

SWIMS News



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

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.**

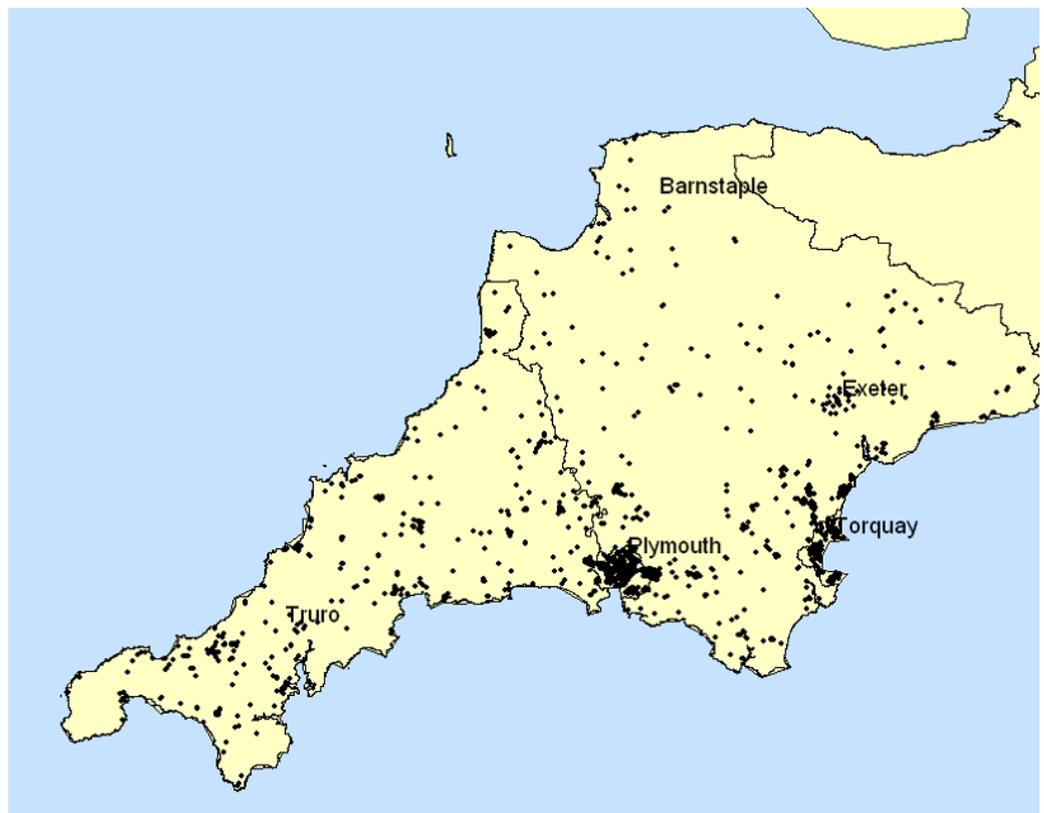
The SWIMS Project is currently funded by the Multiple Sclerosis Society of Great Britain, and through the Peninsula Medical School Foundation

We would like to welcome those of you who have recently joined the project. As shown on the map below, new participants have joined from all over Devon and Cornwall and we are delighted that you have all decided to take part!

By the end of June 2013 over 1,650 people with MS or CIS had consented to take part. Some of you have been participating since 2004 and we thank you for your huge contribution to date.

In this newsletter we have some information about progress made so far and some news about changes within the SWIMS team.

