

Project Summary

Project Name:

Survey on Dementia Services in Manchester

Duration:

Ongoing. The project was originally proposed in the summer of 2014 (first survey). We relaunched the survey again in the spring of 2015 (second survey).

Aim:

To collect feedback from carers looking after someone living with dementia about their experience with dementia-related services available to them in Manchester.

Background:

Healthwatch Manchester initiated the first survey focusing on post-diagnosis dementia services over March-April 2014 after we discovered through talking to local people and GPs that when someone receives a diagnosis of dementia their experience with support services from that point on can be difficult for them.

Our volunteers collected 28 individual responses from carers by getting in touch with the Admiral Nurses and visiting the Dementia Cafes that they organise. This initial survey provided us with a mixed set of results. About half of the participants gave fairly positive feedbacks, whilst the other half had quite negative experience with the referral process and the amount of support they received. This suggested that there may be discrepancies in the standard of dementia care across different parts of Manchester that required further investigation. We had to put this project on hold last year after the volunteer leading this project left Healthwatch Manchester.

We relaunched the project in 2015, redesigned the survey based on the top 20 essential services outlined on the Dementia Action Alliance website. The aim this time round was twofold:

- To continuously monitor the quality of dementia related services including services related to pre-diagnosis support and people's experience with the referral system.
- To identify whether there are 'gaps' in essential dementia services in Manchester that people urgently need.

Methodology:

The survey was made available online through SurveyMonkey and advertised on the Healthwatch website, Twitter and Facebook pages. We have also shared the survey link with Manchester Dementia Action Alliance members to help us gather more responses.

We again got in touch with the Admiral Nurses and carried out the second survey by having our volunteers visit a number of Dementia Cafes in Manchester and spoke to carers face-to-

face. After we established links with these locations, we provided the online web link and paper copies of the survey to the organizers to allow carers to share their experience with us at any time on an ongoing basis.

Dementia Cafes Visited:

Throughout February, March and April 2015, our volunteers visited the North, Central and South Dementia Cafes organised by the Admiral Nurses plus Fred's Café in Chorlton organised by Linda Dutton.

Key Findings:

Healthwatch Manchester have so far collected 21 responses for our second survey. The average number of attendees to a Dementia Café is typically around 15-20 people (including carers). Each of the responses are from carers (and the person living with dementia in some cases) that have been through the dementia referral process and are or have been users of dementia services in the past 5 years.

A number of issues have emerged from the responses gathered so far. Namely:

- 1. The time it takes for the referral to the Memory Clinic. The referral experience can be very different in different parts of Manchester. Some users had to wait for around 6 months and in some cases, up to several years to get referred to specialists. In the meantime, there is very little support or information given on available services.**
- 2. The lack of information on local services available at each stage of care. It is quite common that carers and patients don't find out about essential services until they have been visited by an Admiral Nurse or attended a dementia café.**

Carers have also shared with us the following positive experiences:

- 1. A number of users have told us that they received very good support from the Community Psychiatric Nurses (CPN) where this service was available to them in their area.**
- 2. The Admiral Nurse Service was pointed-out by the majority of service users as a vital service and user's experience with the supports provided by the Admiral Nurses have been very positive. There are strong calls for more Admiral Nurses.**
- 3. Carers highly recommend the Dementia Cafes but said it can be difficult for people to find their local support groups.**

Updates & Actions since the survey findings:

In July 2015 Healthwatch Manchester arranged a meeting with the Manchester Mental Health and Social Care Trust (MMHSCT) to share our initial findings with them. The MMHSCT team mentioned that they were in the process of redesigning their services to deal with some of these issues and shared with us their *Later Life service redesign* plan.

Update 1: It is hoped that the Community Mental Health Teams and the more community based care approach in the Later Life plan will reduce referral time and provide a more consistent service standard across Manchester. Healthwatch will continue to monitor people's feedback on the services after these changes.

We have also shared what carers have told us with the Manchester Dementia Action Alliance (DAA) members, and the Clinical Commissioning Group Commissioners (through Central Manchester CCG). Our recommendation was that more information regarding dementia support services should be made available at accessible locations such as:

- From GP practices (information on pre-diagnosis support)
- From Memory Clinics right after diagnosis (information on post-diagnosis services available close to the user's home)
- From other strategic locations such as Dementia Cafes, libraries, churches etc.

Update 2: There is now a Dementia Connect online service directory hosted by the Alzheimer's Society that shows what dementia-related services are available in different cities across the country. Healthwatch Manchester considers this to be a very useful development for users, professionals and practitioners. To address the concerns that many senior users can be less confident about accessing online resources, paper copies of the directory can also be made available. Healthwatch will work with other DAA members to help more potential users gain access to this information.

Update 3: Provided that Healthwatch Manchester has the resources and volunteers required to continue this project next year, we are seeking to sign up to the Manchester DAA as a full member. This will allow us to share user feedbacks directly with dementia service stakeholders that are DAA members as we monitor the effectiveness of the service changes that are currently taking place.

Volunteer involvement:

Name	Involvement
Ken Hsu	Ken helped to redesign the survey, visited the Dementia Cafes, and provided general oversight of the project. Ken also represents Healthwatch Manchester at various dementia-related meetings.
Mike Molete	Michael helped to conduct and promote the survey. He is also an ambassador for Healthwatch Manchester and represents Healthwatch at meetings with various stakeholders.
Kaf Bays	Katherine helped to develop the initial survey, carried out the initial background research and contributed to the redesign of the second survey. She also helped to collect feedback from carers and helped to promote the survey.

Acknowledgement

We would like to thank the following organizations for their continuous support of the project:

- The Admiral Nurses (North, Central and South Manchester Dementia Cafes)
- Linda Hutton (Fred's café, Chorlton)
- Manchester Mental Health and Social Care Trust (MMHSCT)
- Manchester DAA members (Special thanks to Marion Coleman, DAA Coordinator for the information on Dementia Connect. And the Central Manchester CCG that also attend the DAA meetings)

Ken Hsu
November 2015