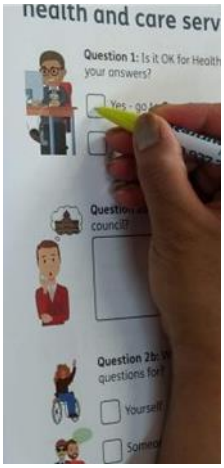

Different outcomes, Different access to care

the views & experiences of people who are likely to experience health and care inequalities in Buckinghamshire, Oxfordshire, Reading, West Berkshire & Wokingham Borough

healthwatch Bucks healthwatch Oxfordshire healthwatch Reading healthwatch West Berkshire healthwatch Wokingham Borough

15 December 2020

Contents

Summary

We carried out a review of 21 reports published by the five local Healthwatch since 2018 that are relevant to the topic 'addressing inequalities in health and care access and outcomes'. We compared the main findings and the recommendations and identified two consistent themes.

The reports we reviewed represent the experiences and views of more than 1200 people.

> *'Sometimes I wonder if it is because I am Muslim that I am not listened to. I feel the doctor can be quite rude.'*

Our Healthwatch call to action:

To ensure equality of access, better outcomes, and good experiences of health care and social care for all, services in the BOB ICS area must be personalised to people's individual needs.

- **Communication** Each and every service must be able to communicate effectively and respectfully with everyone who needs to use it.
- **Access** Each and every service must be able to adapt its offer to meet the needs of all service users, so that the service is truly accessible to them - whatever their personal characteristics, including their sex, age, ethnicity, sexual orientation; whether they live with a disability; whether they have chosen to change their gender; their maternity status; their partnership status; and their religion or belief.

We urge all ICS member organisations to listen to patients, service users, families and unpaid carers in the BOB ICS area and to improve care quality as a result.

We urge the BOB ICS senior management team

1. **to include patient experience metrics as part of BOB ICS assurance mechanisms, to obtain assurance that the ICS member organisations are**
    a. **using appropriate patient and service user experience measures* locally as part of evaluating the quality of services and**
    b. **using feedback from patients, carers and families to inform service design and quality improvement and**
    c. **involving patients, carers and families in the design of services, in accordance with the NHS Constitution right to involvement (both strategic involvement and co-design of services)**

2. **to ensure that BOB ICS assurance mechanisms require ICS member organisations to communicate these patient experience measures clearly to the residents of BOB together with evidence to show how the measures lead to improvements in the quality and safety of health and social care services**

'I am deaf and entitled to free dental treatment. When I went to the dentist the receptionist put a form in front of me to sign. I didn't understand the form as deaf people often have a reading disability too. The receptionist didn't seem to be deaf aware and when I told them I didn't understand the form they just told me loudly to just sign it.'

Recent reports directing attention nationally to the quality of health and care services, including Build Back Fairer: The COVID-19 Marmot Review and the interim Ockenden Report (on maternity services in Shropshire and Telford) have emphasised how services need to listen to patients, service users, families and unpaid carers to achieve a high quality of care and to ensure safety, as well as improving outcomes that reflect current health inequalities.

Your local Healthwatch is the statutory body in place to advise on this aspect of quality improvement work locally – our statutory function includes forming a view on the standard of local care and whether and how it could be improved by listening to and involving local people.

We have not included experiences of care during the COVID-19 pandemic in this report. A later report will summarise what we have heard from people between March 2020 and autumn 2020, since the start of national pandemic measures, and will also look at the issue of health and care inequalities.

(*More information on how organisations create and use 'patient experience measures' from data they collect about people's experiences can be found here)

Introduction

People's rights in health & social care

Different people have different experiences of access to services, different experiences of care and different outcomes – good and bad - in health and in social care (care provided by local authorities). Sometimes people have different experiences and outcomes from others because some people are treated differently from others in society.

- Some people experience lack of the same access to good quality care that others have.
- Some people who do have access to care find that it is not personalised to their particular needs.

The **NHS Constitution** sets out people's rights in healthcare, which include -

> **'You have the right to receive care and treatment that is appropriate to you, meets your needs and reflects your preferences.**
>
> **You have the right to expect your NHS to assess the health requirements of your community and to commission and put in place the services to meet those needs as considered necessary, and in the case of public health services commissioned by local authorities, to take steps to improve the health of the local community….**
>
> **You have the right not to be unlawfully discriminated against in the provision of NHS services including on grounds of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status'**

How listening to local people can help public services to reduce inequality

How health and social care needs are met can make a positive difference to people's outcomes and their experiences of care. Listening to people about their experiences of care and their views about how care could be improved is at the heart of the work of local Healthwatch.

