healthwatch
Wiltshire

Better Care Plan engagement report:
Information provision for people living with long-term conditions

Local health and care shaped by you

Notes:

Carers

Where we talk about carers in this report we are referring to unpaid carers:

"A carer is anyone who cares unpaid for a family member or friend who cannot always manage without their support. They might look after someone with a physical disability, long-term health condition, mental health issue or a problem with substance misuse." (Carers Support Wiltshire[1])

Where the report refers to paid care workers, we will make this clear, for example by stating "agency care worker."

References

[1] https://carersinwiltshire.co.uk/are-you-a-carer/#amiacarer

[2] Healthwatch Wiltshire report: *Talking to people about dementia: a focus on information provision*

https://www.healthwatchwiltshire.co.uk/wp-content/uploads/2016/04/dementia_report_2.pdf

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Background

This report is part of Healthwatch Wiltshire's Better Care plan workstream. Healthwatch Wiltshire is working with the Better Care Plan programme partnership (Wiltshire Council and the Clinical Commissioning Group), to assist in meeting their aspiration to see health and social care integrated by 2020. The vision for better care is based on the four priorities set out in Wiltshire's Joint Health and Wellbeing Strategy:

> "I will be supported to live healthily, I will be listened to and involved, I will be supported to live independently and I will be kept safe from avoidable harm".

To be successful, services need to improve in these areas:

- admissions to residential and nursing care
- success of reablement and rehabilitation
- delayed transfers of care
- avoidable emergency admissions
- patient and service user experience

One of the main focuses of the Better Care Plan is to ensure that people are well informed and able to take responsibility for their own health, whether through preventing illness or managing it effectively with as little medical intervention as necessary.

The last Joint Strategic Assessment in 2013 identified the key long-term conditions in the county to be: Cardiovascular Disease, Diabetes, Respiratory Disease, Cancer, Dementia, Musculoskeletal, Mental Health and Wellbeing. This project aims to evaluate the current provision of information for the five most common of these conditions in Wiltshire.

The objective of the project is to use the information gathered during the evaluation to inform future countywide information strategies and to shape new suites of information on Wiltshire's health and care information website: *Your Care Your Support Wiltshire*. Ultimately, the project aims to improve the quality and accessibility of information available to those with long-term conditions in Wiltshire.

What we did

During October and November 2017, we engaged with people in a number of different ways.

We prepared information for local people which included an overview of the project and details of how they could get involved.

We prepared a survey which was available online and in hard copy, and discussion questions to use in focus groups.

We promoted the engagement in several ways including through social media. Information was also available on *Healthwatch Wiltshire*'s website and it was promoted on *Your Care Your Support Wiltshire*. We made local voluntary sector organisations and Area Boards aware of the engagement and invited them to help promote it.

We identified a number of local support groups in Wiltshire where we would be able to talk to people with long-term conditions. We attended a number of these groups to tell them about our engagement and held informal one-to-one and focus group discussions with the people attending. We also shared electronic and hard copy information and surveys with those groups where it wasn't convenient for us to attend.

How we engaged with people

- we attended **13** local groups where we spoke to **202** people
- **75** people completed our survey

Our volunteers

Healthwatch Wiltshire has a team of trained volunteers. Seven of our volunteers were involved and contributed about 30 hours of their time. They supported the engagement by:

- helping to promote the engagement
- supporting the visits to local groups and focussed discussions
- promoting the online survey
- distributing hard copy information and surveys
- typing up the focus group notes and inputting surveys
- sharing their own personal experiences

The key messages

An analysis of the survey responses and what people told us at groups suggested the following:

People told us that they currently used a variety of different ways to find out information about their long-term conditions. Most of those we spoke to had used more than one source of information.
People had different preferences about how they would like to receive information. People said that they thought a reliance on any one form of information would mean that it would not reach everyone who needs it.
The most popular places that people told us they would go to for information about their conditions such as medication or possible complications were their GP, practice nurse or hospital consultant.
When looking for information about local support services, 43% of people said that they used one of a variety of local and national websites. The same percentage said they used their GP surgery.
Overall, there was no consensus about the best way to receive information; different people had different preferences.
Most people said that they would like to receive information in more than one way. The most popular ways that people said they would like to receive information were: face-to-face (76%), leaflet/book (68%), and online written information (43%).
People told us that they would like to receive hard copy information from GP surgeries, hospital waiting areas and local libraries.
The information that most people told us they had looked for recently was advice on managing their condition and information about current treatments.