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



SWIMS Project Progress — CIS

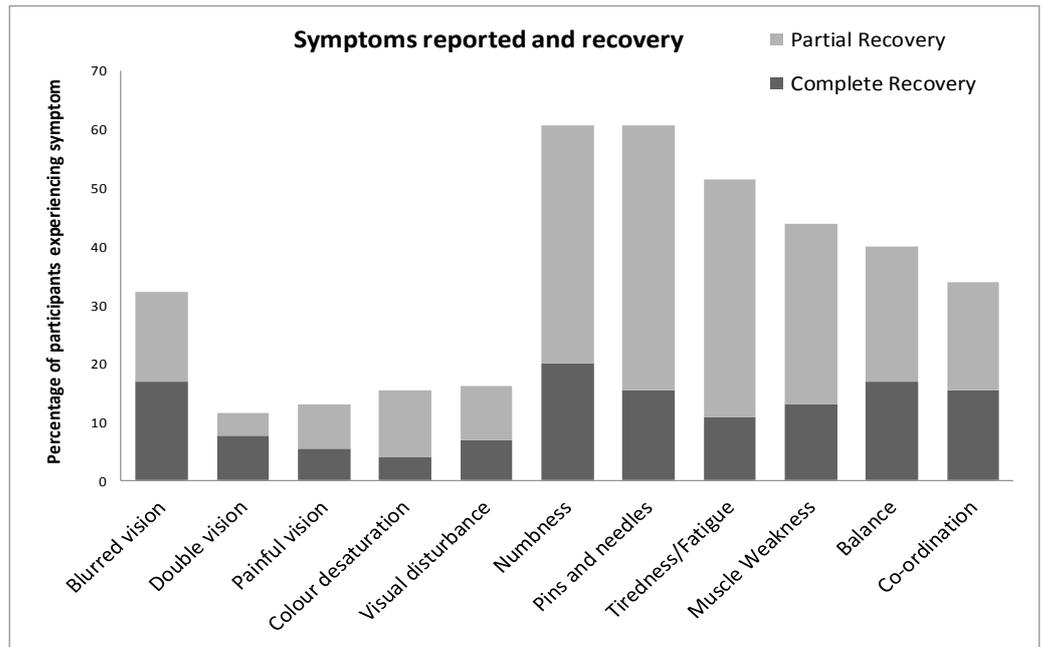
Recruitment to date

We have now recruited a total of 129 participants with CIS to the SWIMS project, 40% of whom are male and 60% female. The average age of CIS participants is 44 but age ranges from early 20s to early 70s.

Symptoms reported when joining SWIMS

The most commonly reported symptoms when diagnosed with CIS were numbness and pins and needles (or tingling). The least commonly reported was double vision.

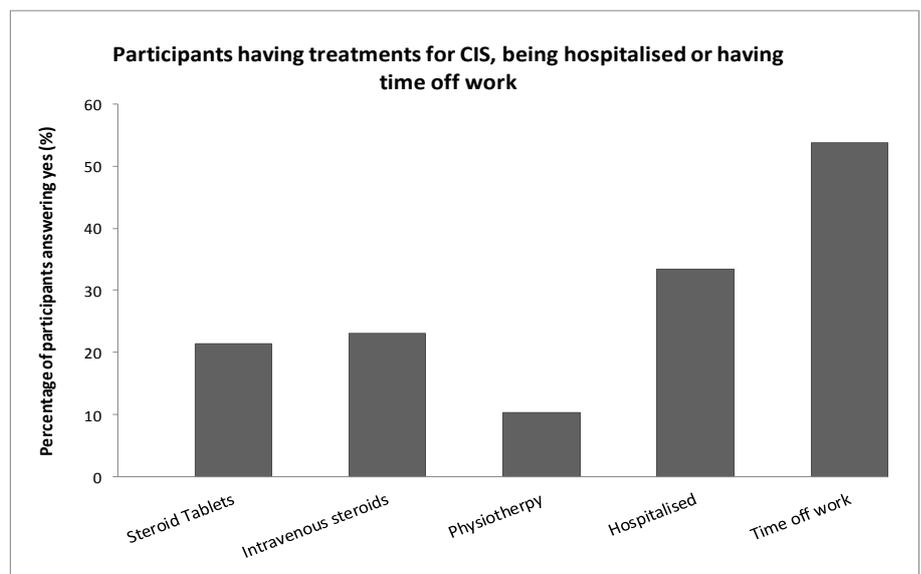
Overall more people had only a partial recovery from their initial symptoms than were able to recover fully.