This report has been written jointly by five local Healthwatch. We want to highlight the themes in what we have heard from people who are likely to experience inequalities in their health outcomes, compared to others in society – people such as those who are older, people with long term health conditions and people from ethnic minorities.

By sharing these themes, we will influence the local managers who design and commission (buy) local health and care services. We want to help local managers to work more closely with local residents, local Healthwatch and local community organisations to design and deliver services, and to monitor how well services are doing. Importantly, we want to help them to improve local services by working together well in partnerships that include residents and local organisations.

What geographical area does this report cover?

The five local Healthwatch are Healthwatch Bucks, Healthwatch Oxfordshire, Healthwatch Reading, Healthwatch West Berkshire and Healthwatch Wokingham Borough. We have come together to help ensure that the voices of patients and users of social care inform and influence the development and delivery of health and care services across the Buckinghamshire, Oxfordshire and Berkshire West Integrated Care System (BOB ICS). The statutory role of local Healthwatch is explained here.

The BOB ICS brings together health and care organisations to work in partnership to improve health and care services by developing coordinated service plans built around the needs of the 1.8 million people who live in this area.

healthwatch Bucks	healthwatch Oxfordshire	healthwatch Reading	healthwatch West Berkshire	healthwatch Wokingham Borough
521,922 people	691,700 people	167, 780 people	158,450 people	159,097 people

Who have we heard from?

We carried out a review of 21 reports that are relevant to the topic 'addressing inequalities in health and care access and outcomes'. The reports were published by the five local Healthwatch. Eleven were published between October 2019 and November 2020. We also included 10 reports published in 2018 and earlier in 2019, to ensure that we covered a wide range of people likely to experience inequalities in access to care and in health outcomes. We compared the main findings and the recommendations and identified two consistent themes – communication and access to services.

In total, the reports we reviewed for this report represent the views of more than 1200 people. Our comments about the themes we identified are informed by all of our work and conversations with local people. We have taken quotations from different reports to illustrate the themes identified.

Theme 1 - Better communication

Clear communication, person to person, is key to dignity in health and social care. It is also important for safety in care. People need to be heard as individuals, and to understand their rights and the decisions that they need to make, whether that is choosing dinner from todays' menu in a care home, or deciding between different drug treatments that a doctor offers as alternative options.

Research in 2011 about what matters most to patients, carried out by King's College London for The King's Fund (a charity), showed that '*relational aspects of care – e.g. dignity, empathy, emotional support – are equally as important as 'functional' aspects*'. Everything that the five Healthwatch hear from residents in their local areas reflects this – and relating is expressed in communication, verbal and non-verbal.

What we hear from patients, service users, families, and unpaid carers always includes comments about the quality of communication by paid carers and healthcare professionals.

Getting communication right is central to developing a positive culture in services, with good, personalised care.

People want to feel valued, heard, seen and understood. They do not want to feel judged or be made to feel 'different'. A theme that often emerges when local Healthwatch hear from people whose protected characteristics may mean they have unequal access to care, poorer outcomes, and less positive experiences of care is how much just being accepted and respected matters

People need their health and care professionals to

- listen respectfully
- support communication needs – making sure that interpreters and special communication formats (such as easy-read information leaflets) are used when needed.

Health and care professionals need NHS organisations and local authorities to support them to develop and maintain attitudes, awareness, and knowledge that will enable the professionals to support good communication. This is part of providing safe, compassionate and respectful care. The support that professionals need is likley to include an appropriate workplace culture, regular training, and good working practices.

'Ensure that factors such as physical or learning disabilities, sight, speech or hearing problems and difficulties with reading, understanding or speaking English are addressed so that the patient is able to participate as fully as possible in consultations and care'

NICE Guideline CG138 Patient experience in adult NHS services – improving the experience of care' Recommendation 1.1.2

Respectful listening

Simply being listened to respectfully is important, and being listened to can make a difference to problems being properly addressed, and care being safe:

> *'Some people are very good or at least act professionally, while others are completely ignorant and/or have no idea how to behave, but I have no way of knowing how they will react or what assumptions they will make until I am actually talking to them.'*
> (person from LGBT+ community)

> *'I went to GP feeling tired and my hair was falling out, and wanted a blood test. The GP said "All Asian people have vitamin D deficiency" and told me to go to the chemist and buy some vitamins. I said "you should check my blood". When they finally did, my Vitamin D level was [very low]. I needed a high dose of Vitamin D, and only the GP could give this, the chemist ones, over the counter, would not help at all. The GPs need to do a good job and at least check.'*

> *'(They) don't always ask what food you want.'*
> (person living in a care home)

Support for communication needs

People are often not aware of their right to an interpreter and use of the service by NHS and social care services can be patchy. This is a recuring theme in what we hear from patients and service users.

