

Talking Point survey 2014

Executive Summary

Talking Point is Alzheimer's Society's online community, facilitating peer support 24 hours a day, 7 days a week to people living with dementia.

In 2014, Talking Point launched a real-time online chat service, following numerous requests from service-users for this type of feature. The service has been available to registered members of Talking Point on a sessional basis twice a week, and has been named the Talking Point chat room. Sessions have ranged from dementia support chats, to Question and Answer (Q&A) chats with a guest 'speaker', and social chats, which provide an extra opportunity for informal contact and support. The Q&A chats have been particularly successful; guests at these sessions have included Alzheimer's Society National Dementia Helpline Advisers, Information Officers, Volunteers and Ambassadors.

The way in which people interact with Talking Point is changing, with an increasing number of users accessing the service via their smartphones and tablets. As of December 2014, 51% of visits to Talking Point came from mobile devices. It appears that people tend to use websites and online communities differently on mobile devices, often viewing webpages for shorter periods of time and in a wider range of physical locations.

We carry out the Talking Point survey on an annual basis, to get service users' feedback on their experience of the community. The previous survey was undertaken in November 2013.

This year's Talking Point survey took place during November and December 2014, and was completed by 472 users of the forum*.

All registered members of the community were notified about the survey via monthly email updates in November and December. The survey was also promoted on Talking Point and via the Society's website and social media channels.

The results of this year's Talking Point survey are, as in previous years, very positive overall, with high rates of user satisfaction being maintained, and several ratings being improved upon.

The next Talking Point survey will be carried out in November 2015.

*Total membership on 31 December 2014 was 37,886.

Key findings

How satisfied are users with the Talking Point service?

- **90%** of respondents agreed or strongly agreed that Talking Point was a good source of information about dementia. *(This figure was also 90% last year).*
- **92%** of respondents said they would be likely or very likely to recommend the service to others. *(This figure was 90% last year).*
- **89%** of respondents agreed or strongly agreed that they found Talking Point helpful. *(This figure was 87% last year).*

What is the impact of the service?

- **79%** of respondents agreed or strongly agreed that Talking Point helped them to feel less isolated. *(This figure was 78% last year).*

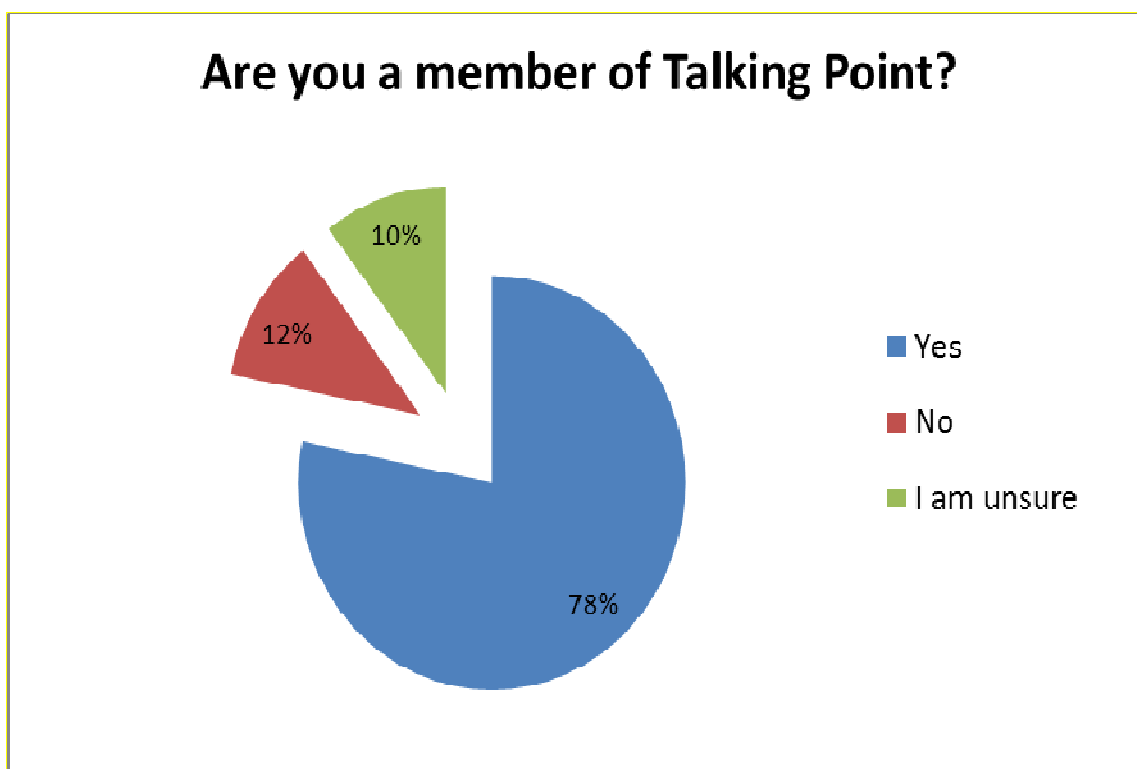
Who uses the service?

- **83.5%** of respondents are female; **16.5%** are male.
(Last year, 80% of respondents were female, and 20% were male).
- **37%** of respondents are between 55 and 64 years of age, and **27%** are between 45 and 54. **20%** are between 65 and 74 years of age, **7%** between 75 and 84, and **6%** are between 35 and 44. *(Last year, 34% of respondents were between 55 and 64; 24% were between 45 and 54; 21% between 65 and 74, 10% between 75 and 84, and 7% between 35 and 44).*
- **88%** of respondents describe themselves as White British and **7%** as 'White: Other'. Of the remaining respondents, **3%** preferred not to state their ethnic group and **2%** described themselves as either Mixed/Multiple or Other Ethnic Group. *(Last year, 91% of respondents described themselves as White British and 7% as 'White: Other'. The remaining 2% preferred not to state their ethnic group).*
- **40%** of respondents describe themselves as a 'carer'; **39%** describe themselves as a 'relative of someone with dementia'; **12%** as a 'former carer' and **3%** as 'a person with dementia'. *(Last year 42% of respondents were relatives of a person with dementia; 34% were carers; 13% were former carers and 4% had a dementia diagnosis).*

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- **78%** of respondents are members of Talking Point; **11%** are not members and **10%** are not sure whether they have registered as members or not. (*Last year, 87% were members of Talking Point; 4% were non-members and 9% were not sure*).

