

18 May 2017

Subject: Healthwatch Wiltshire engages with people with dementia and children and young people

Executive Summary

Healthwatch Wiltshire's (HWW) work plan priorities for 2016/17 have included engaging with people living with dementia and children and young people. This report provides information about the outcomes of the engagement carried out with:

- people living with dementia and their carers on their experiences of accessing support through primary care settings (appendix 1).
- with Alzheimers Support to map availability of dementia community support services across the county and find out what is important to people with dementia and their carers in accessing these services (appendix 3).
- children and young people through the Young Listeners project (appendix 2).

Proposal(s)

It is recommended that the Board:

- i) notes the outcomes of the extensive engagement that has taken place in Wiltshire since March 2016
- ii) note the key messages within the 3 reports included as appendices
- iii) recognises the commitment of Healthwatch Wiltshire's Young Listeners and the part they have played in listening to children and young people across the county;
- iv) recognises the constructive partnership approach between the voluntary sector, commissioners and providers which ensure that local people's experiences are collected and taken into account;
- v) confirms its commitment to the voice of local people influencing the commissioning and provision of services

Reason for Proposal

Dementia:

In Wiltshire there are about 6,600 people living with dementia and this is forecast to rise by almost 30% by 2020¹. Through the Wiltshire Dementia Strategy, the Health and Wellbeing Board confirmed its commitment to dementia so it is important that the Board is kept informed about local people's

¹ Figures obtained from <https://www.england.nhs.uk/publication/dementia-diagnosis-rate-workbook>

experiences.

Children and Young People

Children and young people often feel that they don't have the opportunity to share their experiences of using health and social care services. The views of children and young people are just as important as those of adults.

Healthwatch Wiltshire is keen that the Board is informed about what young people experience in Wiltshire.

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Purpose of Report

1. This report provides information about the outcomes of the engagement carried out with:
 - people living with dementia and their carers on their experiences of accessing support through primary care settings (appendix 1).
 - Alzheimers Support to map availability of dementia community support services across the county and find out what is important to people with dementia and their carers in accessing these services (appendix 3).
 - children and young people through the Young Listeners project (appendix 2).

Background

Talking to people about dementia: a focus on primary care

2. Healthwatch Wiltshire (HWW) has a statutory duty to speak up for local people on health and social care. Dementia is one of HWW's priorities. This was decided following engagement with local people and through talking to people about the Dementia Strategy during the consultation on the draft. Local people told HWW that they wanted to be informed about the delivery of the strategy and to have further opportunities to share their views and experiences.
3. HWW has designed an approach so that it can gather information about people's experiences and views of dementia services. The aim is to analyse this information and reflect it back to commissioners and providers of services. HWW will highlight good practice and areas where people have poor experiences so that these can be addressed. This programme of work started in November 2014. Healthwatch Wiltshire last reported to the Board on its engagement was in April 2016: [http://cms.wiltshire.gov.uk/\(S\(wm5gga55b130f045qoanija5\)\)/ieListDocuments.aspx?CId=1163&MId=8865&Ver=4](http://cms.wiltshire.gov.uk/(S(wm5gga55b130f045qoanija5))/ieListDocuments.aspx?CId=1163&MId=8865&Ver=4)
4. HWW is committed to working in partnership where possible and where this does not interfere with its independence. We work in partnership with specialist voluntary sector organisations through a 'dementia engagement steering group' convened by Healthwatch Wiltshire. The members of this group are SWAN Advocacy, Age UK Wiltshire, Carer Support Wiltshire, Alzheimer's Support, and Alzheimer's Society. The group is chaired by Chris Graves (Chair of HWW) and meets quarterly. The group is

committed to sharing information about service user experience to support the implementation of the Dementia Strategy action plan. The organisations involved have played an important role in providing opportunities for HWW to engage with people living with dementia and their carers.

5. Our work has included engaging with people through workshops and outreach to existing groups. It has also included talking to people where they use services (including in their homes). We have attended a variety of groups including Dementia café's, singing for the brain groups, day centres, carers groups and support groups. HWW has conducted a number of informal interviews with people living with dementia and their carers which are presented as case studies. The purpose of all this work is to 'reality check' people's experiences of services throughout the life of the Wiltshire Dementia Strategy. Over 400 people in Wiltshire have been involved in our dementia engagement. With a seat at Wiltshire's Dementia Delivery Board key messages and reports have been welcomed by the Dementia Commissioners and have been used to inform service development and improvement.
6. In our earlier engagement people living with dementia and their carers said that if they were worried about their memory they would firstly talk to their doctor. People reported varied experiences of this. We wanted to find out more about people's experiences of using primary care, what they had found useful and what could be improved. Through our engagement, we spoke to about 200 people on this subject.

7. Key messages

- There is a lack of clarity and consistency in the dementia care people can expect and experience from their health care centre;
- People said that they valued a clear, direct dementia diagnosis and onward referral to a dementia adviser or support. Not everyone experienced this;
- People appreciated proactive dementia reviews where these were offered. There was some concern about the availability of ongoing support from their health care centre for people living with dementia;
- Unpaid carers said that their health care centre, and its approach, had an impact on their quality of life. Being recognised as a carer and given priority appointments had a positive impact however this isn't consistently being seen across the county;
- Most people said that they could access opticians and dentists fairly easily;
- People found local pharmacists useful and felt more people may benefit from their service;
- People also said they valued seeing the same GP and having longer appointments. Some people told us that their health centre was aware of their dementia and made allowances for this when they needed to see the GP which was welcomed;
- People reported variations in how knowledgeable their GP was concerning dementia. People spoke about other health care centre staff who were helpful like nurses and care coordinators;

- Carers and people living with dementia who accessed Leg Clubs said they enjoyed going to them and felt they helped motivate them to keep active.

