

SWIMS News 14



The South West Impact of MS Project: a long-term study of the impact of MS and CIS on those living with these conditions in Devon and Cornwall

Summer Progress Report

“The SWIMS Project will do three things. It will enable us to (1) understand what it is like to have MS or CIS, (2) improve the way that changes in MS symptoms and disability are measured—a vital step forward for the testing of new and emerging treatments for MS, and (3) predict what will happen to individuals with MS over time” **Prof John Zajicek, Chief Investigator for SWIMS.**

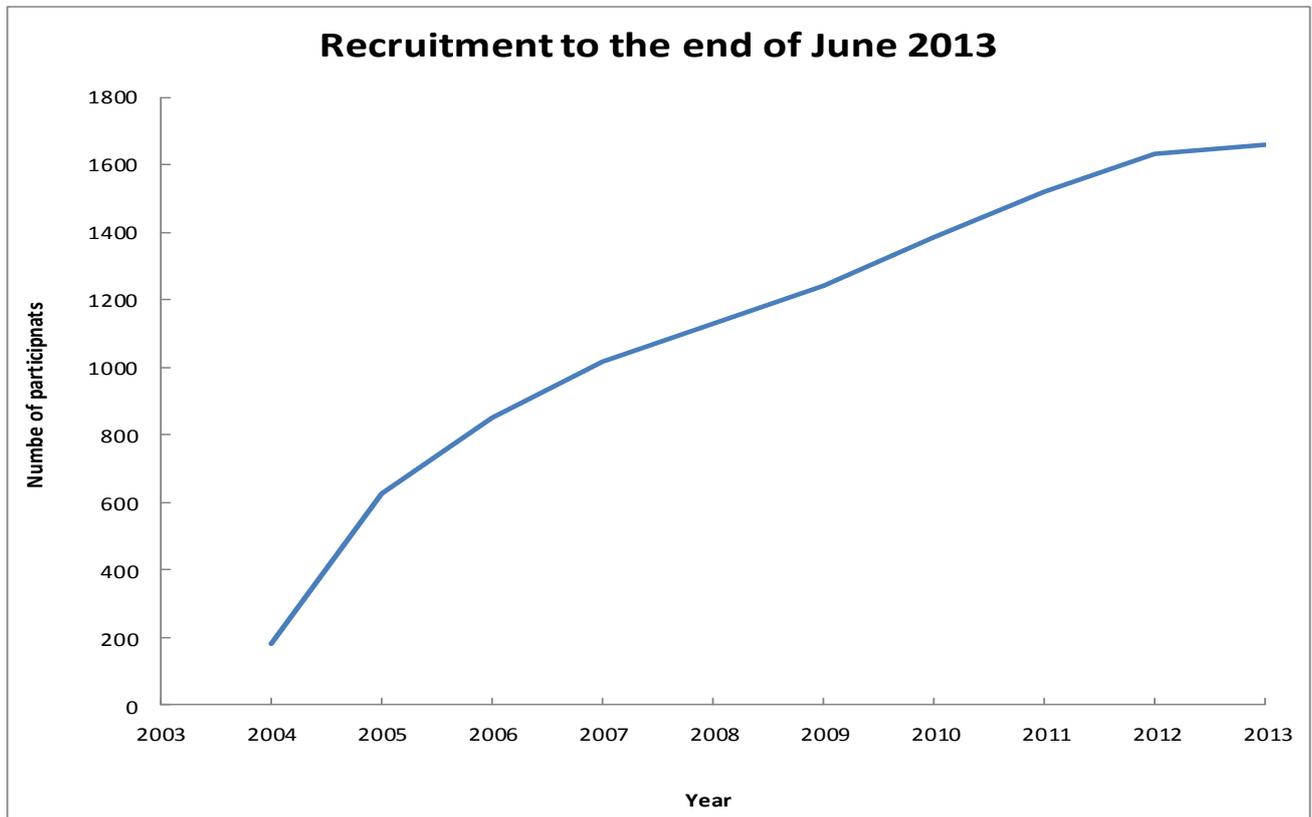
The SWIMS Project is currently funded by the Multiple Sclerosis Society of Great Britain, and through the Peninsula Medical School Foundation

Welcome to all of you who have recently joined the project and thanks to everybody for the time and effort spent completing your questionnaires.