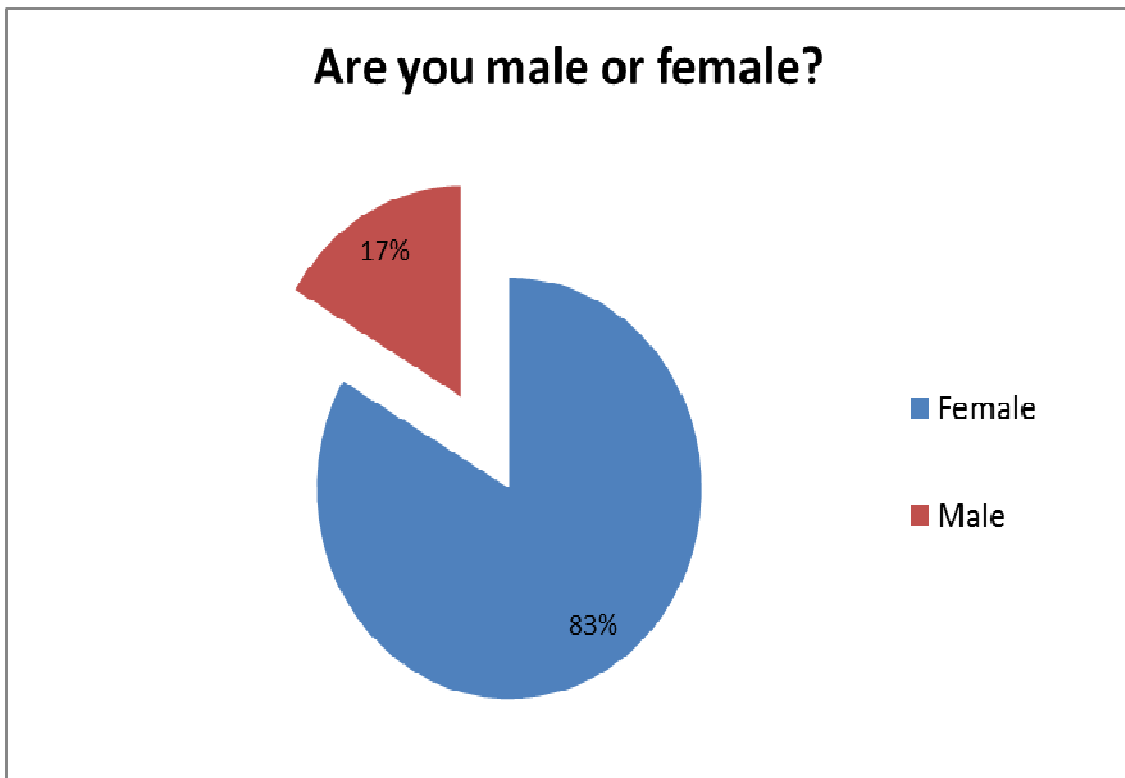
Question 1 – Are you a member of Talking Point?

The number of respondents who identify themselves as being members of Talking Point has decreased by 9% since last year (from 87% to 78%). Correspondingly, the number of responses from non-members has tripled, from 4% to 12%. The amount of people who are not sure whether they are forum members or not has remained similar, at 10%. (Note: anyone can access Talking Point for information, but only registered members are permitted to post messages and write blogs on the forum).



Question 2 – Are you male or female?

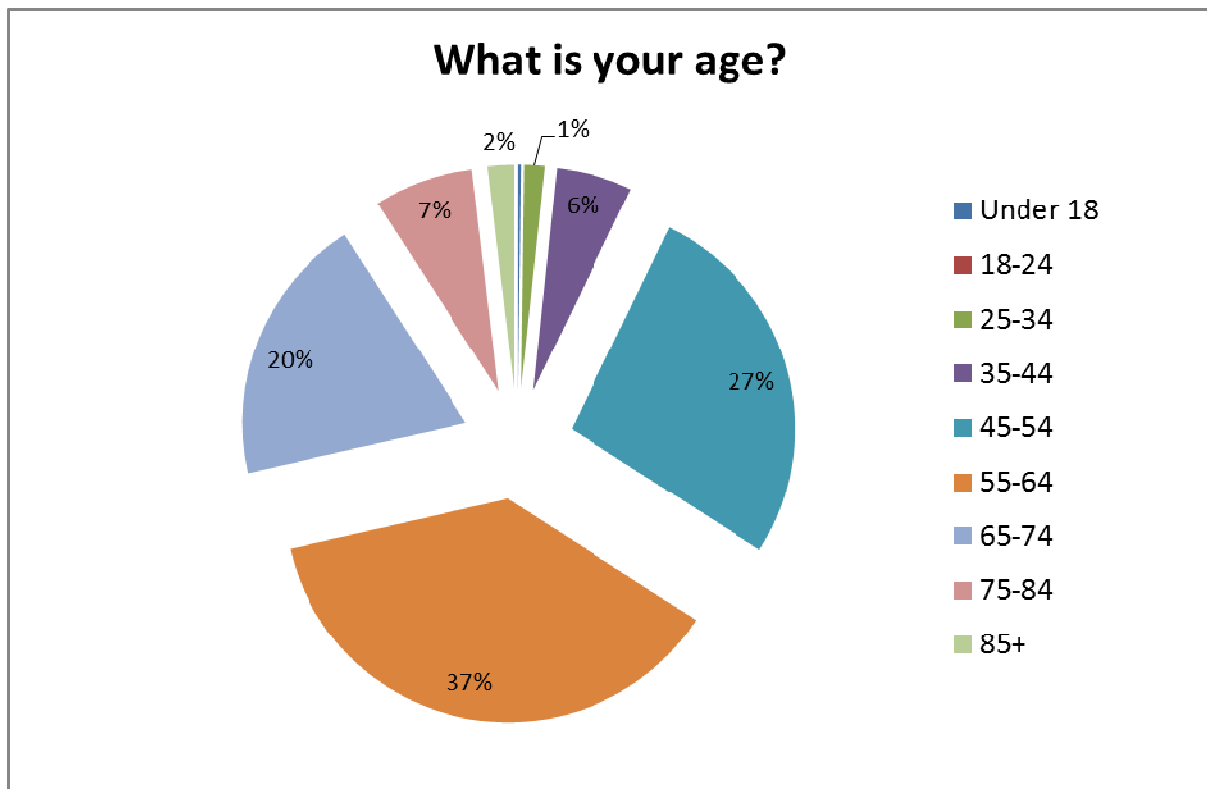
Over three quarters of the Talking Point users who have responded to the survey are female. The number of male users this year is 17% (this was 20% last year).



Question 3 – What is your age?

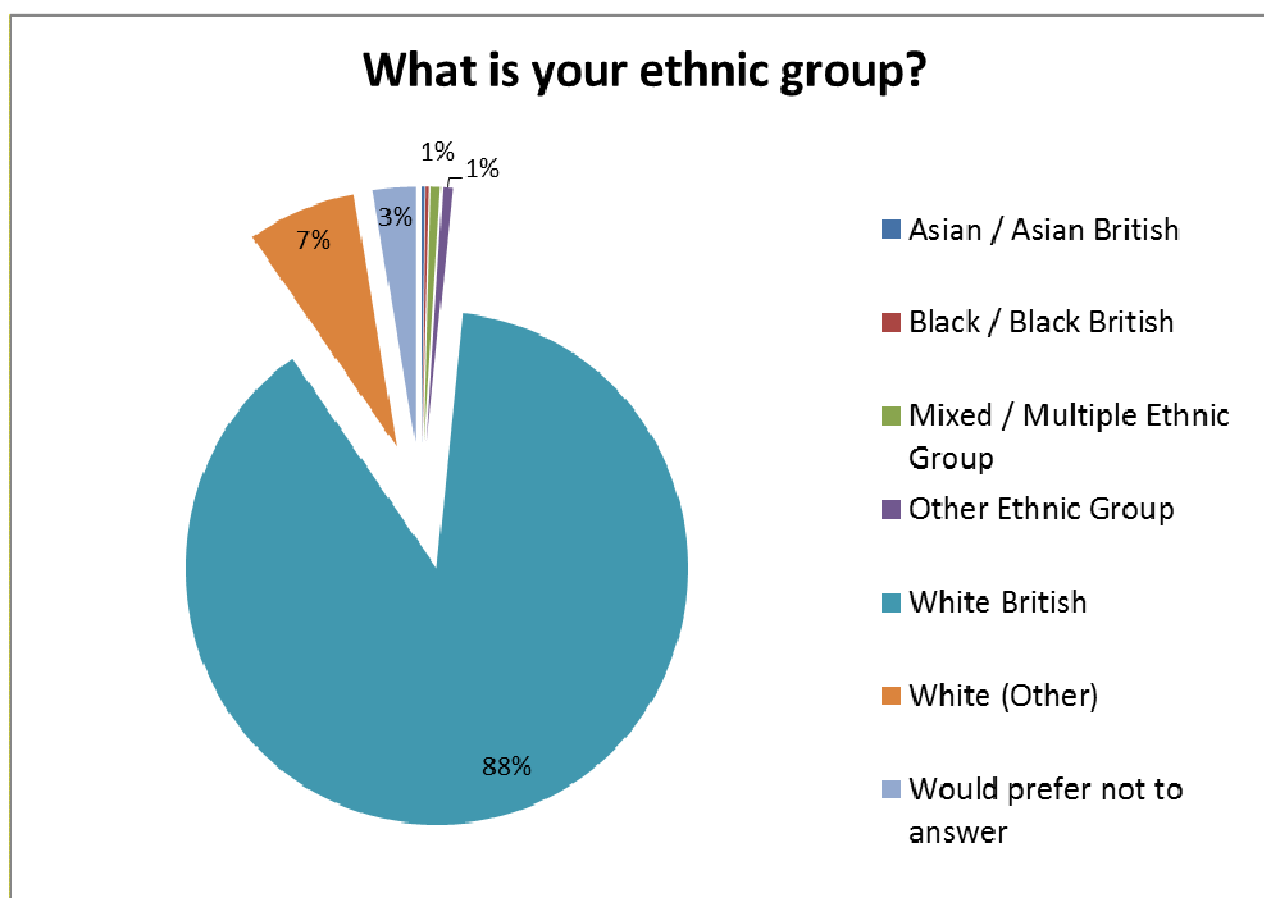
There have only been marginal changes to the ages of respondents this year. The most prevalent age group for respondents this year remains those aged between 55-64, which has increased from 34% to 37%. Respondents aged 35-44 have decreased marginally, to 6% as have 25-34 year olds (from 2% to 1%).

