

Results of the 2011 MSAC Oral Medications Survey

This survey was conducted in August-September 2011. Its purpose was to find out whether the MS community in Australia have heard about new (and proposed) oral treatments for MS, where they have heard about them, whether or not they believe it is important that oral medications should be available for the treatment of MS and what types of support they would like from MSL (the MS Society) if they, or someone they know, was considering starting an oral MS treatment. MSAC wanted community views on this subject to feed back to the Board of MSL because it has been very topical recently, with one oral MS treatment already listed on the Australian Pharmaceutical Benefits Scheme and another proposed oral MS treatment withdrawn.

The survey was available to be answered on line or as a hard copy (to be mailed back free of charge). Information about the survey was sent to everyone who has already registered on the MSAC database as willing to participate in surveys (to register, go to msac.org.au). The survey was also publicized through MS-related email groups, facebook pages and so on, and in all cases people were encouraged to let their own networks know about the survey.

THANK YOU to the 556 people who took part in this survey! Here are the results:

Who took part in the survey? (more details given at the end)

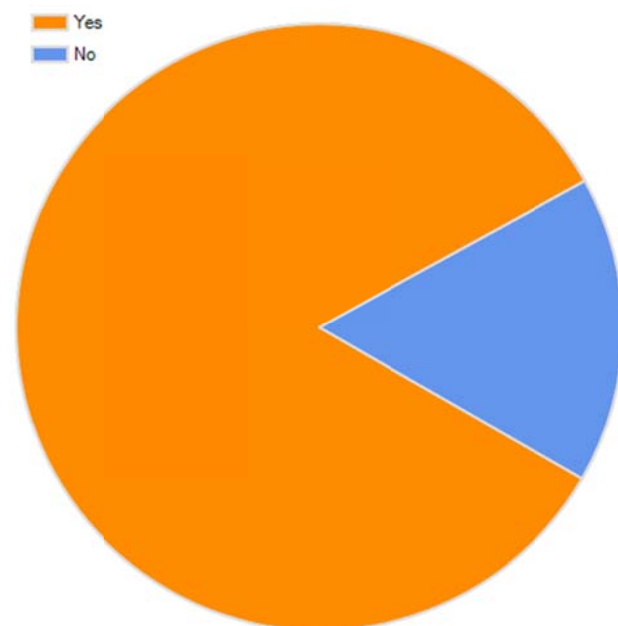
How many people who took part have MS?

Of the 535 respondents who answered this question, 501 (94%) were people who have MS and 34 (6%) were members of the MS community who do not personally have MS.

How many people live in capital cities and how many live in rural or regional areas?

Of the 532 people who told us where they live, 529 were living in Australia. Among those living in Australia, 360 (68%) live in a capital city and 169 (32%) live in a regional, rural or remote area.

Have you heard about oral medications for treating MS?