As shown below there are now over 1650 people who have agreed to take part in SWIMS, with all types of MS. We also have a small number of people with Clinically Isolated Syndrome taking part.

In this latest issue of our Newsletter we have some information about work that we are undertaking to analyse your answers from the survey in the last newsletter, and a summary of some other research projects taking place in Devon and Cornwall that might interest you.

If you have any feedback about the content of the newsletter or issues you would like to see covered then, as always, please contact us.



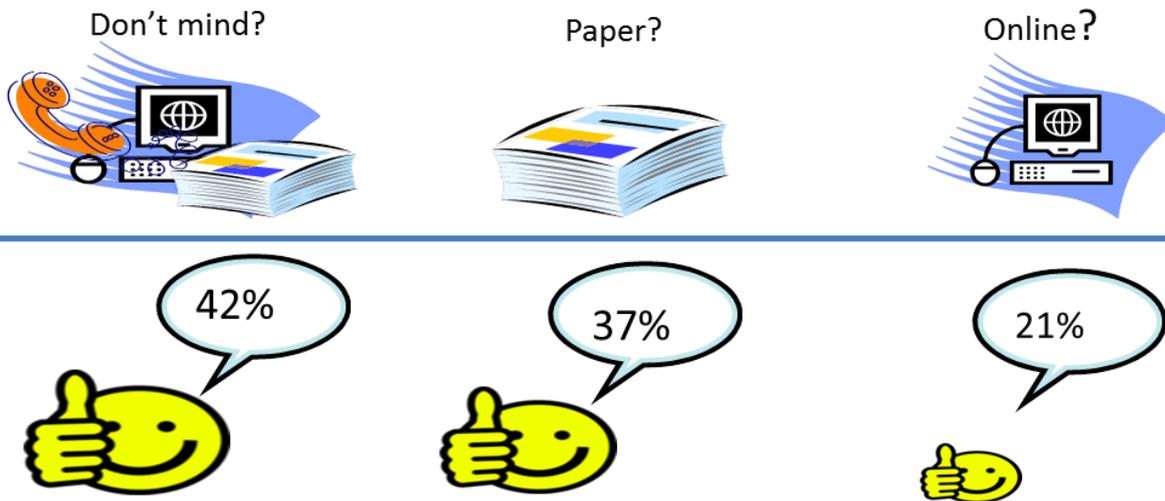
Last time we asked you some questions about the best ways for us to collect information from you.

You may remember that in the last newsletter we asked for some feedback about: the size of our questionnaires; how often we send booklets; and the way in which you answer our questions.

Firstly, we would like to thank all of you who were able to let us know your opinions; so far 369 people have returned the survey, which is a really fantastic response. 20% of those returning the survey are already completing online questionnaires, which is very similar to the percentage of people within SWIMS overall (22%) who currently fill in booklets via the internet. This suggests that the answers we received are a good reflection of all SWIMS participants.

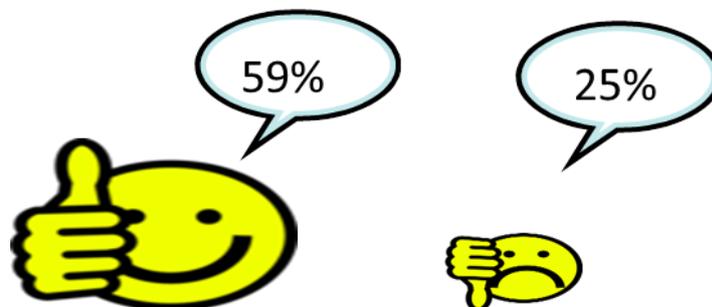
Below we summarise some of the things you have told us.

What method do you prefer to use to answer questions about MS?



