

Healthwatch Islington Report



Long-Term Conditions



March 2014

Contents

- 1. Introduction..... 1
- 2. Methodology.....2
- 3. Findings4
- 4. Summary of findings7
- 4. Comments and recommendations7

- Appendix A: Survey questions 8
- Appendix B: Membership Form..... 11



1. Introduction

About Healthwatch Islington

- 1.1 Healthwatch Islington (HWI) is a user-led independent organisation that is part of the community, led by local volunteers. It is part of a national network of Healthwatch organisations that involve people of all ages and from all sections of the community in local health and social care services.
- 1.2 HWI builds on the knowledge and experience of Islington LINK (Local Involvement Network). It will continue to; gather views from the local community; report these views to the people responsible for local services; engage local people in decisions about services, and monitor services. As part of its work to gather views it has the right to visit services.
- 1.3 HWI also has a new role - to give local people information about local health, care and related complaints services.
- 1.4 In some areas local Healthwatch organisations provide complaints advocacy for people making a complaint about NHS services. For Islington residents, this service will be provided by VoiceAbility: details are given at the end of the report.



Local Healthwatch gather views on people's experiences of health and social care services, one of the ways they can do this is by visiting local services.



What we mean by long-term conditions

- 1.5 The Department of Health defines a long-term condition as 'a condition that cannot, at present be cured; but can be controlled by medication and other therapies'. Examples include diabetes, heart disease and chronic obstructive pulmonary disease.

Why Healthwatch Islington is looking at long-term conditions

- 1.6 At a meeting of our members in January 2013 then chair of the Health and Well-Being Board gave a presentation to Healthwatch on the Board, its role and the local priorities. Members voted on long-term conditions as the priority for Healthwatch Islington to include in its work plan for 2013 - 14.
- 1.7 Islington Clinical Commissioning Group (CCG) had also commissioned some research in this area so Healthwatch Islington liaised with the CCG to ensure that this piece of work could add value. The CCG felt that it would be useful for HWI to speak to more patients.
- 1.8 We know from Islington's public health reports that there are large numbers of people living with at least one or more long-term condition in the borough and that this can impact on people's well-being.

2. Methodology

- 2.1 Healthwatch Islington liaised with the CCG and Public Health to ensure that it was up to date with local services and provision for people with long-term conditions. We then visited a local patient group to talk to people about their experiences which we followed

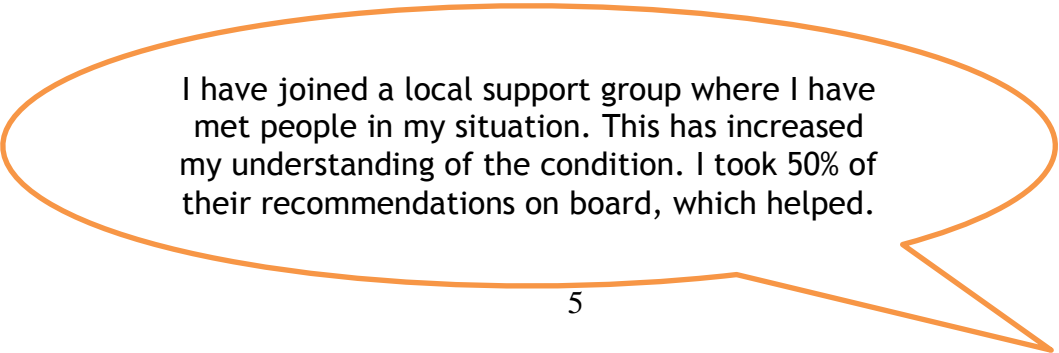
with a paper-based survey. We used these findings to test our research question and focus our work.

- 2.2 A survey was developed by the working group with the aim of being as open as possible to give service users the chance to let us know what really matters to them in relation to living with and managing their condition(s).
- 2.3 Interviewers were made aware of the council's safeguarding procedures and took the council's safeguarding leaflet with them to interviews and where interviewees needed further information about local services Healthwatch Islington was able to provide this.
- 2.4 In October 2013, HWI made initial contact with local organisations and our membership to promote this work and encourage people to take part. We also raised the profile of this work through our out-reach activity.
- 2.5 Our report is based on the feedback service users gave us in the one-to-one interviews conducted. Most were conducted face-to-face though some were carried out over the telephone as suited interviewees.
- 2.6 We had planned to gather a snapshot of views to feed in to the CCG's evidence gathering on how services should be developed to support people with long-term conditions to manage their conditions.