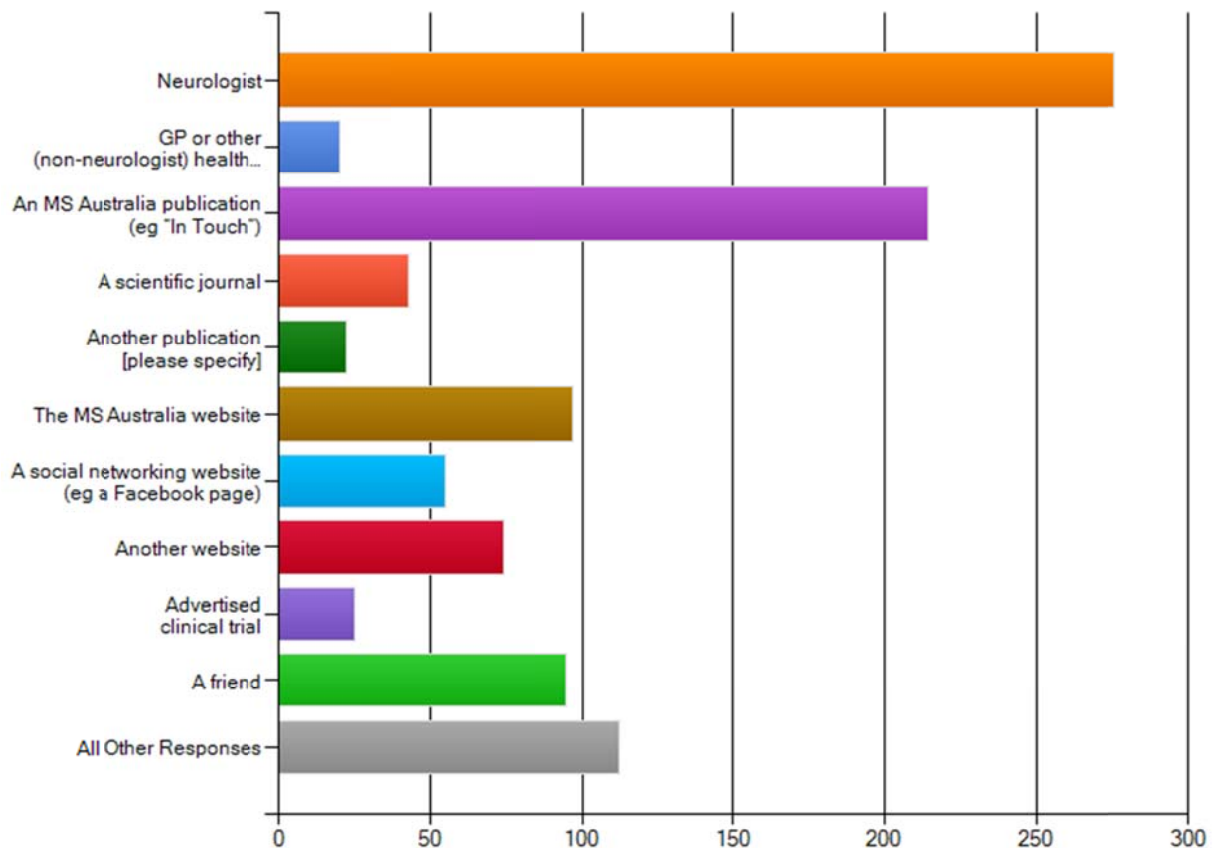
Overall, 84% (465) of people who responded had heard about oral medications for treating MS, but 16% (91) had not (figure).

Those living in a capital city were more likely to have heard of oral MS treatments than those living elsewhere in Australia. Overall, 87% (312) of those living in a capital city had heard of oral MS treatments versus 78% (131) of those living elsewhere in Australia ($p=0.008$, Chi^2 test).

People with MS did not answer differently from those without MS. Overall 16% of people who identified as having MS and 24% of people in the MS community who do not personally have MS had not hear of oral medications to treat MS. This was not a significant difference ($p=0.24$, Chi^2 test).

Where have you heard about oral medications for treating MS?

This question was only answered by those who *had* heard of oral MS treatments. People were asked to select all the answers that applied to them and also had the option of selecting “other” and telling us about information sources not covered by the options given. The graph below shows how many people (out of 465) selected each option. Overall, the most common place where people had heard about oral MS treatments was from a neurologist. The next most commonly selected option was an MS Australia publication, followed by the MS Australia website. Friends and other websites (including social networking websites) were other places where >10% of people who responded had heard of oral MS treatments.



111 people selected “other”. The responses they gave can be summarized as follows:

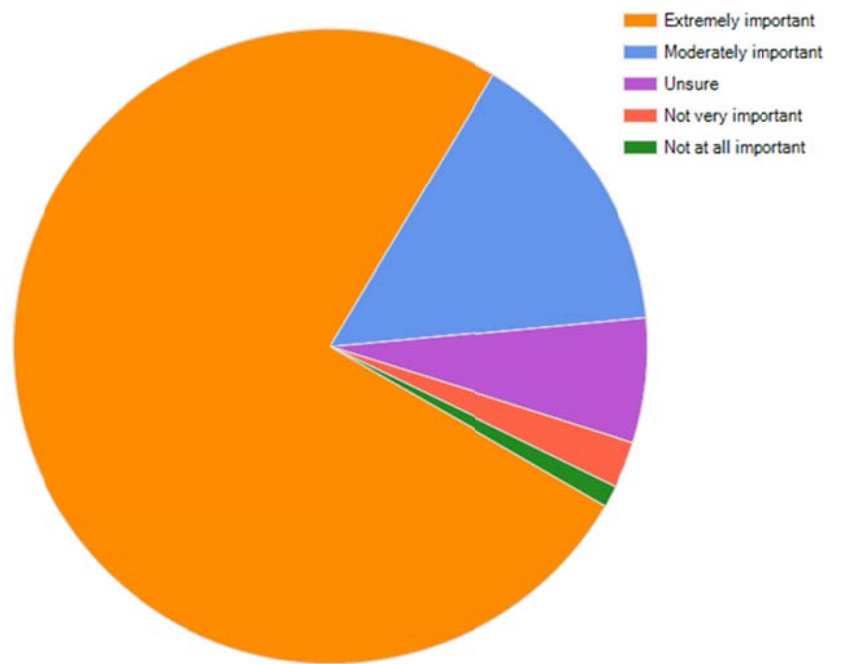
1. MEDIA - 61 people (this included: Media not otherwise specified – 8, Newspaper – 12, News – 15, Television – 26)
2. INTERNET – 11 people (included social networking and academic websites)
3. PEER SUPPORT - 10 (included group and individual peer support)
4. MSL INFORMATION DAY/CONFERENCE – 5 (included one in Ballarat)
5. MS NURSE – 5
6. FAMILY MEMBER – 4
7. ANOTHER PWMS – 3
8. EMAIL – 3 (included MSIF updates, email group, information emailed by MSL)
9. PHARMACEUTICAL COMPANY OR REP – 3
10. BEING ON A TRIAL – 2
11. JELINEK BOOK – 2
12. One person each listed personal research, Google Reader, the MS Australia Office and involvement in advocacy work

How important is it to you that oral medications are available in Australia to treat MS?

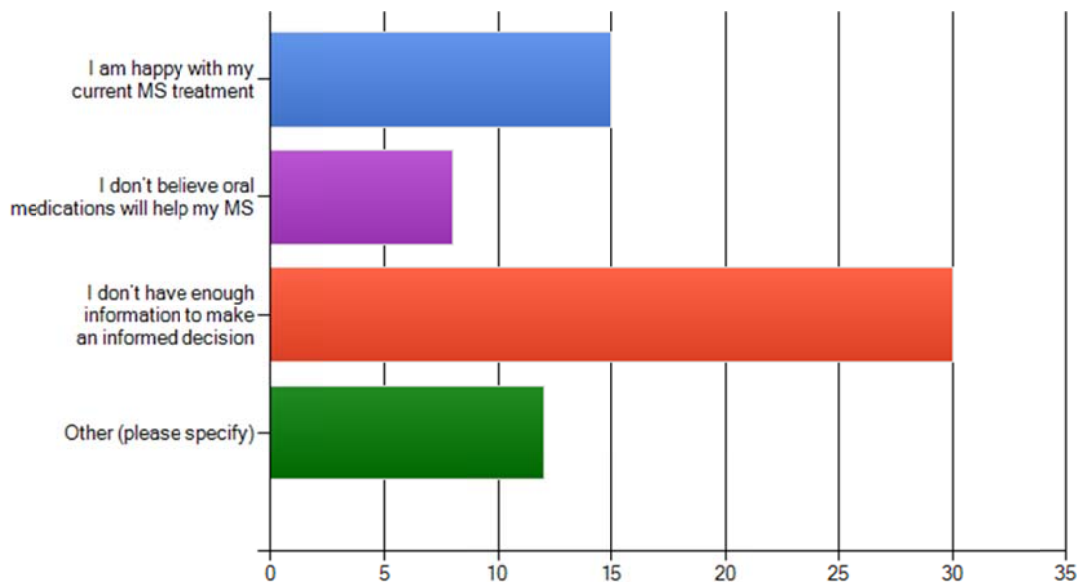
549 people answered this question. Overall, most (90%) feel that it is either moderately or extremely important that oral MS treatments should be available in Australia.

