

# “Our top three priorities”

By people from groups and communities that are seldom heard, and the charities that support them



A report by Healthwatch Reading





## Summary - themes

People in Reading who are sometimes described as ‘seldom heard’ have been given a voice through this Healthwatch Reading project. We also talked to charities that support those people.

When we reviewed all of the reports together, we could see these common themes in what people told us, which we think the managers who design, buy and run health and social care services in Reading need to be aware of:

### From listening directly to people

1. **Rights** - knowing your individual rights in health and social care and having your rights respected.
2. **Information** - having enough information, at the right time, in a form that is right for the individual
3. **Enough good quality and culturally sensitive care to meet the needs of the individual**

### From listening to the charities who support them

1. **Inclusivity matters** - people themselves have valuable information about their needs that can inform how services are designed and provided. Charities that work directly with particular groups can provide valuable additional insights
2. **Mental health services need to be sensitive to cultural issues and individual needs (in services day-to-day & when involving people in service improvement work)**
3. **Unpaid carers have a vital role, and their needs must be addressed** when planning services and thinking about when, where and how service users will have their needs assessed and met.

## Introduction

People in Reading who are sometimes described as ‘seldom heard’ have been given a voice through this Healthwatch Reading project.

Our team went out and spoke to people whose experiences, feedback and suggestions might be overlooked or not sought by local services because of various barriers. These might include having a disability, not being able to speak English, or not understanding their right to have their say to help influence the quality of local health and social care services.

We worked in partnership with charities who support these people to arrange listening sessions where people could share their ‘top three priorities’.

We have previously published the five reports in our series of short reports (see summary boxes). In this summary report we are now bringing these priorities together to share with organisations responsible for providing, funding or planning health or social care for these groups of people.



**People attending the Reading Community and Learning Centre for language or other classes, said they need:**

- access to interpreting services when using the NHS
- culturally aware and timely provision of accurate information about locally available services
- longer appointments, if they do not speak English as their first language, so they can adequately discuss serious health or care concerns and understand their options

*“My GP called the [interpreting] phone service. It was good.”*

**People supported by learning disability charity Talkback said they need:**

- services to be sensitive to the needs of carers such as family members, who help them with things like arranging and attending appointments
- easy-read leaflets or other adapted information to help them understand services, their options and their care
- their rights to be known and upheld - such as the right to have reasonable adjustments made to services so they can use them

*“They put up on a screen when it’s your time to see the doctor, but I need support to read this.”*

**People supported by Reading Mencap told us they need:**

- health and social care staff who are properly trained about learning disabilities
- to be able to see the same GP each time they visit their surgery
- to get enough, good quality care to help keep them safe and to live as independently as possible

*“Sometimes they [care support workers] cancel on the day [and] no-one comes.”*

**People supported by Reading Refugee Support Group said they need:**

- better access to interpreting services
- better and more accessible information, including details about what they can expect in and from healthcare services
- healthcare professionals who make sure that people understand the outcome of appointments - including any diagnosis, what they need to do or what will happen next with their care

*One person said a hospital wanted to charge him £240 for a blood test, even though he had papers connected to his asylum application showing he did not need to pay for NHS services. He went back to his GP, who did the blood test at the surgery instead.*

**People with housing needs, supported by Launchpad Reading told us they need:**

- more time for healthcare professionals to listen so that individual needs can be met
- better coordination between healthcare professionals
- to be treated as experts in their own lives, whether in health or in social care





The individual project reports are attached at the end of this report.

## Themes

Drawing out the themes from the individual reports, what people told us matters was

1. **Rights** - knowing your individual rights in health and social care, and having your rights respected.
2. **Information** - having enough information, at the right time, in a form that is right for the individual
3. **Enough good quality and culturally sensitive care to meet the needs of the individual**

What people told us about their experiences included praise for good practice, but they also told us that services are not always getting things right. Some of the most vulnerable people are not getting the support they need.

We found that people found it more difficult to share experiences on some topics with us in our listening sessions than on other topics. We were guided by the charities we worked with on whether, if at all, it was appropriate to mention mental health in terms of health/illness. We did offer the opportunity for people to speak to us privately, if they wished. In the light of the advice given to us by our partner organisations, we were unsurprised that we heard relatively little about support for mental health issues.

To inform our understanding of additional issues, we also asked staff at the charities supporting those who spoke to us to tell us what they think are the 'top 3 issues in health and social care' affecting their clients. What we understood from what they told us is summarised on the following page. (Please refer to the individual partnership reports for the explanation in wording agreed with us by each partner organisation).

**What we heard from Reading Mencap** - a charity supporting people with learning disabilities

1. Social care: care and support plans - **getting an assessment that reflects the real needs of the individual matters**, and various current issues and problems with this were highlighted
2. When social care is provided - **the experience of care from Learning Disability Support Workers is affected by high staff turnover, short periods of time allocated for care, and a need for better staff training**
3. Healthcare - **are the needs of people with learning disability understood? are reasonable adjustments made?** We heard that some key aspects of care from GP surgeries can make an important difference (appointments at a time when the person with a learning disability can be accompanied; follow-up by the surgery if a person does not attend an appointment; taking care to obtain proper consent to treatment). Also, that a 'lead' GP in Reading to raise awareness about the needs of patients with learning disabilities in Reading could make a real difference.

**What we heard from Talkback** - a charity supporting people with learning disabilities

1. The **quality of support**, both personal and social, that people with learning disabilities receive is of vital importance.
2. **How people communicate with people with learning disabilities really matters.** Making appointment letters and information leaflets easy-read may not be the whole answer, but it can make a real difference.
3. **People having meaningful activities** that in some way contribute to the local community are of real importance to people. We can all learn from meeting a diverse range of people in service and activities that are inclusive and welcoming to all.

**What we heard from Reading Community Learning Centre (RCLC)** - a charity that provides education and support for the most disadvantaged and socially isolated women in Reading, most of whom do not speak English, and many of whom are not literate in their own language

1. Women who are learners at RCLC experience difficulties in **getting access to health and in understanding services**, including social services, generally - barriers including language, interpreter availability, cultural issues of expectation and understanding
2. There is a **lack of enough support for mental health** - not getting timely, appropriate and culturally sensitive treatment for mental health problems
3. **People needing home care need care that is culturally sensitive and appropriate** - RCLC learners as family carers supporting in this situation face extra pressures that may affect their health

**What we heard from Reading Refugee Support** - a charity supporting refugees and asylum seekers including those in Reading

1. **Difficulties in getting access to health** - barriers including language, interpreter availability, quality and suitability of information resources, and cultural issues of expectation and understanding
2. **Lack of enough support for mental health** - not getting timely, appropriate and culturally sensitive treatment for mental health problems
3. **Additional stress for people who act as carers for family members** - these pressures can affect their health

**What we heard from Launchpad Reading - an organisation supporting people with housing needs**

1. Mental health services need to be more responsive and accessible to meet the needs of homeless people and people at risk of homelessness.
2. NHS and social care services are very stretched currently due to funding pressures - this makes contacting services and getting the responses that Launchpad clients need difficult
3. There is little evidence that the preventative element of the Care Act is being implemented in practice - many Launchpad clients with eligible needs could benefit from the early and creative intervention to promote wellbeing as the Act requires, and Launchpad Reading has assisted some clients to be aware of their eligibility by using an 'eligibility checker', resulting in positive outcomes.

**The themes that Healthwatch Reading concludes these conversations add to what we heard in our listening sessions are:**

1. **Inclusivity matters** - people themselves have valuable information about their needs that can inform how services as are designed and provided. Charities that work directly with particular groups can provide valuable additional insights
2. **Mental health services need to be sensitive to cultural issues and individual needs (in services day-to-day & when involving people in service improvement work)**
3. **Unpaid carers have a vital role, and their needs must be addressed** when planning services and thinking about when, where and how service users will have their needs assessed and met.

## How can services be designed that are sensitive to individual needs and hear all voices, including people who use services, their families and carers?

Listening to people about their experiences of NHS services, using their views to shape quality improvement work, and involving people in planning of services is a requirement for NHS services. Involvement in service planning and design is often called 'co-design' or 'co-production'.

The NHS Constitution gives people the right to have a say in shaping their own care. They also have the right to be involved, directly or through representatives, in planning and designing services. When planning and carrying out their involvement work, services must have regard to the Equalities Act 2010, which protects individuals from unfair treatment and promotes a fair and more equal society.

Reflecting on this project, Healthwatch Reading has produced a short guide to involving local people in planning and designing NHS services which is attached to this report.

For listening, involvement and co-design/ co-production of services in social care, the Social Care Institute for Excellence, a national charity, has a useful suite of online training materials and resources.

Practically, two things are essential when doing engagement (listening to people and talking to them) and involvement work (people taking part in planning and designing services):

### 1. Commitment to the idea

Know that engagement and involvement are different - be committed to involvement, so that it is an automatic part of all strategic planning: 'how soon can we involve the public and/or patients/service users and how will we do it?'

### 2. Lived Practice

Know who to talk to - build relationships of trust locally and in your professional networks. Ask for help early, be open to new ideas. Make real involvement happen.