Analysis of Dementia Community Support Services in Wiltshire

8. Alzheimer's Support is an independent charity which is commissioned by Wiltshire Council to provide dementia specific community services across the whole of Wiltshire. HWW was pleased when they approached us to assist them to evaluate the provision and quality of dementia community support services across Wiltshire.
9. Alzheimer's Support is committed to using service user experience to inform how their services are planned and managed. As an independent body, Healthwatch Wiltshire can impartially evaluate services and service users can be open and honest. Alzheimer's Support welcomes this and have signed up to Healthwatch Wiltshire's Collaboration Agreement which is designed to safeguard our independence.
10. The aim of this project was to map and evaluate dementia community support services across Wiltshire, considering both equity and quality of provision. In order to do this HWW carried out analysis of current dementia community support services across Wiltshire by researching the provision of current services to get an up to date picture, reviewed previous dementia engagement data and collating people's views and experiences
11. HWW also wanted to ensure the quality of these services was taken into account by asking service users accessing these groups to identify what is important to them when they attend community groups. Using this information HWW developed a quality framework which Alzheimers Support and other organisations could use in the future to monitor the quality of the services they provide from the user perspective.
12. Key messages
 - People feel that specialist dementia community services are good quality and value them. These groups are the most popular and well attended by people living with dementia and their carers. People have told us that they feel these groups have lasting positive effects to their well-being and day to day lives. The provision and variety of such groups is not evenly spread across Wiltshire;
 - Healthwatch Wiltshire produced a report for Alzheimers Support based on the engagement activity and what people living with dementia and their carers told us. The report includes a number of recommendations for areas of improvement or to bridge gaps where community services are lacking. It also includes a Quality Framework which can form a basis of measuring the quality of dementia community support services and incorporates the views of local people. The report is attached as appendix 3.

Young Listeners Project: listening to children and young people

13. Understanding children and young people's experiences of using health and social care is one of Healthwatch Wiltshire's priorities. We wanted to use an approach that gave children and young people the opportunity to talk to and share their experiences with other young people using a 'peer to peer' approach.
14. HWW is working in partnership with Youth Action Wiltshire (part of Community First) in order to recruit and train a team of 10 Young Listeners. We worked with the Young Listeners to design the engagement approaches and the questions they would use in their listening.
15. Young Listeners were supported to carry out 174 'listening' with children and young people across the county through youth groups and holiday activities.
16. The project was so successful that it was nominated for a prestigious Children and Young People Now! Award in the 'Youth Volunteering and Social Action' category. The Young Listeners had an amazing evening in London with dinner and dancing thrown in.
17. The Young Listeners themselves have gained not only the skills and learning they received throughout their training but also increased confidence, more social awareness and improved literacy and communication skills. One Young Listener said. *"A lot of the skills we have picked up I believe to be truly valuable to later in life. I can't speak for all the Young Listeners, but I know that for myself, I feel a lot more confident when talking to groups of people and I know how to conduct myself around different age groups."*
18. Key messages
 - Children and young people want to be treated as individuals and to be given a choice;
 - Young people want to be given the choice about who the health or care professional addresses during an appointment. This could be them or their carer, parent or guardian as long as they are able to decide who. Young Carers particularly found this challenging when professional address only the adult;
 - Several young people (aged 9 up) said they hadn't felt listened to by a professional and that they thought it was linked to their age. This made them feel patronised and that they hadn't been taken seriously;
 - Support in school was raised by many young people with varying experiences. Some felt their school nurse to be helpful and approachable other had no idea who to approach for help and support about a physical or mental health issue whilst at school;
 - Many young people had experienced mental health service (including CAMHS). They felt that the waiting time for an appointment after being referred was too long, some waiting over 8 weeks. Some also felt that they didn't feel listened to and that seeing different professionals each

time didn't help, especially having to explain life events and their experiences more than once.

- Transitioning to adult services, specifically the lack of continuity, was reported as being challenging especially in relation to mental health services;
- All the young people spoke in a positive way about the ambulance service after having to call them for themselves or the person they care for.

Next Steps

17. We will continue to engage with and listen to people living with dementia and their carers and we commit to feeding back to them about what has been done as a result. This will take the form of a 'You Said, We Did' reports and will incorporate responses from commissioners and providers.
18. We will work with the Dementia Commissioners and providers to help improve referrals to the Dementia Advisor Service (perhaps through the provision of written information about the service so that they have it available to make contact when they are ready).
19. We will work with Alzheimers Support to ensure community services for people living with dementia and their carers reflects the need of local communities and takes into account what local people have told us.
20. We will work together with the Young Listeners to share what they have heard with the commissioners and providers of services so that the voices of the children and young people who spoke to the Young Listeners can help shape services in the future.
21. The Young Listeners will also carry out further listening's looking at some of the key messages that were heard. Focusing on health, mental health and emotional wellbeing in schools
22. We are in the process of developing YouthWatch Wiltshire. This will be a group of young people that meet regularly (either in person or virtually) to look at health and social care issues for children and young people. YouthWatch Wiltshire will ensure the voices of children and young people are heard by decision makers. Young people involved will also have the opportunity to take part in meaningful volunteering opportunities, represent the voice of their peers and help to influence the work of Healthwatch Wiltshire and commissioners and providers across the county.

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Appendix 1 – *Talking to people about dementia: a focus on primary care* - attached

Appendix 2 – *Analysis of dementia community support services in Wiltshire* - attached

Appendix 3 – [Listening to children and young people: your experience of health and social care](#)