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Title:	Co-ordinated care? Patients' and their carers' experiences of living with long-term health conditions in Westminster 2018.
Report of:	Healthwatch Central West London
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1. Executive Summary

- 1.1 This draft report contains findings from our engagement with people living with long term health conditions, or carers of people with long term health conditions living in Westminster.
- 1.2 This report sets out the experiences of people with long term health conditions and their carers of accessing support to manage their health conditions through their GP practices. It also sets out their aspirations for what support should be available in the future.

2. Key Matters for the Board

- 2.1 We ask the Health and Wellbeing Board to acknowledge the experiences that people with long term health conditions have had of receiving support through their GP practice.
- 2.2 We also ask the Health and Wellbeing Board to comment on the report before we make the report generally available to members of the public.

3. Background

- 3.1 Healthwatch Central West London 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 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.

What did we do?

- 3.2 In April 2017 we set up a Project Group made up of members from the Older Adults Group at the Advocacy Project to provide advice and direction. As local primary care services are undergoing reconfiguration in Westminster, with further changes yet to be implemented, the Project Group agreed that we should find out more about people's experiences of support offered through GP practices to help them manage their long-term health conditions, to ensure that it is meeting people's health and support needs.
- 3.3 During June to August 2017 we surveyed people with long term health conditions and their carers living in Westminster. We held four focus groups in August and September 2017, including one for carers. In September and November 2017, further telephone interviews were held with people with long term health conditions. In total, we spoke to 85 people. The people we spoke to had a range of long term health conditions including Diabetes, respiratory conditions, Multiple Sclerosis, and Muscle Skeletal Disorders amongst others.

Report conclusions

- 3.4 This report aimed to provide a picture of the current 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.
- 3.5 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 was varied depending on which GP practice participants were registered at.
- 3.6 We heard that some patients and carers have good experiences of receiving help to manage their, or the person's that they care for, long-term health condition. The relationship built up with the GP and having a personalised response to their health or care needs seemed to be key to this.
- 3.7 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 from their GP practice. They, and the focus group participants highlighted a range of difficulties that they encountered:

Clear patient pathway

- 3.8 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.
- 3.9 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.
- 3.10 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.

Patient Participation Groups

- 3.11 We heard clearly in the focus groups that both 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.
- 3.12 When informed about Patient Participation Groups, 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.

Support for mental health conditions and wellbeing

- 3.13 Both 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.

Carers

- 3.14 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 felt that they were expected to co-ordinate a lot of the care themselves and did not feel that they had enough information of support to do this.

- 3.15 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.

Attitude of staff working in primary care settings

- 3.16 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.

Report Recommendations:

- 3.17 **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.
- 3.18 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
- 3.19 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
- 3.20 **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.
- 3.21 **Recommendation 3:** Recruitment and engagement of new and existing PPG members should target patients with long-term health conditions and their carers.

- 3.22 **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.
- 3.23 **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.
- 3.24 **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.
- 3.25 **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.

4. Options / Considerations

4.1 N/A

5. Legal Implications

5.1 N/A

6. Financial Implications

6.1 N/A

If you have any queries about this Report or wish to inspect any of the Background Papers please contact:

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