



**healthwatch**  
Bristol

## WEST OF ENGLAND CENTRE FOR INCLUSIVE LIVING (WECIL): EXPERT BY EXPERIENCE GROUP

Healthwatch Bristol engaged with WECIL's Expert by Experience Group to listen to their views and experiences of accessing Health and Social Care services in Bristol.

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## West of England Centre for Inclusive Living (WECIL): Expert By Experience Group

Wednesday 15 March 2017

### Introduction

The West of England Centre for Inclusive Living (WECIL) is a charity run by and for disabled people in Bristol and the surrounding areas. They offer a range of services which support over 4,000 disabled people every year. Their main aim is to support, promote and maintain the independence of disabled people.

The Experts by Experience group is a project funded by the Department of Health. The project is dedicated to providing a voice for disabled people to enable individuals to have their voices heard by participating in various consultations.

The group provides the opportunity for disabled people to give their feedback on a wide range of subjects including healthcare provision, work health & pensions and access to services in Bristol and the surrounding areas.

These consultations are open to all disabled people in Bristol and the surrounding areas and WECIL cover travel expenses for those who are able to attend. In addition to getting involved in consultations; "Experts by Experience" will be delivering holistic support to people that enables them to achieve better health and wellbeing outcomes over the next couple of years.

The group mostly meets at The Vassall Centre, in Fishponds, Bristol.

If you would like to get involved with this project or get the expertise of the group then please contact Duncan Stokes by phone or email.

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### HEALTHWATCH BRISTOL

Healthwatch is the official framework through which local people can have their say about health and social care services. Healthwatch works on behalf of the whole of the community - children, young people and adults and needs people to tell it what's going on in the health and social care services in their area. Healthwatch can tell services about patient experiences of care and hold them to account; it can also enter and view services such as care homes and hospitals, observe what is happening and report back to commissioners.

People can feel excluded from services and we know that access to services and treatment is not always equal to all, so Healthwatch also has a signposting function to navigate the



health and social care system. Healthwatch Bristol is independent, transparent and accountable and powerful, with the strength of the law and the national influence of Healthwatch England behind it. Healthwatch Bristol is provided by The Care Forum.

W: [www.healthwatchbristol.co.uk](http://www.healthwatchbristol.co.uk)

W: [www.thecareforum.org](http://www.thecareforum.org)



### *Members of the Expert by Experience Group*

#### **The Group Members Profile**

**Attendee 1 (A1):** WECIL volunteer. A1 advised that he is going to be an Expert by Experience for the Care Quality Commission. A1 also has a visual impairment.

**Attendee 2 (A2):** advisor and accesses diabetes support services and is a Journey to Employment client.

**Attendee 3 (A3):** came to WECIL via J2E course as they are on jobseeker allowance, and is a volunteer at Arnolfini.

**Attendee 4 (A4):** peer Support volunteer.

**Attendee 5 (A5):** MSc social work student on placement at WECIL.

**Attendee 6 (A6):** heard of WECIL through Job Centre Plus and has made an application for healthcare assistant with North Bristol NHS Trust. This is being processed at the moment. Post-traumatic epilepsy.

**Attendee 7 (A7):** suffered from testicular cancer which was initially missed. A7 has a long-standing diagnosis of depression and Asperger's and was referred to BASS. A7 was introduced to WECIL via Macmillan.

**Attendee 8 (A8):** WECIL Volunteer Support Coordinator.

**Attendee 9 (A9):** Healthwatch Bristol Development Officer and Facilitator.

## The Engagement

Healthwatch Bristol welcomed and thanked the members of the group for attending the engagement session and outlined the structure of the morning's proceedings.

The Healthwatch Bristol representative asked the group how many people knew about Healthwatch Bristol prior to the session today and only one attendee indicated that they knew about Healthwatch. Healthwatch Bristol emphasised the importance of engagement with the members of the Expert by Experience Group and the general public.

Healthwatch provided the group members with a bag of Healthwatch information which contained briefing notes and other goodies.

The Healthwatch Bristol representative explained to the group what their roles are and the purpose of the engagement. The representative further informed the group members about what happens next with information that they have shared with Healthwatch Bristol.

## The Briefing / Focus Group Questions

The purpose of engaging with the group was part of the Healthwatch Bristol quarter theme looking at the Accessible Information Standard and the questions asked and discussed were based on this. To find out more: <https://www.england.nhs.uk/ourwork/accessibleinfo/>

### 1. Access to Services - thinking about when you use NHS or social care services:

- Do you usually get information in a format you can understand?
- Do you usually get the communication support you need?
- Do you think there is any information you are missing out on?