The number of respondents aged 45-54, 65-74 and 75-84 has remained the same, at 27%, 20% and 7% respectively. Those aged 85+ have also remained the same at 2%.



Question 4 – What is your ethnic group?

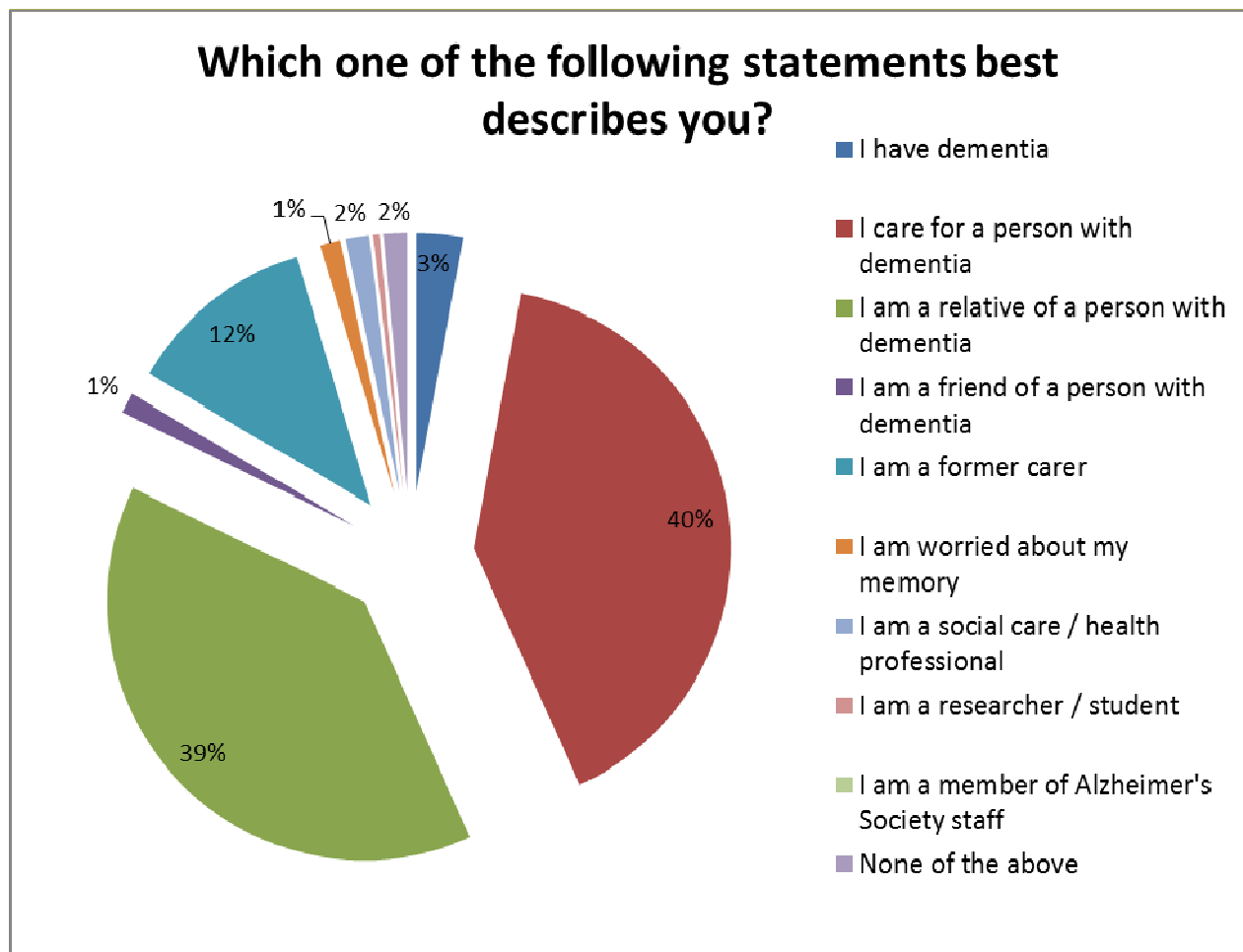
As was the case last year, the majority of respondents (88%, compared to 91% last year) identify themselves as being 'White British'. Of the remaining respondents, 7% identify as 'White: Other,' 1% as 'Mixed/Multiple Ethnic Group' and 1% as 'Other Ethnic Group'. There were 3% of respondents who preferred not to answer this question. We have carried out more tailored promotional activity with the aim of better reaching people from BAME communities, and we intend to undertake further research in this area.



Question 5 – Which one of the following statements best describes you?

Our core user group this year has changed, as for the second year the number of respondents defining themselves as a carer for a person with dementia has increased, from 34% to 40%. The number of respondents who identify as relatives of a person with dementia remains high, at 39% (a decrease from 42% last year).

There have been marginal decreases in both the proportion of respondents who have a dementia diagnosis (from 4% to 3%) and those who identify as former carers (from 13% to 12%).