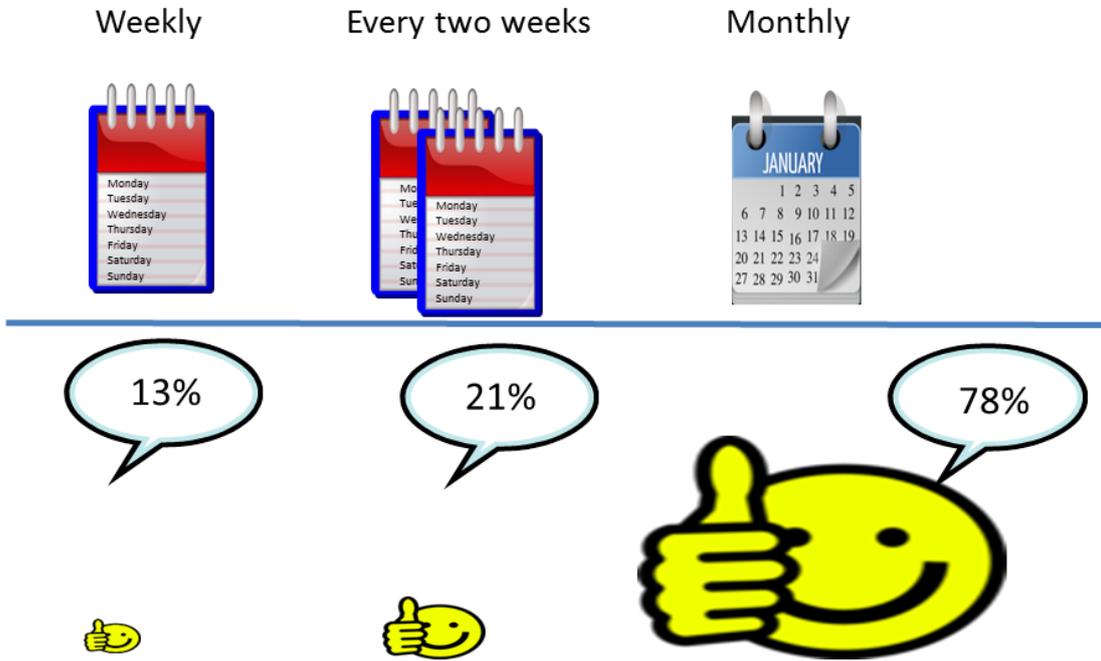
42% of those who replied stated that they had no preference as to how they answered questions about MS. Amongst those who did express an opinion, 37% would prefer to complete paper questionnaires and 21% preferred to respond online.

Would you be willing to receive prompts every week to two weeks asking about symptoms?



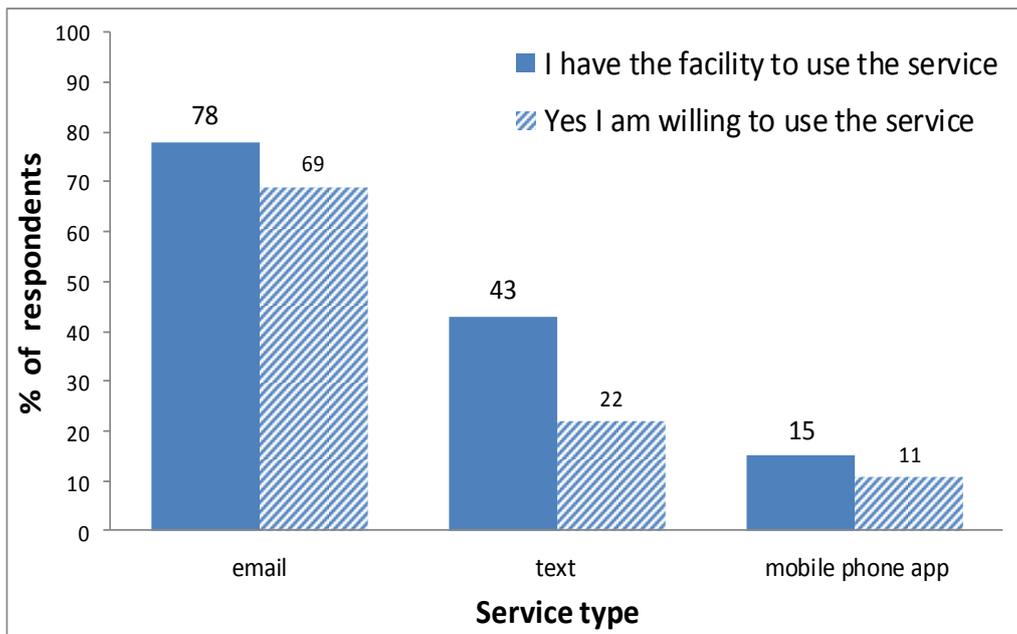
Most people (59%) were willing to be contacted every week or two weeks to be asked about any new symptoms they were experiencing although 25% did not want to receive such frequent prompts and 16% did not express any opinion.