### 2. Helping you to help yourself / self-care:

- What do you understand by self-care?
- What support do you need to self-care? How do you need this support to be provided?
- What do you think the positives and negatives of supporting people to self-care may be?

### 3. Making a difference at an individual level:

- Do you know how to give feedback directly to service providers? If yes, please give examples.

- What barriers are there to giving feedback about the health and social care services you use?
- Are you aware of advocacy services in your area? If yes, what is your understanding/experience?



## You Said...

### Focus Group - Responses

#### 1. Access to Services: Thinking about when you use NHS or social care services.

<p><b>1.1. Do you usually get information in a format you can understand?</b></p>	<p><b>Leaflets</b></p> <p><b>A7:</b> About 50% of time information leaflets have very long sentences and use a lot of long words.</p> <p><b>A6:</b> I have done human biology and have a good understanding of words. However, other people may not know or understand some of the terminologies used in leaflets. There should be a glossary of sorts regarding this and short sentences.</p> <p><b>A7:</b> Having two leaflets can possibly be a solution to this issue. therefore, everyone can understand.</p>
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	<b>A1:</b> Production cost will considerably be increased with a multi-level leaflet. People with dyslexia needs need to be catered for when producing accessible leaflets.
	<b>At the surgery</b> <i>How doctors communicate with you - could be about anything. E.g. signs at GP Practices, would this be in an accessible format. E.g. Visual presentation.</i>
	<b>A1:</b> Keeps getting written to by his GP despite repeatedly asking for more accessible method for example, email. A1 has a visual impairment.
	<b>A1:</b> Recently a nurse at the GP practice was totally unaware of my visual impairment and called me without thinking about whether I would need an arm or guidance assistance to the room. The nurse should have known that I have a visual impairment.
	<b>A3:</b> Clear signage and marking of where rooms are located at GP practices would be helpful.
	<b>A7:</b> Music being played in GPs waiting rooms can be a cause of confusion and distraction for some people.
	<b>A2:</b> Gave an example of finding a polyp in hospital diagnosis. However, the language of the report given as a result of the investigation contained words such as ‘pedunculated’ (polyp on a Stalk). I had no idea of what some of the words in the report meant. I would have preferred the report to be written in layman’s terms rather than having difficult words included in the report. A medical terms glossary as part of the report would have been useful.

<b>1.3. Do you think there is any information you are missing out on?</b>	<b>A1:</b> In most health and social care services, patients without a visual impairment are able to access information. For example in most GP practices, there will be leaflets on tables. However, as an individual with a visual impairment, I will not be able to access the information in those leaflets due to my impairment but I consider myself to be a person who is confident and therefore will be able to ask for information if needed. However, some patients may not be able to access those leaflets and are not confident enough to ask for assistance. It is a very difficult scenario to rationalise because it is very costly to produce braille copy of every leaflet which would be impractical.
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	<b>A1:</b> I am able to get information sent through to my email when requested.
	<b>A1:</b> As a smoker, you are provided with verbal information about stopping on regular basis.
	<b>A3:</b> St George's Surgery sends out a newsletter via email now. This is in an accessible format.
	<b>A4:</b> Close Farm Surgery provides information in an accessible format for dyslexic people - yellow paper for information sheets.

<b>1.2. Do you usually get the communication support you need?</b>	<b>A1:</b> The answer in general, is no. Some GP practices are good and some are not so good. My GP at Montpelier health centre knows my needs and will come and get me in the waiting area.
	<b>A1:</b> It's very difficult to get organisations to communicate to you due to apparently data protection. Users can't understand why this would be a breach of the Data Protection Act.
	<b>A4:</b> Problems with Bristol Eye Hospital - I will not go back there as the staff are not consciously aware of visually impaired people's needs. People are ignorant of how to guide an individual with a visual impairment - on many occasions I have been put in a chair by pushing on shoulders. I have also been asked by nurses if they can put things in my eyes without checking my notes or anything as I have artificial eyes.
	<b>A6:</b> Some services in her experience have braille.
	<b>A7:</b> In relation to individuals with hearing impairments: My GP practice is brilliant. They used a dot matrix board but now use an announcement service. Recent cancer check-ups: people are called from a room and can be missed by people with hearing impairment. A visual aid would be helpful also an additionally a number and hook system can also be helpful.
	<b>A1:</b> An audiovisual display would be really helpful; similarly to the system used on buses.