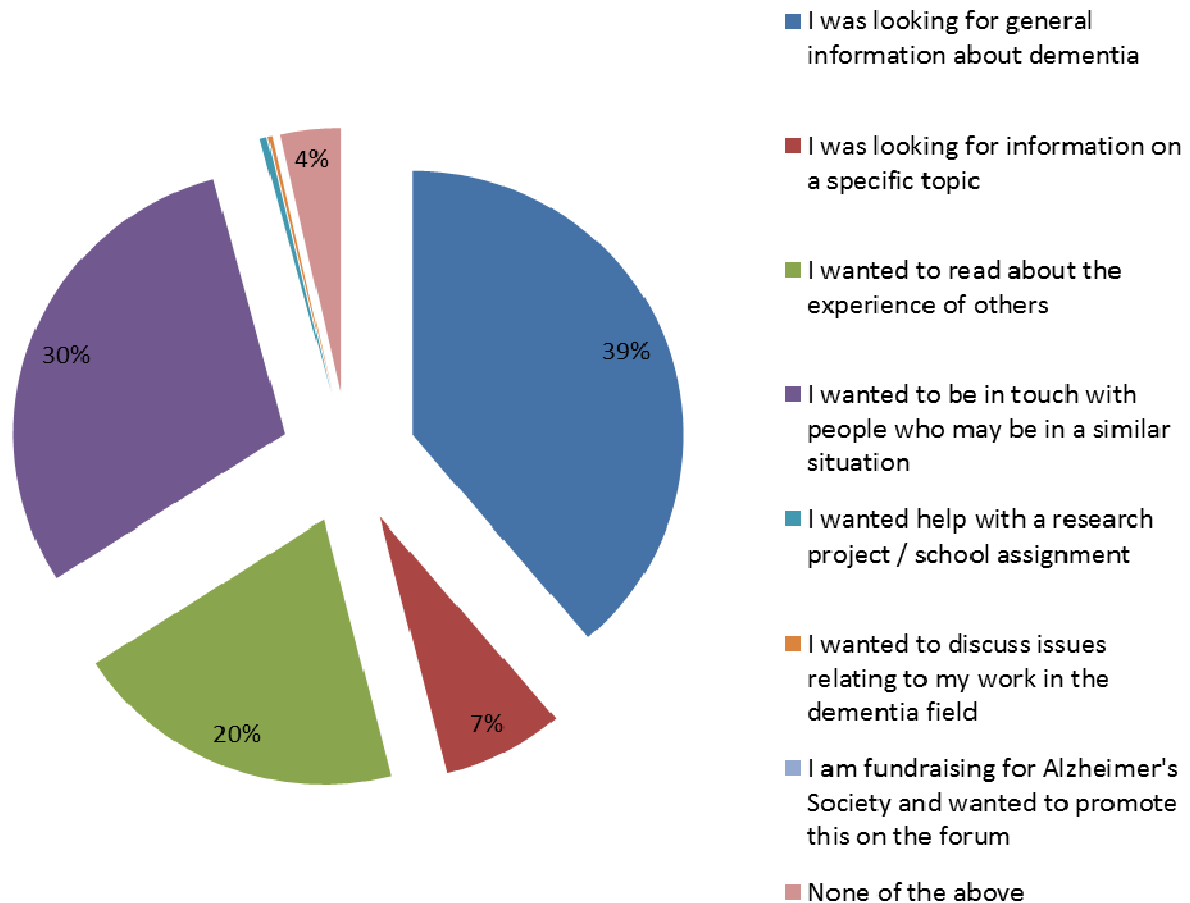
Question 6 – What first brought you to Talking Point?

As has been the case in previous years, the majority of respondents said they first came to Talking Point for 'general information about dementia,' and the proportion has remained at 39% this year.

Half of the survey respondents (50%) were attracted by the peer support ethos of Talking Point: the number of respondents who report that they came to the forum primarily to be in touch with people in a similar situation has increased from 24% last year to 30% this year. The number of respondents who said they came to read about the experiences of others has decreased slightly, from 23% last year to 20% this year.

As we have noted in previous surveys, Talking Point consistently has a high number of 'guest' users (i.e. people who are viewing content on the forum but not actively contributing content). It is difficult to capture information about these users, but these figures would appear to reinforce the value that can be gained from reading about other people's experiences in relation to dementia.

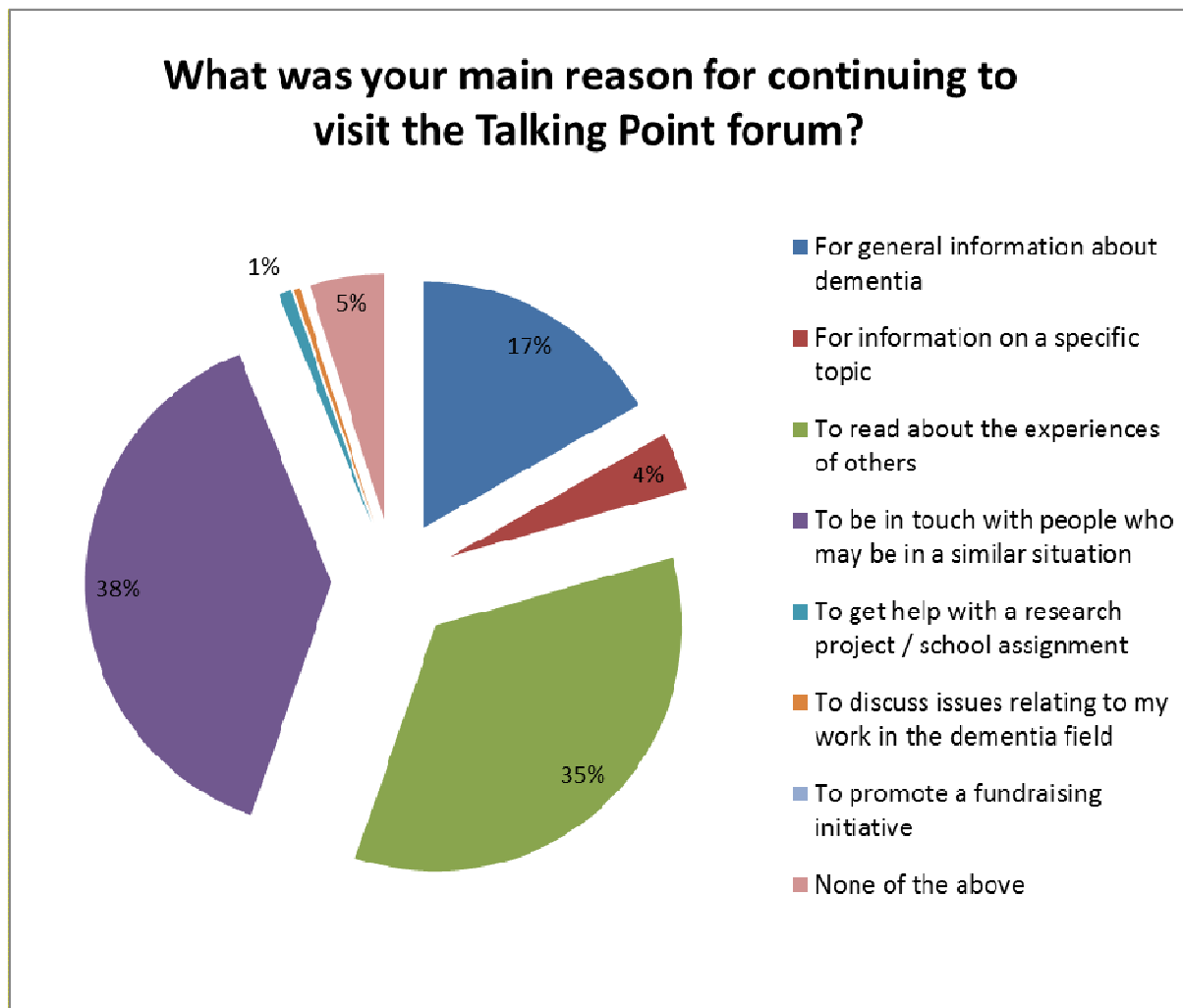
What first brought you to Talking Point?



Question 7 – What is your main reason for continuing to visit Talking Point?

As in previous years, peer support is what motivates the majority of respondents (73%) to continue to visit Talking Point. There has been an increase in the proportion of respondents visiting the forum to be in touch with people in similar situations; this is now the largest single group from 30% last year to 38% this year. There has been a decrease in the proportion of respondents continuing to visit Talking Point to read about the experiences of others (35% compared to 40% last year).

17% of respondents continue to visit Talking Point as a source of general information about dementia (this figure was 19% last year).



Question 8 – How often do you visit Talking Point?

The most pronounced changes to respondents' experience of using Talking Point relate to their regularity of visits to the site. Like last year, the largest single group of respondents said they visit Talking Point once a month; however this has dropped from 32% to 22% of respondents.