The 13 people who selected “not very important” and the 6 people who selected “not at all important” were all people with MS.

Otherwise, there were no major differences in how people answered this question based on where they live or their MS status.



Those who selected “unsure” (n=34), “not very important” (n=13) or “not at all important” (n=6) were invited to comment on why it is not important to them that oral MS treatments should be available in Australia (more than one answer could be selected). The main reason given was that people did not have enough information to make an informed decision.

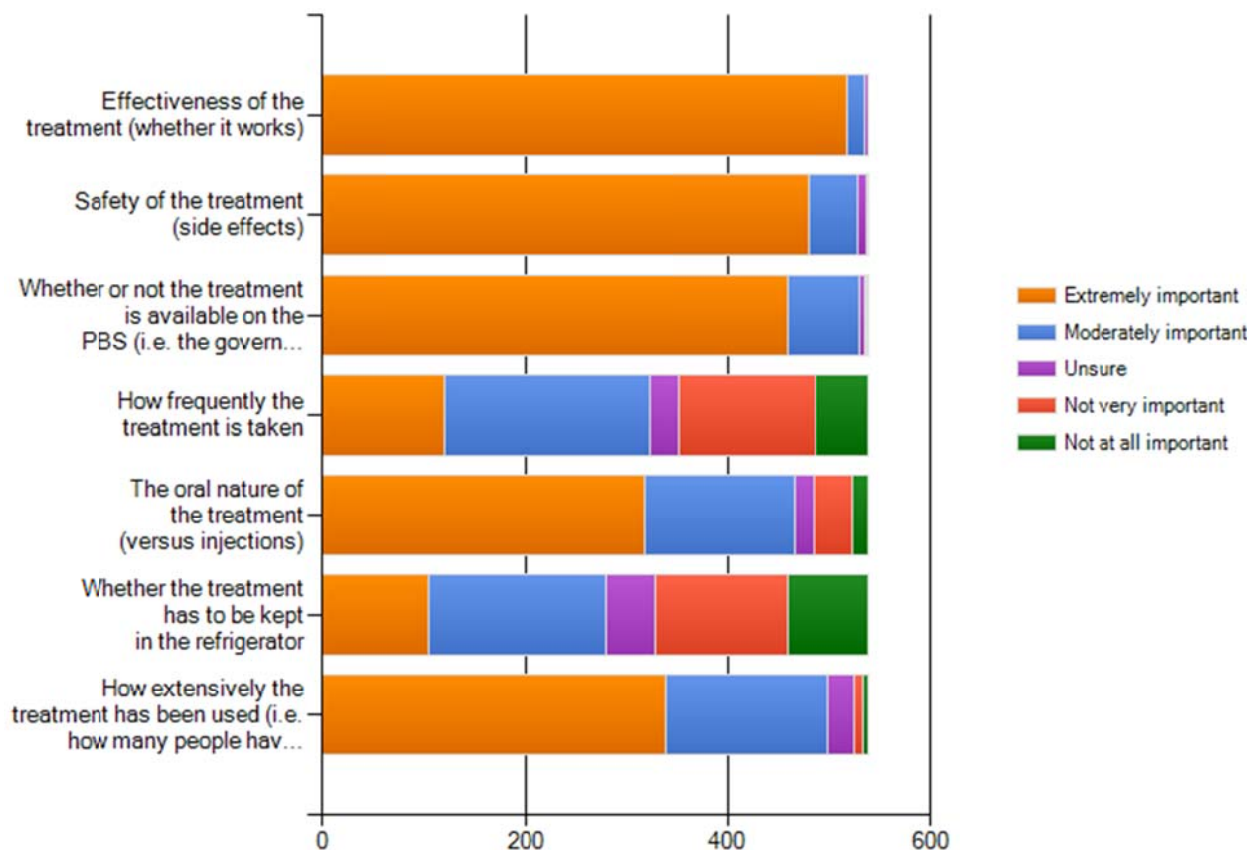


Eleven people who selected “other” provided comments. Most (6) expressed concerns about the potential toxicity of oral treatments, with 2 people wanting to see them in widespread use before they would consider trying them. Two people believed their current treatments were superior to currently available oral MS treatments (one was using Tysabri and one has had their veins treated with angioplasty). One person prefers to use diet rather than medication to treat MS. Two people felt that they (or their partner’s) MS was not a type that would respond to oral medications.