**A2:** If jargon is used by professionals, some people will be confident to ask for clarification, whereas some people may not be. At St George Medical Centre; you get a fact sheet with everything you're told about.

## 2. Helping you to help yourself / self-care:

<p><b>2.1. What do you understand by self-care?</b></p>	<p><i>The Healthwatch facilitator explained the concept of self-care to the group -looking after their own health and well-being. For example if someone is diabetic then how they can manage their own health by being more healthy, exercising rather than requesting insulin. There was a good level of understanding of what self-care was.</i></p>
	<p><b>A4:</b> Home adaptations in relation to accessibility and the promotion of self-care. E.g. Having bathroom converted into a wet room. The installation of a wet room improves my well-being, it also promotes independence as I will be able to stay in my own home.</p>
	<p><b>A6:</b> Taking responsibility for self. Avoiding certain foods, taking medications (Self-administration of medication)</p>
	<p><b>A3:</b> Self-awareness, knowledge.</p>
	<p><b>A2:</b> Letting people know about your condition - so they can help you to manage it. "If I do something weird or have (a hypo) then give me a can of coke". Carry medication with you.</p>
	<p><b>A1:</b> Gave an example of a person who lived opposite him with mental health issues who committed suicide (fire to flat). This person was regularly sectioned by two police officers a time. They should have had a healthcare professional there as police did not have the training to properly support this individual. One officer said, "do you want some effing mace in your face" when challenged by A1.</p>
	<p><b>A9:</b> Police cannot lock you up anymore in this way, Individuals who are considered to be experiencing a psychotic episode, will now be taken to a place of safety (at Southmead) where they will undergo a mental health assessment. In some cases, if an individual is known to be aggressive the police will make an arrest but in most cases, a health care professional will also be present.</p>
	<p><b>A9:</b> The roles of health care professionals needs to be clarified in these situations where individuals are experiencing psychotic episodes in the community in relation to support needs. However, it is much better now than in past years.</p>



	<b>A1:</b> Advised information between social services, healthcare and police should be joined up.
	<b>A3:</b> Lack of awareness by police led to a blind man being tasered recently.

<b>2.2. What support do you need to self-care? How do you need this support to be provided?</b>	<b>A4:</b> This depends on the individual. Having a good awareness of organisations that provide support is good. However, I am able to self-refer but what about others who are not able to.
	<b>A9:</b> Community pharmacies are very useful for advice and support to keeping people healthy.
	<b>A1:</b> It would be helpful to patients if doctors would highlight these things such as self-care options to people.
	<b>A2:</b> I was told that I had cancer by a particular doctor at Southmead hospital, who then walked off. The Macmillan nurse was there straight away and was much more empathic than the doctor. I was very impressed with the Macmillan nurse. However, I found the doctor’s approach being very cold but I also understand that he may have many people to tell. (“MOT bay” analogy - felt Doctor had lots of patients to see.)
	Other group members were unimpressed with the doctor’s coldness and would have made a complaint.
	<b>A9:</b> Introduced the concept of social prescribing to the group as the new buzz word/service on the health and social care sector.

<b>2.3. What do you think the positives and negatives of supporting people to self-care may be?</b>	<b>A6: Positively-</b> encouraging patients to take responsibility will reduce strain on NHS services. <b>Negative</b> - people may forget some aspects of their self-care.
	<b>A3: Negative</b> - People need to have things explained to them in order for them to see the bigger picture, in relation to why a particular task or activity they do will make them better / improve their condition/wellbeing.
	<b>A1:</b> It is vital that people need to have the desire to want to do something (e.g. stop smoking/ drinking) for self-care to work.
	<b>A9: Negative</b> - If someone has a diagnosis of depression, they might well want to be left alone.

	<p><b>A4:</b> Society has changed so people around might not know who is available to speak to or services they can contact</p>
	<p><b>A4:</b> There is a great community spirit in my street which is very rare to find now. For example; one resident has a diagnosis of dementia but continues to live in her own home. Prior to her dementia diagnosis, this lady has been very helpful to the community all of her life and is now able to rely on her neighbours, who looks after her. While it is nice to have the generosity and kindness of community to support this woman, it is, , important that social services and the NHS do not neglect their statutory duties to provide support because this model may not be reflected in all communities</p>
	<p><b>A9:</b> Networks such as this are an example of the big society and social prescribing.</p>
	<p><b>A7:</b> Struggles with self-care; I find it hard to find organisations to support and meet my need and in some cases, my depression is increased. For example; I am good at cooking for myself but bad at cleaning</p> <p><b>A9</b> asked what system would help. <b>A7</b> replied by stating that accessing professional companion would really help him (buddy system). <b>A7</b> feels that this would help reduce his level of depression.</p>