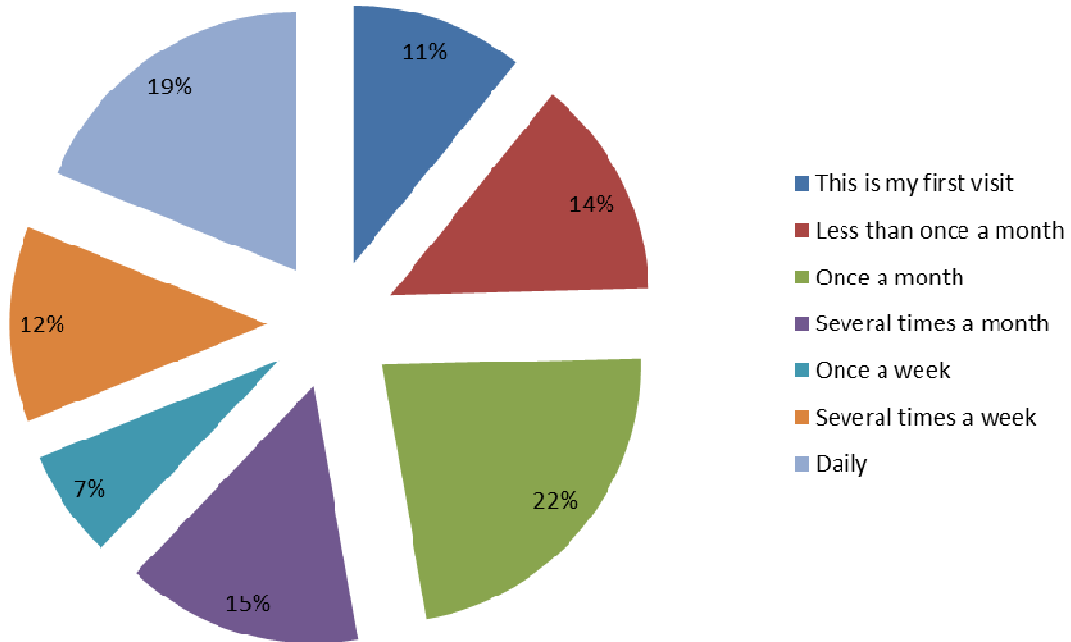
There have also been increases in the number of people visiting the site several times a week (from 9% to 15%) and on a daily basis (from 11% to 19%).

14% of respondents (down from 26% last year) visit the forum less than once a month, whilst the number of respondents who visit several times a month (13%) or once a week (7%) remains similar.

11% of respondents reported that this was their first visit to the site, an increase from 4% last year.

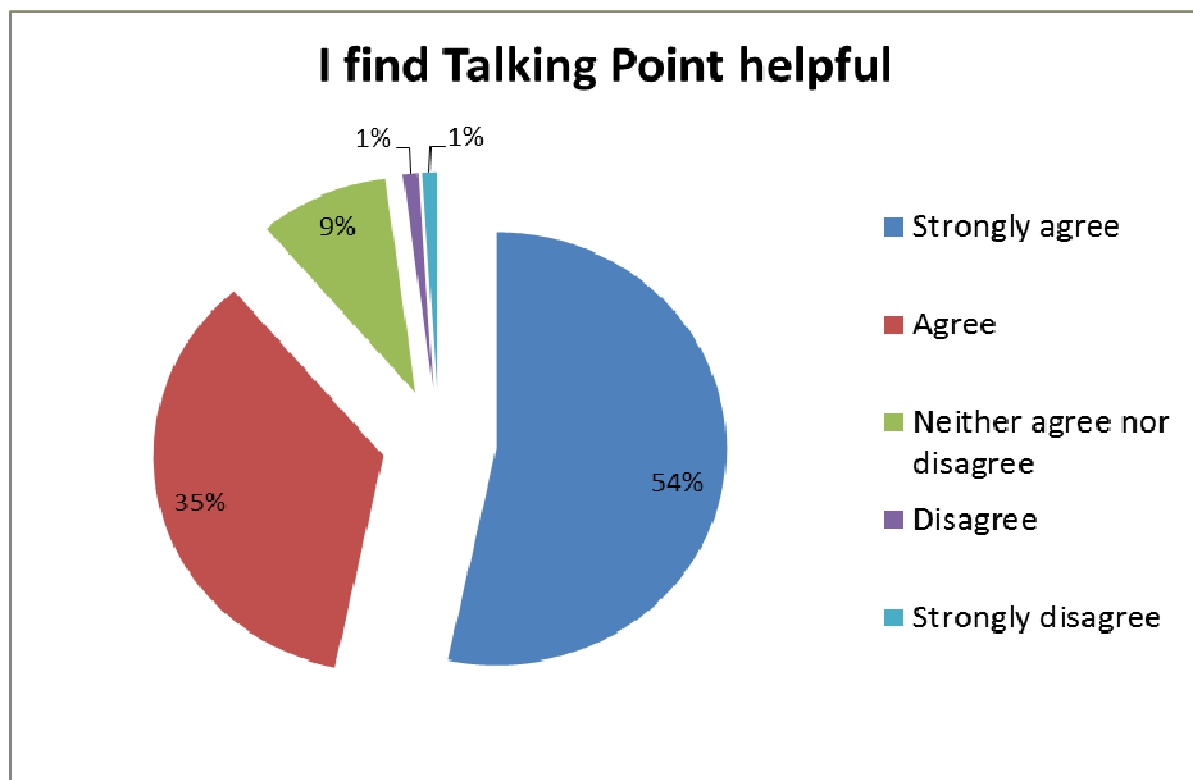
There may be a number of reasons for these changes, but it seems likely that users' increased regularity of visits to Talking Point may, at least in part, reflect their increased use of mobile devices (which tend to be used frequently throughout the day, for shorter periods of time).

How often do you visit Talking Point?

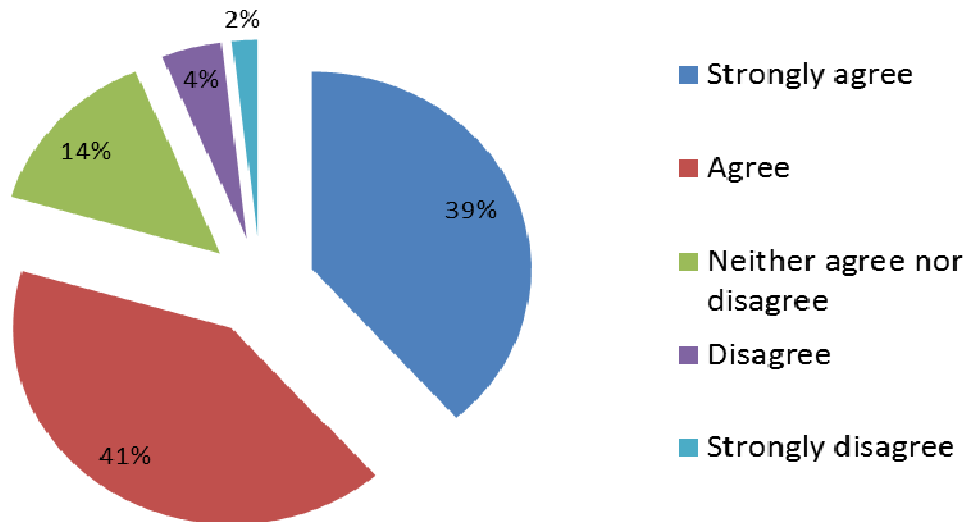


Question 9 – Respondents were asked if they felt Talking Point was helpful; easy to use; a good source of information about dementia; and helped them feel less isolated.