How important is each of the following factors when considering whether an oral MS treatment may be appropriate for you or someone you know?

539 people answered this question and rated the importance of each factor on a five-point scale ranging from “extremely important” to “not at all important”. Three things stood out, with almost everyone selecting “extremely important” or “moderately important”:

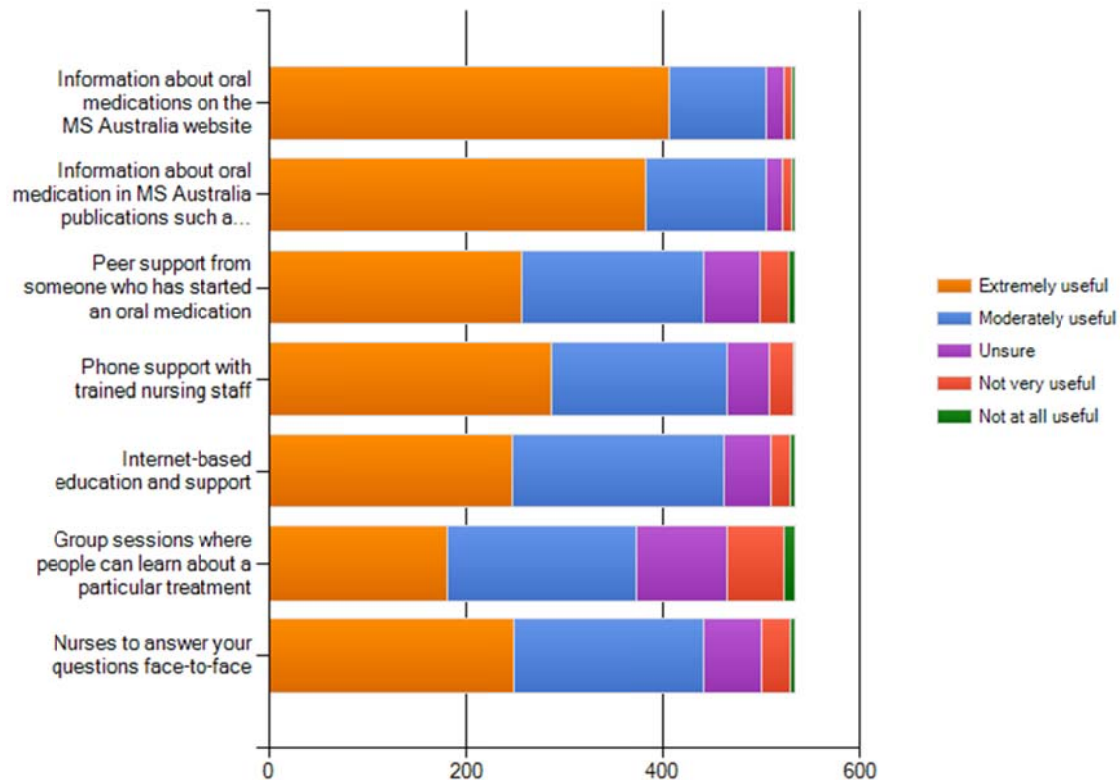
1. The EFFECTIVENESS of the treatment
2. The SAFETY of the treatment (note that how extensively the treatment has been used was also thought to be important by the majority of respondents)
3. The COST TO THE PATIENT of the treatment



Of note, all but one of those who felt the oral (versus injectable) nature of the treatments was “not very important” (n=38) or “not at all important” (n=15) were people with MS. Otherwise there were no obvious differences in how people answered this question according to whether they have MS, where they live or other demographic factors.