Where do people currently go for information?
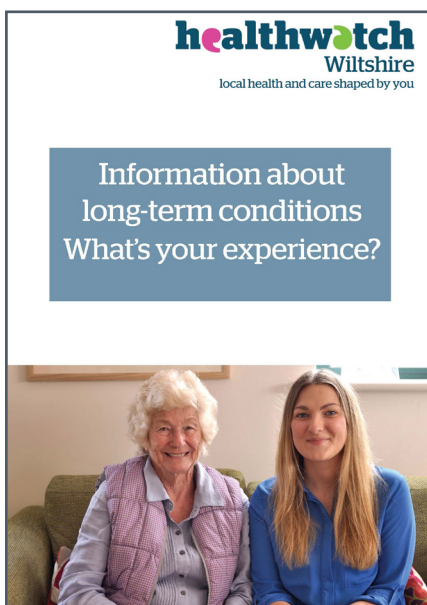
In our survey and at local groups we asked people where they would go to find out information about long-terms conditions. People mentioned a variety of different places and many people told us that they would go to more than one place to find information. However, the most popular response from people was that they would go to their GP.

In our survey we asked people where they would go to find out information about particular aspects of long-terms conditions. We found that there were some differences in where people would most commonly look for this type of information. For example, when we asked people where they currently went for information about medications and possible complications, the top two answers listed were their GP (80%) and their practice nurse (49%). However, when we asked people where they currently go to look for local support services, only 37% said they

would go their GP. The same number said that they would use *Your Care Your Support Wiltshire* to look for this information. In general, we found that people were more likely to go to a medical professional (GP, nurse or hospital consultant) to learn more about their condition or living well with it, than use a website such as *NHS choices* or *Your Care Your Support Wiltshire*. Where people were looking for information about local support services, fewer people said they would ask their GP and more said that they would look at one of a number of different websites.

There may be potential to develop accessible online and hard-copy information about living with long-term conditions, so that more people are able to access this. A number of people we spoke to at local groups told us how useful the groups were in terms of providing and sharing information about long-terms conditions. In particular, for people who don't have internet access or prefer not to use it.

What sort of information are people looking for?

We asked people about what sort of information they had looked for recently. The top five things that people had looked for were about:

- advice on managing their condition
- information about current treatments
- information about new treatments
- services available in their area
- when to access professional help

Are people able to find what they are looking for?

We asked people whether they were able to find the different types of information that they were looking for. Responses indicated people were able to find some types of information about long-term conditions more easily than others.

- information on managing their condition
- information on current treatments
- information about where to access professional help

The three types of information where most people said that they had not been able to find what they were looking for were:

- information about finding care
- information about paying for care
- information about paying for equipment
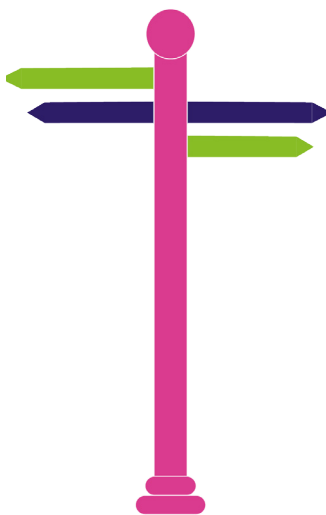
This pattern is similar to what people told Heathwatch Wiltshire during previous dementia engagement about information provision[2]. Here, many people told us that they were able to access good quality information about the symptoms and types of dementia but had more difficulty finding clear information about local services. They also said that, at times, this information could be overwhelming and confusing.

> "I was looking for information about singing groups for people with respiratory problems. Found them on the British Lung Foundation website."

> "Some information needs to be provided individually, therefore needs to be provided by someone who knows the person well. Information often isn't holistic, meaning people don't always get all the elements of things that could support them."

At the support groups people told us that they found factual information about long-term conditions, symptoms, treatments and medications, easier to access than information about what was available to support them to live well in their day to day life. They also acknowledged that information about services and benefits was often more complex, involving a number of different organisations. Therefore, they often didn't know what was available or might be helpful to them. This makes it more difficult for people to look for and access this type of information. We were told about the value of talking to other local people with the same condition (peer support) about their experiences, and finding out the sort of things that other people found helpful. Peer support and information sharing should not be undervalued as a way of enabling people to access more targeted local support.