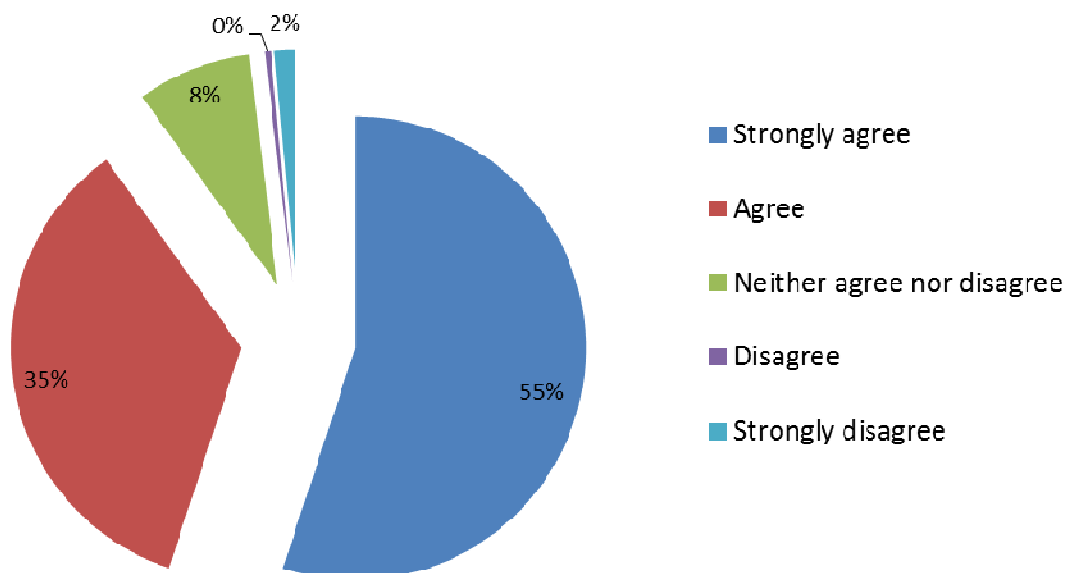
This question asked how much respondents agreed or disagreed with the following four statements:



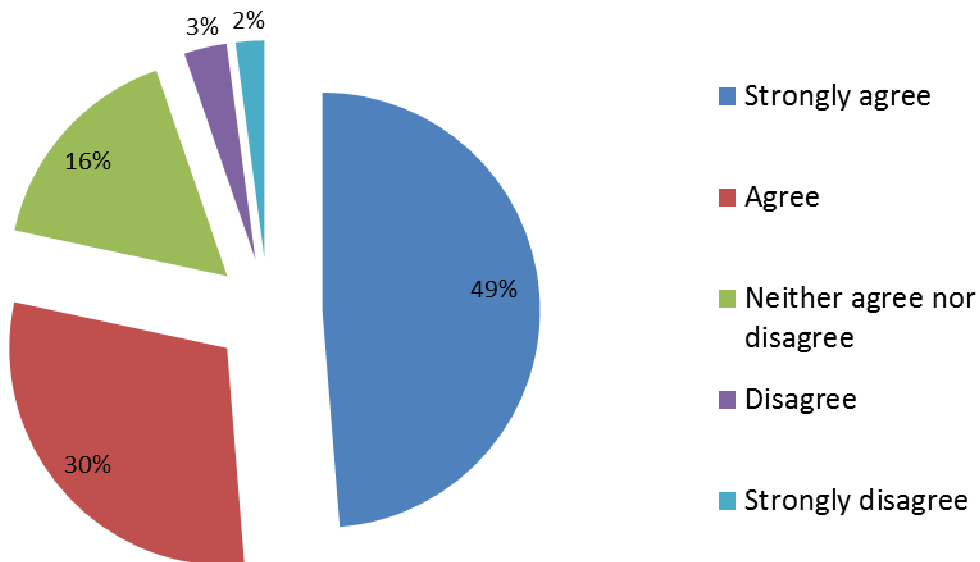
I find Talking Point easy to use



Talking Point is a good source of information about dementia



Talking Point helps me to feel less isolated



As in previous years, the number of respondents giving positive answers to each statement remains consistently high, with either the same or slightly improved ratings given for all statements.

The number of respondents who agreed or strongly agreed that Talking Point was easy to use has increased from 76% to 80%. We created a new [Help Guide](#) for Talking Point users last year, which we hope has helped to improve ease of use.

Question 10 – Respondents' experiences of using Talking Point

Respondents were asked to comment further if they had strongly agreed or strongly disagreed with any of the four statements listed in Question 9.

Some respondents felt strongly that the site could be easier to use:

"I found posting rather complicated and have been unable to work out how I respond to people that have commented on my post."

"Find logging in order to contribute / give comments / raise issues difficult to do."

There were a small number of respondents who struggled to find the information they were looking for on Talking Point:

"My husband has young onset semantic variant Picks disease and I cannot find links to others easily. I wish there was a subsection for FTD as he doesn't have Alzheimer's."

"Not much on the end of life but I do enjoy the chat."

Most of the feedback given in this section was from respondents who strongly agreed that Talking Point was helpful to them. The comments below give a flavour of the responses received:

"Talking Point is an example of the internet at its best, bringing together people who otherwise would not be able to share experiences and help one another with advice and support. Simply reading about the experiences of others is extremely helpful, even if one chooses not to participate."

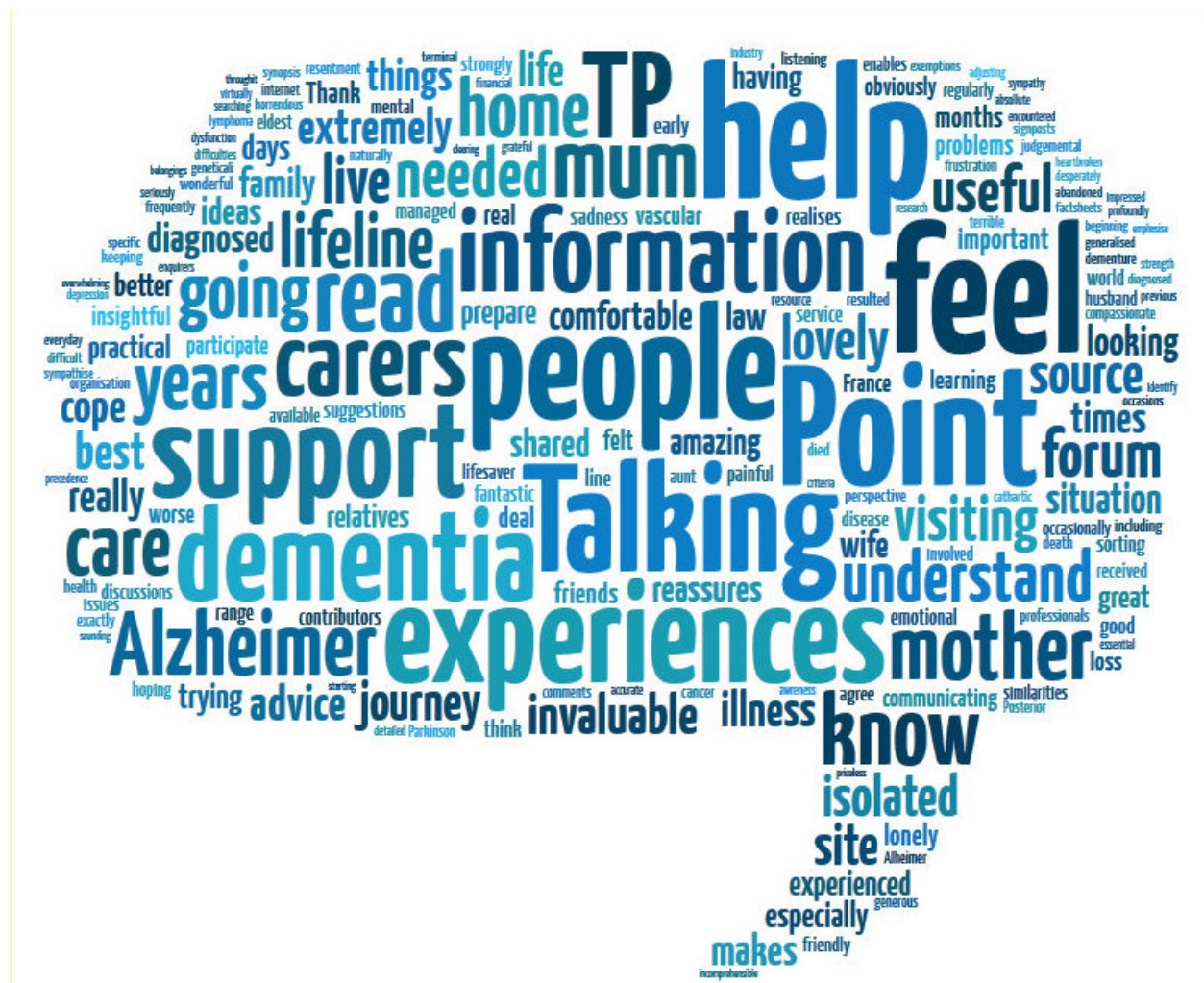
"TP has helped me say things I can't talk about to my lovely family."