How useful would it be if MS Australia were able to offer each of the following types of support for people considering or trying an oral medication to treat MS?

539 people answered this question and rated the usefulness of each type of support on a five-point scale ranging from “extremely useful” to “not at all useful”. All the types of support listed were rated highly by most people, but in general *information* was seen as the most useful thing MSL can provide to clients, with both information on the website and information in MSL publications seen as “extremely useful” by the majority of respondents. Group sessions to learn about a particular treatment were rated least highly, but 34% of respondents did rate these as “extremely useful”.



Are there other types of support you would like MSL to provide?

A full list of all comments provided has been sent to the Board of MSL exactly as people provided them. To summarize, the things that people said they wanted included:

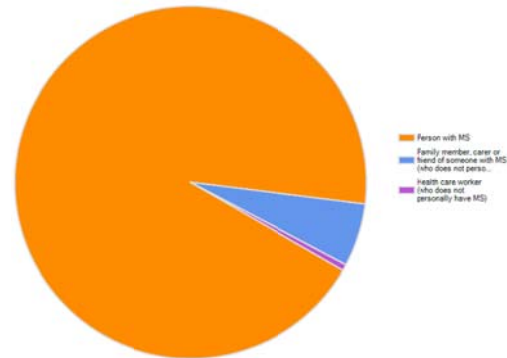
1. Unbiased (free from the influence of pharmaceutical company) information
2. Detailed, up to date information to assist people making choices about MS treatments, including comparative information on the side effects and effectiveness of different treatments as they are used in the “real world” (ie updated as side effects occur)
3. Support for GPs
4. Support for family members
5. Plain English summaries of the latest scientific information and studies
6. Information provided in ways that are accessible to those who live in rural and remote areas, those who do not have internet access, and for younger people with MS
7. Information on non-drug treatment options for MS
8. Information sessions at MSL with neurologists
9. Internet-based support (peer support and support from nurses, videos on the website)
10. Referral to non-MSL sources of information
11. Several positive comments on the support MSL provides to the community were received

The “recurring theme” was that people want INFORMATION and they want it to be accurate, up to date, free from pharmaceutical company influence and accessible.

Who took part in this survey – a bit more detail.

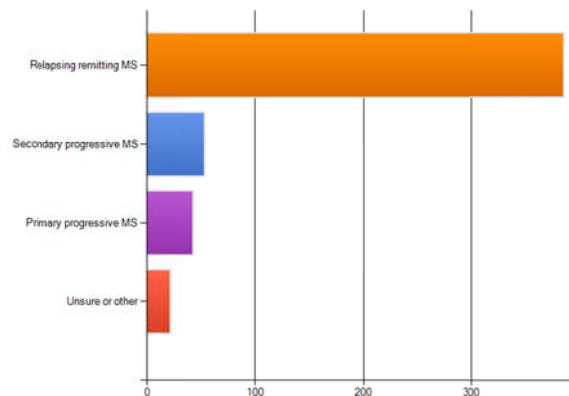
Respondents were asked to provide some information about themselves at the end of the survey. Most people did answer these questions, and here are their answers:

1. WHICH BEST DESCRIBES YOU? (n=535)
 - a. Person with MS – 501 (93.6%)
 - b. Family member, carer or friend of someone with MS – 31 (5.8%)
 - c. Health care worker caring for people with MS – 3 (0.6%)



The proportion of respondents who had MS was similar among those who live in capital cities and those living elsewhere.