Would you answer fewer questions but more often than every six months?



78% of respondents would be prepared to answer questions more frequently if fewer questions were asked. Answering questions more often than once a month, however, was not very popular.

Are you willing and happy to use emails, or mobile phone texts or apps to answer questions?



Many participants were both willing to answer questions by email and had access to email providers. In contrast, very few participants were willing or able to make use of a mobile phone “app” although 22% would be willing to use text messaging to answer questions.

What reasons make completing an online questionnaire more difficult than a postal questionnaire?

Many different reasons were suggested as to why it might be more difficult for an individual to complete online questionnaires. Reasons broadly fell into three categories: concerns about accessing or using a computer; physical difficulties with using a mouse, sitting at a computer or reading text on screens; and finding it more comfortable to choose where and when to complete questionnaires. Some of the more common responses include:

Concerns about using a computer

I am not computer literate....I share a laptop....My computer is slow!!....emails can be forgotten too easily.... broadband not working....Computer viruses or crashing, power cuts....Do not trust any privacy 'safeguards'.

Physical problems with computers

My hands lock with overuse of the computer/mouse....When using the laptop I get double vision.....Eyes, neck, arms more uncomfortable, more tiring.....looking at screen for a while gives me headaches.....I find it frustrating using keyboards because of nerve damage in my finger tips.

Reasons why using computers is less convenient or comfortable

It's more stressful (can't just curl up in a chair with the paper copy).....I find easier to do privately (by paper).....I work on a computer - at home I try to go on my computer as little as possible....postal one is more tangible and I see it which reminds me.....With a postal questionnaire I (as carer) can more easily sit down with my wife and go through the questions with her.

What reasons make completing an online questionnaire easier than a postal questionnaire?

Reasons suggested as to why online participation could be easier for some individuals were mostly related to convenience, physical difficulties with the postal booklets or cost effectiveness. For example:

Online can be more convenient

Away from home a lot - I can deal with questionnaires without having to take yet more paperwork.....not having to find a post-box.....more private than receiving mail.....no need to get someone to post a letter for me”.

It can be less physically demanding to complete questionnaire online

I find it easier to type than write due to the tremors in my hands.....I can blow up the font.....If balance is affected then you are unable to walk the distance to the closest post-box.

Online participation can be more cost-effective

It saves postage.....Saves paper!.....more environmentally friendly.....printing/paper costs.....quicker.

Did you express an interest in trying online?

We do not mind how you complete your questionnaires, but some people did write on the forms that they had not realised an online option was available and they would like to try it. The forms were anonymous so we have no way of knowing who did ask for online booklets, but at the end of all future SWIMS paper booklets there will be a box to tick if you want to swap to online booklets — but please remember to give us your current email!

Some people were interested in completing online booklets but raised concerns that they would have to complete booklets “all in one go”; this is not the case. The booklets remain available on line for 8 weeks and during that time you can re-visit the booklets as often as needed. At the end of each page there is a “Submit” button which will take

you to the next page. Once you have submitted the page, all data on that page is saved and is not lost if you decide to take a break! When you log back on later you can choose to change previous answers or just move on to the next set of questions.

22% of our participants now complete online booklets but some people have tried it and decided it was not for them; it is easy to move back to postal booklets. There is no pressure whatsoever to switch to online booklets and we are more than happy to use postal questionnaires.

Why are there so many similar or irrelevant questions?

One of the aims of SWIMS is to track changes in MS over time. This is why we have kept the questions in the booklet the same over the years as this provides the data we need to 'model' changes in MS in a large group of people.