"Talking Point is a lifeline that is helping me on this awful journey through the hell of Posterior Cortical Atrophy."

"Knowing you are not alone is comforting."

"I cannot stress enough how it makes me feel less isolated. Reading about practical but also emotional stuff other people are going through just makes it a bit better."

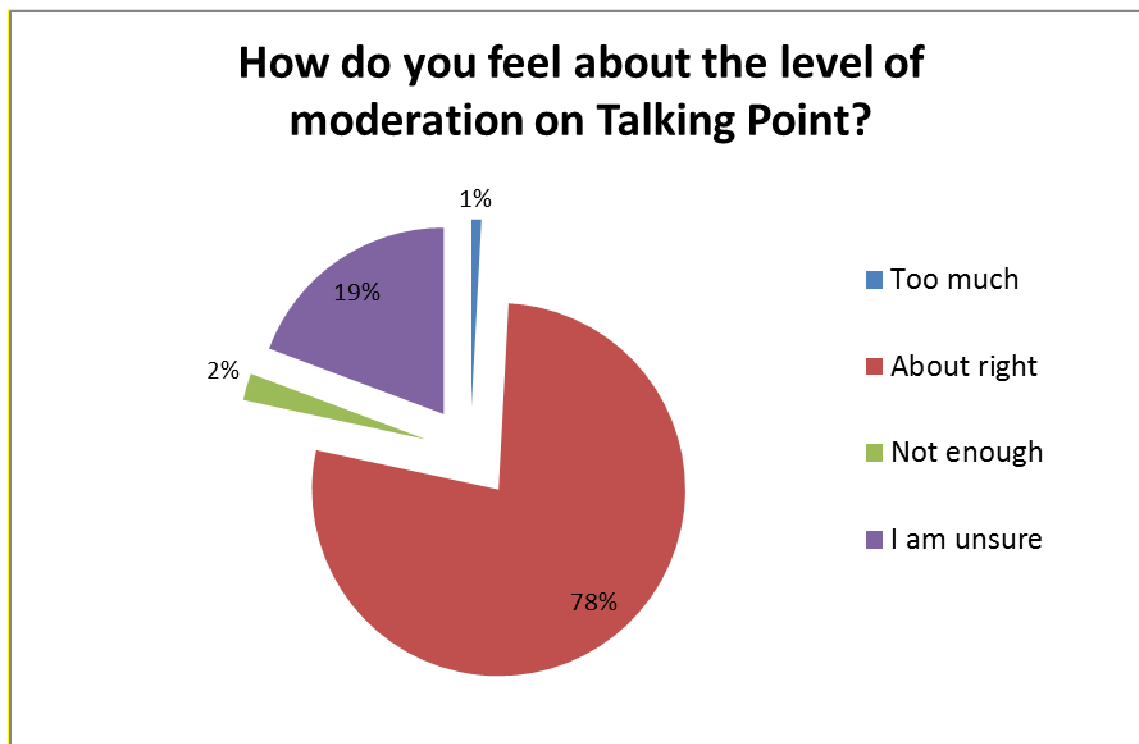
The word cloud below was generated from the responses to this question. The words that featured most frequently in respondents' answers are those that appear most prominently in the cloud.



Question 11 – What do you feel about the level of moderation on Talking Point?

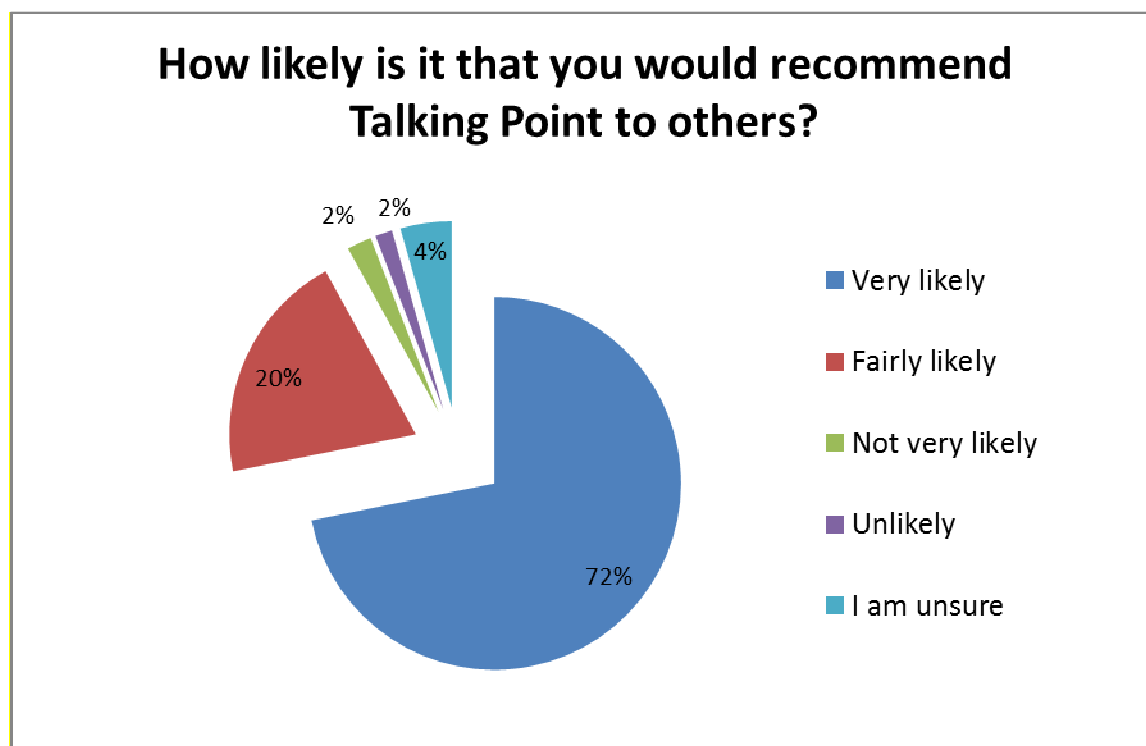
Talking Point is supported by a team of Alzheimer's Society staff, volunteer hosts and volunteer moderators. The team oversee and moderate the forum, welcoming new users and clarifying forum rules.

Respondents were asked how they felt about the level of moderation on Talking Point. It is positive to note that 78% said they felt that the level of moderation was 'about right' (up 3% from last year). Of the remaining respondents, 19% (down 1% from last year) were 'unsure'. Again, a small amount of respondents (3%, down 2% from last year), said they felt the forum was either under or over-moderated.



