support mental wellbeing.

4. Carers

The carers we spoke to were caring for relatives and friends with a range of health needs. The people they were caring for tended to need a high level of support and were accessing a number of different health services. Carers told us that they were expected to co-ordinate a lot of the care themselves and did not feel that they had enough information or support to do this.

None of the carers we spoke to had had their own needs assessed and they reported that they would like to have someone who was looking after their own health and wellbeing.

Recommendation 6: All carers for people with long-term health conditions should be offered a named professional based in the GP practice, with clear information on how they can be contacted, focused on supporting their own health and mental wellbeing.

5. Attitude of staff working in primary care settings

The negative and unhelpful attitudes that both patients and carers experienced from staff working in a range of primary care settings, including GP practices adds to the difficulties they face in managing their, or the person's they care for, long-term health condition.

Recommendation 7: Staff across the range of provision in GP practices should be regularly reminded of their responsibilities under guidance from NHS England on how to support long-term conditions to ensure that people with long-term health condition have access to home visits, medication reviews, etc. to support a good quality of life.

6. What happens next?

Under the Health and Social Care Act 2012 Healthwatch CWL has a statutory duty to:

1. Promote and support the involvement of local people in the commissioning, the provision and scrutiny of local care services.

2. Enable local people to monitor the standard of provision of local care services and whether and how local care services could and ought to be improved.

3. Obtain the views of local people regarding their needs for, and experiences of, local care services and importantly to make these views known.

4. Make reports and recommendations about how local care services could or ought to be improved.

These should be directed to commissioners and providers of care services, and people responsible for managing or scrutinising local care services and shared with Healthwatch England. In line with these duties a copy of this report will now be circulated to the following organisations:

- Central London Clinical Commissioning Group;
- Central London Healthcare;
- Westminster Scrutiny Committee;
- Westminster Health and Wellbeing Board;
- The Care Quality Commission
- Healthwatch England

7. Appendix

Survey

When it comes to managing your health condition, do you get the support that you need from your GP practice?

Healthwatch Central West London and the Older Adults Group at the Advocacy Project want to know more about how well people living in Westminster are supported by their GP practice to manage health conditions that last longer than six months.

We will use the answers you give us in this survey to tell GPs and health commissioners how well people with longer term health conditions are being supported to manage their conditions.

Where improvements are needed, we will make recommendations for change.

Thank you for taking the time to share your experiences, we will make sure that they are heard by those with the power to make a difference.

If you would like more information, please contact Carena Rogers, Healthwatch Central West London Engagement Coordinator for Westminster:

carena.rogers@healthwatchcentralwestlondon.org

Survey questions

1. Please tell us what health condition(s) you, or the person that you care for, have

2. How long have you, or the person you care for, had your health condition(s) for?

   ☐ Less than 6 months

   ☐ 6 months to a year

   ☐ More than a year

   ☐ More than 3 years

3. Which of the following has your GP, or someone from your GP practice helped you with? Please tick all that apply.

   ☐ Help to create a care plan that was tailored to your, or the person you care for, health needs and goals

   ☐ Booking and co-ordinating your, or the person you care for, appointments

   ☐ Referring your, or the person you care for, to services identified in your care plan

   ☐ Being a single point of contact for all your, or the person you care for, care plan and co-ordination queries

   ☐ Assisting your, or the person you care for, in better maintaining and improving your health and wellbeing

   ☐ Checking in with your, or the person you care for, regularly to see how you are getting on and providing encouragement

   ☐ Giving extra support for your, or the person you care for, extra support when you feel that your health was getting worse and when you needed help to improve or maintain it

   ☐ Providing assistance for your, or the person you care for, when you are struggling to co-ordinate care for yourselves/someone you care for

   ☐ Telling your, or the person you care for, about community based wellbeing services or activities

   ☐ None of these options

4. Do you feel that it is easy or difficult to get support for you, or the person you care for, health condition(s) from your GP practice if you need it?

   ☐ Very easy

☐ Easy

☐ OK

☐ Difficult

☐ Very difficult

Please tell us why you chose this option:

Does your GP practice offer any other support for people with long term health conditions that is not part of the Care Co-ordination Service?

☐ Yes

☐ No

☐ Unsure

Is there anything else you would like to tell us about support for people with long term health conditions living in Westminster? Please tell us in the box below

Thank you for taking the time to fill in this survey.

If you would like more information, or would like to tell us more about your experiences of supporting people with long term health conditions in Westminster, please contact Carena Rogers, Healthwatch Central West London Engagement Coordinator for Westminster:

carena.rogers@healthwatchcentralwestlondon.org

Information on the Care Co-ordination Service

The Care Coordination Service (CCS) is provided by Central London Healthcare. It aims to provide patients with extra support when they need it. They do this by making a plan with the patient for their future care that centres on *their* goals for their health and well-being as well as what actions the patient can take to achieve these themselves.

The CCS works with the GP Practice to
- Help create care plans tailored for patients' needs and goals
- Booking and co-ordinating patients' appointments
- Referring patients to services identified in their care plan
- Being a single point of contact for all the patient's referral, care plan and co-ordination queries
- Assisting patients in better maintaining and improving their health and wellbeing
- Checking in with patients regularly to see how they are getting on and providing encouragement
- Giving extra support for those who feel that their health is getting worse and needs help to improve or maintain it
- Providing assistance for anyone who is struggling to co-ordinate care for themselves/someone they care for

Who is eligible for the Care Co-ordination Service?
- Anyone over the age of 65 years
- Anyone over the age of 18 who has one or more long-term condition
- Anyone whose clinician agrees they would benefit from the service

Contact details:
If you would like to find out more about the Care Co-ordination Service, please ring **0333 200 1234** or email clh.ccs@nhs.net

7. Contact us:

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