Many of you have told us that the repetitive style of the questions can be frustrating, especially when some of the questions are not relevant to your individual circumstances. We understand that this makes the questionnaire difficult to complete at times. However it is important that the same questions are asked.

MS is very variable and it is precisely this variability that makes everyone's responses so valuable. We need to include people who show no change, or few symptoms, alongside those who are more severely affected. We need to know which problems you do not have as well as those that you do! The only way to do this is to collect answers to a large number of broad-ranging questions from many people. We aim to identify patterns in the data that we can use to predict the likely disease course for any individual. Ultimately, being able to predict disease course should, for example, make it easier for individuals to decide whether or not they want to take certain medication.

What happens now?

It is clear from all the various responses that each individual has very different needs and we are committed to doing our best to ensure participating in SWIMS is as easy as possible. This means continuing with all the existing ways in which booklets can be completed as well as exploring any new possibilities.

Our statisticians are now looking at data from the SWIMS booklets to begin to answer some of the questions which are core aims of SWIMS: what impact do relapses have upon physical and mental wellbeing from the patient perspective; which are the best measures of changes in disability; and what information do we need to predict what will happen to individuals over time. We will update you on this work as we proceed.

Every booklet is valuable

Although we know that completing SWIMS booklets is time-demanding and for some individuals can be quite unsettling we really do need everyone's help to collect as much information as possible. We are only just starting to analyse the existing data and really do need to collect more so that the results represent everyone with MS *and* reflect the long-term effects of MS.

If you have stopped returning booklets recently please consider completing the next one; our statisticians can cope with gaps in the information you give us and every extra bit of information helps. If you stop filling in booklets because your MS makes completing them too difficult then please tell us—we really do need to know.

Please don't remove the front cover from our booklets: our booklets are anonymous, and the project number is the only way we have of matching up your booklets over several years—without the front cover we can't use all of your information.

If you are moving or have changed your email address please let us know. Sadly we lose contact with many people each year.

Research Opportunities in Devon and Cornwall

We know that contributing to SWIMS takes up valuable time and energy; however, some people may be interested in participating in other additional studies that are taking place. Below is information about some local research that our colleagues are conducting and details of how you could get involved.

Clinical Neurology Research Group, Peninsula College of Medicine and Dentistry

Clinical trials allow different approaches to preventing and treating illness and health problems to be investigated. Health professionals and patients need the evidence from trials to know which treatments work best.

We anticipate that there will be some new clinical trials starting in the autumn for people with various types of MS. Usually, we hold clinics at either Derriford Hospital or the Tamar Science Park, Plymouth, and travel expenses are reimbursed. We will not have full details of the individual trials until later in the year but, if you would like further information about our studies, or you would like to register your interest in taking part in clinical trials, please feel free to call:



Marie Roy or Alison Anderson

N7, ITTC Building 1, Tamar Science Park, Derriford, Plymouth, PL6 8BX

Telephone: 01752 315222. email plh-tr.N7Research@nhs.net



School of Health Professions, Plymouth University

Do you experience severe impairment as a consequence of MS which may cause you to feel isolated?

If so, you may be interested in volunteering to take part in a new research study.

Dr Jenny Freeman at the School of Health Professions, University of Plymouth, is working alongside the MS Society (South West) to undertake a study to gain a deeper insight into the isolation that people with MS may feel when they are severely impaired by MS, from the perspective of people with MS. A further aim of the study is to explore what support may help to reduce the isolation that people with MS may feel.

The study will require you to participate in one confidential interview lasting about 45 minutes to one hour, held in your own home. This interview will be undertaken by Dr Sarah Robens, a researcher who is very experienced in undertaking interviews.

If you are aged over 18 years, have significant impairments to the extent that you need to use a wheelchair for your mobility, and you feel isolated as a result of this, then you may be eligible to take part in this study.

If you would like further information please feel free to call

Jenny Freeman, on 01752 588835 or email Jenny.freeman@plymouth.ac.uk



The research team (from left): Jenny Freeman, Andrew Kemp, Esther Fox, Hilary Gunn and Jane Grose.