### 3. Making a difference at an individual level:

<p><b>3.1. Do you know how to give feedback directly to service providers? If yes, please give examples.</b></p>	<p><b>A7:</b> I recently had a slight problem with ordering my prescriptions over the internet. <b>A7</b> advised that for the last several years, he used an online secure service “Patient Emails” Several group members have used this system. They advised you must ask at reception to be signed up for this service. However, <b>A7</b> was not made aware that you needed more than 48 hours for the doctor to send prescription and pharmacy to dispense (Doctor advised 48 but pharmacy needed longer. <b>A7</b> told GP about this and changes were made. Service is for repeat prescriptions only.</p>
	<p><b>A9:</b> Queried usefulness of the online system -The group agreed that it is a very useful service.</p>

	<b>A6:</b> always gets email or text from surgery asking for feedback after every visit.
	Many group members advised they also get text reminders when they have an appointment. These also have a cancel options.
	<b>A5</b> depends on the service. Not all have the same systems. Many put the expectation on you of finding a feedback form on their website. Hospitals
	<b>A2:</b> I have had text appointments from the hospital.

<b>3.2. What barriers are there to giving feedback about the health and social care services you use?</b>	<b>A6:</b> Some places do not have automated feedback text request systems.
	<b>A7:</b> Lots of places do not often have feedback mechanisms and this means if people aren't often proactive enough to do this it is not done. A7 advised that there need to signs about to post people to a place to do both positive and negative feedback.
	<b>A2:</b> For cancer patients in Bristol; pharmacist is in Bristol Royal Infirmary not in the oncology department. This is not very accessible for people with limited mobility.
	<b>A7:</b> Experienced delay in chemotherapy as had been miscommunication between the Dr and oncology department.
	<b>A6:</b> Advised a friend who had this experience too.
	<b>A2:</b> How do we know, how services act upon the feedback? Unless you work for a service provider, they will never tell you what they do with it.

<b>Are you aware of advocacy services in your area? If yes, what is your understanding/ experience?</b>	All members of the group generally aware of what advocacy services are.
	<b>A7:</b> Struggles with access to advocacy services in South Gloucestershire. This is because WECIL can't support people in South Gloucester for e.g. PIP form filling and she is unsure of other places to turn.
	<b>A9:</b> Advised that if the group know anyone (especially people with e.g. dementia) that they should signpost them to Healthwatch's advocacy services.

	The Healthwatch facilitator closed the session. The facilitator advised that the report will be written up and will then be disseminated to all the organisations mentioned and the Clinical Commissioning Group. All members will be sent a copy of the report.
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## Comments received 11

7 Negative



2 Mixed



2 Positive

### Primary care

#### St George Surgery:

- A commentator informed Healthwatch Bristol that their GP practice in St George provides them with a newsletter via email and is in an accessible format.
- A commentator highlighted issues with the use of jargon by professional in the health sector. The commentator stated that some people will be confident to ask for clarification by the GP when jargon is used. However, some people may not be confident to ask. The commentator further stated that at St George Medical Centre; patients are able to request a fact sheet with everything they are told about during their consultation.

#### Close Farm Surgery:

- The commentator stated that Close Farm Surgery provides information in an accessible format for dyslexic people, they also ensure people who have a visual impairment are able to access the information they are sharing for sending out correspondences and printing information sheets on yellow paper.

#### Montpelier Health Centre:

- The commentator stated that in general, some G.P practices are good and some are not so good in relation to meeting their communication and support needs. However, Their GP at Montpelier health centre knows of their needs and will come and get them in the waiting area.

#### General Comments in relation to Primary Care Services:

- Commentator informed Healthwatch that it would be useful for doctors at G.P Practices to promote and create awareness of services such as Self-Care and Social Prescribing.
- A commentator stated that they keep getting written to by their GP despite repeatedly asking for a more accessible method of communication and correspondence such as via emails as they have a visual impairment.

- Commentator informed Healthwatch Bristol of a recent situation where they attended an appointment at their GP practice and when their name was called by the nurse no offer of assistance was given as the nurse was totally unaware of his visual impairment and was and he was expected to make his way to the consultation room independently without any guidance. The commentator felt that the nurse should have read his files prior to calling him to the consultation room.