3. Findings

- 3.1 Overall we involved 37 people in the two phases of this work. In the initial phase of the research we heard from 14 respondents with a broad range of conditions including: depression, diabetes, high blood pressure, arthritis and epilepsy. 10 respondents had more than one condition with one participant having eight different conditions.
- 3.2 We asked participants about their relationship with their GP in relation to their long-term condition(s). Five of the 14 found their GP 'very helpful' in supporting them, four found them 'quite helpful', four found their GP 'not very helpful' and one found their GP 'not at all helpful'.
- 3.3 In addition to their GP most participants (11 of 14) were in contact with other health professionals, these included hospitals, counsellors, community services such as podiatry, pharmacists and opticians, practitioners of alternative medicine. Only two were in contact with local voluntary and community organisations outside of the patient group where we met them.
- 3.4 We asked respondents what other information or support would have been helpful. Not all respondents answered this question, but suggestions fell in to two main themes. Firstly some respondents wanted more information on their condition and related medication, side effects and alternatives as well as preventing their condition from deteriorating or leading to other conditions. They were also interested in more information about living healthily including eating well, local activities and health clubs, being able to access staff and experts in the community. This showed an appetite for supported 'self-management' of their condition. One respondent also needed some practical support with managing bills and tasks around their home.

- 3.5 In terms of managing their condition, we asked respondents what made this difficult. All respondents had been involved in a self-management programme. They told us that the following impacted on their ability to manage; their own motivation and momentum, the unpredictability of the condition, feeling isolated, living with the pain caused by their condition and the need for help to plan how they do things. One felt that they were able to manage their condition well) and one felt that the 'local authority interfered too much'.
- 3.6 In phase two of the research we interviewed 23 respondents using structured interviews. Four respondents were male, eight were female and 11 did not answer. Respondents ranged from '25-44' (two) to over 80 (four) with two respondents aged '45-64' and five aged '65 - 80'. 11 respondents did not answer this question.
- 3.7 We asked respondents what condition(s) they had. Ten respondents had at least one condition, four had at least two conditions, three had three conditions, four had four and one person had six conditions. Disabilities were included where people felt that their disability impacted on them in the way a long term condition. Two respondents included a disability as one of their multiple conditions, though no respondents reported a disability only.
- 3.8 Conditions that respondents were living with included asthma (five) Chronic Obstructive Pulmonary Disease or COPD (four), chronic heart disease (one), stroke or stroke related (two), depression (one), chronic depression (one), anxiety (one), hypertension (two), arthritis (eight), high blood pressure (one), other conditions listed included thyroid problems, Irritable Bowel Syndrome, Osteoporosis, injuries/ joint replacements and related impaired mobility. As most respondents reported living with multiple conditions this adds up to more than 23.
- 3.9 Respondents reported living with their conditions for between four months and sixty-two years. Most had had their conditions for eight years or more. 17 respondents stated that their condition(s) fluctuated meaning that some days it was easier to manage than others.
- 3.10 Most respondents' diagnosis had come from their GP or local hospital. One person was diagnosed at a drop-in 'well clinic', though hadn't known they had their condition before this, another read up on the internet, and then sought confirmation of a diagnosis from their GP.
- 3.11 When asked what helped them manage their conditions six said that the support of friends and family to carry out tasks was a help. Three had support from volunteers from local groups and three said paid carers made life more manageable, one person found living in sheltered housing a support. Most needed medication for their condition and reported this as helping. Several also took steps to adapt their diet and avoid smoking or drinking to manage their condition. Several respondents reported attending local self-help



I have joined a local support group where I have met people in my situation. This has increased my understanding of the condition. I took 50% of their recommendations on board, which helped.

or community groups and found talking to others useful. One had used exercise classes until they were able to exercise independently and no longer needed the classes. Other support highlighted was support from the police to make their home more secure and another valued their street parking and congestion charge being covered by the council.