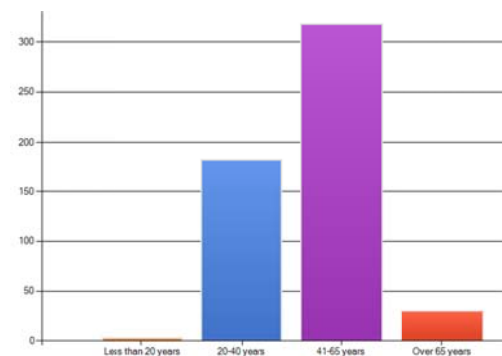
2. WHAT TYPE OF MS DO YOU CURRENTLY HAVE? (n=500)
 - a. Relapsing remitting – 383 (76.6%)
 - b. Secondary progressive – 53 (10.6%)
 - c. Primary progressive – 43 (8.6%)
 - d. Other or unsure – 21 (4.2%)



3. WHEN WERE YOU DIAGNOSED WITH MS? (n=500)

People had been diagnosed with MS for an average of 8.6 years (median 7, range <1 to 56 years)

4. HOW OLD ARE YOU? (n=532)
 - a. Less than 20 years – 2 (0.4%)
 - b. 20-40 years – 182 (34.2%)
 - c. 41-65 years – 318 (59.8%)
 - d. Over 65 years – 30 (5.6%)



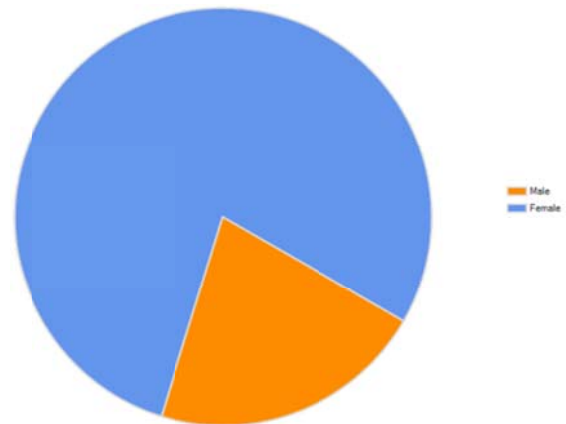
The ages of those with and without MS, and those living in capital cities versus other areas were similar.

5. WHAT IS YOUR GENDER?

532 people answered this question.

418 (78.6%) were female

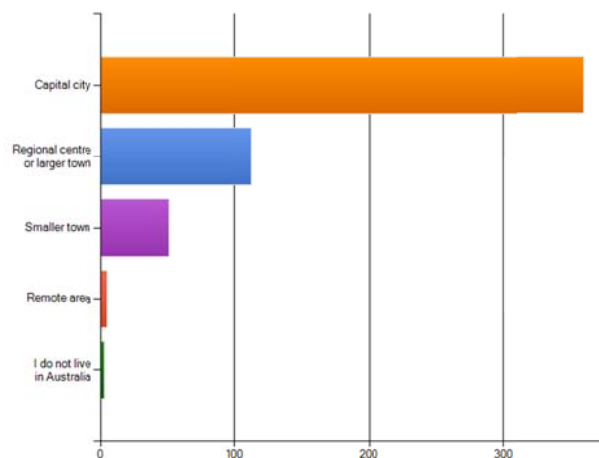
114 (21.4%) were male.



6. WHERE IN AUSTRALIA DO YOU LIVE?

(n=532)

- a. Capital city – 360 (67.7%)
- b. Regional centre – 113 (21.2%)
- c. Smaller town – 51 (9.6%)
- d. Remote area – 5 (0.9%)
- e. Not in Australia – 3 (0.6%)



Overall, these results show that most of the people who took part in this survey were people with MS. In terms of age, gender, type of MS and where in Australia they live, they are approximately what we would expect from a representative sample of people living with MS in Australia. We were pleased also to have responses from 34 members of the MS community who do not themselves have MS. Their knowledge and views on oral treatments for MS were generally similar to those of respondents who have MS.

THANK YOU to everyone who took part in this survey!

The results of this survey have been given to the Board of MSL to help them understand the views of the MS community on the subject of oral treatments for MS.



To learn more about MSAC (the MS Advisory Council) or register your details on the MSAC database, please visit our website msac.org.au.