## Secondary care

### **Bristol Eye Hospital:** (University Hospitals Bristol NHS Foundation Trust)

- Commentator highlighted problems with staff at Bristol Eye Hospital. The commentator stated that he will not go back to the Bristol Eye Hospital as the staff lack awareness of visually impaired people's needs. The commentator further compared this lack of awareness to that of ignorance because you would expect better from a staff team working in an institution that supports individuals who are visually impaired. The commentator highlighted further highlighted that on many occasions he have been put in a chair by pushing on shoulders. They commentator also highlighted that they have been asked by nurses if they can put things in his eyes, such as eyes drops without checking his notes as he has artificial eyes and doesn't require eye drops.

### **Bristol Royal Infirmary:** (University Hospitals Bristol NHS Foundation Trust)

- The commentator stated that there are current issues affecting cancer patients at the Bristol Royal Infirmary, as currently there are no pharmacy located in the oncology department and, if a patient needs to access a pharmacy they need to walk a long way to the main hospital pharmacy to collect their prescriptions. This is not very accessible for people with limited mobility.

### **Southmead Hospital:** (North Bristol NHS Trust)

- Commentator informed Healthwatch Bristol that he is very dissatisfied with the service received due to the delay in receiving chemotherapy due to a miscommunication between the doctor and the oncology department.

### **General Comments in relation to Secondary Care Services:**

- Commentator informed Healthwatch of their experience of finding a polyp during an exploratory procedure. However, the language of the report given as a result of the investigation contained words such as 'pedunculated' (polyp on a stalk). The commentator stated that they had no idea of what some of the words in the report meant. The commentator further stated that they would have preferred the report to be written in layman's terms rather than having difficult words included in the report or the additional of a medical terms glossary as part of the report, would have been useful.

## Key themes / Recommendations

## Primary Care Service

- In relation to access to services, the majority of commentators felt that services were generally meeting their need, particularly in relation to access to information, where information was provided in an accessible format. However, commentators felt that more needs to be done in relation to the use of jargon when accessing treatment and care.
- Treatment and care in relation to treatment explanation, commentators felt that better explanation is needed between medical practitioners and patients who have a disability or access needs especially during consultations or when corresponding with patients. It was also felt that the use of jargon should be avoided.
- Dignity and Respect; commentators identified a lack of awareness of patient needs which could result in poor practices. Commentators also felt that staff could benefit from training development in relation to disability awareness.

## Secondary Care services

- Access to services in relation to service delivery and a lack of service provision at the oncology department at the BRI. Waiting times for treatment in hospitals was a major issue identified.
- Staffing, staff training and development was highlighted as a major issue in relation to treatment, patient care and the experience of patients when accessing the eye hospital as a result of a lack of awareness of visually impaired patients who access the service.

## Services included in this report:

St George Surgery, Close Farm Surgery, Montpelier Health centre, Bristol Eye Hospital, Bristol Royal Infirmary and Southmead Hospital

## Healthwatch will....

All the feedback Healthwatch Bristol gathers is analysed and used to inform the Healthwatch Bristol quarterly Feedback Feed Forward reports which are shared with Healthwatch Bristol partners including Bristol Clinical Commissioning Group, the Bristol Health and Wellbeing Board, Bristol City Council, the Care Quality Commission, NHS England and Healthwatch England. The quarterly report is also presented to the Healthwatch Bristol Advisory Group to propose further uptake of the issues identified in the report. The report will be available on the Healthwatch Bristol website ([www.healthwatchbristol.co.uk](http://www.healthwatchbristol.co.uk)) and circulated to our mailing lists via the monthly e-bulletin.

## Looking forward...

### Plans for future work between Healthwatch Bristol and WECIL

Healthwatch welcomes and encourages members of the WECIL Expert by Experience Group to continue to contribute their feedback to us using the communication methods included at the end of this report.

Healthwatch also supports members of community groups to become Volunteer Champions so that they can represent the experiences and needs of their community group. If you would like to find out more about volunteering with Healthwatch, please contact us using the details below.

## Tell Us Your Story...

Healthwatch Bristol wants to hear from you about your experiences so that we can tell services your needs to create the best local services.



Text us - text bris followed by your message to 07860 021 603



Email us at [info@healthwatchbristol.co.uk](mailto:info@healthwatchbristol.co.uk)



Call us: 0117 2690400



Write to us at Healthwatch Bristol,

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Or visit our website to see more at [www.healthwatchbristol.co.uk](http://www.healthwatchbristol.co.uk)