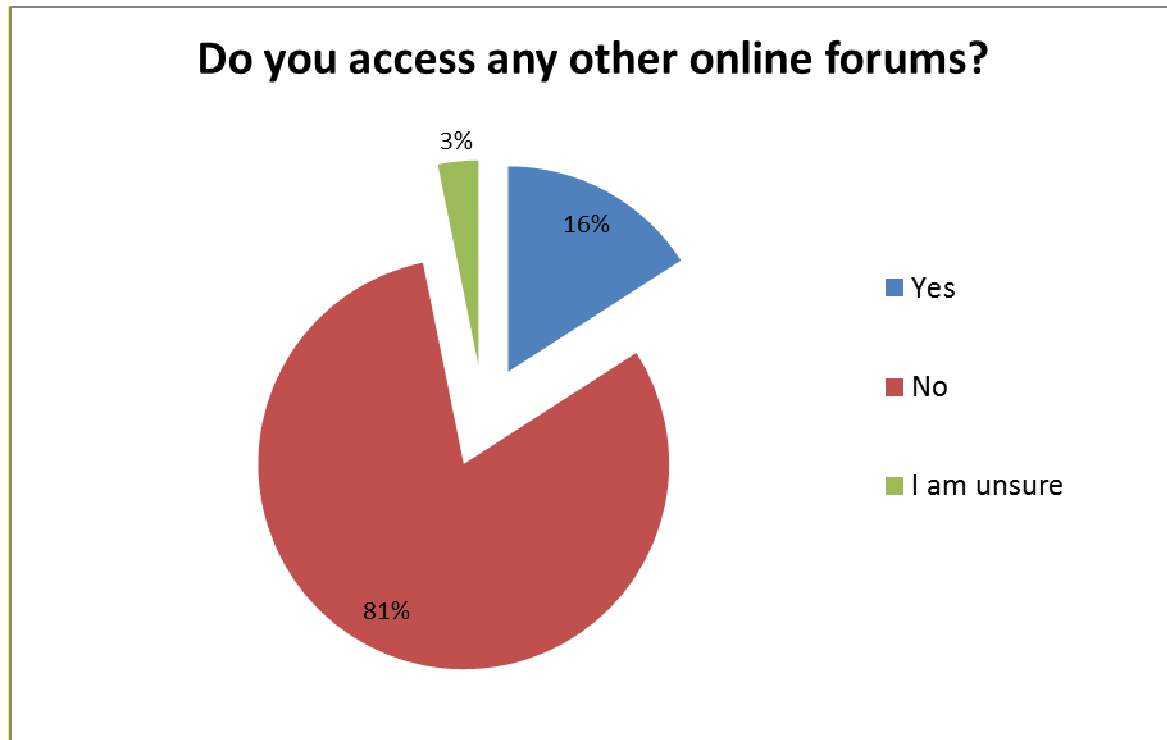
Question 12 – How likely is it that you would recommend Talking Point to others?

It is positive to note that the figures for this question have remained similar to those in preceding surveys: 92% of respondents said they would be fairly or very likely to recommend Talking Point to other people (this figure was 90% last year).



Question 13 – Do you access any other online support forums?

The figures for this question remain similar to the previous two years, with the vast majority (81%) of respondents telling us they do not access other online support forums.



Question 14 – Which other online support forums do you use?

Survey respondents were asked to comment further if they had answered 'Yes' to the previous question. 45 respondents gave us information about 27 forums and websites that they accessed (respondents told us about 66 forums and other sites last year). Of these, 9 related to dementia information or support (this figure was 15 last year); 3 to carers' information or support (5 last year) and 10 to a range of other health and/or support needs (34 last year). The remaining 5 sites related to miscellaneous topics.

As has been the case in previous years, not all of the websites mentioned are online forums: some sites offer other types of information or support.

Alz Connected

Alzheimers Reading Room (US site)

Cancer Buddies Network

Carers Trust

Carers UK

Caring for Carers

Cockers Online Forum - for cocker spaniel owners

Dementia Alliance International

Diabetes

Encephalitis Global

Facebook dementia group pages

Friends of dementia

FTD Support Forum

Gransnet

Lewy Bodies Association

Health Unlocked

M.S. Society Forum

Money Saving Expert

Mumsnet

Netmums

Myaware (Myasthenia Gravis Association)

Oral Cancer Foundation

Parkinson's

Royal College of Nursing

SEN (Special Educational Needs)

The Lundbeck South African AD support group

Young Dementia UK

Question 15 – Are there any ways you think Talking Point could be improved?

Finally, respondents were asked to comment on anything they felt might improve Talking Point.

As was the case last year, some respondents felt there were too many sub-forums on Talking Point, whilst others requested more:

“More headings for topics, e.g. Medication, care homes, pain control.”

“Too many sections which could mean people may miss out on some pearls of wisdom.”

“I know there are lots of categories already, but it would be so useful if there were sections on the rare dementias.”

Ease of use was again touched on by some respondents, and experiences were mixed. Navigation was the main issue highlighted for improvement:

“The pages aren't easy to navigate.”

“It is easier now to find specific issues, which is great.”

“The site in its entirety seems easy to use.”

“I don't find it easy to navigate and am not sure how to make a comment.”

“Instant, clearer navigational help, for technophobes like me!”

Some respondents requested a ‘like’ button (this was also requested last year; see page 26), but others felt this would not work well on Talking Point:

Sometimes I really “like” the answers given and feel like I would like to press a “like” or something similar button.

“I thought about a “thanks” button, but then this might make posters who weren't thanked much feel unvalued. It's fine, because if I don't agree with a post, I don't comment about it, and I find that seems to be the view of many.”

“Can we have a like/empathy button please?!”

A number of respondents fed back suggestions for improving and developing the new chat room feature:

"Perhaps access to a specialist nurse on weekly or monthly chats."

"Re. the chat room - make it into a webcam chat room so people have direct contact and interaction with each other."

"Chat rooms are excellent in principle but the ball does not get rolling soon enough and I neither have time nor patience to stare at a screen when it's immobile."

"I haven't used a forum before and I'm thinking that the chat room may be more useful as it's more instantaneous support."

The majority of responses to this question were from respondents who felt that no further improvements to Talking Point were needed:

"Nothing springs to mind - the topics and threads of discussion are good."

"Why tinker with something that works well? - An excellent source of information and support. THANK YOU."

"This is an excellent resource, can't see how it could be improved."

"I think the balance is about right. I feel quite reassured that I am coping fairly well and take note of the tips given in the forum. Thank you."

"Nothing, I feel that it's good to be able to express yourself freely, in complete anonymity."

"I can't think of anything but would like to take the opportunity to say thank you to the moderators and the Society for making this site possible!"

Conclusions

The results of this year's Talking Point survey are very positive overall, with high levels of user satisfaction with the service being maintained, and several ratings being improved upon, as the community continues to grow. At the end of December 2014, Talking Point had 37,886 members; a 21% increase on the same month in 2013.

While users' feedback has been broadly positive, there are some areas for improvement and development.

Ease of use is an issue for some survey respondents, with navigation being a key concern highlighted this year. In 2014 we carried out a research project into forum users' experience of the site. We'll be drawing from the project findings, from survey responses and from ongoing user feedback, to make further improvements to Talking Point over the coming year.

We have carried out some additional promotional activity with the aim of better reaching people from BAME communities, but there is still more work to be done in this area.

A 'like' or 'thanks' button was suggested by a number of respondents both this year and last, and we carried out some initial testing of this feature in 2014. We don't have plans to incorporate a like or thanks button into Talking Point in the near future. A key concern of those testing the feature was that it could lead members to click 'like' or 'thanks' and not respond to others at all, when the personal connection between members is what is most valued about our community.

Lastly, respondents also made some interesting suggestions for ways of further developing our chat room, and these will be explored further in the year ahead.

Katherine Watt
Online Community Manager
Alzheimer's Society

January 2015