- 3.12 When asked what makes managing their condition difficult, one of the key themes was dependence. Depending on others not only made things more difficult to do, but made people feel uncomfortable. Two users also talked about being apprehensive about taking medicines when they could not be sure of any consequences or side effects. Again there was an appetite for creative solutions, and for emotional support and talking therapy, with either peers or professionals. Accessing GPs or having very limited time with your GP were also listed as barriers to managing. Patients mentioned wanting the chance to build relationships with practitioners. One respondent noted that changes to the support available to carers had made it harder for them to access this support.
- 3.13 Although respondents used a variety of sources to find out information about how to manage their condition, 18 got this information from professionals. Some also looked to the internet, friends and local organisations. Five did not respond to this question. Only one respondent who had received information did not get some of this information from professionals. In all cases respondents could remember being given information verbally, and about half could remember being given written information. The information that proved most helpful had generally come from healthcare professionals (eight) and organisations (two). One respondent mentioned finding presentations more helpful than leaflets, another mentioned having an email contact for mental health services which was helpful for information. Respondents reported that they found it hard to find information on medications but also on diet and exercise.
- 3.14 When asked for any other comments on what helps, people generally re-iterated the importance of peer-support groups which offered them a safe place to talk through worries and potential solutions. Supportiveness of GPs was also highlighted, though one respondent emphasised again the difficulties in gaining access to GPs. Two respondents mentioned not having access to the internet and one found it hard to concentrate because of their condition making the internet difficult to use. Another patient really wanted to exercise to improve their condition but having several conditions needed support to find the right type of exercise.
- 3.15 We asked respondents what they would ask the people responsible for services to do to help you manage your own condition as independently as possible.
- 3.16 Several respondents stated that they were happy with the support available as a means to helping them live independently. Other suggestions and comments included; concerns about changes to benefits, needing more information about their diet so that they don't have to 'end up eating similar meals each day which is frustrating', knowing where to go to speak to someone regularly about their condition, being able to access reassurance and support. There were also suggestions to make sure that services were as accessible as possible via public transport or other transport solutions such as Dial-a-ride (a door-to-door transport service provided by Transport for London for disabled people who can't use buses, trains or the Tube). One respondent talked about managing the difficulty of managing their condition when they were also caring for someone else who requires a lot

of support but whose support is being affected by changes to the welfare system, they asked healthcare professionals to be mindful of other issues impacting on people's lives.

4. Summary of findings

- Generally diagnosis had been made by respondents GP,
- Respondents valued interactive support from peers which enabled them to talk about their condition, medication and remedies,
- Respondents considered clear and reliable information as essential to managing their own conditions, though there were some gaps in information,
- Respondents were keen to take steps to manage their condition themselves and valued the independence this gave them,
- Conditions fluctuate and support systems need to take this in to consideration, access to professionals can be important when a condition is at a worse state,
- Professionals are still seen as an important source of information for people managing their own condition, though views gathered from other HWI work suggests that information provided varies across practices.

5. Comment and recommendations

- Use the GP and Practice Managers bulletin to keep GPs informed of the sources of information available to patients so that they can be signposted,
- Consider referrals to local voluntary organisations where patients need further information or support around a particular condition (at present there are navigators to support this for patients with complex needs)
- HWI welcomes the work being undertaken in the borough to review how patients access primary care. It could be useful to ensure that patients who have long-term conditions can be identified when booking an appointment and may be able to see their doctor more quickly if their condition is in a bad state.

Appendix A - Survey questions

Living with a long-term condition

Who we are:

Healthwatch Islington is an independent consumer champion for health and social care in Islington. It is led by local volunteers and working on behalf of everybody living in the borough - adults, young people and children. The organisation will help to shape and improve local health and social care in our community.

The purpose of this research:

We want to speak to local people with particular health conditions (described as long-term conditions) to find out about their experiences of support from local health and social care services.

A '*Long-Term Condition*' is a condition that cannot, at present be cured; but can be controlled by medication and other therapies. Examples include diabetes, heart disease and chronic obstructive pulmonary disease.