Full details of the types of health and care information our survey respondents told us they were looking for and whether they were able to find it are shown in the chart in the Appendix.

Information that people told us would have been useful to them

We asked people about what information would have been useful for them at different times:

1. Before diagnosis

We asked people what information would have been useful to them before diagnosis. There were a wide variety of different responses to this question with a few common themes. Responses identifying information that would have been useful included awareness of conditions and their symptoms, risk factors, treatment options, and the procedure for assessments, tests and diagnosis, including waiting times.

> "This seems a stupid question. If you haven't been diagnosed with something why would information in it be useful?."

A number of people responded to this question by saying that they didn't feel that information about long-terms conditions before diagnosis, was useful.

2. Following diagnosis

People gave us a wide variety of different types of information that they thought would have been useful to them following diagnosis. However, general information about a condition and its management was thought to be most useful at this time. At the groups we visited, this was particularly highlighted by people with diabetes and those with fibromyalgia. It was also evident that people had a wide variety of different experiences in the information that they were given following diagnosis. Some people talked about being provided with information, referred to courses and being told about support groups, while others told us that they had received very little information or follow up.

> ""I found all I wanted to know from my lung consultant, respiratory nurse, PACE (Pulmonary Advice and Community Exercise) course at Chippenham and the British Lung Foundation website and helpline."

> "Any information at all (would have been useful) – when I was diagnosed I was told diabetes could be controlled initially by diet, but I wasn't told what to eat or what not to eat."

3. To live well with a long-term health condition

We asked people what information they would have found useful to help them to live well or as well as they wished with their condition. There were a wide variety of responses to this question. The most commonly mentioned were information courses, condition specific support groups and websites, information about medication and information about aids and equipment.

At the support groups it was frequently mentioned that having more knowledge about a condition had enabled people to 'help themselves' to live more healthily and manage their condition better. In general people said that this led to improvements in their day to day lives and sense of wellbeing.

How would people like to receive information?

We asked people how they would like to receive information. In our survey, of the three most popular ways that people said they would like to receive information, 76% of people said face to face, 68% said in a leaflet/book and 43% said by online written information.

In both the survey and at the groups the majority told us that they would like to receive information in more than one way. For example, of the 57 people in our survey who said they liked to receive information face to face, 48 of them (84%) said they would also like information in another form as well.

At the support groups we attended people also talked about the value of receiving different types of information in different forms. People told us that a face to face discussion quite soon after diagnosis was often useful as it gave them the opportunity to ask questions. However, they also said that, in instances, where there may be a lot of information to take in, it was useful to be able to have something in a format that they could go back and check on, and people said that leaflets, books and online information were useful for this.

Use of the internet and online information

Both in our survey and in the support groups, a significant number of people told us that they used the internet to find information about long-term health conditions. They used a variety of different websites such as *NHS choices*, *Your Care Your Support Wiltshire*, condition specific organisational websites, and *Wikipedia*. In general, people who used the internet said that they found it useful. We looked at the age range of people who said that the internet was one of the ways they would like to receive information. From our hard copy and online survey responses, we found that

47% of those were 65 and over, and 60% of those aged 45 - 64, said this.