Effect of initial symptoms on ability to work and whether treatments were provided

Forty-four per cent of participants were treated with steroids for their initial symptoms: 21% received tablets whilst 23% were given the steroids intravenously.

Thirty-three per cent were admitted to hospital due to the severity of their symptoms but only ten per cent received physiotherapy.



Fifty-four per cent needed to have time off work and of those, the majority (nearly 90 per cent) were unable to return to work for over 2 weeks.

Over seventy per cent of participants found that their symptoms limited other everyday activities

SWIMS Questionnaire Booklets

CIS booklets available are now available online



Having successfully trialled online questionnaire completion by participants with MS we recently expanded the option to participants with CIS. Receiving booklets by post remains the standard method but you can choose to have online booklets instead, should you wish.

What is involved? Instead of receiving the paper booklet by post, you can log on to our secure website (using a username and password that we will provide) to complete your questionnaire. As with the paper booklets your identity will be protected — you will not have to type in any identifying information.

If you have previously asked to complete booklets online then we should be sending you passwords and logon details about a week before your next booklet is due. If you change your mind at any time you can of course revert to completing postal booklets.

Some people have 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 already entered is saved and so 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 with MS now complete online booklets although some people have tried it and decided it was not for them. There is no pressure whatsoever to switch to online booklets and we are more than happy to use postal questionnaires.

Every booklet is valuable

Although we know that completing our booklets is time-demanding we really do need everyone’s help to collect as much data as possible. We are only just starting to analyse our existing data and really do need to collect more so that our results represent everyone with CIS over the long-term.

If you have stopped returning booklets recently please consider completing the next one, our statisticians can cope with some gaps in the information you give us and every extra bit of information helps. If you stop filling in booklets because your health problems 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, but 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. We know that you have far more important things to think about when moving and we are easy to forget since we only contact you once a year but we really do value your contribution:

Changes to SWIMS Organization

SWIMS was established as a research project based at the Peninsula College of Medicine and Dentistry, Plymouth University. Recent changes to the structure of the College have led to some changes for the SWIMS team.

SWIMS will continue to be based in Plymouth as part of the "Plymouth University Peninsula Schools of Medicine and Dentistry" (PUPSMD).

SWIMS is associated with the Peninsula Clinical Trials Unit (PenCTU) and in future you may find that our newsletters and letters will carry the PenCTU and PUPSMD logos:



These changes will not affect the running of the SWIMS Project at all. SWIMS remains a study of CIS and MS in the whole of Devon and Cornwall, and your contribution to the project is equally important to us, wherever you live within the study area.

Changes to SWIMS Team



Wendy Ingram has been the SWIMS Project Coordinator for some time. Wendy will now be working on some additional studies, but will still be overseeing SWIMS although with less day-to-day involvement.

To help Wendy, Jeanette Sanders will be taking over day-to-day management of the project and will be able to reply to any queries you may have.



Brian Wainman will be responsible for looking after all of your data. Brian already manages other research databases at Plymouth University, and we are pleased to

have Brian on-board to help prepare some of the SWIMS data for analysis.



Denise Hunter and Gay Jones are the other members of our "data team". They continue to be



busy sending out booklets and entering all your data onto our database.

We have recently been able to appoint a new statistician, Alison Jeffrey, to start analysing some of the SWIMS data and we hope to publish some results soon.

Contact the SWIMS Team

Our email address is changing: from the 15th of July our new email address will be:

swimsproject@plymouth.ac.uk

Our other contact details remain the same:

SWIMS Project Coordinating Office,

Room N16, ITTC Building, Tamar Science Park, Plymouth, PL6 8BX

Telephone: **0800 015 3430** (free from most landlines) or **01752 315246**

To visit our website go to <http://sites.pcmd.ac.uk/cnrg/swims.php>