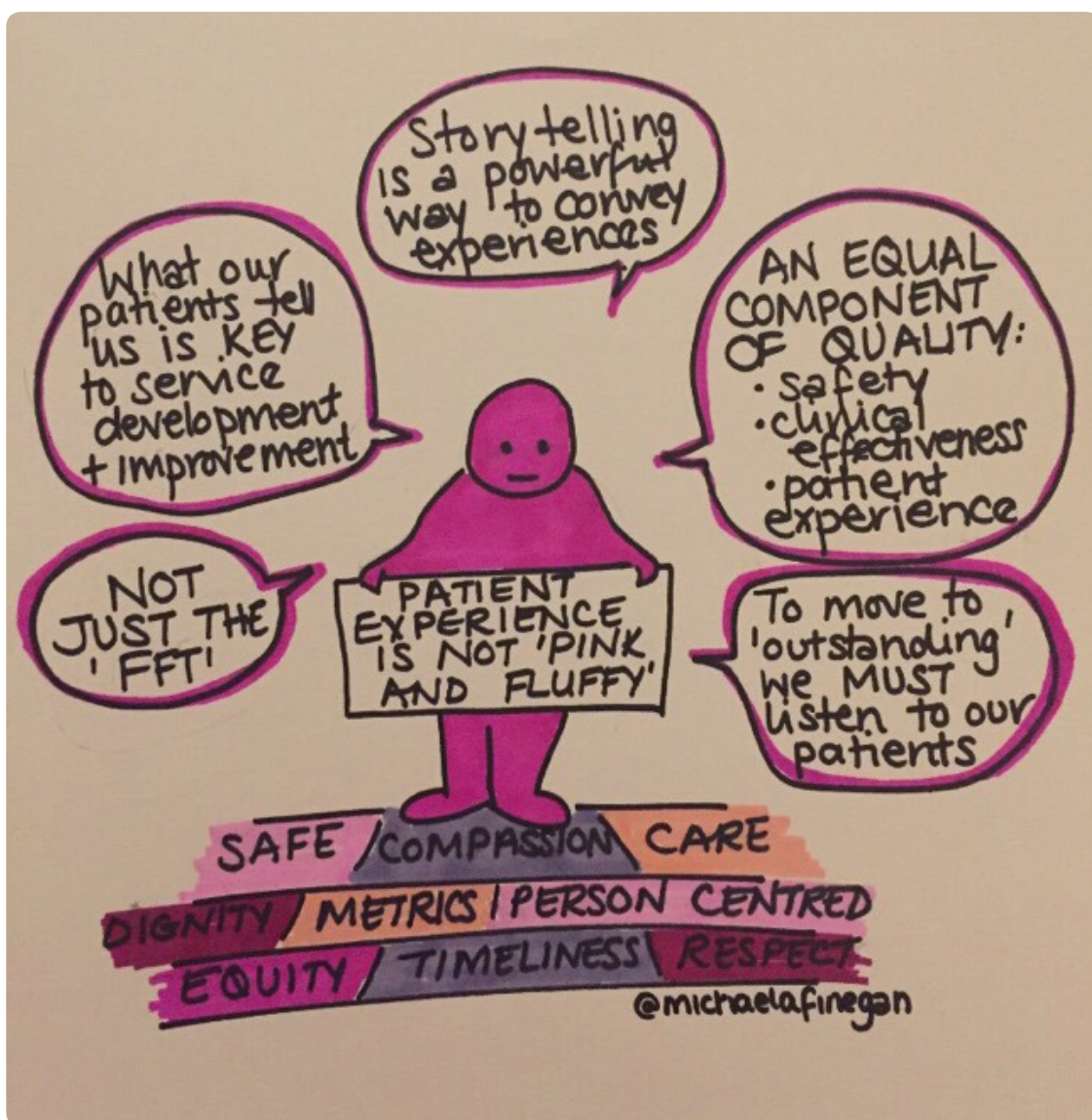
## Conclusion

This project has enabled people in Reading who are 'seldom heard' to share their views and priorities. It shows how opportunities to meet with people and listen to them directly can be arranged by working in partnership with the charities that support local people and taking their advice - and we thank our partners for their help and advice in this project. Involvement of local people in service planning and design could be developed further using this approach,

A key principle of such work is to meet people where they are, at a time convenient to them, and shape the occasion to their needs. Expecting people to fit in with a formal meeting or process, and to understand jargon, is often less successful in achieving true inclusivity.

Not everyone will know that they have the right to be involved. Healthwatch Reading can support services to involve local people if commissioners (the managers who buy services), and also NHS and social care services themselves, tell us when services are going to be reviewed or changed. It is important to involve service users and families/carers directly or through their representatives right from the start, when the work is being planned. This doesn't always happen.

'Involvement' in planning & improving health services - a Healthwatch Reading practice guide for NHS organisations



*Innovative organisations also have positive approaches to inclusion and participation, high-quality teamworking and an ethos of optimism, cohesion, co-operation, support and collaboration across boundaries, with a strong commitment to ensuring high-quality care for the communities they serve.'*

<https://www.kingsfund.org.uk/blog/2017/09/compassion-and-innovation-nhs>

## Engagement, Consultation, Involvement - is there a difference?

Yes. Engagement is making a connection with people, talking to and listening to them, but not necessarily doing what they suggest. Consultation is a formal process for engaging people - which might have involved them in service design, depending on how you engage them in the process, and how much influence their views can have. Involvement is just what it says - people are working alongside you as equals, helping to improve or redesign services. When people are involved in this way, often the work done is called 'co-design' or 'co-production.'

## Why do we need to do it?

Most people working in services recognise that it is the right thing to do - people who use services have expertise to offer about their own lives, experiences, health conditions, wellbeing, disability, culture and characteristics. People in discussion, sharing their stories, can often shed light on real experiences that 'tick the box that applies' data does not. Their experience is different from that of anyone who knows how a service works from the inside, as an employee, whether in they speak in that role or as a service user.

The work also has an important role in ensuring that services are inclusive - helping services to comply with the Equalities Act 2010.

Where national policy directs what will happen in services, the local detail of how it happens, and whether the public feel that this has been 'done to' them or whether they have a sense of ownership, depends on whether involvement happens, or not.

## The right to public involvement in planning healthcare service is set out in the NHS constitution:

'You have the right to be involved, directly or through representatives, in the planning of healthcare services commissioned by NHS bodies, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services.'

<https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england#patients-and-the-public-your-rights-and-the-nhs-pledges-to-you>

## 'But we understand the patient experience already'

If this is you, it is worth spending a few minutes listening to breast cancer oncologist and patient Liz O'Riordan:

<https://www.nuffieldtrust.org.uk/media/summit-2018-snapshot-liz-o-riordan-a-consultant-plastic-surgeon-on-becoming-a-breast-cancer-patient>

and also watching this 20 in minute panel discussion in which Liz and a senior NHS manager with a clinical background explain how they discover how little they understood what it is like to be a patient or service user, how their professional knowledge always gives them a different view. Only a service user who is not a clinician knows what that experience is like - for them:

<https://www.nuffieldtrust.org.uk/media/panel-discussion-at-summit-2018-when-nhs-staff-become-patients>

## The latest guidance for CCGs on refreshing commissioning plans says:

‘Public Engagement As systems make shifts towards more integrated care, we expect them to involve and engage with patients and the public, their democratic representatives and other community partners. Engagement plans should reflect the five principles for public engagement identified by Healthwatch and highlighted in the Next Steps on the Five Year Forward View’

<https://www.england.nhs.uk/publication/refreshing-nhs-plans-for-2018-19/>

## These five Healthwatch principles call for organisations to:

- Set out the case for change so people understand the current situation and why things may need to be done differently.
- Involve people from the start in coming up with potential solutions.
- Understand who in your community will be affected by your proposals and find out what they think.
- Give people enough time to consider your plans and provide feedback.
- Explain how you used people’s feedback, the difference it made to the plans and how the impact of the changes will be monitored.

<https://www.england.nhs.uk/wp-content/uploads/2017/03/NEXT-STEPS-ON-THE-NHS-FIVE-YEAR-FORWARD-VIEW.pdf> (See p35)

## So what do we need to do?

- People are diverse, so you will need to use different approaches with different groups
  - You need to think about people with protected characteristics under the Equality Act and be especially careful to include them
  - The general principle is ‘go to where people are, and think about them, not any message that you want to communicate - be curious, ask open questions, listen, ask for clarification, listen again’
  - Uses language and ways of meeting with, and listening to, that are right for different groups - not Powerpoint, policy jargon, and the language of your meetings
  - Going out for coffee or tea, or to join in with a crafting event, or to have an informal question and answer session, might be just the thing
  - Always be clear about who you are, how views shared with be used, where any write-up will be published, that views will be kept anonymous if wished etc - agree ground rules at the start, and stick to them
  - Voluntary sector organisations and local Healthwatch are key sources of advice for this work - involve them and ask for advice when you are planning what you will do
  - Think about whether this is a one-off event or series of events supporting a piece of work, or do you need to build something longer-term and sustainable? How will you fund the work?
  - It is not difficult to do this well if you allow enough time to build and develop relationships with community groups - and if you recognise that parachuting in, asking what matters to you in your language, and then leaving, with no commitment to developing a continuing connection, will rarely work
- You need someone - ideally more than one person in a large organisation - as a community liaison person, devoting a significant amount of time, regularly, to this work - someone who becomes known and recognised in the local community, and is a key contact for Healthwatch, the voluntary sector, local councillors and community leaders
  - For your community liaison person, time spent out drinking tea and networking is time well-used - people help people - people connect people - people have the answers to the problems that need to be addressed locally in the services you commission or provide

There are many published guides about engagement and involvement. Easy to find, easy to quote. More difficult in a busy and pressured working life to live the practice.

Practically, two things are essential:

### 1. Commitment to the idea

Know that engagement and involvement are different - be committed to involvement, so that it is an automatic part of all strategic planning: ‘how soon can we involve the public and/or patients/service users and how will we do it?’

### 2. Lived Practice

Know who to talk to - build relationships of trust locally and in your professional networks. Ask for help early, be open to new ideas. Make real involvement happen.

If you need more detail on that statutory background and ‘how to’, we recommend this excellent suite of guides by Healthwatch Kent:

<http://www.healthwatchkent.co.uk/public-consultations>

But above all, talk to us at Healthwatch Reading. We are here to help.



## Healthwatch Reading

3rd Floor, Reading Central Library  
Abbey Square, Reading  
RG1 3BQ

Tel 0118 937 2295

[info@healthwatchreading.co.uk](mailto:info@healthwatchreading.co.uk)

[www.healthwatchreading.co.uk](http://www.healthwatchreading.co.uk)

 @HealthwatchRdg

 HealthwatchReading

## Reading Voice

Tel 0118 937 2295

[helpdesk@readingvoice.org.uk](mailto:helpdesk@readingvoice.org.uk)

<http://readingvoice.org.uk>

**healthwatch**  
Reading  
advice • advocacy • action

  
Home of  
**ReadingVoice**  
Your local advice & advocacy hub

# “Our top three priorities”

By people with learning disabilities and the charity that supports them



# “Our top three priorities” Report summary

## People supported by Reading Mencap would like:

1. Staff trained on learning disabilities
2. To see the same GP, and time for the GP to listen
3. Enough, good quality, care



## Reading Mencap called for:

1. Quality care needs assessments
2. Consistent and adequate care
3. The NHS to adjust for the needs of people with learning disabilities

“Sometimes they [care support workers] cancel on the day and no-one comes.”

This report is based on local listening visits carried out in February 2018. It is one of a series of short reports that Healthwatch Reading is producing in partnership with local charities, to ensure that the views and needs of people and communities who are ‘seldom heard’, are available to the NHS locally, and Reading Borough Council, to inform planning and funding of health and social care services and quality improvements to services.

## Why have we produced this report?

The Quality Statements produced by Healthwatch England for measuring the impact and effectiveness of local Healthwatch include:

**Community Voice and Influence** - enabling local people to have their views, ideas and concerns represented as part of the commissioning, delivery, re-design and scrutiny of health and social care services;

**Making a difference locally** - by identifying where services need to be improved by collecting experiences of local people.

A local Healthwatch needs to formulate views on the standard of health and social care provision and identify where services need to be improved by formally or informally collecting the views and experiences of the members of the public who use them. (Healthwatch England)

Healthwatch Reading is therefore working with other local charities on a series of short 'top three issues' reports to ensure that the views and needs of people and communities who are least often heard are available to the NHS locally and to Reading Borough Council, to inform both commissioning and quality improvement in services

## How did we produce this report?

Our first listening meeting was with Leslie Macdonald, Chair of Trustees, Mandi Smith, CEO and Kate Stonehouse, Family Support Team Leader at Reading Mencap.

Our second listening meeting was with Reading people with learning disabilities, at their regular Coffee Club meeting on 26 February, 2018, at Reading Mencap premises.

## Part 1: What we heard from Reading Mencap

People with learning disabilities are some of the most vulnerable people in society, and they and their families and carers can often have difficulty in communicating their needs and experiences in health and care services.

These three themes emerged when we listened to Reading Mencap staff talking with us about the experiences of their clients:

### 1. Social care: care and support plans - getting an assessment that reflects the real needs of the individual

We heard that people with a learning disability need a high-quality assessment so that the social care plan written for them meets their needs.

It is also very important that family carers of people with a learning disability have a carers' assessment, so that their own needs can also be considered. Some people with learning disabilities live with their parents (60% of whom are retired or not working and are often frail themselves according to Reading Borough Council), or other family members, and caring responsibilities are often tiring and stressful, as well as often expensive (e.g. needing to pay for structured activity outings for the cared for person), adding to the stress that carers experience.

Other people live on their own, with some support from paid carers depending on their level of need.

We heard that the way in which social care plans are drawn up and implemented is having a serious impact on the mental health of many people with learning disabilities, who typically will experience high anxiety about forms and processes. People with learning disabilities will have very limited understanding of the process, or how what they say may affect what is put in their plan. This is resulting in social care plans that do not meet their needs.



We heard that:

- + a social care assessment is typically carried out by a social worker who has not met the person before and does not necessarily have training in learning disability
- + the assessment takes less than half a day, and lack of training in how to ask questions in the right way can mean, that a person's abilities are not correctly recorded

In one case, a person who told the assessor that they 'liked to make curry' meant that they could only make themselves a curry-flavoured instant soup. Heating up microwave meals is also deemed adequate nutrition, rather than being able to cook fresh food.

## 2. When social care is provided: the experience of care provided by learning disability support workers

We heard that there is a high turnover of care support staff generally, with varying abilities, in agencies that are used to support people with learning disabilities. It is a particular problem that a person with a learning disability may need to visit their GP surgery on more than one occasion to get their needs fully looked at - it can be difficult to get an appointment at a time when the person's support worker can also attend.

Care staff are often kind, but allocated care time is typically very short. This can affect the quality of the care provided.

People with learning disabilities are not able to understand fully how this might affect them, or how to try to change this so that their needs are met.

*Mortality rates for people with learning disabilities are 13 years earlier for men and 20 years for women, than for people generally (University of Bristol)*

We heard that care support providers may not always be providing training that makes sure that care staff really are alert to health issues for clients and that clients themselves might not be alert to these.

## 3. Healthcare: are the needs of people with learning disabilities understood and do services make reasonable adjustments?

Reading Mencap suggests that the following would be key reasonable adjustments:

- + surgeries ensuring that they offer appointments both for the annual health check for a person with a learning disability and for any non-routine things that are at a time when the person can be supported by someone they know
- + if a person with a learning disability does not attend a health appointment, following up with the person to call them in for an appointment can make a difference and ensure that they are seen - but that too often there is a lack of effort beyond what would be done for a person without a disability
- + taking care to obtain proper consent to treatment - it takes more time to do this well when a person has a learning disability
- + A 'lead' GP in Reading to raise awareness about the needs of patients with learning disabilities - when NHS staff are so busy, having a local 'awareness champion' could make a real difference.



“My support has been reduced because of all the cutbacks.”

## Part 2: What we heard from people with learning disabilities at a Reading Mencap coffee group

We asked the group to tell us what it is like when they visit their GP or the hospital, and what it is like if someone is helping them with their care at home. Are the people who help with health and care, kind and clear in what they say? What is done well? What could be better?

We spoke with eight people with learning disabilities and one carer. Several Reading Mencap staff and volunteers were present to host the session and contributed when appropriate.

The session was facilitated by Healthwatch Reading and was a mixture of whole group discussion and informal discussion over coffee. (Some contributors use GP services outside the Reading Borough Council area that we cover - where their comments highlighted what is important to people with learning disabilities, we included them in preparing this report).

### GP & other primary care services

We heard that the experiences of people with learning disabilities at GP surgeries are varied.

- + Some have good experiences with GP surgeries. They like to see the same doctor each time and they like to have enough time to explain things and for the doctor to talk to them. It is also important that the doctor listens to them.
- + Some doctors don't seem have a good understanding of learning disabilities.
- + One person had moved from Circuit Lane Surgery to another surgery because of “lack of seeing the same doctor and not feeling known”.
- + One person had found a GP to be unsympathetic about depression - they had moved to another surgery where the doctor was much more helpful.

“I can't get one [a social worker] at all.”  
“Sometimes they [agency support workers] cancel on the day - no-one comes.”

It can be difficult to make an appointment at a time when the person's support worker can go to the appointment with them.

Some people feel that appointments could be given sooner - waiting several weeks to see a named doctor is difficult. Some people have to visit to visit the surgery to make an appointment because it is not easy to be understood by the receptionists on the phone. We heard that anxiety is a problem for many people with learning disabilities and that it is important to feel known, valued and understood. This can reduce the anxiety that goes with making and going to appointments. One person talked to us about using dental services and being told that they would have to pay for expensive treatment which they did not take - when in fact they would have been entitled to free NHS treatment.

**Hospital**

One person told us about an experience at a hospital some years ago. After their surgery they were left in a room opposite the theatre where they could see people walk in and out.

This was because the hospital could not find them a bed. They stayed there until they were discharged. They had to make their own way home on the minibus. This had not been a pleasant experience.

The few people in the group who had used hospital services generally told us they were happy with the treatment they had.

The group also discussed Health Passports (which people themselves hold to show various professionals important information). These can support and empower people, but local NHS funding for these has now stopped and GP records could be used more to hold details.

People with learning disabilities rely on their GPs to make the transition smooth for them when they have to attend hospital appointments, especially if they have no carer or support worker to bring them.



The Healthwatch Reading session at a Reading Mencap coffee group



## Social care

The group told us strongly that they are not getting the support they need at home and to support them in going out.

Several have had their care needs reassessed recently, resulting in the allocated number of care hours being reduced. Most people in the group do not have a social worker and if they need to speak to one, they are getting through to a duty officer, who has no background knowledge of their needs.

People told us that things are not so good now as when there was a specialist learning disabilities team of social workers at the council.

Some told us that if care support workers were sick there was no cover for them. We also heard that care is not always provided over Bank Holidays and that this has an impact on people. One participant told us this 'does not make me feel valued'.

Changing care providers means lots of paperwork. This is difficult for people with learning disabilities, the group told us, and reduces their choices. Sometimes they want to change who provides their care, but the process is very difficult.

Several people told us that support workers do a tremendous job. One said that they were happy to tell their care support worker what they were happy with or not.

We heard that a few of the group have their money looked after by the Deputy's Office at Reading Borough Council.

This office does a good job of handling their

The top three issues raised by the group:

- health & social care staff need to be better trained about learning disabilities
- they need continuity of care at their GP's
- care packages don't always meet full needs

money but it is very busy and has a long waiting list.

We heard about a positive experience of using IRiS, the alcohol and drug treatment service in Reading. The person told us that the service listened to them and had helped the person with their addiction and now they are doing really well.

Transport to and from health and other appointments can be a significant barrier to getting good access to services. We hear that travelling by public transport can be difficult. For example, staff are not always helpful when a person has physical needs that mean they need to have the access ramp lowered on a bus.

Healthwatch Reading observed in talking with this group that it is not always easy to tell that a person has learning disabilities, so staff in various services might wrongly assume a person does not have additional needs.

## Conclusion

In both listening sessions it was clear how important it is for there to be a care plan that reflects and meets a person's real needs, and how important continuity of care is, as well as training for health and care staff specific to working with people with learning disabilities.

Themes from this report, and our recommendations spanning the whole series of reports in this project, will be included in a final report in due course.

Healthwatch Reading thanks Coffee Club members and Reading Mencap staff for giving their time to share their views. Healthwatch Reading is an independent charity with some statutory powers. We can take your feedback in confidence, help you make complaints, and refer serious concerns to other agencies.



Healthwatch Reading  
3<sup>rd</sup> floor  
Reading Central  
Library  
Abbey Square  
Reading  
RG1 3BQ

[www.healthwatchreading.co.uk](http://www.healthwatchreading.co.uk)  
t: 0118 937 2295  
e:  
[info@healthwatchreading.co.uk](mailto:info@healthwatchreading.co.uk)  
tw: @HealthwatchRdg



# “Our top three priorities”

By people with learning disabilities,  
supported by the charity Talkback

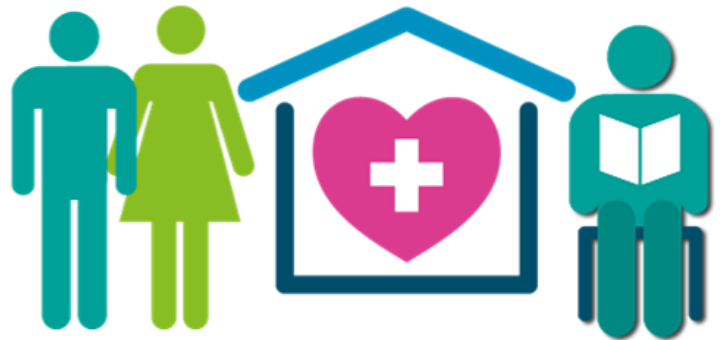




# “Our top three priorities” Report summary

## People with learning disabilities would like:

1. Easy-read leaflets about services, and for use during visits to healthcare professionals
2. To know about their right to ask for reasonable adjustments to make services more accessible
3. More consideration given to the needs of carers, who help support them with daily life



## The Talkback charity called for:

1. The right support in place for people with learning disabilities
2. Better communication, tailored for people with learning disabilities

3. People with learning disabilities to have the opportunity to take part in meaningful activities that contribute to the community

*I don't know when the surgery opens or closes. My support worker does it all on my behalf.*

This report is based on listening visits carried out in March 2018. It is one of a series of short reports that Healthwatch Reading is producing in partnership with local charities, to ensure that the views and needs of people and communities who are 'seldom heard', are available to the NHS locally, and Reading Borough Council, to inform planning, funding and quality improvements to services.

## Why have we produced this report?

The Quality Statements produced by Healthwatch England for measuring the impact and effectiveness of local Healthwatch include:

**Community Voice and Influence** - enabling local people to have their views, ideas and concerns represented as part of the commissioning, delivery, re-design and scrutiny of health and social care services;

**Making a difference locally** - by identifying where services need to be improved by collecting experiences of local people.

A local Healthwatch needs to formulate views on the standard of health and social care provision and identify where services need to be improved by formally or informally collecting the views and experiences of the members of the public who use them. (Healthwatch England)

Healthwatch Reading is therefore working with other local charities on a series of reports to ensure that the views and needs of people and communities who are least often heard are available to the NHS locally and to Reading Borough Council, to inform both commissioning and quality improvements of services.

### How did we produce this report?

Our first listening meeting was with Talkback staff member Sue Pigott on 7th March 2018.

Our second listening meeting was with 28 people with learning disabilities at a Talkback Matters session held at Salvation Army, Anstey Road Reading on 13<sup>th</sup> March 2018

## Part 1: What we heard from Talkback

Talkback is a charity working in the community to amplify the voices of people with a learning disability. It says there are three key issues in health and social care for people they support:

1. **The quality of the support they receive.** Support, both personal and social, are of vital importance to people and many people have a restricted number of support hours which can prove difficult when emergency situations occur, someone gets ill, or relationships at home break down. Sometimes misunderstandings around relationships occur which can impact on people's mental health. Having the right support in place to guide, advise and find ways of supporting these is vital for people to develop their confidence, gain more independence, learn how to sort out these issues (wherever possible) as well as engaging in the local community.
2. **How people communicate with people with learning disabilities.** As more people live independently, receiving long letters, in small print, with no pictures, using jargon words, does not support people to attend appointments. Issuing easy read letters may not be the whole answer- but it may support people with learning disabilities to get some idea of what they 'could' do towards attending an appointment. Easy read leaflets on medical conditions would go a long way too to supporting people in looking after themselves. Having their 'Health Passport' (an easy-to-use record designed specifically for people with learning disabilities, that service users bring to various appointments) read when it's shown is also of great importance to some people - it can lead to a better understanding of the person's support in attending appointments.
3. **People having meaningful activities that contribute to the local community.** Historically, people have simply attended day services, and although some have enjoyed the opportunity to socialise, and take part in activities, they have not always been able to meet people outside of their disability, which would add to everyone's personal development.

## Part 2: What we heard from people with learning disabilities

Talkback staff helped us to run the listening session attended by 28 people, and wrote its own report to record what happened in the session and what people said. The session focused on access to GP services.

# Talkback Matters



Talkback Matters is an opportunity for people with learning disabilities to meet up once a month.

We want to know what it is like in your GP surgery

Have you been to see your doctor

What was it like waiting for your appointment?

Did the nurse understand your support needs?

### DATE:

Tuesday 13th March 2018



until



### Venue:

Salvation Army, Anstey Road  
Reading RG1 7JR



Come along and tell us  
your stories and  
experiences.....

For more details.....

Contact :

[sue.pigott@talkback-uk.com](mailto:sue.pigott@talkback-uk.com)

Or 07912732362



Talkback, Amersham Community Centre, Chiltern Avenue, Amersham, Bucks, HP6 5AH



## Introduction

Talkback are a charitable organisation who work in the community to amplify the voices of people with a learning disability.

Through engaging and consulting with people with a learning disability, Talkback capture their thoughts, feelings and opinions about their lives and the issues which affect them, recording these insights in various creative formats and presenting them to professionals. The information gathered is fed into the Learning Disability Partnership Board to ensure that people's voices are heard by service providers in Reading, affecting positive change which is influenced by the lived experience of people with a learning disability.

## Talkback Matters

One way of achieving this is through the monthly meetings called TALKBACK MATTERS.

These groups have different topics each month and give people the opportunity to come together in a social way. Individuals are supported by carers who know them and are encouraged to take full active part in the discussions. By using pictures and symbols individuals are supported to speak up about their experiences.

There is always a beginning to every Talkback Matters group. To make sure people feel valued and part of something important we sign in our names. This gives individuals the opportunity to make choices and be seen by everyone else in the room. It also facilitates taking turns.



Individuals have the opportunity to choose who signs in next and this acts as a way of introducing people to each other.



## GP Surgeries

Today's topic was around doctors surgeries. Healthwatch Reading are keen to establish a way for people with learning disabilities to access their services and through attendance such as this group we can establish how this can be achieved.

We had some picture set up on a flip chart and so individuals were encouraged to answer the questions, offer their opinion and tell us about their experiences. Support staff were also there to add their contribution as some of the individuals who attend need more support to remember some of the finer details.

Here's what people said to some of the questions asked.

The door of the surgery is not sliding so when I'm in a wheelchair I have to get someone to help me to open the door.

The surgery doesn't have a big car park so my sister has to pay to park her car even when she's only picking up a repeat prescription for me.

I don't know when the surgery opens or closes. My support worker does it all on my behalf.



I have to walk to the surgery as there is no bus route. When you are not feeling well this is hard. I don't get paid support for health appointments





Here are a few experiences of people on waiting rooms:

"I didn't know that I could ask for a quiet room to wait in. I have been told that if I ask before my appointment the surgery can provide me with a quieter place to wait as I do find the waiting room a bit noisy"

"The waiting room is big, it can be noisy with kids running about"

"It can get a bit hot really"

" You seem to have to wait for a long time"

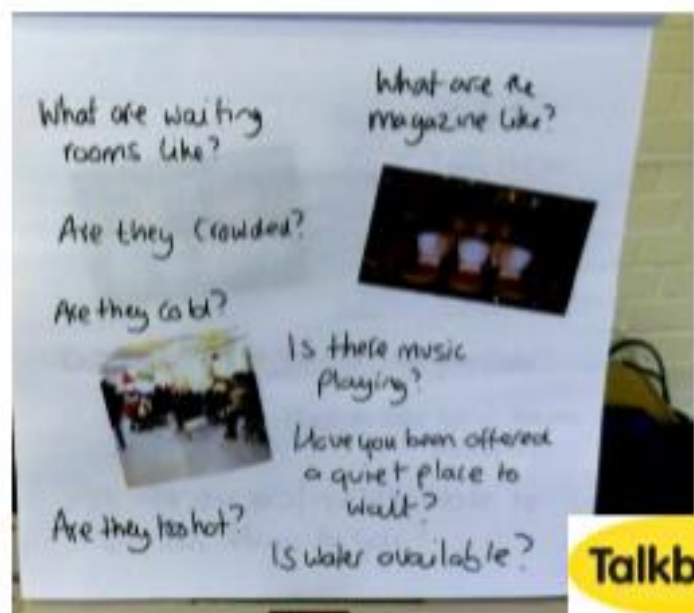
" The magazines are ok, but there's no where to get a drink of water"

" The seats aren't very comfortable, they can be a bit hard, especially if you are sitting there a long time"

"They put up on a screen when it's your time to see the doctor, but I need support to read this"

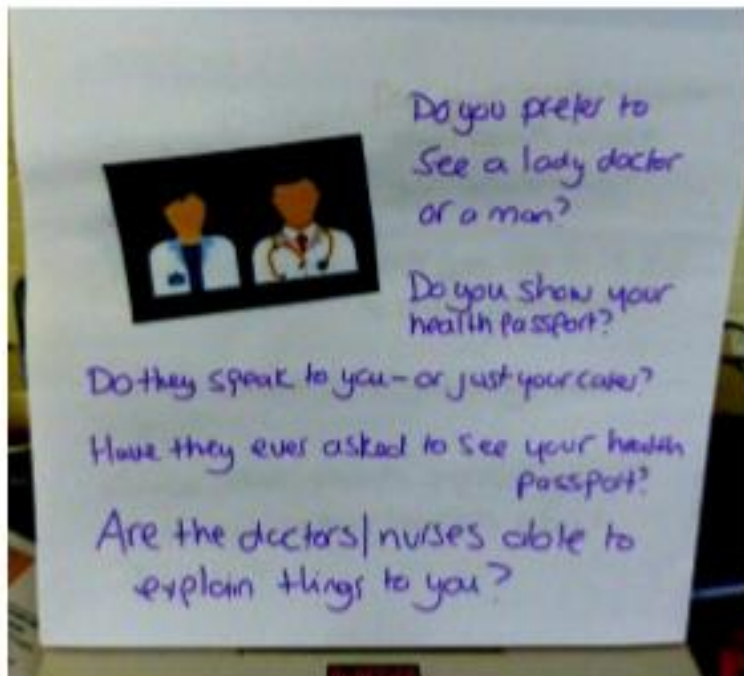


"The receptionist is ok, sometimes I can't see her because the counter is in the way- I'm in a wheelchair and I can't see over the counter"



**Talkback**

Reading



I do feel a bit rushed when I am talking to the doctor. He is very busy.

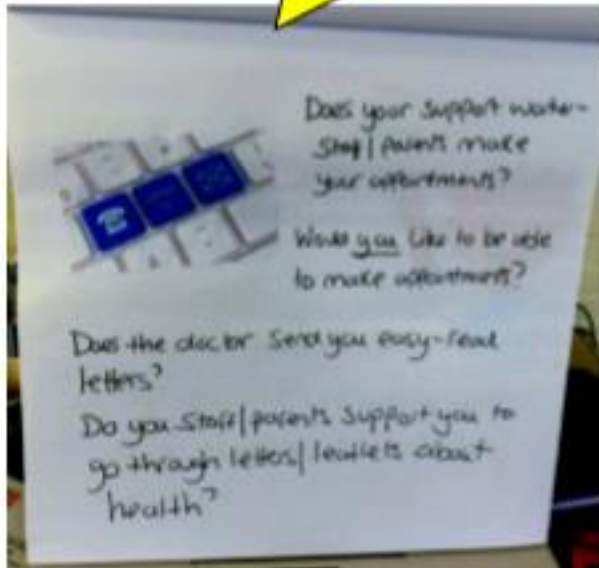
I don't mind if I see a man or a lady doctor.

I have not seen any leaflets/easy read for me to look at. Not in the surgery.

My support worker makes the appointments. I have had a letter about my annual health check but sister has done all that for me.

I've been getting some support from Reading Mencap to go to appointments. My other support time doesn't include time for health.

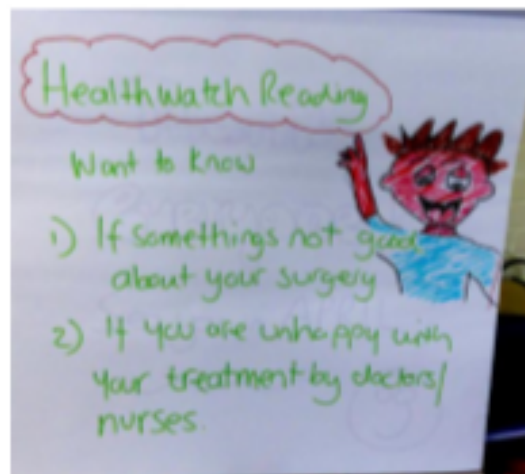
The doctor does speak to me. He checks things out with my carer.



Talkback have lots of easy read leaflets so it will be good to go through them

I can tell the doctor what I'm feeling like and if I need anything.





Healthwatch Reading would like to know if there are any problems with accessing surgeries. They make sure that everyone has a good service to health care.

## Recommendations

1. Talkback will provide people with the contact number of Healthwatch Reading, plus a few other helpful contacts in regards to health.
2. For Healthwatch to raise with GP's that not everyone who lives in the community has support and they may need to rely on family members to take them.
3. When attending an appointment some individuals would like easy read leaflets that they can go through conditions/with support staff.
4. Some people were unaware of the reasonable adjustments that could be provided by the GP surgery. Eg a quiet room to wait, or a double appointment. These need further explanation so that people know how to get these adjustments.
5. For many people with more complex support needs, family members are instrumental in making appointments, explaining the symptoms and caring for their son/daughter. This can put added stress onto the carer as well as have an impact of the amount of care/support as a result of being poorly.

## Conclusion

Listening to both people with learning disabilities and people who work with them, these three themes emerged:

- 1. Support is key** - people with learning disabilities may have family support, though not all do. Understanding that people with learning disabilities have different situations and different needs, and that being sensitive to the needs of their carers matters, is important
- 2. Information is important**, for people with learning disabilities and for their carers. Again, needs and preferences will be individual. Some people with learning disabilities would like easy read leaflets available, for example.
- 3. Knowing your rights** - particularly the right to have reasonable adjustments - is important and services need to actively offer adjustments, as not everyone knows that they can ask.

It is important that everyone involved in arranging and providing services understands that these things matter. If they do, then they can help make things work better for everyone by making sure that services are designed to include these important things.

Themes from this report, and our recommendations spanning the whole series of reports in this project, will be included in a final report in due course.

Healthwatch Reading thanks the people who talked to us and Talkback staff for giving their time to share their views. Healthwatch Reading is an independent charity with some statutory powers. We can take your feedback in confidence, help you make complaints, and refer serious concerns to other agencies.





Healthwatch Reading  
3<sup>rd</sup> floor  
Reading Central  
Library  
Abbey Square  
Reading  
RG1 3BQ

[www.healthwatchreading.co.uk](http://www.healthwatchreading.co.uk)  
t: 0118 937 2295  
e:  
[info@healthwatchreading.co.uk](mailto:info@healthwatchreading.co.uk)  
tw: @HealthwatchRdg

# “Our top three priorities”

By women attending the Reading Community Learning Centre and the charity that supports them



# “Our top three priorities” Report summary

## Women learners would like:

1. Access to interpreting services when using the NHS
2. Culturally aware and timely provision of accurate information about locally available services
3. Longer appointments, if they do not speak English as their first language, to have time to discuss serious health or care concerns

## Reading Community Learning Centre called for:

1. People to get access to interpreting services when using NHS and social care services



2. Quicker, better and culturally sensitive support for people with mental health issues
3. Culturally sensitive social care at home - for people with care needs, and family carers

This report is based on listening visits carried out in February and March 2018. It is one of a series of short reports that Healthwatch Reading is producing in partnership with local charities, to ensure that the views and needs of people and communities who are ‘seldom heard’, are available to the NHS locally, and Reading Borough Council, to inform planning, funding and quality improvements to services.

*My GP called the [interpreting] phone service. It was good.*

## Why have we produced this report?

The Quality Statements produced by Healthwatch England for measuring the impact and effectiveness of local Healthwatch include:

**Community Voice and Influence** - enabling local people to have their views, ideas and concerns represented as part of the commissioning, delivery, re-design and scrutiny of health and social care services;

**Making a difference locally** - by identifying where services need to be improved by collecting experiences of local people.

A local Healthwatch needs to formulate views on the standard of health and social care provision and identify where services need to be improved by formally or informally collecting the views and experiences of the members of the public who use them. (Healthwatch England)

Healthwatch Reading is therefore working with other local charities on a series of short 'top three issues' reports to ensure that the views and needs of people and communities who are least often heard are available to the NHS locally and to Reading Borough Council, to inform both commissioning and quality improvements of services.

### How did we produce this report?

Our first listening meeting was with staff members Aisha Malik, Shaheen Kausar, Parveen Brar, Premalatha Sudarshan, and Hemamalini Sundararajan at Reading Community Learning Centre (RCLC) on 1 February 2018.

Our second listening meeting was with 14 women at RCLC, at a listening session and lunch held between classes, at the centre on 7<sup>th</sup> March 2018.

## About the Reading Community Learning Centre

RCLC provides education and support for the most disadvantaged and socially isolated women in Reading. Many of the women have had little or no previous educational experience and feel unable to attend mainstream establishments because of the cultural, economic and personal barriers they face. Most do not speak English and often they are not literate in their own language. For some, the centre offers their only contact outside their immediate family.

The service provides social, educational, civic engagement and volunteering opportunities for marginalised women from Black and Minority Ethnic (BME) communities and provides services that address barriers to learning, including child care through a crèche, and supports progression into further education, social and employment opportunities.

### BME communities in Reading

Reading has an ethnically diverse population. South Asian groups (Indian, Pakistani and Other Asian) accounted for 12.6% of all residents in the [2011 census](#). A further 4.9% identified themselves as Black, and those identifying as 'Other White' (including several other nationalities, including Reading's Polish community) accounted for 7.9% of the population.

Local BME communities are in themselves diverse and will have different needs when accessing services. RCLC provides support and opportunities for particularly marginalised women from BME communities.

## Part 1: What we heard from RCLC staff

These three themes emerged when we listened to RCLC staff views about women's experiences:

1. **Difficulties in getting access to health and in understanding services, including social care.**



**Barriers include language, interpreter availability, cultural issues of expectation and understanding.**

We heard that women know to call the GP when something is wrong, but it is usual then to then have to wait a long time to for an appointment. Language can be a barrier to communication and understanding at all points in the process, as is lack of knowledge of how the system works. Interpreters are not always available for appointments.

**We heard that the centre is seeing more women and families affected by domestic abuse...and it is important social workers use interpreters to help women understand both council processes and their rights.**

If the woman or a family member needs a hospital referral, women report to RCLC staff that they often cannot understand the referral letter. Women often feel that the wait for the hospital appointment is long, and do not understand why this would be.

We heard that waiting rooms at Royal Berkshire Hospital could be more child friendly, and it was suggested to us that at times priority should be given to those who have younger children instead of parents having long waiting times. Children get restless so sometimes women do not stay for their appointments - they report to RCLC staff that they end up leaving to care for their child in a more appropriate setting.

We also heard that the centre is seeing more and more women and families affected by domestic abuse, who need support and advice about their situation.

**The loss of a local service providing counselling in a variety of languages, had reduced opportunities for staff to signpost learners to culturally appropriate support.**

They might want support on immigration, or might be on a spousal visa, which then leaves them destitute as they have no access to benefits, any money or social housing once they leave their family home and go into refuge. These women are the most vulnerable of all as they will not know their rights or how to access what they might need.

In many cases of domestic abuse social services are involved, and it is important that social workers work with interpreters to help women understand both the council process and their rights.

**2. Lack of enough support for mental health - not getting timely, appropriate and culturally sensitive treatment for mental health problems.**

Staff told us that in many cultures there is a stigma attached to mental illness, or it is simply not acknowledged to exist. So it can be very difficult for families to get the help that a person who is unwell needs, and such help needs to be culturally sensitive.

Women who do want support with mental health often lack the knowledge of the NHS and where to access help. They may not understand that a GP is able to talk about mental health, or not have access to a computer, or the skills, to search for information and advice online.

Sometimes cultural issues mean that GPs do not identify an underlying mental health issue, and medication is given for a physical symptom instead.

“Some people would not be comfortable with male care workers. They might also not want care workers to come at prayer time.”

The underlying illness remains untreated and may get worse. Staff suggested to us that advertising more about mental health in community languages could raise awareness and signpost sources of help.

We heard that loss of a local service that had provided counselling in a variety of Reading's languages had reduced the opportunity to refer RCLC learners and families to culturally appropriate services - we heard that RCLC learners made very limited use of Talking Therapies, and it did not seem to include easy provision for working with an interpreter.

**3. People needing home care need care that is culturally sensitive and appropriate. RCLC learners as family carers supporting in this situation face extra pressures that may affect their health.**

We heard many workers provided by home care agencies are not trained in and aware of the cultural and religious needs of the families of RCLC learners. Some family members would not be comfortable with male workers and might want a female to do their personal care. They also might not want them to come round when it is prayer time. Many elderly parents want to keep their independence and may not want to move in with a son or daughter but still may need some sort of support at home.

We heard that culturally inappropriate arrangements can cause much unhappiness and distress. Where RCLC learners are supporting family members who receive home care, the impact on them as carers can be considerable - most would not be aware that they are entitled to a Carer's Assessment.

## Part 2: What we heard from learners at RCLC

We asked the 14 women to tell us what it is like when they visit a GP or hospital, and what it is like if they have responsibility for caring someone else who they support in accessing services. Are doctors, nurses and others kind, and clear in what they say? Is an interpreter always available? What is done well?

**Very limited use was made of Talking Therapies and it did not seem to include easy provision for working with an interpreter.**

We also asked, what could be better? Interpreting was provided informally during this session by RCLC staff and women who attended. Languages spoken included Arabic, Mandarin Chinese, Pakistani/Urdu, Spanish (Ecuador), Nepali and Punjabi.

Comments about what is done well:

“Yes, [I had access to an interpreter] at hospital - in Arabic’.”

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

“My GP called the phone [interpreting] service. It was good.”

“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.”

“I was asked if I prefer a man or a woman doctor” [at reception at a GP surgery].

“For me the service in my GP is very good - I don’t know my doctor but for me any GP is good.”

Comments about what could be better:

“With the phone it’s difficult to get appointments [at the GP].”

“Having to tell at reception what the appointment is for and it only being possible to ask about that even if you have time and [another] problem is of the same nature.”

One woman described a traumatic experience of miscarriage some time ago when she was sent home from A&E to wait one month for a test result and a clinic appointment. No emotional support was given:

● In my country they would help, give some medication or something. We were told [at A&E], “we don’t have a doctor now for a scan”.



The Healthwatch Reading listening and lunch session with learners and staff at the Reading Community Learning Centre.





“I don't know who my GP is - they change whenever they want to.”

“They [GPs] need to see the person as a whole [answer questions about more than one thing].”

“Some GP surgeries use locums - you get a quick diagnosis or a prescription in five minutes, [this is worrying].”

“Explaining what the problem is, is [culturally] hard. English...it is hard to be understood - on phone worse.”

Once I accompanied a friend, who does not speak very good English, to the Walk-in Centre. I could see that the healthcare professional did not take care to read her record.

#### Other general feedback:

##### Dental services

Many told us that they did not understand the dentist and having to pay. They did not feel confident in going to a dentist as they did not understand the charges.

##### Disability support

One of the women explained that she is a carer for her child who has a long-term health condition and disabilities. Her GP surgery has been helpful with her son and has supported her well. Support at the hospital has been good too. However social care support has not been so easy - the parents had to ask for a carer's assessment and also had to make their own enquiries about respite care, as their child's social worker did not know anything about it when asked.

It can also be difficult for family carers to arrange a home visit or telephone call from a GP, although diabetic care is generally good.

The group felt that information about support groups for families with a cared-for person at home was not being passed on to families and information about what statutory services were available was patchy.

##### GP surgeries

Most people had a good experience, with most having no issues getting appointments and were able to see a GP as soon as they possibly could. Several found their GP helpful when they went in to see them.

Others reported that they do not get enough time to speak to the GP during appointments and sometime find it difficult to explain more symptoms when they just have an allocated 10 minutes for their appointments. They would like to have more time. The women were mostly unaware of the possibility of being able to request a double appointment.

We heard that it would be good to see the same doctor for continuity, and building that relationship in which repeating the patient's story at every visit is not necessary and it becomes easier to talk about private matters. There are cultural barriers to asking for help and care for certain conditions and generally, especially for women - it would be better for the GP to offer help.

##### Interpreting

We heard that Western Elms Surgery offers a translating service for patients who have English as a second language, but not many had that option at other surgeries and they were not offered it when they made an appointment. In contrast, most who used hospital services were offered interpreters for appointments, which made the experience better as they could be understood.



The three key themes that emerged from the session were:

- 1. Interpreting services are very important** in ensuring full and equitable access to NHS services
- 2. Culturally aware provision of accurate information** about services and available support for service users, families and carers, in a timely way, is important in both health and social care services
- 3. At times, it may be necessary to allocate longer appointments** to ensure that serious health and social care matters can be adequately discussed, with interpreting support, with service users and carers who do not speak English as their first language.

## Conclusion

It was clear from both meetings that commissioners and health and care providers need to be aware of the need to ensure access to:

- + interpreting services
- + culturally aware provision of accurate information, with enough time and support to understand the information, and
- + culturally sensitive services (e.g. awareness that a particularly strong stigma attaches to mental health issues in some cultures).

Themes from this report, and our recommendations spanning the whole series of reports in this project, will be included in a final report in due course.

Healthwatch Reading thanks learners and staff for giving their time to share their views. Healthwatch Reading is an independent charity with some statutory powers. We can take your feedback in confidence, help you make complaints, and refer serious concerns to other agencies.



Healthwatch Reading  
3<sup>rd</sup> floor  
Reading Central  
Library  
Abbey Square  
Reading  
RG1 3BQ

[www.healthwatchreading.co.uk](http://www.healthwatchreading.co.uk)  
t: 0118 937 2295  
e:  
[info@healthwatchreading.co.uk](mailto:info@healthwatchreading.co.uk)  
tw: @HealthwatchRdg

# “Our top three priorities”

By refugees and asylum seekers in Reading  
and the charity that supports them



# “Our top three priorities” Report summary

## Refugees and asylum seekers would like:

1. Better access to interpreters
2. Accessible information about what they can expect in and from healthcare services
3. Healthcare staff who make sure people understand things, like their diagnosis and what will happen next with their care

## Reading Refugee Support Group called for:

1. Removal of barriers to healthcare e.g. lack of interpreters and information

*One person said a hospital wanted to charge him £240 for a blood test, even though he had papers connected to his asylum application showing he did not need to pay for NHS services. He went back to his GP, who did the blood test instead.*



2. Quicker, better and culturally sensitive support for mental health issues

3. Acknowledgement of the extra stress faced by people who act as carers for family members

This report is based on local listening visits carried out in April 2018. It is one of a series of short reports that Healthwatch Reading is producing in partnership with local charities, to ensure that the views and needs of people and communities who are ‘seldom heard’, are available to the NHS locally, and Reading Borough Council, to inform planning, funding and quality improvements to services.



## Why have we produced this report?

The Quality Statements produced by Healthwatch England for measuring the impact and effectiveness of local Healthwatch include:

**Community Voice and Influence** - enabling local people to have their views, ideas and concerns represented as part of the commissioning, delivery, re-design and scrutiny of health and social care services;

**Making a difference locally** - by identifying where services need to be improved by collecting experiences of local people.

A local Healthwatch needs to formulate views on the standard of health and social care provision and identify where services need to be improved by formally or informally collecting the views and experiences of the members of the public who use them. (Healthwatch England)

Healthwatch Reading is therefore working with other local charities on a series of short 'top three issues' reports to ensure that the views and needs of people and communities who are least often heard are available to the NHS locally and to Reading Borough Council, to inform both commissioning and quality improvements of services.

### How did we produce this report?

Our first listening meeting was with a manager from Reading Refugee Support Group (RRSG), at the Reading International Solidary Centre (RISC).

Our second listening meeting was with nine men who are refugees or asylum seekers, at a RRSG forum meeting held after the regular drop-in meeting at RISC on 9<sup>th</sup> April, 2018.

## Part 1: What we heard from Reading Refugee Support Group

People who are refugees or asylum seekers are some of the most vulnerable people in society, and they and their families and carers can often have difficulty in communicating their needs and experiences in health and care services.

These three themes emerged when we listened to Reading Refugee Support Group (RRSG) staff talking with us about the experiences of their clients. We heard that refugees and asylum seekers in Reading experience:

- 1. Difficulties in getting access to health.** Barriers including language, interpreter availability, quality and suitability of information resources, and cultural issues of expectation and understanding
- 2. Lack of enough support for mental health** - not getting timely, appropriate and culturally sensitive treatment for mental health problems
- 3. Additional stress for people who act as carers for family members** - these pressures can affect their health.

RRSG helps people from many different countries of origin, including people from Syria, Sudan, Afghanistan and Pakistan. Most are fleeing persecution and violence in their own countries. The charity provides caseworker support across an array of issues from asylum and protection to liaising with the Home Office to follow up on applications. They also provide a drop-in service giving advice.

For most people, coming to a new country is a daunting experience - but imagine if you cannot speak the language or everything about the place where you have sought refuge is alien to you. It's not like being on holiday.

We heard that many RRSG clients have seen devastation and violence in their home country. Others have been trafficked to work in poor conditions the UK, which leaves them in a very vulnerable state.

Accessing healthcare is a priority for all of these people as some will suffer from post traumatic stress disorder (PTSD) or other mental illness or physical illness too, often chronic conditions (Syrian refugees living in Reading may have been granted refugee status because of healthcare needs that make them especially vulnerable).

We heard that many men are young and quite fit when they migrate, even if they come from difficult circumstances.

**In many cultures, mental illness is not talked about and is not acknowledged.**



So the health and social care needs of all these people are diverse, and individual.

Navigating the health system is difficult for many as they come across language barriers; asylum seekers (in contrast to refugees) fear deportation; both groups typically do not know how or where to access healthcare.

We heard that it can take several visits to a GP for a patient and GP to overcome cultural barriers - for the patient to explain what a problem is and to then understand treatment options.

Organising and following through referrals to hospital can be particularly difficult.

Many refugees and asylum seekers, often with their own health problems, are carers for family members and this is an added stress that can affect their health.

Many come from countries where understanding of health and illness, and

Simply understanding what to expect, and what is 'usual' in the UK healthcare system, can be a difficulty.

of what to expect from the health and social care system, is very different from this country - for example, medicines may be prescribed more frequently and for a greater range of conditions, or it may be usual to see a doctor where in the UK a different healthcare professional would be the norm.

## Part 2: What we heard from people who are refugees or asylum seekers

We asked people to tell us what it is like when they visit a GP or a hospital, and what it is like if they have responsibility for caring for someone else who they support in accessing services. Are doctors, nurses and others kind, and clear in what they say? Is an interpreter always available? What is done well? What could be better?

During our discussion with people, informal interpreting support was provided by RRSB staff and by people in the RRSB forum, as agreed in advance and following their advice about what would work best for this group.

Here is what we heard about various services:

### Dental services

'I was sent to the hospital...with a dental problem - by my dentist. I had to wait two weeks for an appointment [there] and was not offered antibiotics. Pain in my tooth over five days. I was told, 'No appointments - not an emergency'.



“I waited for one hour [for help]. I was in a very bad situation. I did not understand why this happened this way.”

I went to [another hospital] and was given painkillers.’ This man reported that both 111 and a pharmacist had given advice but not advised how he could access pain relief, despite him being in acute pain.

### Hospital services

- + One person reported going to hospital two to three months ago with a fever, because he was very ill. He waited a few hours and when seen by the doctor, was offered antibiotics and painkillers.

The doctor said he would return with the prescription in two to three minutes but did not return and after one hour the client left with a paper prescription brought to him by a nurse, but with no tablets. He later used tablets he already had at home.

He said: ‘I waited for one hour - I was in a very bad situation. I did not understand why this happened this way.’ He said it amounted to ‘humanitarian abuse.’

We heard that he did not know whether he could simply have bought the medicines himself without a prescription, and that he wants to do the proper thing, so needs better information.

- + One person had a first hospital assessment about his health some months ago and asked for an interpreter but he was not provided with one. When he asked the staff ‘to explain’ things a nurse gave him a leaflet but it was not in English he could understand, and he needed an interpreter. Eventually some medical tests showed that he did not need an operation. Staff explained this to him, and he felt good - he did not want the operation.
- + One person said that a phone interpreter provided for him was not the same nationality as him, and this was difficult. He also said, ‘All doctors say something different’ so he never knew what was happening or why.

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.

A local interpreter that he had brought along with him was not allowed to be with him during his appointment. During his appointment he was also not asked about medication prescribed by his GP.



- + One person with a back problem reported regularly attending the hospital and his GP surgery. He said that there was usually no interpreter available on the phone or in person - he was told to bring one and usually brought a local contact. He explained that on a visit to A&E about an urgent matter he was not told what was wrong with him, even when he left and went home.
- + Another person told us that when he went to the phlebotomy clinic at the Royal Berkshire Hospital, staff wanted to charge him £240 for a blood test although he had the papers connected to his asylum application to show that he did not need to pay. RRSg advised him that he did not need to pay. He went back to his GP who did the blood test at the surgery instead.

### GP surgeries

One person reported an unsatisfactory sequence of appointments to diagnose a health problem. A GP recommended to him that he drink lots of water for four to five days, but his problem did not settle so he called the surgery again. He was sent to have his blood pressure checked and have a blood test. The blood test was repeated several times after that. The GP said everything was normal but he is still in pain. The client wants to know for sure what is wrong with his health.

One person told us that finding which online information is correct, is confusing - RRSg staff have to explain to their clients which are the best sites for information and advice.

### The Healthwatch Reading session with the Reading Refugee Support Group





The top three issues from the discussion were:

1. Difficulty in accessing interpreting services when needed
2. Needing better and more accessible information, including what to expect in and from healthcare services
3. A need for healthcare professionals to make sure that people understand what is happening - what the diagnosis is, what to do next or what will happen next.

Healthwatch Reading finds it concerning that the NHS tried to charge somebody for a service when they had papers to show they were entitled to free care.

### Conclusion

In both listening sessions it was clear that ensuring that services are inclusive and individual - recognising the person's particular needs, including language needs and the fact that they simply might not know about the UK healthcare system - is important.

We noted some reticence in the group in discussing health with us initially. The 90-minute session began with establishing ground rules of confidentiality, anonymity and respect for privacy (we were not asking about details of any health condition), however it was apparent that building trust and understanding takes some time and care.

Themes from this report, and our recommendations spanning the whole series of reports in this project, will be included in a final report in due course.

Government guidance states that GP surgeries are not required to request proof of identity or immigration status from people wishing to register as new patients.

### Extra information about migrants

A migrant is anyone who seeks to move overseas. A refugee does so in conditions where they have been forced from their homeland. An asylum seeker is someone who says he or she is a refugee, but whose claim has not yet been definitively evaluated.

If you have refugee status, humanitarian protection, discretionary leave or indefinite leave to remain, you have broadly the same rights and entitlements as other UK residents and citizens. You can work, use health services and apply for housing and welfare benefits.

Asylum seekers cannot claim mainstream benefits. Those who are destitute may be eligible for accommodation and financial support in the form of vouchers from the UK Border Agency.

Some asylum seekers, and those who have been refused asylum, are not entitled to any support and may become destitute and homeless.

Government guidance states:

- + refugees and asylum seekers are entitled to free GP and primary care services; GP surgeries are not required to request proof of identity or immigration status from people wanting to register as new patients
- + people granted refugee status, or who are awaiting asylum decisions, are exempt from any charges for secondary care.

See: <https://www.gov.uk/guidance/nhs-entitlements-migrant-health-guide>

Healthwatch Reading thanks Reading Refugee Support Group clients and staff for giving their time to share their views. Healthwatch Reading is an independent charity with some statutory powers. We can take your feedback in confidence, help you make complaints, and refer serious concerns to other agencies.



Healthwatch Reading  
3<sup>rd</sup> floor  
Reading Central  
Library  
Abbey Square  
Reading  
RG1 3BQ

[www.healthwatchreading.co.uk](http://www.healthwatchreading.co.uk)  
t: 0118 937 2295  
e:  
[info@healthwatchreading.co.uk](mailto:info@healthwatchreading.co.uk)  
tw: @HealthwatchRdg

## What are the top three issues in health and social care for Reading people who are homeless or have other housing difficulties?

This is one of a series of short reports on key issues in people's experiences of health and social care in Reading shared with us by local organisations who work with vulnerable groups. These reports will be shared with the Reading Health and Wellbeing Board, bringing together any common themes and our recommendations.

A partnership project with: [Launchpad Reading](#)

**Where** Launchpad Reading, The Stables, 1A Merchants Place, Reading, RG1 1DT

**Why** The Quality Statements produced by Healthwatch England for measuring the impact and effectiveness of local Healthwatch include:

- **Community Voice and Influence** - Local Healthwatch enable local people to have their views, ideas and concerns represented as part of the commissioning, delivery, re-design and scrutiny of health and social care services.
- **Making a difference locally** - A local Healthwatch needs to formulate views on the standard of health and social care provision and identify where services need to be improved by formally or informally collecting the views and experiences of the members of the public who use them.

Healthwatch Reading is therefore working with other local charities on a series of short 'top three issues' reports to ensure that the views and needs of people and communities who are least often heard are available to the NHS locally and to Reading Borough Council, to inform both commissioning and quality improvement in services

### **How**

**Our first listening meeting was with:** Wendy Webster, Floating Support Officer at Launchpad Reading on 21 February 2018

**Our second listening meeting:** was on 5 June 2018 with 5 Reading people with housing needs - we met some in person at Launchpad, and spoke to others by telephone

## **Part 1: What we heard from Launchpad Reading**

People with housing needs are some of the most vulnerable people in society, and they and their families and carers can often have difficulty being heard in wider society. [Launchpad Reading](#) provides a drop-in service, housing with support, and supports single parents, families, couples and individuals to stay in their own homes by helping with landlord issues ('Floating Support'). The Floating Support service also helps find appropriate housing for people housed in unsuitable accommodation, such as families in B&Bs (support is for three to six months.)

These three themes emerged when we listened to feedback from the Floating Support Team at Launchpad about the experiences of their clients.

### **1. Mental health services need to be more responsive and accessible to meet the needs of homeless people and people at risk of homelessness.**

We heard that the Common Point of Entry for mental health service is not always able to respond with an intervention that the client feels is satisfactory. On occasion Launchpad staff have made multiple referrals for the same individual who they feel is in mental health crisis, and the client have not been able to access immediate mental health support. We heard that when people have no phone and/or no fixed abode, it is difficult to arrange mental health assessments and follow up. Launchpad are not always updated with client's progress, needs and risk information and are often required to phone statutory services on multiple occasions to get accurate information.

### **2. NHS and social care services are very stretched currently due to funding pressures - this makes contacting services and getting the responses that Launchpad clients need difficult.**

We hear that the threshold for accepting safeguarding referrals appears to be high. On some occasions, Launchpad staff are not updated with the progress and actions once a Safeguarding referral has been made.

We heard some people are discharged from hospital with no care package or to poor-quality housing that could be deemed as unsuitable for their health needs. We heard from Launchpad that it is an extremely valuable resource to be able to work alongside the HOLT team who provide a service to homeless people in Reading.

We heard that a Launchpad client reported not having dental charges explained to them clearly. Launchpad clients often struggle to prioritise health related costs on a low income and do not always appear to be informed about their options in relation to the NHS.

### **3. There is little evidence that the preventative element of the Care Act is being implemented in practice - many Launchpad clients with eligible needs could benefit from the early and creative intervention to promote wellbeing the Act requires**



We heard that there are many homeless people who may have eligible needs under the Care Act wellbeing principle. This includes, for example, people who are obese and need adjustments to their homes to support their wellbeing.

We heard that there are homeless people whose needs are such that they would benefit from the support of a social worker.

Launchpad staff use an eligibility checker template to present clients' needs. This has resulted in positive outcomes including a client with mobility issues being accepted for an OT assessment and adaptations being made to their property.

## **Part 2: What we heard from people who use the services provided by Launchpad Reading**

We asked the group to tell us what it is like when they visit their GP or the hospital, and what it is like if someone is helping them with their care at home - are the people who help with health and care clear in what they say and kind? What is done well? What could be better?

We spoke with 5 people - some in a listening session at Launchpad, and some individually by telephone. Unless otherwise indicated, the comments relate to GP surgeries and dental surgeries in Reading, and to the Royal Berkshire Hospital, Reading.

We heard:

*'They missed the big bit [of my health problem] until one [day a consultant got it right]*

*'At a change of shift [at the hospital] it's "needs must" - it's busy'*

One person we listened on the phone reported difficulty getting prescriptions sorted by their GP surgery in a timely way, a problem that had persisted over months.

A person in the focus group described visiting their GP surgery over several years describing increasingly worrying symptoms of mood change, and, eventually, disturbances of vision and hearing. They told us that they were never sent for blood tests or any other investigations and were offered advice about relaxation, and a herbal complementary treatment was suggested by the GP. A serious physical illness was eventually diagnosed after a visit to a non-medical healthcare professional, who raised immediate concern and made an urgent and immediate referral to hospital. This person reported not feeling listened to at their GP surgery and disappointed in the service - *'I feel my health has been sabotaged because [making a referral to hospital] will cost GPs money.'*

One person told us that their dentist is 'an excellent dentist' and that, 'He listens, and he understands my history - he knows I get anxious and he is good with my son. Getting quick appointments is difficult these days - if not on the phone by 8am, you're doomed.'

Another person also reported having to call their GP surgery at 8am to have any chance of getting an appointment.

One person in the focus group described to us attending hospital for a biopsy after feeling that something was stuck in their throat. In all, attended hospital Ear, Nose and Throat Department 10 or 12 times over a period of time complaining of discomfort. Eventually they were sent for a scan and a growth was seen on the scan result, which was then treated. This person felt that this could have been found sooner if they had been taken seriously and sent for a scan.

Another contributor reported 'good' care and nurse being 'ok' when they experienced a broken leg as a result of a fall. They reported having to insist three days after the accident that their wound was treated to avoid infection - 'This was on my insistence, because the wound was oozing blood'.

One person we spoke to reported that both they and their partner are disabled, and both have significant mobility issues. They reported being disappointed at times with services, including repeat prescriptions not being issued in a timely way, and ambulance and hospital staff being poorly trained and equipped, in their view, to assist with moving a person with a physical disability - not taking advice from the person's carer.

When one person was admitted to hospital there was a six hour wait at the hospital to be given a bed. They felt that they were kept advised, and the reason for the delay was explained - *'I was given good information about why the delay - it was because of prioritisation'*

One person said, 'Traditionally we have a lot of trust in the doctor - you tend to believe what they say.' This person feels that doctors 'too easily now suggest a condition with a "special name" which turns to be a fancy name for "it's all in your head" when you look it up'. This person felt that doctors should listen to patients more.

One contributor expressed concern about doctors prescribing the wrong medication and about patients not having a care plan.

One person felt that their GP is *'not particularly good.'* They felt that personnel changes at their GP surgery had changed things - *'I feel that the personal touch I got with my old doctor isn't there. I don't feel they know me - it feels impersonal'* This person has a chronic health condition and visits the surgery several times a year in connection with their long-term condition. They do feel confident in the treatment they receive.

One person has been using the Talking Therapies service for about a year - *'It has all been really good, but difficult to know if it is helping. I do feel recognised as a fellow human being. Very positive.'*

One person reported very good service at Boots pharmacy in Reading - *'It can be very busy, but staff know this person and will bring out the prescription and be friendly - it is a personal service.'*

One person reported having a generally good experience when staying in hospital in connection with a chronic health problem last year. However, they observed that there were lots of staff rushing around (the service was very busy).

One person reported difficulties with obtaining their insulin supply for diabetes treatment and getting into problems communicating with their health team about this because of being depressed and also being reluctant to use their phone because of the cost of calls.: '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, they reported being discouraged from using a messaging service in preference to phoning to speak to their care team.

One person we listened to shared concerns about social care administrative arrangements for a close family member - we heard that trying to sort things out can be a source of significant stress for the person who acts as unpaid carer and tries to keep care arrangements stable, and appropriate for their family member.

One person reported the frustration felt by family members at not being given information about someone's health and care for reasons of confidentiality.

What are the top 3 issues? These themes emerged:

1. **Lack of time for healthcare professionals to listen** It is very important that your healthcare professional knows you, knows your story and has time to listen, so they can work out with you what really is the matter - not making wrong assumptions and understand your individual needs.
2. **Poor coordination between health professionals.** 'You need one to oversee all'. We heard that GPs sometimes manage this coordinating role well, and sometimes do not.
3. **Not being treated as an expert in your own life, in health or in social care.** It is very important that your account is listened to - you have information that the other person needs if they are going to help you with your health or care. Also, you may have individual needs, for example in how it is best for you to communicate with your care team, that are important to share and have respected.

## Conclusion

In the listening sessions it was clear that ensuring that services are recognising people's particular needs, treating them as individuals, and providing an appropriate level of care is important.

Themes from this report, and our recommendations spanning the whole group of reports in this project, will be included in the final report that will bring all of these short reports together at the end of this

Healthwatch Reading thanks Launchpad clients and staff for giving their time to share their views. Healthwatch Reading is an independent charity with some statutory powers. We can take your feedback in confidence, help you make complaints, and refer serious concerns to other agencies. Phone us 0118 937 2295, email [info@healthwatchreading.co.uk](mailto:info@healthwatchreading.co.uk), visit our website [www.healthwatchreading.co.uk](http://www.healthwatchreading.co.uk) or visit us on the 3<sup>rd</sup> floor, Reading Central Library, Abbey Square, Reading, RG1 3BQ