We also talked to a number of people who didn't use the internet. In general, people expressed concern that information should not only be available online, as they thought that this would exclude some people, particularly those who may be isolated or vulnerable. However, this was not seen as a reason that information shouldn't be made available online. People were just keen to emphasise that it should also be available in other formats. Some of the survey responses about the use of the *Your Care Your Support Wiltshire* website seemed contradictory. For example, 37% of survey respondents said that they currently went to it to look for information about local services in response to one question; yet in response to another question, 91% said they had never used it. Although this does make this finding hard to accurately interpret, it seems likely that quite a number of people are using websites to find information even without being sure which ones they have used.
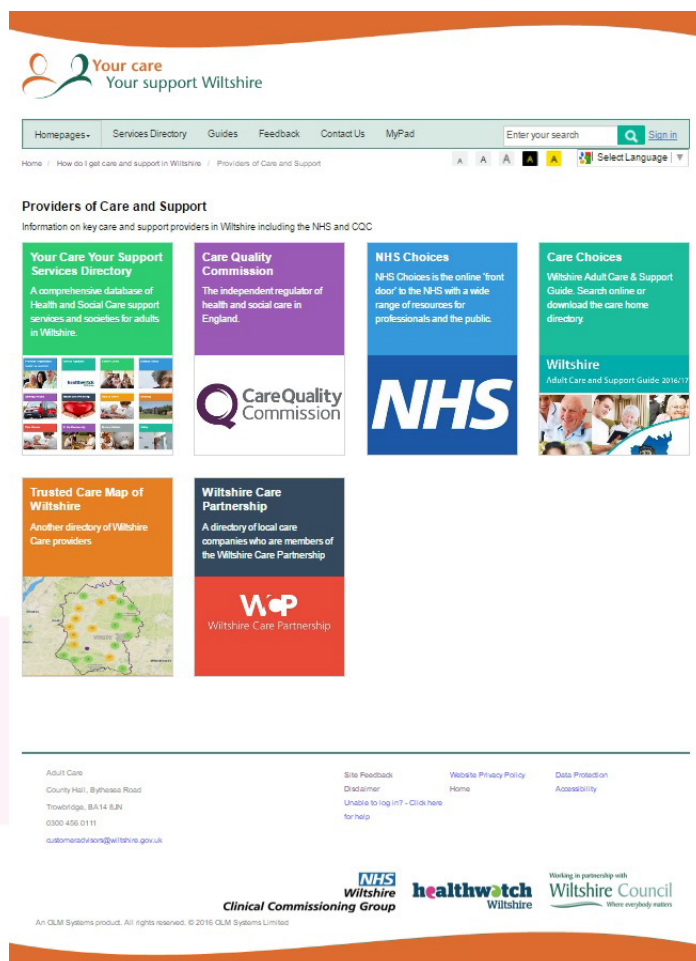
Recommendations

Commissioners and providers should:

1. Ensure that information about long-term conditions is available in as many forms as possible, including making use of community resources.

2. Raise awareness of the different types of information that is available about long-term conditions, including websites.

3. Support GP practices to better enable their patients with long-term condition to access information appropriate to them.

4. Recognise the value of peer support for people living with long-term conditions, particularly in giving individually tailored advice.

5. Increase awareness about the ways that information can empower people by:

   • prevention of long-term conditions developing and/or becoming worse

   • providing information for people in the process of being diagnosed

   • enabling people to make informed life style choices about living with their condition

Next steps

We know that it is important that people know what has happened as a result of them sharing their experiences with us. We will be working with commissioners to respond to the issues raised during this engagement. In due course we will publish a "Information about long-term conditions – You said, we did" report to bring together the key messages from this work and the action that is underway to address our recommendations.

Thank you

Healthwatch Wiltshire would like to thank everyone who took the time to contribute their views and experience through the many engagement activities as described in this report.

Thanks also to our dedicated volunteers and the voluntary and community sector organisations who helped to support the engagement activity. Without their assistance we would not have been able to reach the numbers of people which we did.

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Appendix: Analysis of survey responses

Table showing the types of health or care information about long-term conditions that people said they had recently looked for and whether they had been able to find it. The list is ordered by the types most people had searched for.

Type of health and care information	% who looked for this type of information	% who found what they were looking for	% who did not find what they were looking for	% who had not looked for this type of information
Advice on managing my condition (such as diet, exercise)	56% (39)	72% (28)	28% (11)	33% (23)
Information about my current treatments	53% (37)	65% (24)	35% (19)	13% (19)
Information about new treatments	34% (24)	58% (14	42% (10)	40% (28)
Services available in my area	33% (23)	35% (8)	65% (15)	21% (15)
When to access professional help	30% (21)	62% (13)	38% (8)	19% (31)
Whether I need to make a routine appointment or access emergency health care	28% (20)	60% (12)	40% (8)	43% (30)
Information about taking part in research	20% (14)	50% (7)	50% (7)	51% (36)
Accessing Equipment	20% (14)	43% (6)	57% (8)	54% (38)
Finding care	11% (8)	12% (1)	88% (7)	67% (47)
Paying for equipment	10% (7)	29% (2)	71% (5)	61% (43)
Other sorts of information - various	8% (6)	33% (2)	67% (4)	20% (14)
Paying for care	7% (5)	20% (1)	80% (4)	64% (45)

Why not get involved?

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