> *"Never [did I have access to an interpreter] at GP. Three times at hospital. It makes me feel comfortable."*

"I went to a GP because I wasn't good [at] English. I was shocked that I could speak with her [communicate, be understood]. She spent a long time with me. She explained everything. She was very helpful to me."
(women from ethnic minorities at community learning centre)

'Very limited use was made of Talking Therapies and it did not seem to include easy provision for working with an interpreter.'
(women from an ethnic minority talking about a family member)

Case study 'Farzad*, a man in his 40s, originally came from Iran and does not speak or understand English. He spoke with [Healthwatch] via an interpreter. He told us that he had had a bad toothache for several weeks; he had holes in his teeth, they were bleeding, and he was in a lot pain. He had no access to pain relief and was limiting what he ate because he was struggling with solid foods. He was desperate and did not understand how he could get treatment.

[Healthwatch] made enquiries and established Farzad had an HC2 certificate (he had not known beforehand he had this and that it would enable him to access an NHS dentist). We rang and found a local dentist who agreed to see him, but said an emergency appointment within a few days wasn't possible as it would take longer to arrange an interpreter to be at the appointment. Farzad agreed to wait two weeks so an interpreter could be present at the appointment, even though he would be in pain during this time. We rang the hotel on the day of his appointment to ask staff to ensure Farzad understood he needed to go. He attended and finally received treatment he needed, including antibiotics.

* Name and identifying details have been changed.

There can be other barriers to communication – such as the expectation that texting will be easy and affordable for patients, when in some cases it is neither:

'When low with depression I find it really difficult to talk to people and message and text is an easier way to talk at this time.' Despite this, this person was discouraged from using a messaging service, in preference to phoning to speak to their care team.
(resident with housing needs)

Or an assumption that everybody can read easily, or that talking loudly is the best way to communicate with a person with a hearing impairment:

'I am deaf and entitled to free dental treatment. When I went to the dentist the receptionist put a form in front of me to sign. I didn't understand the form as deaf people often have a reading disability too. The receptionist didn't seem to be deaf aware and when I told them I didn't understand the form they just told me loudly to just sign it.'
(resident with hearing impairment)

Staff attitudes, awareness and knowledge have a real impact on communication and quality of care

We hear about both good examples of staff attitudes and respect for individuals, reflected in respectful, positive communication, and examples where attitudes, awareness and knowledge need to improve.

> *'Assuming my wife is either a sister or my mother. Questions from GP about contraception. General lack of knowledge about my orientation and therefore making assumptions.'*
> (woman in same sex relationship)

> *'I expressed myself as much as I could, but after that I never heard again. I go to the GP all the time saying I feel awful. All they do is just try and get you on drugs. Wait 'til you have a breakdown.'*
> (service user about community mental health team)

> '*They treat me like a human being.'*
> *'I get treated as a person not a patient.'*
> (people living in care homes)

> *'After going to ENT at least 10 times for throat discomfort, one person was finally sent for a scan and a growth was found –they felt they had not been taken seriously soon enough.'*
> (staff member, housing support charity)

> *'A bit more compassion and understanding especially of what it is like to be a boater. I have no heating, only just got a cooker, no hot water, lighting comes off solar, they have no idea what it is like...they say 'go home and get cosy and wash your clothes'....I don't have a fridge'*
> (people living on Oxfordshire's waterways)

> *'Some people would not be comfortable with male care workers. They might also not want care workers to come at prayer time'*
> (woman from ethnic minority at community learning centre)

> 'When one person asked staff to explain things, the nurse 'was rude' and 'frowned' and gave him a leaflet in English he could not understand.'
> (reported by a refugee)

Theme 2 - Better access to care

Access to services is affected by a wide range of factors including

- the availability of culturally sensitive and appropriately communicated information about the services (part of communication – see above)
- the geographical location of services and whether people are able to travel there themselves or need to be accompanied by a carer – and transport costs, as well as any financial impact of taking time off work for appointments
- whether the services themselves are culturally sensitive and welcoming - whether using them seems 'possible'
- whether patients and service users, and family/carers supporting them, feel that the care or service available is suitable and appropriate.

Feedback about services collected by the five Healthwatch consistently indicates that barriers to access need to be better understood by commissioners and that there are people who cannot access services that they need to. Some examples of people have told us about access to services are given below.

Administrative barriers to access

This is a theme in calls to local Healthwatch helplines. We hear about letters from medical services being difficult to understand or arriving late – or being texted to people who have not been warned that this is how the service will communicate with them and are concerned about whether the contact is genuine.

> *'I need counselling and counselling for the counselling, I need actual advice from the right people i.e. Adult ADHD team, mental health teams instead of just being told 'sorry there's not much we can do because your homeless.'*
> (person who is homeless)

> **Case study** 'Nyadeng*, a woman in her 30s, is originally from Sudan and arrived at the hotel from Kent. She had limited English and no mobile phone to enable communication. Before being moved to [town], Nyadeng had been diagnosed with a medical condition which required lengthy and complex treatment and considerable input from a team of health professionals. She also had diabetes. Her move to the hotel posed a risk to the continuity of her healthcare. The clinic that initiated her complex treatment had contacted a local health professional, who visited Nyadeng at the [town] hotel. During this visit, the health professional found she had not been registered with a local GP and needed to be taken straight to hospital to be assessed. Nyadeng also had run out of needles to administer insulin and had no way of checking her blood sugar. The same health professional carried out a follow-up visit three days later and found she still did not have a GP or prescription.
>
> * Name and identifying details have been changed.

Geographical barriers – service organised to suit services, not all residents

> *'Henley is on the border in the middle of 3 different counties. We just fall through the gaps as everything is in the centre of the county or the north'*
> (family/carer of service user of community mental health team)

Access thresholds that leave patients/service users without help

> *'You literally have to be on the insanity level or suicidal before you get help from mental health service'*
> (service user of acute mental health services)

> *'Awful. Dealing with [] on the assessment team and have felt nothing but ignored, shut down, talked over and fobbed off. No understanding at all of what help I can receive while awaiting complex needs. basically being sent away to wait even though I am having suicidal thoughts and self harming. Family and friends are disgusted with the way I have been treated.'*
> (service user in community mental health service)

'Inform the patient about healthcare services and social services (for example, smoking cessation services) that are available locally and nationally. Encourage and support them to access services according to their individual needs and preferences.'

NICE Guideline CG138 Patient experience in adult NHS services – improving the experience of care' Recommendation 1.3.2

System barriers to help that people need

Social care staff and health professionals can only perform at their best in systems that enable them to treat people as individuals deserving of their rights and dignity.

The five Healthwatch hear examples of processes that work well – whether a health referral pathway, or a system in a care home for ensuring regular access to dental care for the residents – and, sadly, examples of processes that get in the way of good care.

'No dentist will have me and I'm scared of the dentist so I've missed appointments but they won't give me another chance.'
(person who is homeless)

Case study 'Mrs A (86 year old) also discovered she can't order her medications in a medication compliance aid as she did previously. The pharmacist at her GP surgery advised that she had to find a [different] pharmacist which could do it. But she can't find a pharmacy in Wokingham - they have all said they are at capacity and cannot fulfil her prescription in this way. Age UK Berkshire have found a pharmacy in Twyford who are able to do it. But the charity is now having to collect the prescription from Twyford and bring it to Mrs A because she's outside their delivery area.'

The 21 reports we reviewed included case studies that show other examples of 'system barriers' to accessing the right help in the place where the individual needs it. For example:

Case study – David*, who has a learning disability, was admitted to the RBH (Royal Berkshire Hospital) for a hip replacement early in 2018. David struggles to communicate and lacks capacity, however his Care Plan clearly stated that he was allergic to strawberries. This had not been taken into account and he was given a diet based around strawberry 'milkshake' food supplements. He knew he could not have it and his anxiety levels increased. He could not verbally explain to staff what the problem was and his behaviour meant that he was then labelled as a 'difficult patient'. This made his stay in hospital much more distressing than it needed to be, showcasing the importance that Care Plans are read and understood by those caring for adults with learning disabilities. There was also an issue with confirming what treatment David had received, with even the carers unsure. This unfortunately led to David's discharge notes from the hospital being incorrect and there was also a lack of aftercare.

* Name and identifying details have been changed.

Conclusion and Call to Action

Listening to patients, service users, unpaid carers and family members, and acting on collated feedback and views to inform service improvement and service design, is a legal obligation for all health and social care providers and service commissioners (NHS and local authority managers who 'buy' services from NHS Trusts, care home owners and others, for local residents).

The BOB ICS (like its constituent Integrated Care Partnerships) has a particular duty, as a strategic, regional group of organisations dealing with health and social care, to ensure that the voices of patients, service users and carers influence all strategic projects, and that there are opportunities for residents to influence (directly, or through their representatives) strategic planning and decisions. 'Representatives' can include local Healthwatch, local people appointed as 'patient voice representatives' on working groups, and people from charities and voluntary sector organisations.

Our Healthwatch call to action:

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(*More information on how organisations create and use 'patient experience measures' from data they collect about people's experiences can be found here)

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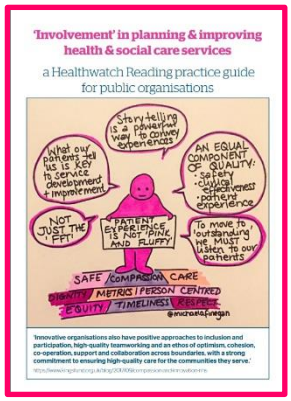
healthwatch Bucks healthwatch Oxfordshire healthwatch Reading healthwatch West Berkshire healthwatch Wokingham Borough

Appendix - the local Healthwatch reports reviewed to write this summary report



A local Healthwatch toolkit 'How to carry out effective involvement and engagement' - resources from several Healthwatch nationally, and a 3 page local toolkit document is available online to support public organisations in their own engagement and involvement work.

Report title & link	Healthwatch	Date
Homelessness and Rough Sleepers report 2018	Healthwatch West Berkshire	Feb 2018
Our Top 3 Priorities: Joint report with Reading Refugee Support Group	Healthwatch Reading	May 2018
Our Top 3 Priorities: Joint report with Reading Community Learning Centre - listening to women from ethnic minority backgrounds	Healthwatch Reading	May 2018
Our Top 3 Priorities: Joint report with Launchpad Reading - listening to people with housing needs	Healthwatch Reading	May 2018
Our Top 3 Priorities: Joint report with Reading Mencap - listening to people with learning disabilities	Healthwatch Reading	May 2018
Our Top 3 Priorities: Joint report with Talkback - listening to people with learning disabilities	Healthwatch Reading	May 2018
Summary Report: Listening to the 'seldom heard' project	Healthwatch Reading	Jun 2018
LGBT+ Your experiences as Lesbian, Gay, Bisexual, Transgender people accessing Health & Social Care Services in Reading	Healthwatch Reading	Sept 2018
Student Health and Wellbeing in Reading	Healthwatch Reading	Feb 2019

NHS Long Term Plan Engagement Programme -listening to adults with learning disabilities	Healthwatch West Berkshire	May 2019
Some perspectives on GP services in Oxfordshire A report from a visit to an Asian women's group by Healthwatch Oxfordshire	Healthwatch Oxfordshire	May 2019
Community Mental Health Team - Survey	Healthwatch Bucks	Sept 2019
Oxfordshire Military Families: Our experiences of health services in Oxfordshire	Healthwatch Oxfordshire	Jan 2020
Thank you for asking - Boaters' experience of accessing health and social care services	Healthwatch Oxfordshire	Feb 2020
Are pharmacies in Wokingham Borough supporting residents assessed as needing medication compliance aids (MCAs)?	Healthwatch Wokingham	Feb 2020
Lesser Heard Voices Veterans in Buckinghamshire	Healthwatch Bucks	Mar 2020
Dignity in Care - annual report 19-20	Healthwatch Bucks	Apr 2020
Let's Talk About Mental Health: Mental Healthcare in Oxfordshire July 2020	Healthwatch Oxfordshire	July 2020
Social care in Oxfordshire: how did local people experience the Council's 2018 change in contributions policy?	Healthwatch Oxfordshire	July 2020
Healthwatch West Berkshire Maternity Report	Healthwatch West Berkshire	Sept 2020
Health of asylum seekers and refugees placed in a Reading hotel during the pandemic	Healthwatch Reading	Dec 2020

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https://www.healthwatchwokingham.co.uk/

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