

Draft copy submitted to Reading Health and Wellbeing Board 4 July 2018

“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

[photographs to be added to cover of publication copy]

June 2018

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

- access to interpreting to get enough, good quality care to help keep them safe and to live as independently as possible
- 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/flexible to the needs of the individual, their support workers and family members, who support individuals with arranging and attending appointments.
- easy-read leaflets to support individuals to understand medical conditions. Services that are available and how to these access them.
- their rights to be known and upheld - such as the right to have reasonable adjustments made to services so they can use them and how to go about receiving 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 Refugee Support Group said they need:

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

One person said a hospital would charge him £240 for a blood test, 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

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 from people themselves 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 by us on the following page. (Please refer to the individual partnership reports for the explanation of the issues 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 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.

Healthwatch Reading will share this report and our new short guide to involving local people in planning and designing NHS services with Berkshire West Clinical Commissioning Group (the organisation that purchases most NHS services for the public in Reading) and local NHS services. We will also highlight to Reading Borough Council the materials on co-production of social services that are published by the Social Care Institute for Excellence.

Response to be added at later date

Acknowledgements

[insert details]

[HWR Address/Date details}

'Our top 3 priorities' - the reports

Listening to people in Reading in partnership with

1. Reading Mencap
2. Talkback
3. Reading Community Learning centre
4. Reading Refugee Support Group
5. Launchpad Reading

Attach

Reading Mencap

<http://healthwatchreading.org.uk/wp-content/uploads/LDtop3.pdf>

Talkback

<http://healthwatchreading.org.uk/wp-content/uploads/Talkbacktop3.pdf>

RCLC

<http://healthwatchreading.org.uk/wp-content/uploads/Learnerstop3.pdf>

RRSG

<http://healthwatchreading.org.uk/wp-content/uploads/RefugeeTop3.pdf>

Launchpad Reading

<http://healthwatchreading.org.uk/wp-content/uploads/Launchpadtop3.pdf>

'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.

HWR details/address/contact footer