1. Do you have any of the following conditions?

(Please tick all that apply)

Condition	Tick
•Atrial fibrillation	
•Asthma	
•Cancer	
•Chronic depression	
•Chronic heart disease	
•Chronic kidney disease	
•Chronic Obstructive Pulmonary Disease	
•Depression	
•Diabetes	
•Epilepsy	
•Heart Failure	
•High blood pressure	
•HIV	
•Mental health condition	
•Physical disability	
•Stroke (or stroke related)	
•Other, please state	
•I have one (or more) condition(s) but I'd prefer not to say which	

2. How long have you been living with that condition?
3. Is your condition changeable?
4. How were you diagnosed?

	1. Condition	2. How long have you been living with your condition?	3. Is your condition changeable? Yes or no? 'Good days' and 'Bad days'?	4. How were you diagnosed?
1				
2				
3				
4				
6				
7				

- At home
- People friends
 - family
 - professionals
 - other
- Services
 - Expert patient group
 - peer group
 - local activity group
 - other
- Activities
 - Sports group
 - Cooking class
 - Other .
- What is missing?

7. How do you get information about your condition(s)?

Please tick all that apply and give details.

<input type="checkbox"/>	Organisations	_____
<input type="checkbox"/>	Internet	_____
<input type="checkbox"/>	Professionals	_____
<input type="checkbox"/>	Patient/ Service User Group	_____
<input type="checkbox"/>	Family/ Friends	_____
<input type="checkbox"/>	Other	_____

Verbal Written

Any other comments

8. What information has been useful? (from the above)

9. What information has been more difficult to find?

About you - Equality & diversity monitoring questions

Healthwatch Islington is funded by the Department of Health.
 As such we are required to monitor who we speak to.
 This is to ensure that we are involving a diverse range of people.
 Any answers given are confidential but you do not have to answer the following monitoring questions.

Are you

Male Female Prefer not to say

Do you consider yourself to have a disability?

Yes No

Age

16 - 24
 25 - 44
 45 - 64
 65 -80
 80+
 Prefer not to say

How do you describe your ethnic background?

Asian/ Asian British

Bangladeshi
 Chinese
 Filipino
 Indian
 Pakistani
 Vietnamese
 Other

If 'other', please specify....

Black African/Caribbean/British

African
 Caribbean
 Eritrean
 Ghanaian
 Somali
 Other

If 'other', please specify....

White or White British

British
 Greek/ Greek Cypriot
 Irish
 Kurdish
 Turkish/ Turkish Cypriot
 Other White Background

If 'other', please specify...

Dual Heritage

Asian & White
 Black African & White
 Black Caribbean & White
 Other

If 'other' please specify...

Other ethnic background

Please specify:
 Prefer not to say

Healthwatch Islington Membership Form

Contact details

Title First name Surname

Organisation (if applicable)

Address

Post code Email

Telephone Number

Mobile Number

My areas of interest / expertise in health and social care are:

Primary Care (eg doctors, dentists, podiatry, eye tests)

Secondary Care (eg hospitals, specialist clinics)

Social / Community Care (eg Meals on Wheels/Home Help/District nurse)

Residential Care and Nursing Homes

Emergency services (e.g. ambulance service)

Other (Please state)

I am interested in services for:

Children & Young People

Older People

Carers

Disabled People

People with learning difficulties

People with mental health issues

Black and Minority Ethnic (BME)

Lesbian, Gay, Bisexual and Transgender (LGBT)

Other

Data Protection

Any information you have given us here will be treated as confidential.
We will not share your contact details unless indicated below.

Please tick the box to **share** your contact details with other LINK members

Equality monitoring form

We would like to gather monitoring information so that we can understand the diversity of the people involved with the LINK to make sure that we are reaching out to the whole community. We are required by the Department of Health to record this data. You do not have to complete this form.

Please help us by answering these questions:

1. Are you?

Male Female Transgender Transsexual

2. Would you describe yourself as?

- White British
 White Irish
 White Other: please specify
 Black British
 Black - African
 Black - Caribbean
 Black - other: please specify
 British Asian
 Indian
 Pakistani
 Bangladeshi
 Chinese
 Other - please specify

3. Would you describe yourself as having a disability?

- No
 Yes - please describe in your own words:

4. Would you describe yourself as:

Gay man Lesbian woman Bisexual Heterosexual

5. Which age group do you belong to?

Under 18 years 18 to 30 years 31 to 45 years 46 to 60 years
 61 to 75 years 76 years & over

6. Do you have a religion or belief?

- No
 Yes - please specify:

